



Central Directory of  
Early Intervention Resources

## Purpose of the Central Directory

The First Steps Central Directory ensures that:

- Parents, family members, service providers, and members of the public, including those with disabilities, can get information on the early intervention resources available throughout the State in a timely and organized manner, and
- Information regarding the nature and scope of these resources is available through internet, telephone or written requests at state and local levels.

If you cannot find the information you need about First Steps, call (877)41STEPS, visit the web sites at <http://chfs.ky.gov/dph/firststeps.htm> or <http://kyfirststeps.org/> , or e-mail us at [chfs.firststeps@ky.gov](mailto:chfs.firststeps@ky.gov).

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## Overview of Kentucky First Steps

### What is First Steps?

First Steps is Kentucky's Early Intervention System (KEIS) that serves children from birth to age 3 who have a developmental delay or a particular medical condition that is known to cause a developmental delay. First Steps services are provided statewide and coordinated by the Cabinet for Health and Family Services.

Early Intervention means providing appropriate services and supports to families to enhance children's growth and development. First Steps believes that all families know their child best and are the primary decision makers.

### Why Provide Services?

Typically, children who participate in early intervention experience significant improvement in development and learning. Children with developmental delays or conditions likely to cause delays benefit greatly from First Steps services during critical developmental years.

Services and support also benefit families by reducing stress.

Early intervention services can decrease the need for costly special education programs later in life by remediating problems early in the child's development.

### Who Does First Steps Serve?

First Steps serves children from birth to age 3 and their families. Child eligibility for the program is determined two ways:

1. By developmental delay - A child may be eligible for services if an evaluation shows that a child is not developing typically in at least one of the following skill areas: communication, cognition, physical, social and emotional or self-help.
2. Automatic entry - A child may be eligible if he or she receives a diagnosis of physical or mental condition with high probability of resulting developmental delay, such as Down Syndrome.

### What Services Are Available?

The First Steps program provides a wide variety of services and supports including:

- Service Coordination
- Evaluation
- Assessment
- Developmental intervention
- Occupational therapy
- Speech therapy

- Physical therapy
- Audiology services
- Vision services
- Nutrition
- Psychological
- Social Work

Eligibility for services is determined through a process of child and family assessment.

### **Where Are Services Provided?**

First Steps is available in all Kentucky counties. Early Intervention services are provided in a child's natural environment which includes their home, at child development or other designated centers or in a clinical setting, depending on the needs of the child and family and the availability of services in a given area.

### **Who Can Make a Referral?**

Anyone can refer a child for First Steps.

Referrals are directed to teams at the district Point of Entry offices that help children and families access needed services. Services are available to any child and family who meet developmental eligibility criteria, regardless of income. A family's participation in First Steps services is always voluntary.

### **What is the Cost?**

Once determined eligible, families must pay a participation fee. This is called "Family Share" and it is based on the family's total household income and household size. The fee amounts range from \$0 to a maximum of \$100 per month.

### **Who Pays for Services?**

First Steps uses a variety of funding sources including: Family Share Participation fees, private insurance and Medicaid. However, no family is denied services due to the lack of insurance or the inability to pay Family Share.

## State Lead Agency Contact Information

The state lead agency has set up a toll-free telephone number, 877-417-8377 or 877-41 STEPS and a dedicated e-mail account, [chfs.firststeps@ky.gov](mailto:chfs.firststeps@ky.gov) to assist points of entry, service coordinators, providers, parents and other stakeholders in accessing state lead agency office staff.

**First Steps State Lead Agency mailing address:**

First Steps Program  
Department for Public Health  
275 E. Main St., HS2W-C  
Frankfort, KY 40621

**Phone:** (877) 41STEPS or (877) 417-8377

**Fax:** (502) 564-0329 or (502) 564-8003

**Websites:** <http://chfs.ky.gov/dph/firststeps.htm> or <http://kyfirststeps.org/>

Regular hours are 8 a.m. to 4:30 p.m. (EST) Monday through Friday

For questions regarding program services or to make a referral to the First Steps program, contact the local First Steps Point of Entry (POE) office.



## Point of Entry (POE) Contact Information

Primary referral sources, families and other interested parties access the First Steps program locally through 15 system points of entry (POEs) covering the 15 Area Development Districts (ADDs).

POEs are responsible for receiving all referrals to the First Steps program, facilitating eligibility determination through the coordination of developmental evaluations and assessments and coordinating the development of the initial Individualized Family Service Plan (IFSP).

POEs also are responsible for local Child Find activities, local public awareness activities, local interagency coordination/collaboration, administrative monitoring and analysis of POE and district performance.

### **Barren River District**

P.O. Box 6499

380 Suwannee Trail

Bowling Green, KY 42103

(270) 901-5749 or (800) 643-6233

Fax: (270) 746-0729

Counties served: Allen, Barren, Butler, Edmonson, Hart, Logan, Metcalfe, Monroe, Simpson, Warren

### **Big Sandy District**

104 South Front Ave.

Prestonsburg, KY 41653

(606) 886-4417 or (800) 230-6011

Fax: (606) 886-4434

Counties served: Floyd, Johnson, Magoffin, Martin, Pike

### **Bluegrass District**

343 Waller Ave., Suite 201

Lexington, KY 40504

(859) 271-9448 or (800) 454-2764

Fax: (859) 272-6893

Counties served: Anderson, Bourbon, Boyle, Clark, Estill, Fayette, Franklin, Garrard, Harrison, Jessamine, Lincoln, Madison, Mercer, Nicholas, Powell, Scott, Woodford

### **Buffalo Trace District**

611 Forest Ave.

Maysville, KY 41056

(606) 564-3919 or (800) 335-4249

Fax: (606) 564-3936

Counties served: Bracken, Fleming, Lewis, Mason, Robertson

**Cumberland Valley District**

P.O. Box 568

Corbin, KY 40702

(606) 523-0229 or (800) 509-9559

Fax: (606) 528-9623

Counties served: Bell, Clay, Harlan, Jackson, Knox, Laurel, Rockcastle, Whitley

**FIVCO District**

5850 U.S. 60

Box 11 Summit Plaza

Ashland, KY 41102

(606) 929-9155 or (800) 650-1329

Fax: (606) 929-9833

Counties served: Boyd, Carter, Elliott, Greenup, Lawrence

**Gateway District**

P.O. Box 290

Owingsville, KY 40360

(606) 674-3204 or (800) 942-4358

Fax: (606) 674-8390

Counties served: Bath, Menifee, Montgomery, Morgan, Rowan

**Green River District**

1501 Breckenridge St.

Owensboro, KY 42301

(270) 852-2905 or (888) 686-1414

Fax: (270) 852-2941

Counties served: Daviess, Hancock, Henderson, McLean, Ohio, Union, Webster

**Kentuckiana (KIPDA) District**

Seven Counties Services, Inc.

3717 Taylorsville Road

Louisville, KY 40220

(502) 459-0225 or (800) 442-0087

Fax: (502) 452-9079

Counties served: Bullitt, Henry, Jefferson, Oldham, Shelby, Spencer, Trimble

**Kentucky River District**

115 Rockwood Lane

Hazard, KY 41701

(606) 439-1325 or (800) 328-1767

Fax: (606) 436-0577

Counties served: Breathitt, Knott, Lee, Leslie, Letcher, Owsley, Perry, Wolfe

**Lake Cumberland District**

113 Hardin Lane

Somerset, KY 42501

(606) 678-2821 or (800) 378-2821

Fax: (606) 679-4156

Counties served: Adair, Casey, Clinton, Cumberland, Green, McCreary, Pulaski, Russell, Taylor, Wayne

**Lincoln Trail District**

108 New Glendale Road

P.O. Box 2609

Elizabethtown, KY 42702

(270) 737-5921 or (800) 678-1879

Fax: (270) 982-0829

Counties served: Breckinridge, Grayson, Hardin, Larue, Marion, Meade, Nelson, Washington

**Northern Kentucky**

401 East 20th Street, 2nd Floor

Covington, KY 41014

(859) 655-1195 or (888) 300-8866

Fax: (859) 665-1194

Counties served: Boone, Campbell, Carroll, Gallatin, Grant, Kenton, Owen, Pendleton

**Pennyrile District**

735 North Drive

Hopkinsville, KY 42240

(270) 886-5186 or (800) 609-0047

Fax: (270) 886-0393

Counties served: Caldwell, Christian, Crittenden, Hopkins, Lyon, Muhlenberg, Todd, Trigg

**Purchase District**

425 Broadway, Suite 204

Paducah, KY 42001

(270) 442-6223 or (800) 648-6599

Fax: (270) 442-3326

Counties served: Ballard, Carlisle, Calloway, Fulton, Graves, Hickman, Livingston, Marshall, McCracken

## Referral to First Steps

Children referred to the Point of Entry (POE) are processed through intake either as an inquiry or referral. Upon receiving a written or verbal inquiry/referral from sources other than the parents, POE staff confirms that the parents know the inquiry/referral was made to the POE.

Inquiries are notifications to the POE of children who have a possible developmental concern that needs further clarification.

Referrals are made on children who meet the following criteria:

- Child is under the age of three (3) years
- Child is a resident of Kentucky and/or the POE geographic region or is homeless and located within the boundaries of the Commonwealth of Kentucky and/or POE geographic region; and,
- Child has an Established Risk Condition or a developmental concern that has been confirmed through the administration of a Cabinet-approved screening instrument.

Each POE shall have staff designated to take incoming phone calls. Individuals interested in services for a child must provide the following information:

Age of child	Must be under three (3) years of age
Prematurity status	Gestational age (or # of weeks born early) determined by parental or referral source report
Location/address of residence	Must be within Kentucky boundaries
Primary language	Must identify if an interpreter is needed
Possible Established Risk Condition	Identify the possible condition
Parent(s) name or caretaker	
Telephone number	If no telephone number, identify alternative way to contact family

If the inquiry meets the age and residency criteria, the POE staff contacts the family within five (5) working days of receipt of the inquiry. Once the family is contacted and agrees to a screening, the request is forwarded to the individual designated to conduct the screening and an appropriate screening instrument is mailed to the family. The screening instrument is completed by the POE staff in conjunction with the family. The District Child Evaluation Specialist (DCES) typically conducts screening for the POE. Results from the screening determine the action that is taken and if the child is referred for further evaluation.

## Eligibility for First Steps

Eligibility for First Steps is determined for every child referred to First Steps through an evaluation. Evaluation in Part C is not synonymous with testing. Evaluation as defined by Part C of IDEA means the procedures to determine a child's eligibility. Procedures include formal testing, observations, review of relevant health records, and other records pertinent to the child's developmental status, comparison to eligibility criteria and final determination of eligibility. Evaluation is conducted on all children referred due to an Established Risk Condition and children referred due to a suspicion of developmental delay.

Assessments reflect the child's unique strengths and needs, the identification of the services appropriate to meet their needs, the family's resources, priorities, and concerns and the supports and services necessary to enhance the family's capacity to meet the developmental needs of their child. The Routines-Based Interview (RBI) is the family assessment required by federal and state regulations.

Assessments include both a direct assessment (use of a Cabinet-approved Instrument) and an indirect assessment method of one or more of the following:

- Observation,
- Interview of the parents using the Routines-Based Interview (RBI), or
- Behavior checklist or inventories.

First Steps uses a two (2)-level evaluation system that consists of Primary Level Evaluation and Record Review.

## State Agency Listings

### **Child Care Assistance Program (CCAP)**

(502) 564-2524

<http://chfs.ky.gov/dcbs/dcc/>

This program helps parents pay for child care services from licensed, certified or registered child care providers. A parent must need child care to: allow the parent to work (income must be within 150 percent of the federal poverty level), allow a parent receiving benefits under the Kentucky Transitional Assistance Program (K-TAP) to participate in the Kentucky Works Program, protect the child from abuse or neglect or to prevent abuse or neglect, allow a teen parent to attend high school, allow a working parent to participate in education or vocational training, and/or allow a parent to participate in student teaching practicum or internship.

### **Child Care Health Consultation for Healthy Start in Child Care**

(502) 564-3756 x3756

<http://chfs.ky.gov/dph/mch/ecd/healthystart.htm>

Child Care Health Consultation Program (CCHC) provides targeted consultation and education to licensed child care centers and certified family homes on health, safety, nutrition, and social/emotional issues.

### **Child Care Provider Licensure**

(502) 546-7962

<http://chfs.ky.gov/os/oig/drcc.htm>

This service provides for the licensure and regulation of child care centers and certified family child care homes.

### **Child Care Resource and Referral Agencies (CCR&Rs)**

(877) 316-3552

[www.kentuckypartnership.org/General/About/ccrr.aspx](http://www.kentuckypartnership.org/General/About/ccrr.aspx)

Per KRS 199.892, the Kentucky network of nine Child Care Resource and Referral Agencies (CCR&R's) serve the 15 regional area development districts in the Commonwealth of Kentucky. CCR&Rs work to improve child care in Kentucky through coordinating services to help families' access early care and education and school-age child care options. CCR&R services include parent referrals, training, technical assistance and professional development opportunities to child care providers, employers and the community.

### **Child Protective Services**

(502) 564-6852

<http://chfs.ky.gov/dcbs/dpp/>

Child protective services include the intake, acceptance or referral, investigation or assessment, and interventions of reports alleging child abuse, neglect and dependency.

### **Children Ready to Read for Health/Reach Out and Read (ROAR)**

[www.reachoutandread.org](http://www.reachoutandread.org)

Children Ready to Read for Health/Reach Out and Read works with pediatric health care providers including local health departments, pediatricians, and family practice providers to help raise pre-reading skills among young children of low income, so they begin school ready to learn.

### **Children's Advocacy Centers (CACs)**

(502) 564-9444

[http://chfs.ky.gov/dcbs/dvpr/ca\\_default.htm](http://chfs.ky.gov/dcbs/dvpr/ca_default.htm)

The 15 designated regional Children's Advocacy Centers are designed to promote the well being of children while facilitating the most effective investigation and prosecution of child sexual abuse cases.

### **Child Support Enforcement Program**

Child Support Enforcement Hotline (800) 248-1163

Child Support Interactive Voice Response Payment Line (800) 443-1576

<http://chfs.ky.gov/dis/cse.htm>

The Child Support Enforcement Program provides assistance to custodial parents or legal guardians of minor children in obtaining financial support from a non-custodial parent. The program is based on federal and state regulations and laws which require the establishment of paternity, child support, medical support, location of non-custodial parents, collection and disbursement of support, and reimbursement of welfare benefits expended on behalf of children.

### **Commission for Children with Special Health Care Needs**

(502) 429-4430 or (800) 232-1160

<http://chfs.ky.gov/ccshcn/>

CCSHCN, through its 12 offices, provides care for children with physical disabilities and adults with hemophilia. Services include care coordination, hospitalization, surgery, laboratory tests and x-rays, medication, durable medical equipment, physical, occupational and speech therapies, hearing tests for newborns (i.e., Early Hearing Detection and Intervention Program), and assistance with eye examinations.

### **Commission on Philanthropy**

(859) 866-2020

<http://www.kyphilanthropy.org>

The commission will initially focus on early childhood education and child health. As part of its mission, the group held a Summit on Philanthropy in October 2009, to engage Kentucky's philanthropic interests in dialogue about issues facing the state's youngest citizens.

### **Community Early Childhood Councils (CECC)**

(502) 564-8341

<http://www.education.ky.gov/KDE/Instructional+Resources/Early+Childhood+Development/Community+Early+Childhood+Councils.htm>

Community Early Childhood Councils were designed to improve the quality and availability of child care, especially in low-resource or high-need areas. CECCs are a vehicle to gather community support for important children and family issues. CECCs provide a mechanism for attracting and assessing the unique local early care and education needs of a community.

### **Council on Developmental Disabilities**

(877) 367-5332

<http://chfs.ky.gov/kcdd/>

The Kentucky Council on Developmental Disabilities (KCDD) was authorized by Executive Order of the Governor, in accordance with Public Law 106-402, the Developmental Disabilities Assistance and Bill of Rights Act. The KCDD is comprised of 26 members, 16 of whom are appointed by the governor. The makeup of the KCDD is unique in that 60 percent of its members are individuals with developmental disabilities or are parents or guardians of individuals with disabilities. The remaining members are representatives of each major state agency that serves people with developmental disabilities in Kentucky.

### **Early Childhood Development Authority**

(502) 564-8341

<http://www.education.ky.gov/KDE/Instructional+Resources/Early+Childhood+Development/Early+Childhood+Development+Authority.htm>

The authority makes recommendations to the legislature regarding Master Tobacco Settlement Fund allocations for early childhood programs under the KIDS NOW initiative. It was created to build upon existing resources, foster public-private partnerships, and ensure collaborative planning and implementation. The authority mobilizes communities to support and strengthen families, assures that all children grow and develop to their full potential, provides high quality, accessible, affordable early care and education options, and promotes public awareness of the importance of the first years for the well-being of all Kentucky's citizens.

### **Early Childhood Development Scholarship**

(502) 564-2524

<http://www.kheaa.com/website/kheaa/ecds?main=1> and <http://chfs.ky.gov/dcbs/dcc/>

Non-repayable tuition scholarships are available for Kentucky citizens who are pursuing a Commonwealth Child Care Credential, child development associate, associate degree in early childhood education, bachelor's degree in interdisciplinary early childhood education or related program, or Director's Credential. Professional Development Counselors serve as guidance counselors for scholarship applicants and recipients.

### **Early Childhood Mental Health Program**

(502) 564-4456 or TTY (502) 564-5777

<http://dbhdid.ky.gov/dbh/early%20childhood%20mh.asp>

The Early Childhood Mental Health Program supports 14 early childhood mental health specialists statewide to provide: free consultation to early care and education staff, assessments to children age birth to five years with mental health needs, therapeutic treatment to children age birth to five years, collaborative efforts and consultation with local health and therapeutic providers, assistance to families in accessing resources, training, and community planning around early childhood mental health. Services are restricted to children in a licensed, certified or registered child care setting.

### **Early Childhood Professional Development Council**

(502) 564-8341

<http://www.education.ky.gov/KDE/Instructional+Resources/Early+Childhood+Development/Th+e+Early+Childhood+Professional+Development+Council.htm>

Work with existing entities to develop an early care and education credential system to attract and retain providers of early childcare and education services. The council is also tasked with working to develop a seamless system of professional development beginning with entry-level employment in early child care and education and proceeding through a master's degree-level program.

### **Early Head Start**

(800) 869-9257

[www.khsa.org](http://www.khsa.org) and <http://eclkc.ohs.acf.hhs.gov/hslc/Early%20Head%20Start>

The Early Head Start (EHS) program is for low-income infants, toddlers, pregnant women and their families. Early Head Start programs enhance children's physical, social, emotional and intellectual development; assist pregnant women to access comprehensive prenatal and postpartum care; support parents' efforts to fulfill their parental roles; and help parents move toward self-sufficiency.

### **Even Start Family Literacy**

(502) 564-7056 x4736

<http://www.education.ky.gov/KDE/Instructional+Resources/Literacy/Kentucky+Even+Start/>

Programs provide intensive family literacy services that integrate learning activities for parents and children, help parents to become active partners in their children's education, and help children achieve a high level of success in school and life. Even Start offers educational opportunities to families most in need, as defined by levels of literacy, income, poverty, English as Second Language, and other related factors.

### **Family Resource and Youth Service Centers (FRYSCs)**

(502) 564-4986

<http://chfs.ky.gov/dfrcvs/frysc/default.htm>

The Kentucky Family Resource and Youth Services Centers initiative was established with the passage of the Kentucky Education Reform Act (KERA) of 1990, as amended. The mission of these school-based centers is to enhance students' abilities to succeed in school by developing and sustaining partnerships that promote: early learning and successful transition into school, academic achievement and wellbeing, and graduation and transition into adult life. The goal of the FRYSCs is to meet the needs of all children and their families who reside in the community or neighborhood served by the school in which the center is located.

### **Folic Acid Supplementation Program**

<http://chfs.ky.gov/dph/mch/cfhi/>

All local health departments (and six contract agencies, including three state universities) provide counseling on folic acid and supplements to all women of childbearing age who visit the departments. Use of folic acid by women of childbearing age can significantly reduce the incidence of spina bifida.

### **Head Start**

(800) 869-9257

[www.khsa.org](http://www.khsa.org) and <http://eclkc.ohs.acf.hhs.gov/hslc/About%20Head%20Start>

Head Start programs promote school readiness by enhancing the social and cognitive development of children through the provision of educational, health, nutritional, social and other services to enrolled children and families. They engage parents in their children's learning and help them in making progress toward their educational, literacy and employment goals. Significant emphasis is placed on the involvement of parents in the administration of local Head Start programs.

### **Health Access Nurturing Development Services (HANDS)**

(502) 564-3756

<http://chfs.ky.gov/dph/mch/ece/hands.htm>

HANDS is a voluntary, intensive home visitation program for overburdened first-time parents, regardless of income, and their first child prenatal to age two years. It is designed to improve both the health and social outcomes for the child. HANDS aims to achieve positive pregnancy outcomes, optimal child growth and development, children living in healthy and safe homes, and family decision-making and self-sufficiency.

### **Heuser Hearing and Language Academy**

(502) 515-3320 or TDD (502) 515-3323

<http://www.thehearinginstitute.org>

The Heuser Hearing and Language Academy established its Hearing Services Center to provide comprehensive, in-depth services related to diagnosis/evaluation, intervention/rehabilitation, amplification and listening devices/other technology, medical services and research regarding hearing loss for adults and children.

### **Human Development Institute (HDI)**

v/TTY (859) 257-1714

<http://www.hdi.uky.edu/Home.aspx>

The Human Development Institute is the University of Kentucky's Center for Excellence in Developmental Disabilities Education, Research and Service. The institute provides a strong foundation for more than 40 research, training and service projects, addressing a wide range of topics and issues in areas such as early childhood, education and alternate assessment, transition across the lifespan, employment, community living and personnel preparation.

### **Immunization Program for Under-Insured Children**

(502) 564-4478

<http://chfs.ky.gov/dph/epi/Immunization+Program.htm>

The Immunization Program for Under-Insured Children greatly increases access to immunizations for under insured children who typically would not be eligible for federally funded immunization services. Children can receive immunization services through local health departments or a provider who is a part of the Kentucky Vaccines for Children Program.

### **IMPACT**

(502) 564-4456 or TTY (502) 564-5777

<http://dbhdid.ky.gov/dbh/ky%20impact.asp>

Kentucky IMPACT is a statewide program that creates partnerships to serve children with severe emotional disabilities (SED) and their families in their home, school and community. Children and youth with SED and their families work with a service coordinator who uses a strengths-based, highly individualized, and collaborative model of case management to assess strengths and needs across life domains (e.g., family, financial, living situations, education/vocational, behavioral/emotional, psychological, health, legal, safety). The services are intended to help children function in their communities and avoid the need for higher levels of care. A child or youth must be under age 18 years at the time of admission into the program, have a diagnosis of a psychiatric disorder, require service coordination, and present substantial limitations that persist for one or more years.

### **IMPACT Plus**

(502) 564-4797 or TTY: (502) 564-5777

<http://dbhdid.ky.gov/dbh/impact%20plus.asp>

IMPACT Plus is a behavioral health program serving Medicaid-eligible children with complex behavioral healthcare needs who are most at risk for entry into state foster care and/or institutionalization. Services are intended to be short term. The program ensures wrap-around services for eligible children and offers case management, individual therapy, group therapy, parent-to-parent services, therapeutic child support, after-school and summer programs, behavioral health intervention, crisis stabilization services, collateral services, day treatment services, intensive outpatient behavioral health services, partial hospitalization service, therapeutic group residential and foster care services.

### **Kentucky Administrative Regulations**

Listed by Title or searchable by keyword

<http://www.lrc.state.ky.us/KAR/frntpage.htm>

### **Kentucky Administrative Regulations- Education = Title 700**

<http://www.lrc.state.ky.us/kar/titles.htm>

### **Kentucky Children's Health Insurance Program (KCHIP)**

(877) KCHIP-18

<http://kidshealth.ky.gov/en/kchip/>

The Kentucky Children's Health Insurance Program (KCHIP) is free or low-cost health insurance for children. KCHIP is for children under the age of 19 years who do not have health insurance and whose family income is below 200 percent of the federal poverty level.

### **Kentucky Commission on Services and Supports for Individuals with Mental Retardation and other Developmental Disabilities**

The Kentucky Commission on Services and Supports for Individuals with Mental Retardation and other Development Disabilities is established by KRS 210.575:

<http://www.lrc.ky.gov/KRS/210-00/575.PDF> Its mission is to provide the most flexible, effective and integrated system of quality supports and services to meet the educational, residential, vocational and social needs of all persons with intellectual or developmental disabilities and their families.

### **Kentucky Deaf-Blind Project (Kentucky School for the Blind)**

(859) 257-3730

<http://www.deafblind.com/usa.html#Kentucky%20Deaf-Blind>

The Kentucky Deaf-Blind Project (Kentucky School for the Blind) serves individuals from birth to 22 years of age. The program provides training and consultation to families and service providers of persons with deafblindness to lead toward full community integration. In-service training is provided. Project coordinators consult with the faculty of state universities on providing pre-service training on the topic of deafblindness.

### **Kentucky Department for Libraries and Archives (KDLA)**

(502) 564-8300

[www.kdla.ky.gov](http://www.kdla.ky.gov)

The Kentucky Department for Libraries and Archives works with public libraries in 119 counties to develop early childhood literacy programs. A consultant can provide assistance in program development and materials selection. KDLA also develops, provides and coordinates training for library staff in serving needs of young children and coordinates statewide initiatives such as Summer Reading Clubs and Prime Time Family Reading and provides grants for programming in local libraries.

### **Kentucky Department of Education**

500 Mero Street  
Frankfort, KY 40601  
(502) 564-4770 or TTY (502) 564-4970.

<http://www.education.ky.gov/KDE>

The Kentucky Department of Education is a service agency of the Commonwealth of Kentucky. The department provides resources and guidance to Kentucky's public schools and districts as they implement the state's K-12 education requirements. The department also serves as the state liaison for federal education requirements and funding opportunities.

### **Kentucky Department of Education, Division of Early Childhood Development**

500 Mero Street  
Frankfort, KY 40601  
(502) 564-8341

<http://education.ky.gov/kde/instructional+resources/early+childhood+development>

The Division of Early Childhood Development has oversight of the KIDS NOW initiative (Kentucky Invests in Developing Success NOW!) and the Head Start Collaboration Office and direct responsibility for the administration of the Community Early Childhood Councils. The Kentucky Preschool Program and Even Start Family Literacy are other programs in the division. The work is divided among two (2) branches, Early Care and Education and Preschool.

### **Kentucky Department of Education: Division of Exceptional Children Services**

500 Mero Street  
Capital Plaza Towers  
Room 801  
Frankfort, KY 40601  
(502) 564-4970

[www.education.ky.gov/KDE/Instructional+Resources/Exceptional+Children/default.htm](http://www.education.ky.gov/KDE/Instructional+Resources/Exceptional+Children/default.htm)

Leads state efforts to assure students with special needs receive appropriate education and related services consistent with state and federal guidelines.

### **Kentucky Division of Regulated Child Care**

(502) 564-7962

<http://chfs.ky.gov/os/oig/drcc.htm>

The Division of Regulated Child Care is responsible for licensing and investigating complaints against child day care programs, residential child caring facilities and child-placing agencies. The division also is responsible for certifying and investigating complaints against certified family child care homes.

### **Kentucky Early Childhood Data System (KEDS)**

(859) 257-4918

<https://www.kedsonline.org/>

The Kentucky Early Childhood Data System is designed to provide a data system that will allow teachers and providers at the local level to implement high quality curriculum-based

assessments that inform instructional and classroom practices yet provide data at the regional/district and state level on the extent to which children are meeting the Kentucky Early Childhood Standards and Office of Special Education Program Child Outcomes.

## **Kentucky Early Intervention System Interagency Coordinating Council (ICC)**

The Kentucky Early Intervention System Interagency Coordinating Council is established by KRS 200.658: <http://www.lrc.ky.gov/KRS/200-00/658.PDF>. Its mission is to: maximize the potential of infants and toddlers (birth through two) having, or at risk of having, developmental delays; through the development and implementation of a comprehensive statewide intervention system; and provide services that are available as soon as it is possible to identify needs and services that are family centered, coordinated, community-based, normalized, accountable, culturally competent, individualized, accessible, quality, timely, interdisciplinary, and linked to services outside of the Early Intervention System.

## **Kentucky Oral Health Program (KOHP) - Early Childhood Oral Health**

(502)564-3246

<http://chfs.ky.gov/dph/info/dpqi/oralhealth.htm>

KOHP has led the way to ensure that 96 percent of Kentucky's citizenry are on a fluorinated water supply. KOHP provides training to nurses, teachers, and the general public and has helped design and promote a curriculum for children in kindergarten through sixth grade (Kentucky Smile). Through the Early Childhood Oral Health, fluoride varnish is provided twice a year to prevent tooth decay in children. Additional local partnerships have helped link children with acute needs to restorative care.

## **Kentucky Partnership for Early Childhood Services**

(800) 956-8950

<http://www.kentuckypartnership.org/Home.aspx>

The Kentucky Partnership for Early Childhood Services is a multi-project consortium housed at the University of Kentucky Human Development Institute. The partnership's goal is to provide research, training and outreach to support and enhance quality early care, intervention and education.

## **Kentucky Partnership for Early Childhood Services, Child Care Resource and Referral Agency office listing**

(800) 956-8950

<http://www.kentuckypartnership.org/General/About/ccrr/ccrr.aspx>

Child Care Resource and Referral Agencies: know the importance of quality child care, assist parents and families to locate and identify local quality child care, provide early care and education services to families, providers, and the community, and build relationships with community organizations and agencies to help increase the availability of safe, affordable quality child care.

## **Kentucky Preschool Program (KERA Pre-K)**

(502) 564-7056 x7056

<http://www.education.ky.gov/KDE/Instructional+Resources/Preschool/>

Kentucky's preschool education programs are available for all four-year-old children whose family income is no more than 150 percent of poverty; all three- and four-year-old children with developmental delays and disabilities, regardless of income; and other four-year-old children as placements are available based on district decision. The preschool program is designed to be developmentally appropriate for young children. Developmentally appropriate is defined in law to mean that the program focuses on the child's physical, intellectual, social and emotional development, including interpersonal, intrapersonal and socialization skills.

### **Kentucky Revised Statutes TITLE XIII - EDUCATION**

Listed by Title

<http://www.LRC.state.ky.us/KRS/TITLES.HTM>

### **Kentucky School for the Deaf (KSD)**

(859) 239-7017

<http://www.ksd.k12.ky.us>

The Kentucky School for the Deaf has an Early Childhood Program with locations throughout the state with teachers providing consultation, early intervention home visits, and preschool classes (not residential) as determined by the needs of each region. Founded in 1823 as the first state-supported school for the deaf in the United States, KSD is dedicated to providing quality education to Kentucky's deaf and hard of hearing students birth to 21 years of age. KSD encompasses the Statewide Educational Resource Center on Deafness as established by the Kentucky General Assembly. Outreach services include consultation, curriculum evaluation, program planning, and professional development activities.

### **Kentucky System to Enhance Early Development (KY SEED)**

<http://dbhdid.ky.gov/kdbhdid/default.asp>

The Kentucky System to Enhance Early Development (KY SEED) is a cooperative effort to enhance the system of care for children age birth to five years who have social, emotional, and/or behavioral challenges, and their families. KY SEED builds upon the statewide IMPACT and the Early Childhood Mental Health programs to better meet the needs of children age birth to five years by increasing access to high quality, integrated services and supports in Kentucky communities. Implementation began in October 2009 with four Regional Interagency Councils for Services to Children with Emotional Disabilities serving Kentucky River, Salt River, Jefferson, and Bluegrass West communities. Statewide implementation will be accomplished by the final year of the grant.

### **Kentucky Transitional Assistance Program (K-TAP) & Kentucky Works Program (KWP)**

(502) 564-7050

<http://chfs.ky.gov/dcbs/dfs/KTAP.htm>

These programs provide assistance to eligible children and families and offer supportive services to promote family self-sufficiency.

### **Lexington Hearing and Speech Center**

(859) 268-4545 v/TTY

<http://www.lhscky.org>

The Lexington Hearing and Speech Center is a private agency serving deaf, hard of hearing, and speech and language delayed individuals. The center is approved as a Kentucky Preschool Vendor for public school contracts and is partially funded by the United Way. The center continues to provide services to infants and children with hearing loss, including early identification of hearing loss, preschool and kindergarten educational programs and complete, on-site hearing services.

### **Medicaid**

(800) 635-2570

<http://chfs.ky.gov/dms/default.htm>

Medicaid provides a wide scope of medical services to individuals who are aged, blind or have a disability; children in foster care; and family members who meet qualifying events and income guidelines. The program is administered in compliance with Title XIX of the Social Security Act and includes the Early Periodic Screening, Diagnosis, and Treatment Services (EPSDT).

### **Michelle P. Waiver (MPW)**

<http://chfs.ky.gov/dms/mpw.htm>

The Michelle P. Waiver is a home and community-based waiver under the Kentucky Medicaid program developed as an alternative to institutional care for individuals with developmental or intellectual disabilities. MPW allows individuals to remain in their homes with services and supports. To be eligible, an individual with a developmental or intellectual disability must meet the requirements for residence in an intermediate care facility or a nursing facility and meets financial eligibility requirements for Medicaid.

### **Newborn Metabolic Screening Program**

(502) 564-3756 x3761 or (800) 462-6122 x2

<http://chfs.ky.gov/dph/mch/ece/newbornscreening.htm>

Kentucky law requires that all newborns receive screening before the newborn leaves the hospital. Kentucky screens for 29 core conditions – the full panel recommended by the American College of Medical Genetics and the March of Dimes. Components of this program include provider and parent education, laboratory screening, short-term follow-up, treatment and diagnosis, long-term follow-up, and program evaluation.

### **Office of Vocational Rehabilitation**

(502) 564-4440 or (800) 372-7172 (V/TTY)

<http://ovr.ky.gov/>

The Kentucky Office of Vocational Rehabilitation assists Kentuckians with disabilities to achieve suitable employment and independence.

### **Out-of-Home Care Services**

(502) 564-2147

<http://chfs.ky.gov/dcbs/dpp/>

Out-of-home care services are provided to children who are dependent or maltreated and require a living arrangement alternative to their home of origin. They can include service to reunify a child with his/her home of origin or find other permanency options. Out-of-home care services include private and public foster care, pre-adoptive homes, relative care, and facility services. Placements are a result of a court order.

### **Special Supplemental Nutrition Program for Women, Infants and Children (WIC)**

(502) 564-3827 or (800) 462-6122

<http://chfs.ky.gov/dph/mch/ns/wic.htm>

The Special Supplemental Nutrition Program for Women, Infants and Children (WIC) is a short-term nutritional intervention program designed to influence lifetime nutrition, health behavior and contribute to increased brain development in high-risk populations. WIC provides nutrition education, breast-feeding promotion and education, a monthly food prescription of nutritious foods, and access to maternal, prenatal and pediatric health-care services. To participate, WIC requires that clients have one or more documented nutritional risks and income less than or equal to 185 percent of the federal poverty level. Roughly 95 percent of all WIC participants are at income levels below 150 percent of the federal poverty level.

### **STARS for KIDS NOW**

(502) 564-2524 or (800) 421-1903

[www.starsforkidsnow.com](http://www.starsforkidsnow.com)

This program is a voluntary, quality-based, graduated child care rating system for licensed child care and certified family child care homes. Providers who exceed minimum licensure standards can apply to be rated. Successful applicants who meet a STARS rating level are eligible for financial incentive(s).

### **State Interagency Council for Services to Children with an Emotional Disability (SIAC)**

(502) 564-4456 or TTY: (502) 564-5777

<http://dbhdid.ky.gov/dbh/siac.asp>

The State Interagency Council for Services to Children with an Emotional Disability (SIAC) is a legislated council consisting of state agency representatives and a parent of a child with an emotional disability, that oversees coordinated policy development, comprehensive planning, and collaborative budgeting for services to children with emotional disabilities. SIAC oversees KY IMPACT and coordinates with other child-serving programs to help children with severe emotional disabilities in their homes, schools and communities. Regional (RIAC) and Local Interagency Councils (LIAC) help carry out the work of KY IMPACT on the regional and community levels.

### **State P-16 Council**

(502) 573-1555

<http://www.cpe.ky.gov/committees/p16/>

The Kentucky Board of Education and the Council on Postsecondary Education formed the state P-16 Council to improve cooperation and communication among elementary, secondary and postsecondary education.

**Strong Start Kentucky: Quality Pre-K for Every Child**

(859) 233-9849 or (800) 928-2111

<http://www.prichardcommittee.org/StrongStart/tabid/32637/Default.aspx>

Making high-quality preschool available to every Kentucky child is the goal of Strong Start Kentucky: Quality Pre-K for Every Child, an initiative of the Prichard Committee for Academic Excellence and a growing coalition of partners. Strong Start Kentucky is a nonpartisan, citizen-led effort to ensure that every child has the opportunity to receive the highest-quality education possible.

**Substance Abuse Treatment for Pregnant and Post-Partum Women (KIDS NOW Plus)**

(502) 564-4456 or TTY: (502) 564-5777

<http://dbhdid.ky.gov/dbh/womens%20services.asp>

The goal is to identify and intervene with pregnant women who are using or at risk of using alcohol, tobacco and other drugs. Early intervention begins with a brief screening at a local health departments, private doctor practices, and community services. Brief intervention skills are used to refer women to KIDS NOW Plus or other appropriate community services. Prevention classes provide needed information on the effects of substance use on the developing baby. The highest risk women receive case management services designed to meet their individual needs with continued prenatal care and substance abuse treatment.

**Supplemental Nutrition Assistance Program (SNAP)**

(502) 564-7050

<http://chfs.ky.gov/dcbs/dfs/foodstampsebt.htm>

The Food Benefit Program helps people with little or no money buy food for healthy meals at participating stores. Food benefits increase a household's food buying power when added to the household's money.

**Visually Impaired Preschool Services, Inc. (VIPS)**

(502) 636-3207 or (888) 636-8477

<http://www.vips.org/index.php>

The mission of Visually Impaired Preschool Services, Inc. (VIPS) is to offer appropriate services to infants, toddlers and preschoolers who are visually impaired or blind and to their families; to maximize each child's development potential through direct services, advocacy, and community education. VIPS provides a variety of programs and services. VIPS serves blind or visually impaired infants, toddlers and preschoolers who live within a 50-mile radius of Louisville, including several counties in Southern Indiana, through the VIPS-Louisville Office. Children who live in central Kentucky within a 50-mile radius of Lexington, are served by the VIPS-Central KY Office. VIPS also has an Outreach Program to serve children and families who reside in other areas throughout Kentucky.

**Well Child/EPSDT Preventive Health Care Program**

[www.chfs.ky.gov/dph/mch](http://www.chfs.ky.gov/dph/mch)

The Well Child/EPSDT Preventive Health Care program is delivered through local health departments within the commonwealth. This program promotes and safeguards the health and wellness of children by providing a comprehensive history and physical examination of children from birth to 21 years of age. Nursing assessments on children are performed by Certified Well Child Registered Nurses.

## Other Kentucky Resources

### **The Arc of Kentucky**

(502) 875-5225; (800) 281-1272

<http://www.arcofky.org/>

The ARC of Kentucky promotes self advocacy, helps to raise public awareness of the needs, rights and abilities of persons with developmental and related disabilities, monitors state progress made in the areas of community inclusion, encourages progressive legislation, and educates the public on precautions that can be taken to prevent disabilities.

### **Autism Society of Kentuckiana**

(812) 896-3556

<http://www.ask-lou.org/>

The Autism Society of Kentuckiana (ASK) is a non-profit organization serving Greater Louisville and Southern Indiana that provides support for families affected by Autism Spectrum Disorders. ASK provides resources and education for families and individuals through our monthly meetings, workshops and social events.

### **Autism Society of the Bluegrass**

(859) 299-9000

<http://asbg.org/>

The Autism Society of the Bluegrass is a resource and support group for families and professionals in the Central Kentucky area who are involved with autism.

### **Bluegrass Technology Center**

(800) 209-7767 or (859) 294-4343

[www.bluegrass-tech.org](http://www.bluegrass-tech.org)

The mission of the Bluegrass technology Center is to support and assist all persons with in their efforts to access technology and to increase their awareness and understanding of how technology can enhance their ability to participate more fully in the community. We seek to help redefine human potential by making technology a regular part of the lives of people with disabilities.

### **Brain Injury Alliance of Kentucky**

(502) 493-0609 or (800) 592-1117

<http://www.biak.us>

BIAK is a non-profit 501(c)(3) organization. Our sole mission is to serve Kentucky citizens whose lives have been affected by brain injury. We do this through advocacy, education, prevention, research, service and support.

### **Cardinal Hill Healthcare System**

<http://www.cardinalhill.org/>

Cardinal Hill Healthcare System is a 501(c)3 organization owned by the Kentucky Easter Seal Society, Inc., an affiliate of National Easter Seals Society. The mission of Cardinal Hill Healthcare System/ Kentucky Easter Seals is to help people with disabilities achieve maximum independence. Services include inpatient hospital care for physical rehabilitation needs and medically complex clients. In addition to the three inpatient programs, outpatient therapy, childcare, adult day health, home health care and recreational programs are also available.

### **Center For Accessible Living**

(888) 261-6194 or (270) 753-7729 (Fax/TDD); (888) 261-6194

[www.calky.org](http://www.calky.org)

The Center for Accessible Living (CAL), a private, non-profit 501 (c)(3) organization, is a disability resource center for people with disabilities, governed by people with disabilities. It operates on a cross disability basis, which means that individuals will be served regardless of type of disability. Our experienced staff provides information, advocacy and services that create opportunities for people with disabilities to live as independently as possible.

### **Cerebral Palsy K.I.D.S. Center**

(502) 635-6397 or (502) 635-1147

<http://www.kidscenterky.org/>

The K.I.D.S. Center is an outpatient treatment facility that offers physical, occupational and speech therapy services; community referral and resource information; parent/guardian support group; family support, activities and education; orthopedic clinic; wheelchair and seating assessments; casting and splinting; therapeutic horseback riding programs; sensory motor gym; pediatric therapy equipment; and a physical fitness gym.

### **Down Syndrome Association of Central Kentucky**

(859) 494-7809

<http://www.dsack.org>

DSACK is a non-profit volunteer organization comprised of families and professionals who are interested in bettering the lives of people with Down syndrome, and helping them to realize their life aspirations. DSACK's ultimate goal is to provide support, resources, and opportunities for individuals with Down syndrome and their families.

### **Down Syndrome Association of Greater Cincinnati**

(513) 761-5400 or (888) 796-5504

<http://www.dsagc.com/>

The DSAGC is a 501C-3 non-profit organization established in 1981 with a history of responding to the changing needs of individuals with Down syndrome. The DSAGC serves southwest Ohio, northern Kentucky and southeastern Indiana including Hamilton, Butler, Brown, Clermont, Warren, Boone, Campbell, Kenton and Dearborn counties. We believe that knowledge empowers. By providing families with support, inspiration and information, we help individuals with Down syndrome achieve their maximum potential. We believe in inclusion. Including

individuals with Down syndrome in neighborhood schools, community activities and the business world benefits both the individual and their respective communities.

**Down Syndrome of Louisville, Inc.**

(502) 458-6392 or (888) 458-Down

[www.downsyndromeoflouisville.org](http://www.downsyndromeoflouisville.org)

Down Syndrome of Louisville, Inc. (DSL) is a non-profit organization founded in 1977 by Mary Carter, an early childhood educator who established the first Early Intervention Education program for children with Down syndrome in Kentucky. Our grassroots organization grew with parent support to incorporate in 1991 to offer services for individuals with Down syndrome of all ages.

**Down Syndrome Association of Western Kentucky**

(270) 444-9687 or (270) 564-0949

<http://dsawk.com/>

Our mission is to promote public awareness and acceptance of individuals with Down syndrome by providing information, resources and support in our community.

**Enabling Technologies of Kentuckiana (enTECH)**

(800) 896-8941 or (502) 585-9911, ext 2648

[www.spalding.edu/entech](http://www.spalding.edu/entech)

The mission of enTECH is to support all persons with disabilities in their efforts to access technology and to increase awareness and understanding of how that technology can enhance their abilities to participate more fully in the community.

**Epilepsy Foundation of Kentuckiana, Inc.**

(502) 637-4440

<http://www.efky.org>

Provide advocacy, education, outreach and support services to children and adults impacted by epilepsy and seizure disorders in Kentucky and southern Indiana.

**Family Information Network on Disabilities of Louisville**

(502) 587-6500

<http://findoflouisville.org>

The Family Information Network on Disabilities (FIND of Louisville) is a non-profit organization that provides free information, training, referral, and advocacy to parents and professionals working with children with disabilities and special needs.

**Green River Area Down Syndrome Association**

(270) 925-0195

<http://www.gradsa.org/>

GRADSA is a 501(c)3 organization governed by a board of parent and professional volunteers who share an interest in improving the quality of life for individuals with Down syndrome. We are an affiliate of the National Down Syndrome Society and the National Down Syndrome

Congress. We serve nearly 300 families, educators, and professionals in the counties of Daviess, Hancock, Henderson, McLean, Ohio, Union, and Webster.

**Human Development Institute**

University Center for Excellence  
University of Kentucky  
(859) 257-3045

<http://hdi.uky.edu/SF/Home.aspx>

The Human Development Institute is Kentucky's University Center for Excellence in Developmental Disabilities Education, Research and Service. We focus our efforts on improving lifelong opportunities and services for individuals with disabilities, their families and the community.

**Kelly Autism Program**

(270) 745-4527 or (270) 745-4KAP

<http://kap.wku.edu>

KAP provides academic, social, emotional, behavioral, transition, sensory, and communication support for individuals from age 7 through adulthood. Parent support and community participation are available.

**Kentucky Assistive Technology Service (KATS) Network**

(502) 327-0022 (V/TTY) or (800) 327-5287 (V/TTY, in KY only)

[www.katsnet.org](http://www.katsnet.org)

The KATS Network, the Kentucky Assistive Technology Act Program, serves Kentucky residents of all ages with disabilities of all types, their families, employers and employment service providers, educators, health care and social service providers, and others seeking information about assistive technology (AT) and accessible information technology.

**Kentucky Autism Training Center**

<http://kyautism.org/>

The mission of the Kentucky Autism Training Center is to strengthen our state's systems of support for persons affected by autism by bridging research to practice and by providing training and resources to families and professionals. KATC is committed to improving the quality of life for those affected by ASD.

**Kentucky Commission on the Deaf and Hard of Hearing**

(502) 573-2604 (V/TTY) or (800) 372-2907 (V/TTY, in KY only)

[www.kcdhh.org](http://www.kcdhh.org)

The KCDHH acts as an advocate for deaf and hard of hearing persons on legislative issues as well as a consultant to the Governor, General Assembly, and various state and local governmental agencies concerning policies and programs that pertain to people with hearing loss.

**Kentucky Parent Teacher Association**

<http://www.kypta.org/>

PTA is a powerful voice for all children, a relevant resource for families and communities and is a strong advocate for the education and well-being of every child.

**Kentucky Partnership for Families and Children, Mental Health**

(800) 369-0533 or (502) 875-1320

<http://www.kypartnership.net/>

The Kentucky Partnership for Families and Children, Inc. (KPFC) is a private, not for profit, family organization that serves the entire state of Kentucky. KPFC is the state chapter for the National Federation of Families for Children’s Mental Health and is the Center for Mental Health Services Statewide Family Network grantee for Kentucky.

**Kentucky Protection and Advocacy**

(800) 372-2988 (Voice/TTY) or (502) 564-2967 (Voice/TTY)

<http://www.kypa.net>

P&A is an independent state agency made up of advocates and attorneys working together with people who have disabilities to promote and protect their legal rights.

**Kentucky Special Parent Involvement Network (KY-SPIN)**

(502) 937-6894 or (800) 525-7746

[www.kyspin.com](http://www.kyspin.com)

SPIN provides training, information and support to people with disabilities, their parents and families, and information on all types of disabilities and topics for all age groups.

**Kentucky Speech-Language-Hearing Association**

(800) 837-2446

<http://ksha.info/>

The mission of the Kentucky Speech-Language-Hearing Association is to enhance the provision of quality services to persons with communication disorders and their families.

**Learning Disabilities Association of Kentucky, Inc.**

(502) 473-1256 or (877) 587-1256

[www.ldaofky.org](http://www.ldaofky.org)

The Learning Disabilities Association of Kentucky, Inc. is a non-profit organization of individuals with learning differences and attention difficulties, their parents, educators, and other service providers. This organization has been a continuous voice in this state for those who learn differently since 1966.

**Mental Health Association of Northern Kentucky**

(859) 431-1077

<http://mhanky.org>

Mental Health America of Northern Kentucky is dedicated to promoting mental health, preventing mental disorders, and achieving victory over mental illness through advocacy, education, research, and service.

**NAMI Kentucky (National Alliance for the Mentally Ill)**

(502) 245-5284 or (800) 257-5081

<http://ky.nami.org>

NAMI Kentucky is a self-help organization that is part of a nation-wide network devoted to improving the lives of the seriously mentally ill and decreasing the prevailing stigma associated with mental illness. The initials “NAMI ” in our name stand for the National Alliance on Mental Illness, which was founded in 1979 by 284 persons. NAMI Kentucky is an affiliate.

**Parent Outreach: Parents Supporting Parents**

(502) 584-1239

[www.councilonmr.org](http://www.councilonmr.org)

Since 1952 The Council on Developmental Disabilities, a private non-profit association of families and friends of persons with developmental disabilities, has been advocating for persons with developmental disabilities in Jefferson County since 1952.

**Pitt Academy**

(502) 966-6979

<http://www.pitt.com/>

Pitt Academy provides a safe, supportive, innovative learning environment which children with a broad spectrum of learning and communication disabilities can reach their own academic, creative, and social potential.

**Quest Farm**

(502) 535-6064

<http://www.questfarm.org/>

Quest Farm, Inc. is a working farm community where adults with developmental disabilities live in a nurturing and enriching environment. Each individual is encouraged to attain his or her full potential in every aspect of life. The educated and knowledgeable staff encourages and trains individuals to be farmers with skills in areas such as gardening, horticulture, landscaping, crafts, woodworking, cottage industries, vegetable production, animal care, retailing, equipment use and maintenance, lawn care, etc.

**Redwood Assistive Technology Center**

(800) 728-9807 or (859) 331-0880

[www.redwoodnky.org](http://www.redwoodnky.org)

The Assistive Technology Center at Redwood Rehabilitation Center offers a variety of services to support the successful use of technology by children and adults with disabilities.

**Shriners Hospitals for Children- Lexington**

(859) 268-2101

<http://www.shrinershospitalsforchildren.org/Hospitals/Locations/Lexington.aspx>

Shriners Hospitals for Children® — Lexington delivers the highest quality of care to children with a host of orthopaedic and neuromusculoskeletal disorders and diseases. Our hospital is light-filled, colorful and designed to put children and families at ease. Every member of our staff, from surgeons to therapists, nurses to orthotists, is focused on providing the highest quality care that puts the family at the center of the team.

### **Special Olympics Kentucky**

(502) 695-8222 or (800) 633-7403

<http://www.soky.org>

Special Olympics is the world's largest program of sports training and competition for children and adults with intellectual disabilities.

### **Spina Bifida Association of Kentucky**

(502) 637-7363 or (502) 637-1010

[www.sbak.org](http://www.sbak.org)

The Spina Bifida Association of Kentucky's mission is to promote the prevention of Spina Bifida and to enhance the lives of all affected. SBAK is a resource center for children, their families and adults affected by Spina Bifida. SBAK educates parents how to be the best advocate for their child, and helps children and adults overcome physical, learning, and social challenges to become successful and independent.

### **The Kidz Club**

(502) 458-5433 or (888) 902-KIDZ

<http://www.thekidzclub.cc/>

The Kidz Club is a very special place for children who are medically fragile. We are a Prescribed Pediatric Extended Care (PPEC) facility. Our mission is to provide the safest, most up-lifting, and cost effective medical treatment available in a daycare setting.

### **Underwood and Lee Clinic**

(502) 368-2348

<http://www.underwoodandlee.com/>

The Underwood and Lee Clinic serves as a dental home for people with neurodevelopmental disorders and intellectual disabilities (ND/ID). This means that we provide a wide array of general dental services to our patients. It also means that if the services of a dental or medical specialist are required, we will take the time to work with that specialist to ensure the best possible clinical results.

### **VSA Arts of Kentucky**

(270) 781-0872 (V/TTY) or (877) 417-9594

<http://www.vsartsy.org/>

VSA Kentucky is a statewide, nonprofit organization dedicated to promoting arts, education and creative expression for all, with an emphasis on persons with disabilities

**Western Kentucky Assistive Technology Center (WKATC)**

(800) 209-6202 or (270) 689-1738

[www.wkatc.org/](http://www.wkatc.org/)

The Western Kentucky Assistive Technology Center (WKATC) was established in March of 1994 to support and enhance the development of an assistive technology service delivery system in Western Kentucky.

## National Resources

### **9 Trisomy International Parent Support (9-TIPS)**

(909) 862-4470

<http://www.trisomy9.org/9tips.htm>

9 Trisomy International Parent Support (9-TIPS) is an international support network for families of children with Trisomy 9. 9-TIPS connects families whose children have a similar Trisomy 9 diagnoses, updates parents on available medical resources, and circulates annual newsletters.

### **Aarskog Syndrome Parent Support**

(215) 943-7131

[mailto: aarskogsyndrome52@msn.com](mailto:aarskogsyndrome52@msn.com)

The Aarskog Syndrome Parent Support offers professionals, organizations, and Aarskog Syndrome families with information and contacts. Children can participate in the Aarskog Pen Pal Club and parents are connected with other families for mutual support. There is no website.

### **AbilityPath.org**

<http://www.abilitypath.org/>

Ability path is an on-line resource created to offer support for parents of children with special needs.

### **ABLEDATA**

(800) 227-0216 or (301) 608-8998

<http://www.abledata.com/>

Abledata provides objective information about assistive technology products and rehabilitation equipment.

### **Aboutface**

(800) 665-3223

<http://aboutface.ca/>

Aboutface is a nonprofit support and information network which provides emotional support and information to, and on behalf of, individuals who have facial differences and their families. Aboutface provides a newborn care provider package, booklets of information on specific conditions, a quarterly newsletter, hospital visits, school programs, and local chapters across North America. Information is available in English, Spanish and Portuguese.

### **Acoustic Neuroma Association (ANA)**

(770) 205-8211 or (877) 200-8211

<http://www.anausa.org/>

Acoustic Neuroma Association (ANA) provides information and support to patients who have been diagnosed with or treated for an acoustic neuroma or other benign problem affecting the cranial nerves. ANA also furnishes information on patient rehabilitation to physicians and

health care personnel; promotes and supports research on acoustic neuroma and its affects; and educates the public regarding symptoms suggestive of acoustic neuroma, thus promoting early diagnoses and successful treatment.

**ADARA: Professionals Networking for Excellence in Service Delivery With Individuals Who Are Deaf or Hard of Hearing**

<http://www.adara.org/>

ADARA is a professional membership organization. Its mission is to facilitate excellence in human service delivery with individuals who are Deaf or Hard of Hearing. ADARA (1) enhances the professional competencies of the membership; (2) expands opportunities for networking among ADARA colleagues and; (3) supports positive public policies for individuals who are Deaf or Hard of Hearing.

**Administration on Developmental Disabilities (ADD)**

(202) 690-6590

<http://www.acf.hhs.gov/programs/add/>

The Administration on Developmental Disabilities (ADD) ensures that individuals with developmental disabilities, and their families, participate in the design of and have access to culturally competent services, supports, and other opportunities that promote independence, productivity, and integration and inclusion into the community. ADD promotes self advocacy, inclusion, and increases public awareness. ADD is part of the U. S. Department of Health and Human Services.

**Adventures in Movement for the Handicapped, Inc. (AIM)**

(937) 294-4611 or (800) 332-8210

<http://www.aimforthehandicapped.org/>

Adventures in Movement (AIM) for the Handicapped has developed the AIM Method of Specialized Movement Education, a series of rhythmical exercises involving gross and fine motor movements. The purpose of the method is to improve muscle control and coordination, and thereby enhance self-image. The organization's major activity is the training of classroom teachers and volunteers in the AIM Method. Workshops are planned to meet the particular needs of sponsoring groups. Brochures describe the AIM Method and the organization's workshops. A handbook, "Adventures in Movement for the Handicapped", illustrates the exercises used in AIM classes. The organization will provide a list of school systems with AIM programs upon request. There is no charge for information or services.

**Aicardi Syndrome Foundation (ASF)**

(800) 374-8518

<http://www.aicardisyndrome.org/site/>

ASF provides funds for the purchase of medical and adaptive equipment for affected daughters, publication and distribution of the Aicardi Syndrome Newsletter, and contributes to ongoing research into the causes of Aicardi syndrome. The foundation is funded by private donations and various fundraising efforts. Supports also include e-mail groups, newsletter, chat room, and sibling outreach program.

**AIDS.gov**

<http://www.aids.gov/>

AIDS.gov is the official government website that provides information about HIV/AIDS in one place. It is operated by the U. S. Department of Health and Human Services.

**AIDSinfo**

(800) 448-0440

<http://www.aidsinfo.nih.gov/>

AIDSinfo is a U. S. Department of Health and Human Services (DHHS) project providing information on HIV/AIDS clinical research, treatment and prevention, and medical practice guidelines for people living with HIV/AIDS, their families and friends, health care providers, scientists, and researchers. AIDSinfo is a central resource for current information on federally and privately funded clinical trials for AIDS patients and others infected with HIV. There is Spanish-speaking staff, email, and live help capability available.

**Alexander Graham Bell Association for the Deaf and Hard of Hearing (AG BELL)**

(202) 337-5220

<http://nc.agbell.org/netcommunity/page.aspx?pid=348>

AG Bell helps families, health care providers and educators understand hearing loss. They help families understand their legal rights and have a list of local chapters.

**Alliance for Technology Access (ATA)**

(800) 914-3017 or (731) 554-5282

<http://www.ataccess.org/>

The ATA is a national network of community-based resource centers, product developers, vendors, service providers, and individuals. It provides information and support services to children and adults with disabilities, and works to increase their use of technology.

**American Academy of Allergy, Asthma & Immunology (AAAAI)**

(414) 272-6071

<http://www.aaaai.org/home.aspx>

The AAAAI represents allergist/immunologists, allied health professionals and others with a special interest in the research and treatment of allergic disease. The AAAAI serves as an advocate to the public by providing educational information about allergic diseases. Their website provides useful patient information, professional education, member updates, physician referral services, and timely data for the media.

**American Academy of Child and Adolescent Psychiatry (AACAP)**

(202) 966-7300

<http://www.aacap.org/>

The American Academy of Child and Adolescent Psychiatry (AACAP) website page "Facts for Families" provides concise and up-to-date information on issues that affect children, teenagers, and their families. This is available in English, Spanish, German, French, Malaysian, Polish, and

Icelandic. The AACAP is a membership based organization, composed of over 7,500 child and adolescent psychiatrists and other interested physicians.

**American Alliance for Health, Physical Education, Recreation and Dance (AAHPERD)**

(800) 213-7193 or (703) 476-3400

<http://www.aahperd.org/>

The American Alliance for Health, Physical Education, Recreation and Dance (AAHPERD) is a professional organization of those involved in physical education, leisure, fitness, dance, health promotion, and education and all specialties related to achieving a healthy lifestyle. AAHPERD provides members with an array of resources, support, and programs to help practitioners improve their skills.

**American Art Therapy Association (AATA)**

(888) 290-0878 or (703) 548-5860

<http://www.arttherapy.org/>

The American Art Therapy Association (AATA) is a nonprofit organization of professionals and students that has established standards for art therapy education, ethics, and practice. AATA committees actively work on governmental affairs, clinical issues and professional development.

**American Association for Vocational Instructional Materials (AAVIM)**

(800) 228-4689

<http://www.aavim.com/>

The American Association for Vocational Instructional Materials (AAVIM) is a nonprofit association which develops, produces, and distributes instructional materials for instructors, students, and administrators of vocational education.

**American Association of Children's Residential Centers (AACRC)**

(877) 332-2272

<http://www.aacrc-dc.org/>

The American Association of Children's Residential Centers (AACRC) is a national organization of professionals who strive to advance the knowledge of therapeutic living environments for children and adolescents with behavioral health disorders.

**American Association of Kidney Patients, Inc. (AAKP)**

(800) 749-2257 or (813) 636-8100

<http://www.aakp.org/>

The American Association of Kidney Patients (AAKP) exists to serve the needs, interests and welfare of all kidney patients and their families. Its mission is to help them to deal with the physical, emotional and social impact of kidney disease. AAKP engages in a variety of educational and supportive programs.

**American Association of Suicidology (AAS)**

(202) 237-2280

<http://www.suicidology.org/web/guest/home>

AAS is a membership organization for all those involved in suicide prevention and intervention, or touched by suicide. AAS is a leader in the advancement of scientific and programmatic efforts in suicide prevention through research, education and training, the development of standards and resources, and survivor support services.

**American Association on Intellectual and Developmental Disabilities (AAIDD)**

(800) 424-3688 or (202) 387-1968

<http://www.aidd.org/>

AAIDD is an interdisciplinary membership organization of professionals and citizens. It promotes progressive policies, sound research, effective practices, and universal human rights for people with intellectual and developmental disabilities.

**American Behçet's Disease Association (ABDA)**

(800) 723-4238

<http://www.behcets.com/>

The American Behçet's Disease Association is a private not for profit organization. Its mission is to provide support and information to people with Behçet's Disease and their families and to educate the medical community about Behçet's Disease.

**American Brain Tumor Association (ABTA)**

(800) 886-2282 or (847) 827-9910

<http://www.abta.org/>

American Brain Tumor Association (ABTA) provides information about brain tumors, treatment options, clinical trials, and living with a brain tumor. It offers family support, and publishes more than 20 easy-to-understand publications that address brain tumors and treatment, and many more patient services.

**American Cancer Society, Inc. (ACS)**

(800) 227-2345 or (404) 320-3333

<http://www.cancer.org/>

The American Cancer Society (ACS), is a nationwide, community-based, voluntary organization. It shows people how to stay healthy, find support and treatment when needed, study the research on causes and cures for cancer. Spanish language information is at <http://www.cancer.org/Espanol/index> and Asian language materials are at <http://www.cancer.org/AsianLanguageMaterials/index>

**American Childhood Cancer Organization (ACCO)**

(301) 962-3520 or (800) 366-2223

<https://acco.org/>

American Childhood Cancer Organization (ACCO) was formerly called Candlelighters Childhood Cancer Foundation (CCCF). It educates, supports, and advocates for families of children with cancer; survivors of childhood cancer; and the professionals who work with them. It has an

information clearinghouse; advocacy; support groups; publications; and an ombudsman program for health insurance problems, second opinions, insurance, and employment issues.

**American Council for Drug Education (ACDE)**

(646) 505-2061

<http://www.acde.org/>

The American Council for Drug Education is a substance abuse prevention and education agency that develops programs and materials based on the most current scientific research on drug use and its impact on society. It has materials for different groups: parents, youth, educators, employers, and college age students. ACDE is a project of Phoenix House.

**American Council of the Blind (ACB)**

(800) 424-8666 or (202) 467-5081

<http://www.acb.org/>

The American Council of the Blind (ACB) is a national organization of blind, visually impaired and sighted individuals whose purpose is to work toward independence, security, equality of opportunity, and improved quality of life for all blind and visually impaired people.

**American Dance Therapy Association (ADTA)**

(410) 997-4040

<http://www.adta.org/>

The American Dance Therapy Association works to establish and maintain high standards of professional education and competence in the field of dance/movement therapy. ADTA stimulates communication among dance/movement therapists and members of allied professions through publication of the ADTA Newsletter, the American Journal of Dance Therapy, monographs, bibliographies, and conferences.

**American Diabetes Association (ADA)**

1-800-DIABETES (1-800-342-2383)

<http://www.diabetes.org/>

The American Diabetes Association works to educate the public on diabetes, and to encourage research.

**American Foundation for AIDS Research, Inc. (amfAR)**

1-800-39-amfAR or (212) 806-1600

<http://www.amfar.org/>

The Foundation for AIDS Research (amfAR) is a nonprofit organization dedicated to the support of HIV/AIDS research, AIDS prevention, treatment education, and the advocacy of sound AIDS-related public policy.

**American Foundation for the Blind**

(800) 232-5463 or (212) 502-7600

<http://www.afb.org/>

The American Foundation for the Blind (AFB) is a national nonprofit organization that broadens access to technology; elevating the quality of information and tools for the professionals who serve people with vision loss; and promoting independent and healthy living for people with vision loss by providing them and their families with relevant and timely resources.

**American Heart Association (AHA)**

(800) 242-8721

<http://www.heart.org/HEARTORG/>

The American Heart Association's (AHA) mission is the reduction of death and disability due to cardiovascular diseases and stroke. AHA: (1) funds research; (2) gathers information; and (3) disseminates the information through its publications and the media. AHA affiliates give referrals to local services, such as cardiac and stroke rehabilitation centers, dietitians, and smoking cessation classes. AHA has materials in Spanish.

**American Horticultural Therapy Association (AHTA)**

(800) 634-1603

<http://www.ahta.org/>

The American Horticultural Therapy Association (AHTA) is a nonprofit organization that promotes the profession of horticultural therapy as a therapeutic intervention and rehabilitative medium. AHTA: (1) disseminates information; (2) promotes research; (3) establishes professional standards and accreditation; (4) provides professional registration; (5) offers memberships; and (6) manages the Douglas J. Schwartz Greenhouse Grants Program.

**American Indian Parent Network (AIPN)**

(952) 838-9000

<http://www.pacer.org/aipn/>

American Indian Parent Network (AIPN), a project of the PACER Center, is a support and information center for Indian parents of children and adolescents with emotional or behavioral disorders or who are at-risk. AIPN services include: workshops for parents and professionals; parent-to-parent support; written information; culturally competent services; and Indian Family Resource Consultants.

**American Liver Foundation (ALF)**

(800) 465-4837

<http://www.liverfoundation.org/>

The American Liver Foundation is a national, voluntary nonprofit organization dedicated to the prevention, treatment, and cure of hepatitis and other liver diseases through research, education and advocacy. They have materials in Spanish.

**American Lung Association (ALA)**

1-800-LUNGUSA or (202) 785-3355

<http://www.lungusa.org/>

The American Lung Association (ALA) seeks to save lives by improving lung health and preventing lung disease. It works to eliminate tobacco use and tobacco-related lung disease,

improve the air we breathe, and reduce the burden of lung disease on patients and their families. Basic information for families about lung diseases, including asthma is on the web site. Some information is available in Spanish.

**American Mental Health Counselors Association (AMHCA)**

(703) 548-6002 or (800) 326-2642

<http://www.amhca.org/>

The American Mental Health Counselors Association (AMHCA) provides support to professional mental health counselors. AMHCA is committed to improving the availability and quality of mental health counseling services through licensure and certification, political and legislative action, rigorous training standards, and consumer advocacy.

**American Music Therapy Association (AMTA)**

(301) 589-3300

<http://www.musictherapy.org/>

The American Music Therapy Association (AMTA) advances public awareness of music therapy benefits, and increases access to quality music therapy services. AMTA establishes criteria for the education and clinical training of music therapists, and association members adhere to a Code of Ethics and Standards of Practice in their delivery of music therapy services. Research findings and clinical studies relevant to the practice of music therapy are available through the "Journal of Music Therapy," "Music Therapy Perspectives," and other publications. AMTA also provides technical assistance to parents, administrators, and related health care providers about the profession of music therapy.

**American Network of Community Options and Resources (ANCOR)**

(703) 535-7850

<http://www.ancor.org/>

ANCOR is an organization for private providers of services and supports for individuals with disabilities.

**American Orthotic and Prosthetic Association (AOPA)**

(571) 431-0876

<http://www.aopanet.org/>

The American Orthotic & Prosthetic Association (AOPA) is a national trade association committed to providing high quality, unprecedented business services and products to Orthotic and Prosthetic (O&P) professionals, companies, suppliers, and affiliates who design, fabricate, fit, and supervise the use of orthoses (orthopedic braces) and prostheses (artificial limbs).

**American Physical Therapy Association (APTA)**

(800) 999-2782 or (703) 684-2782

<http://www.apta.org/>

The American Physical Therapy Association (APTA) is an individual professional organization representing physical therapists, physical therapist assistants, and students. The web site has a section "For the Public" with useful resources for patients and their families.

**American Printing House for the Blind (APH)**

(502) 895-2405 or (800) 223-1839

<http://www.aph.org/>

The American Printing House for the Blind (APH) produces (1) books and magazines in braille, large-type, and recorded form; (2) writing and recording equipment for use by students and adults; (3) materials for teaching blind students; and (4) special supplies used in education and by adults. APH also maintains LOUIS, an online database of information on special materials available for the education of blind students.

**American Pseudo-Obstruction and Hirschsprung's Disease Society (APHS)**

(978) 685-4477

<mailto:aphs@tiac.net>

The American Pseudo-Obstruction and Hirschsprung's Disease Society (APHS) is an international support organization that promotes public awareness of gastrointestinal motility disorders and Hirschsprung's disease. It provides education and support to families of children who have been diagnosed with these disorders through parent-parent contact, publications, and annual educational symposiums.

**American Psychological Association (APA)**

(800) 374-2721 or (202) 336-5500

<http://www.apa.org/>

The American Psychological Association (APA) is a scientific and professional organization which works to: (1) advance psychology as a science and profession; (2) promote research; (3) increase and disseminate psychological knowledge; and (4) apply research findings to the promotion of the public welfare. The "Psychology Topics" page of the web site provides basic information for the public.

**American School Counselor Association (ASCA)**

(703) 683-2722 or (800) 306-4722

<http://www.schoolcounselor.org/>

The American School Counselor Association (ASCA) supports school counselors' efforts to help students focus on academic, personal/social and career development so they not only achieve success in school but are prepared to lead fulfilling lives as responsible members of society. It provides professional development, publications and other resources.

**American School Health Association (ASHA)**

(800) 445-2742

<http://www.ashaweb.org/>

The American School Health Association (ASHA) unites the many professionals working in schools who are committed to safeguarding the health of school-aged children. ASHA promotes coordinated school health programs including health services, health education, food services, counseling and psychology, physical education, and a healthy school environment.

**American Society for Deaf Children (ASDC)**

(800) 942-2732

<http://www.deafchildren.org/>

The American Society for Deaf Children (ASDC) is a national, nonprofit membership organization that acts as a clearinghouse for exchange of information among parents of the deaf and between parents of the deaf and deafness professionals. ASDC supports sign language, provides general information about deafness and raising children, and refers new inquirers to other parents of deaf children in their own geographical areas.

**American Speech-Language-Hearing Association (ASHA)**

(800) 638-8255

<http://www.asha.org/>

The American Speech-Language-Hearing Association (ASHA) is a professional association for speech-language pathologists; audiologists; and speech, language, and hearing scientists. ASHA promotes the interests of, and provides services for its members, and advocates for people with communication disabilities. Its web site has a section for the public with information about hearing, speech, and language topics.

**American Syringomyelia Alliance Project, Inc. (ASAP, Inc.)**

(800) 272-7282 or (903) 236-7079

<http://www.asap.org/>

ASAP (American Syringomyelia Alliance Project) is a nonprofit organization that works to increase public awareness of Syringomyelia, Chiari Malformations and related disorders. ASAP supports research efforts, raises funds to develop new treatments and to improve existing treatments, and coordinates efforts of related organizations.

**American Therapeutic Recreation Association (ATRA)**

(601) 450-2872

<http://www.atra-online.com/>

American Therapeutic Recreation Association (ATRA) represents the interests and needs of recreational therapists. Recreational therapists are health care providers using recreational therapy interventions for improved functioning of individuals with illness or disabling conditions.

**American Network of Community Options and Resources (ANCOR)**

(703) 535-7850

<http://www.ancor.org/>

ANCOR is an organization for private providers of services and supports for individuals with disabilities.

**Americans with Disabilities Act (ADA) & Accessible IT Resource Center**

(800) 949-4232 (V/TTY)

<http://www.sedbtac.org/>

**Angelman Syndrome Foundation (ASF)**

(800) 432-6435

<http://www.angelman.org/>

The Angelman Syndrome Foundation (ASF) offers support and information to families of children with the syndrome. It provides information about Angelman Syndrome, supports research efforts, and links parents of children with Angelman Syndrome to one another.

**Angioma Alliance**

(866) 432-5226

<http://www.angiomaalliance.org/>

Angioma Alliance is a nonprofit volunteer organization dedicated to improving the lives of those affected by cavernous angioma of the brain and spine. Through their website they provide information about cavernous angioma; a community forum; and contact information for research studies seeking participants.

**Anxiety Disorders Association of America (ADAA)**

(240) 485-1001

<http://www.adaa.org/>

The Anxiety Disorders Association of America (ADAA) promotes the prevention, treatment and cure of anxiety disorders and improvement in the lives of all people who are affected by them. The ADAA has an extensive web site, publishes a variety of materials, convenes an annual conference, advocates for patients' rights, and supports anxiety disorders research.

**Aplastic Anemia & MDS International Foundation, Inc. (AA&MDSIF)**

(800) 747-2820 or (301) 279-7202

<http://www.aamds.org/>

The Aplastic Anemia & MDS International Foundation, Inc. provides patient assistance, advocacy, and support. It provides information on aplastic anemia and myelodysplastic syndromes (MDS), and supports research to find treatments and a cure for AA, MDS, and related bone marrow diseases.

**ARCH National Respite Network**

(703) 256-2084 or (206) 632-5208

<http://www.archrespite.org/>

ARCH National Respite Network and Resource Center assists and promotes the development of quality respite and crisis care programs. It also helps families locate respite and crisis care services in their communities. The web site provides both information and referrals. Email for Maggie Edgar is: [edgar@zipcon.net](mailto:edgar@zipcon.net). ARCH is a project of Chapel Hill Training-Outreach Project, Inc. (CHTOP).

**Arc of the United States**

(800) 433-5255

<http://www.thearc.org/>

The Arc is a community based organization of and for people with intellectual and developmental disabilities. The Arc is devoted to promoting and improving supports and services for all people with intellectual and developmental disabilities through education, research, advocacy, and support of families, friends and community. State and local chapters provide a variety of services to individuals and their families, including advocacy, parent support, daycare centers, employment, and residential programs.

**Arthritis Foundation**

(800) 283-7800

<http://www.arthritis.org/>

The Arthritis Foundation offers support and information for people with arthritis. Its web site has information on types of arthritis, research, and advocacy.

**Asthma and Allergy Foundation of America (AAFA)**

(800) 727-8462

<http://www.aafa.org/>

The Asthma and Allergy Foundation of America (AAFA) is a nonprofit organization dedicated to finding a cure for and controlling asthma and allergic diseases. It provides informational resources on allergy and asthma, has an advocacy component, and supports research. There is information in Spanish on the web site.

**Asperger Syndrome Education Network (ASPEN)**

(732) 321-0880

<http://www.aspenni.org/>

ASPEN is a volunteer non-profit organization headquartered in New Jersey. Aspen's web site has information on Autism Spectrum Disorders, school-related issues, social skills, and bullying.

**Association for Career and Technical Education (ACTE)**

(703) 683-3111 or (800) 826-9972

<http://www.acteonline.org/>

The Association for Career and Technical Education works for the advancement of education that prepares youth and adults for careers. They focus on professional development, career development, program improvement, policy development and advocacy, and promoting career and technical education to the general public. Previously called the American Vocational Association (AVA).

**Association for Children with Down Syndrome (ACDS)**

(516) 933-4700

<http://www.acds.org/>

The Association for Children with Down Syndrome (ACDS) combines national information and research dissemination with direct services at the local level. Direct services include: (1) infant, toddler, and preschool programs; (2) the 5-Plus Program (for older children); (3) programs for the family; (4) community education and services; and (5) bilingual (Spanish-English) services.

**Association for Glycogen Storage Disease (AGSD)**

(563) 514-4022

<http://www.agsdus.org/>

The Association for Glycogen Storage Disease was organized to foster communication between parents, and between parents and professionals in the field. The association provides free brochures and publishes a Parent Handbook.

**Association for Macular Diseases, Inc. (AMD)**

(212) 605-3719

<http://www.macula.org/>

The Association for Macular Diseases (AMD) is a nonprofit corporation organized to promote education and research. AMD publishes a newsletter and provides support to individuals and their families.

**Association for Neuro-Metabolic Disorders (ANMD)**

(419) 885-1809

The Association for Neuro-Metabolic Disorders (ANMD) offers support and education to families with children only with the disorders of maple syrup urine disease (MSUD), phenylketonuria (PKU), galactosemia, and biotinidase deficiency. ANMD offers a newsletter, a membership roster, a yearly parent networking, formal lobbying and educational efforts, and contact with similar organizations nationwide. ANMD also provides educational information for parents and children, provides networking information on support groups for new parents, and supports scientific research into the treatments of neuro-metabolic disorders.

**Association of Specialized and Cooperative Library Agencies (ASCLA)**

(800) 545-2433

<http://www.ala.org/ascla>

The Association of Specialized and Cooperative Library Agencies (ASCLA) represents specialized library agencies, state library agencies, library cooperatives, and independent librarians. Library agencies provide library materials and service to populations with special needs, such as those with sensory, physical, health or behavioral conditions or those who are incarcerated or detained.

**Association of University Centers on Disabilities (AUCD)**

(301) 588-8252

<http://www.aucd.org/template/index.cfm>

This is an association of interdisciplinary centers working to advance policy and practice for individuals with developmental and other disabilities and their families.

**Attachment & Trauma Network**

913-440-0306

<http://www.radzebra.org/>

Attachment & Trauma Network (ATN) is a parent-led organization supporting families of traumatized children. It is a support, education and advocacy system for those raising traumatized and attachment-disordered children.

### **Attention Deficit Disorder Association**

<http://www.add.org/>

The Attention Deficit Disorder Association (ADDA) is the world's leading adult ADHD organization. Our mission is to provide information, resources and networking opportunities to help adults with Attention Deficit/ Hyperactivity Disorder (AD/HD) lead better lives.

### **Autism Information Center**

(800) 232-4636

<http://www.cdc.gov/ncbddd/autism/index.html>

The Autism Information Center is part of the National Center on Birth Defects and Developmental Disabilities within the Centers for Disease Control. The Autism Center provides information about Autism Spectrum Disorders (ASD) and links to related projects within CDC and in other federal agencies; as well as links to ASD programs at the state level; and additional resources for families and researchers.

### **Autism National Committee (AUTCOM)**

(610) 649-9139

<http://www.autcom.org/>

The Autism National Committee (AUTCOM) seeks to protect and advance the human and civil rights of all persons with autism, Pervasive Developmental Disorder (PDD) and related differences of communication and behavior. AUTCOM holds annual conferences; advocates nationally on legislative, regulatory, and legal issues; and supports members through information, networking, and referrals.

### **Autism Research Institute (ARI)**

(619) 281-7165 or (866) 366-3361 or (877) 644-1184 , ext. 5 (Spanish)

<http://www.autism.com/index.asp>

Autism Research Institute (ARI) is a network of parents and professionals conducting and fostering scientific research designed to improve the methods of diagnosing, treating, and preventing autism and other related disorders of childhood. The web site has pages for families, educators, providers, and ASD individuals.

### **Autism Society of America (ASA)**

(800) 328-8476 or (301) 657-0881

<http://www.autism-society.org/>

The Autism Society (ASA) is a grassroots autism organization which exists to improve the lives of all affected by autism. It does this by increasing public awareness about the day-to-day issues faced by people on the spectrum, advocating for appropriate services for individuals across the

lifespan, and providing the latest information regarding treatment, education, research and advocacy.

**Autism Speaks**

(212) 252-8584

<http://www.autismspeaks.org/>

Autism Speaks is an autism science and advocacy organization. It is dedicated to funding research into the causes, prevention, treatments and a cure for autism; increasing awareness of autism spectrum disorders; and advocating for the needs of individuals with autism and their families. Autism Speaks merged with the Autism Coalition for Research and Education (ACRE), the National Alliance for Autism Research (NAAR), and Cure Autism Now (CAN).

**Autistic Self Advocacy Network (ASAN)**

<http://www.autisticadvocacy.org/>

The Autistic Self Advocacy Network (ASAN) is a non-profit organization run by and for people with autism. ASAN was created to provide support and services to individuals on the autism spectrum while working to educate communities and improve public perceptions of autism.

**Bazelon Center for Mental Health Law**

(202) 467-5730

<http://www.bazelon.org/>

Bazelon Center for Mental Health Law is a leading national legal / advocacy organization representing people with mental disabilities. It promotes laws and policies that can enable people with psychiatric or developmental disabilities to exercise their life choices and access the resources they need to participate fully in their communities.

**Beach Center on Disability**

(785) 864-7600

<http://www.beachcenter.org/>

The Beach Center on Disability seeks to make a significant and sustainable difference in the quality of life of families and individuals affected by disability and of those who are closely involved with them. The Beach Center It (a) conducts research, (b) carries out training and technical assistance, and (c) provides international, national, state, regional, and local service. The Beach Center is a part of the University of Kansas.

**Beckwith Wiedemann Children's Foundation**

(508) 994-4839

<http://www.beckwith-wiedemannsyndrome.org/>

The Beckwith Wiedemann Children's Foundation is an organization is for parents, professionals, and others interested in Beckwith-Wiedemann Syndrome (BWS). Major goals of the foundation include: increasing the quality of life for those with this disorder, providing information on the latest research efforts and conferences, and linking to other sources of information.

**Benign Essential Blepharospasm Research Foundation, Inc. (BEBRF, Inc.)**

(409) 832-0788

<http://www.blepharospasm.org/>

The Benign Essential Blepharospasm Research Foundation, Inc. (BEBRF, Inc.) (1) funds and promotes medical research in the search for the cause and a cure for blepharospasm and Meige; (2) provides support, education and referrals to persons with these disorders, as well as hemifacial spasms and other related conditions of the facial musculature; and (3) disseminates information and serves as an authoritative resource to the medical community and the general public.

**Best Buddies International (BBI)**

(305) 374-2233 or (800) 89-BUDDY

<http://www.bestbuddies.org/>

Best Buddies International (BBI) aims to enhance the lives of people with intellectual disabilities by providing opportunities for one-on-one friendships and integrated employment. The non-profit 501(c)(3) organization fosters mutually enriching friendships between people with mild to moderate intellectual disabilities and college students, high school students, middle school students, and community members.

**Better Hearing Institute (BHI)**

(202) 449-1100

<http://www.betterhearing.org/>

The Better Hearing Institute (BHI) is jointly funded by the manufacturers and suppliers who comprise the hearing industry in the U.S. BHI operates a call center where consumers can ask questions about hearing loss, and the organization distributes helpful brochures, including "Your Guide to Financial Assistance for Hearing Aids".

**Blind Children's Center (BCC)**

(323) 664-2153

<http://www.blindchildrenscenter.org/>

The Blind Children's Center (BCC) is a nonprofit organization offering diversified services for young children who are blind, those who have visual impairments, and those who have multiple disabilities including blindness. BCC provides a toll-free national hotline for parents of children who have visual impairments and who live outside the Los Angeles area.

**Bookshare**

(650) 352-0198

<http://www.bookshare.org/>

Bookshare provides an online library of accessible reading materials for people with print disabilities. Through an award from the U.S. Department of Education, Office of Special Education Programs (OSEP), Bookshare offers free memberships to U.S. schools and qualifying U.S. students. Individuals can sign up for membership and access the library on their own.

Organizations that serve individuals with print disabilities (schools, libraries, community centers, etc.) can sign up and provide access to their students or clients.

**Boy Scouts of America (BSA)**

(972) 580-2000

<http://www.scouting.org/>

The Boy Scouts of America (BSA) National Council is designed to include young people with special needs in regular Scout units or in units at schools and homes when inclusion in ongoing scouting activities is not possible. Audiovisual and print publications for Scout leaders contain specific activities for Scouts with special needs and ways to involve people with disabilities in regular scouting activities. Scouting manuals are available on how to involve and include people with different disabilities, including: (1) mental retardation, (2) physical disabilities, (3) deafness or hearing impairment, (4) emotional disturbance, (5) blindness or visual impairment, or (6) learning disabilities.

**Brain Injury Association of America**

(800) 444-6443 or (703) 761-0750

<http://www.biausa.org/>

The Brain Injury Association of America (BIAA) is the leading national organization that provides information, education and support to assist people with traumatic brain injury (TBI) and their families. It has a network of more than 40 chartered state affiliates, as well as hundreds of local chapters and support groups across the country, with contact listings for each.

**Brain Tumor Foundation for Children, Inc. (BTFC)**

(404) 252-4107

<http://www.braintumorkids.org/>

Brain Tumor Foundation for Children aims to provide financial assistance, social support, and information for families of children with brain and spinal cord tumors; fund research projects that improve treatment options and search for a cure; and raise public awareness of the disease and advocate on behalf of children who are affected.

**Burn Survivors Throughout The World, Inc. (BSTTW)**

(936) 647-2256 or (866)712-6164

<http://www.burnsurvivorsttw.org/flashintro/index.html>

Burn Survivors Throughout The World, Inc. (BSTTW) is an International 501 (c)(3) Non Profit Organization. BSTTW offers memberships, peer support, education and advocacy for burn survivors, family, friends, medical professionals and the public around the world. The website offers email lists, weekly and public chats, articles, stories, poems, polls, pictures, newsletters, message boards and links. It is also available in other language formats.

**Cancer Information and Counseling Line (CICL)**

(800) 321-1557 or (303) 233-6501

<http://www.amc.org/>

The Cancer Information and Counseling Line (CICL) is a national toll-free telephone line, providing facts about all aspects of cancer, as well as personal assistance from counselors experienced with the challenges faced by those dealing with cancer. CICL gives the general public access to the latest information on cancer prevention, detection, diagnosis, treatment, and rehabilitation, including the Physicians' Data Query (PDQ).

**Camp Fire USA**

(816) 285-2010

<http://www.campfireusa.org/>

Camp Fire USA is one of the nation's leading not-for-profit youth development organizations, currently serving 750,000 children and youth annually. Camp Fire USA, with national headquarters in Kansas City, Mo., provides all-inclusive, coeducational programs in hundreds of communities across the United States. Camp Fire USA's outcome-based programs include youth leadership, self-reliance, after school groups, camping and environmental education, and child care. Serving youth from birth to 21, Camp Fire USA helps boys and girls learn - and play - side by side in comfortable, informal settings. The Special Sitters program offers training to teens who then babysit children with disabilities.

**Casey Family Programs**

(206) 282-7300

<http://www.casey.org/>

Casey National Center (CNC) is focused entirely on foster care and improving the child welfare system.

**Celiac Sprue Association United States of America, Inc. (CSA/USA Inc.)**

(402) 558-0600 or (877) 272-4272

<http://www.csaceliacs.info/>

The Celiac Sprue Association/United States of America, Inc. (CSA/USA Inc.) is a national network and support organization that offers information and referral services for persons with celiac sprue and dermatitis herpetiformis. CSA/USA Inc. has published a series of low-cost brochures on the gluten-free diet, gluten-free commercial foods, and related topics. A quarterly newsletter, LIFELINE

**Center for Assistive Technology & Environmental Access (CATEA)**

(800) 726-9119 or (404) 894-4960

<http://www.catea.gatech.edu/>

The Center for Assistive Technology & Environmental Access (CATEA) is a research and design center for applications of technology for persons with disabilities. Projects include the development of GATE, online assistive technology information; TechKnowledge, a clearinghouse on AT information; AT assessments and evaluations; Tech Connections, training program for vocational rehabilitation professionals; CAESAR project, collection of data on physically diverse individuals; and Advanced Wood Products Laboratory, high tech design methods to produce wood based products.

**Center for Implementing Technology in Education (CITeD)**

(202) 403-5218 - Technical Assistance

<http://www.cited.org/>

The Center for Implementing Technology in Education (CITeD) identifies evidence-based practices for integrating instructional technology to support the achievement of all students. It is a project of the Technical Assistance and Dissemination Network (TA&D), funded by the U.S. Department of Education, Office of Special Education and Rehabilitative Services (OSERS).

**Center for the Study and Treatment of Usher Syndrome**

(402) 498-6713

<http://www.boystownhospital.org/research/molecularstudies/Pages/UsherSyndrome.aspx>

The purpose of the Center for the Study and Treatment of Usher Syndrome is to support research and provide clinical services for children and adults (and their families) with Usher Syndrome.

**Center for the Study of Social Policy (CSSP)**

(202) 371-1565

<http://www.cssp.org/>

The Center for the Study of Social Policy (CSSP) is a research center which addresses the issue of child welfare. The Center's work is concentrated in the areas of family and children's services, income supports, neighborhood-based services, education reform, family support, disability and health care policy, and long term care for the elderly.

**Center on Disability and Community Inclusion (CDCI)**

(802) 656-4031

<http://www.uvm.edu/~cdci/>

The Center on Disability and Community Inclusion, in collaboration and coordination with individuals with developmental disabilities, their families, and communities, promote opportunities for life outcomes for individuals with disabilities of all ages, in all facets of community life (i.e., meaningful relationships, personal choice and control, meaningful activities, safety and health, and living in a home and community).

**Center on Human Development and Disability (CHDD)**

(206) 543-7701

<http://depts.washington.edu/chdd/>

The Center on Human Development and Disability (CHDD) at the University of Washington makes important contributions to the lives of people with developmental disabilities and their families, through a comprehensive array of research, clinical services, training, community outreach, and dissemination activities.

**Center on the Social and Emotional Foundations for Early Learning (CSEFEL)**

(615) 322-8150

<http://csefel.vanderbilt.edu/>

The Center on the Social and Emotional Foundations for Early Learning (CSEFEL) is focused on promoting the social emotional development and school readiness of young children birth to age 5. CSEFEL is a national resource center funded by the Office of Head Start and Child Care Bureau for disseminating research and evidence-based practices to early childhood programs across the country.

**CFIDS Association of America, Inc.**

(704) 365-2343 [Resource Line]

<http://www.cfids.org/>

The CFIDS Association is transforming from a patient support and advocacy organization to one focused on stimulating and supporting research. Previously called The Chronic Fatigue and Immune Dysfunction Syndrome (CFIDS) Association, Inc.

**CHADD**

<http://www.chadd.org/>

CHADD (Children and Adults with Attention-Deficit/Hyperactivity Disorder) is the nation's leading non-profit organization serving individuals with AD/HD and their families.

**Chapin Hall Center for Children**

(773) 753-5900

<http://www.chapinhall.org/>

The Chapin Hall Center for Children is a research and development center that focuses on the needs of children and the ways in which those needs can best be met. The Center devotes special attention to children facing significant problems, including abuse or neglect, poverty, and mental or physical illness, and to the service systems designed to address these problems.

**Charcot Marie Tooth Association (CMTA)**

(610) 499-9264 or (800) 606-2682

<http://www.cmtausa.org/>

The vision of the Charcot Marie Tooth Association's (CMTA) is to 1. Generate resources to find treatments and a cure for CMT, 2. Create awareness about CMT, and, 3. Improve the quality of life for those affected by CMT.

**CHARGE Syndrome Foundation, Inc.**

(800) 442-7604 or (516) 684-4720

<http://www.chargesyndrome.org/>

The primary mission of the CHARGE Syndrome Foundation is to provide support to individuals with CHARGE syndrome and their families. It also gathers, develops, maintains and distributes information about CHARGE syndrome. Finally, it promotes awareness and research regarding its identification, cause and management.

**CHASER (Congenital Heart Anomalies - Support, Education & Resources)**

(419) 825-5575

<http://www.csun.edu/~hcmth011/chaser/chaser-news.html>

CHASER (Congenital Heart Anomalies - Support, Education & Resources) specializes in children born with congenital heart defects (CHD), "in utero to adult", and also acquired heart disease in infants and children. The primary purpose of the organization is to offer parents, professionals and patients, resources that may help these individuals in their dealings with financial, educational, medical, emotional and other issues that may concern them.

**Child & Adolescent Bipolar Foundation (CABF)**

(847) 492-8519

<http://www.thebalancedmind.org/>

The Child & Adolescent Bipolar Foundation (CABF) educates families, professionals, and the public about early-onset bipolar disorders. It also supports families to maximize the well-being of the child while minimizing the adverse impact of bipolar disorders on the family; and advocates for increased funding for services to families and research on the nature, causes, and treatment of bipolar disorders in the young.

**Childhood Apraxia of Speech Association of North America (CASANA)**

(412) 343-7102

<http://www.apraxia-kids.org/>

CASANA stands for Childhood Apraxia of Speech Association of North America. It supports the Apraxia-Kids Internet Resources, an extensive web site providing information on verbal dyspraxia and developmental apraxia of speech. Topics include evaluation, speech therapy, research, and other childhood communication issues. Contact CASANA by using the web contact form on the web site.

**Children's Brain Diseases Foundation for Research (CBDFR): Batten's Disease Research**

(415) 665-3003

<mailto:jrider6022@aol.com>

The Children's Brain Diseases Foundation for Research (CBDFR): Batten's Disease Research provides information, research updates, and research monies for Batten's Disease. This is an information source only.

**Children's Craniofacial Association (CCA Kids)**

(800) 535-3643 or (214) 570-9099

<http://www.ccakids.com/>

Children's Craniofacial Association (CCA Kids) is a national, 501(c)3 nonprofit organization, headquartered in Dallas, Texas, dedicated to improving the quality of life for people with facial differences and their families. Nationally and internationally, CCA Kids addresses the medical, financial, psychosocial, emotional, and educational concerns relating to craniofacial conditions. Its mission is to empower and give hope to facially disfigured children and their families.

**Children's Hemiplegia and Stroke Association (CHASA)**

(817) 492-4325

<http://www.hemikids.org/>

The Children's Hemiplegia and Stroke Association (CHASA) is a nonprofit corporation that offers support and information for families of children who have cerebral palsy, had a stroke, or suffered a neurological event causing hemiplegia.

**Children's Hospice International (CHI)**

(800) 242-4453 or (703) 684-0330

<http://www.chionline.org/>

Children's Hospice International (CHI) provides education, training and technical assistance to those who care for children with life-threatening conditions and their families. Specifically, CHI seeks to: 1. Promote hospice support through pediatric care facilities, 2. Encourage the inclusion of children in existing and developing hospice and home care programs, 3. Include the hospice perspectives in all areas of pediatric care, education, and the public arena.

**Children's Tumor Foundation**

(212) 344-NNFF [6633] or (800) 323-7938

<http://www.ctf.org/>

Children's Tumor Foundation was formerly called the National Neurofibromatosis Foundation, Inc. (NNFF). It is a non-profit 501(c)(3) medical foundation, dedicated to improving the health and well being of individuals and families affected by the neurofibromatoses (NF). Towards this end the Foundation: (1) sponsors scientific research aimed at finding the cause and cure for both types of neurofibromatosis; (2) promotes the development of clinical activities; (3) develops programs that will increase public awareness; and (4) provides support services for patients and families.

**Christopher and Dana Reeve Foundation**

(800) 225-0292

<http://www.christopherreeve.org/site/c.ddJFKRNoFiG/b.4048063/k.BDDDB/Home.htm>

The Christopher and Dana Reeve Foundation promotes the health and well being of people living with paralysis and their families by providing comprehensive information, resources, and referral services. The Reeve Foundation's Paralysis Resource Center (PRC) promotes the health and well-being of people living with a spinal cord injury, mobility impairment, and paralysis by providing comprehensive information, resources and referral services.

**Chromosome 18 Registry and Research Society**

(210) 657-4968

<http://www.chromosome18.org/>

The Chromosome 18 Registry & Research Society is a lay advocacy organization composed primarily of the parents of individuals with one of the chromosome 18 abnormalities. They also serve affected individuals, extended family members and professionals. Membership is open to any interested person. Their mission is to help individuals with chromosome 18 abnormalities overcome the obstacles they face so they might lead happy, healthy and productive lives.

**Cleft Palate Foundation (CPF)**

(800) 242-5338 or (919) 933-9044

<http://www.cleftline.org/>

The Cleft Palate Foundation (CPF) is the public service arm of the American Cleft Palate-Craniofacial Association. The mission of CPF is to enhance the quality of life for individuals affected by cleft lip and palate and other craniofacial birth defects. It operates a toll-free telephone information line called CLEFTLINE and shares information and referrals.

**Closing The Gap, Inc.**

(507) 248-3294

<http://www.closingthegap.com/>

Closing The Gap, Inc. is an organization that focuses on assistive technology for people with special needs through its bimonthly magazine, annual international conference and extensive Web site.

**Coffin-Lowry Syndrome Foundation (CLSF)**

(425) 427-0939

<http://www.clsf.info/>

The Coffin-Lowry Syndrome Foundation serves as a clearinghouse for information on the syndrome, a support group for parents of CLS children, and a general forum for exchanging experiences, advice, and information. Phone calls are only answered after 5pm PST on weekdays and on weekends.)

**Commission on Accreditation of Rehabilitation Facilities (CARF)**

(888) 281-6531 v/TTY or (520) 325-1044

<http://www.carf.org/home/>

CARF, the Commission on Accreditation of Rehabilitation Facilities, is an independent, nonprofit accreditor of health and human services. Through accreditation, CARF assists service providers in improving the quality of their services, demonstrating value, and meeting internationally recognized standards. Its website has a list of accredited rehabilitative providers and online publications. Some web pages are in Spanish.

**Computer/Electronic Accommodations Program (CAP)**

(703) 681-8813

<http://www.cap.mil/>

This Department of Defense project provides needs assessments, assistive technology and employment accommodations for individuals with disabilities and their employers at the Dept. of Defense.

**Consortium for Appropriate Dispute Resolution in Special Education (CADRE)**

(541) 686-5060

<http://www.directionservice.org/cadre/>

The Center for Appropriate Dispute Resolution in Special Education (CADRE) is the National Center on Dispute Resolution in Special Education. CADRE's website provides resources on

mediation and conflict resolution, training materials, and directories listing trainers, conflict resolution professionals, and state information about mediation. CADRE is a project of the Special Education Technical Assistance and Dissemination Network (TA&D), funded by the U.S. Department of Education, Office of Special Education and Rehabilitative Services (OSERS).

**Cooley's Anemia Foundation, Inc. (CAF)**

(800) 522-7222

<http://www.thalassemia.org/>

The Cooley's Anemia Foundation (CAF) works to advance the treatment and cure for this blood disease by enhancing the quality of life of patients and educating the medical profession, trait carriers and the public about Cooley's anemia / thalassemia major

**Cornelia de Lange Syndrome USA Foundation (CdLS-USA)**

(800) 753-2357 or (860) 676-8166

<http://www.cdlsusa.org/>

Cornelia de Lange Syndrome (CdLS-USA) Foundation increases awareness, encourages accurate and early diagnosis, and enables families and professionals to make responsible decisions about planning for present and future care of children with CdLS.

**Council for Exceptional Children**

(866) 509-0218

<http://www.cec.sped.org/am/template.cfm?section=Home>

The Council for Exceptional Children (CEC) is the largest international professional organization dedicated to improving the educational success of individuals with disabilities and/or gifts and talents. CEC advocates for appropriate governmental policies, sets professional standards, provides professional development, advocates for individuals with exceptionalities, and helps professionals obtain conditions and resources necessary for effective professional practice.

**Craniofacial Foundation of America**

(423) 778-9192 or (800) 418-3223

<http://craniofacialfoundation.org/www>

The Craniofacial Foundation of America is a national resource available for patients with craniofacial anomalies and their families. It produces educational materials and provides networking services for patients and families. It offers financial assistance for non-medical costs such as transportation to the Tennessee Craniofacial Center for evaluation and treatment. It also offers the publication, "Craniofacial Surgery."

**Crohn's and Colitis Foundation of America (CCFA)**

(800) 932-2423

<http://www.ccfa.org/>

The Crohn's & Colitis Foundation of America (CCFA) is a research-oriented voluntary health organization dedicated to finding a cure for Crohn's disease and ulcerative colitis and to

improving the quality of life for those with these conditions. CCFA has both support group and general information.

**Cyclic Vomiting Syndrome Association (CVSA)**

(414) 342-7880

<http://www.cvsaonline.org/>

The Cyclic Vomiting Syndrome Association is an organization for patients, families, and professionals providing support, education, and research for cyclic vomiting syndrome.

**Cystic Fibrosis Foundation (CFF)**

(800) 344-4823 or (301) 951-4422

<http://www.cff.org/>

The Cystic Fibrosis Foundation (CFF) supports efforts to prevent, control, and treat cystic fibrosis.

**Cystinosis Foundation**

(888) 631-1588

<http://www.cystinosisfoundation.org/>

The Cystinosis Foundation is dedicated to supporting for those with cystinosis by means of parental support, education, research support, and affiliations with organizations such as National Organization for Rare Disorders.

**Data Accountability Center (DAC)**

(888) 819-7024

<https://www.ideadata.org/>

The Data Accountability Center (DAC) maintains a website that provides public access to the most recent statewide data about children with disabilities served under the Individuals with Disabilities Education Act (IDEA). DAC is a project of the Special Education Technical Assistance and Dissemination Network (TA&D), funded by the U.S. Department of Education, Office of Special Education and Rehabilitative Services (OSERS).

**Deafness Research Foundation (DRF)**

(866) 454-3924 or (212) 257-6140

<http://www.drf.org/>

The Deafness Research Foundation (DRF) provides private funding for basic and clinical research in hearing science. DRF advocates for detection, prevention, intervention, and research in hearing health for all Americans.

**Depression and Bipolar Support Alliance (DBSA)**

(800) 826-3632

<http://www.dbsalliance.org/>

The Depression and Bipolar Support Alliance (DBSA) is a national patient-directed organization focusing on depression and bipolar disorder. It provides current, scientifically-based tools and

information written in plain language. DBSA supports research to promote more timely diagnosis, develop more effective and tolerable treatments and discover a cure.

**Diabetes Insipidus Foundation, Inc. (DIF)**

<http://www.diabetesinsipidus.org/>

The Diabetes Insipidus Foundation, Inc. (DIF) provides information on diabetes insipidus, also known as "water diabetes." Diabetes insipidus is often mistaken for diabetes mellitus, or "sugar diabetes." It is a rare disease in which the kidneys produce abnormally large volumes of dilute urine. The DIF website includes information on all four forms of Diabetes Insipidus, as well as articles, brochures, stories, FAQ's, networking, research opportunities, a professional section including the Water Deprivation Protocol, and a section for pets.

**Disabled Sports USA**

(301) 217-0960

<http://www.dsusa.org/>

Disabled Sports USA, is an network of chapters offering sports rehabilitation programs to anyone with a permanent disability. Activities include winter skiing, water sports, summer and winter competitions, fitness and special sports events. Participants include those with visual impairments, amputations, spinal cord injury, dwarfism, multiple sclerosis, head injury, cerebral palsy, and other neuromuscular and orthopedic conditions.

**Disability Statistics Center**

(415) 502-5214

<http://www.dsc.ucsf.edu/>

The Disability Statistics Center produces and disseminates policy-relevant statistical information on the demographics and status of people with disabilities in American society. The Center's work focuses on how that status is changing over time with regard to employment, access to technology, health care, community-based services, and other aspects of independent living and participation in society.

**Division for Early Childhood**

[http://www.dec-sped.org/About DEC](http://www.dec-sped.org/About_DEC)

The Division for Early Childhood (DEC) is one of seventeen divisions of the Council for Exceptional Children (CEC) - the largest international professional organization dedicated to improving educational outcomes for individuals with exceptionalities, students with disabilities, and/or the gifted. DEC is especially for individuals who work with or on behalf of children with special needs, birth through age eight, and their families.

**Division on Career Development and Transition (DCDT)**

(804) 827-1403

<http://www.dcdt.org/>

The Division on Career Development and Transition (DCDT) promotes national and international efforts to improve the quality of and access to career, vocational, and transition services for

individuals with disabilities, and to influence policy development regarding these issues. DCDT is a division of the Council for Exceptional Children (CEC).

**Dysautonomia Foundation**

(212) 279-1066

<http://www.familialdysautonomia.org/>

The Dysautonomia Foundation raises funds for research on Familial Dysautonomia and provides information on this rare genetic disorder to the medical community and patients' families. A variety of free printed material is available, including reprints of articles from both professional and lay publications, bibliographies, fact sheets, and brochures on the disease.

**Dystrophic Epidermolysis Bullosa Research Association of America, Inc. (DebRA of America, Inc.)**

(212) 868-1573

<http://www.debra.org/>

DebRA is a non-profit organization working support those affected by Epidermolysis Bullosa by promoting research, education, advocacy, and providing services and support for people with EB and their families.

**Easter Seals**

(800) 221-6827 or (312) 726-6200

<http://www.easterseals.com/>

The mission of Easter Seals is to create solutions that change lives for children and adults with disabilities, their families, and their communities. They work to identify the needs of people with disabilities and to provide appropriate developmental and rehabilitation services.

**Education Commission of the States (ECS)**

(303) 299-3600

<http://www.ecs.org/>

The Education Commission of the States (ECS) is an interstate compact created in 1965 to improve public education by facilitating the exchange of information, ideas and experiences among state policymakers and education leaders. It helps states develop effective policy and practice for public education by providing data, research, analysis and leadership, and by facilitating collaboration, the exchange of ideas and long-range strategic thinking. States learn from one another as they work to improve teaching and learning for students.

**Education Resources Information Center (ERIC)**

(800) 538-3742

<http://www.eric.ed.gov/>

The Education Resources Information Center (ERIC) is a digital library of education-related resources, sponsored by the Institute of Education Sciences of the U.S. Department of Education. It is a free resource for anyone interested in all aspects of education and education-related organizations.

**Ehlers Danlos National Foundation (EDNF)**

(703) 506-2892

<http://www.ednf.org/>

Ehlers Danlos National Foundation (EDNF) disseminates accurate information, provides a network of support, and fosters research for those who have Ehlers Danlos and other connective tissue disorders.

**Exploring Autism**

<http://www.exploringautism.org/>

The Exploring Autism website is the result of a collaboration between researchers, non-profit groups, and families who are living with autism. Organizations who make this site possible range from major universities and medical centers to the National Alliance for Autism Research.

**FACES: The National Craniofacial Association**

(800) 332-2373

<http://www.faces-cranio.org/>

FACES--The National Craniofacial Association is a nonprofit organization serving children and adults throughout the U.S. with severe craniofacial deformities resulting from birth defects, injuries, or disease. All FACES services are free of charge, and its goals include client travel, public awareness and understanding, information, and support.

**Facilitated Communication Institute (FCI)**

(315) 443-9379

<http://soeweb.syr.edu/thefci/>

The Facilitated Communication Institute conducts research, public education, training, and scholarly seminars. It was created to enable the research community, people with disabilities and their families, and practicing professionals to examine, learn about, and share information about facilitated communication.

**Families Anonymous (FA)**

(800) 736-9805

<http://www.familiesanonymous.org/>

Families Anonymous (FA) provides Twelve-Step support groups to family members (parents, grandparents, siblings, and friends) of a loved one who is addicted to drugs and/or alcohol, or other mind-altering substances; or who has behavior problems. FA also has public information materials.

**Families of Spinal Muscular Atrophy (Families of SMA)**

(800) 886-1762 or (847) 367-7620

<http://www.fsma.org/>

The main focus of Families of Spinal Muscular Atrophy (Families of SMA) is on educating the public and providing information and support. Families of SMA also publishes a quarterly

newsletter to keep families and professionals up to date on the latest in research, technology, and day-to-day coping in regards to Spinal Muscular Atrophy.

**Family Center on Technology and Disability (FCTD)**

(202) 884-8068

<http://www.fctd.info/>

The Family Center on Technology and Disability is a resource designed to support organizations and programs that work with families of children and youth with disabilities. Its web site offers a range of information and services on the subject of assistive technologies. FCTD is a project of the Special Education Technical Assistance and Dissemination Network (TA&D), funded by the U.S. Department of Education, Office of Special Education and Rehabilitative Services (OSERS).

**Family Voices, Inc.**

(888) 835-5669 or (505) 872-4774

<http://www.familyvoices.org/>

Family Voices is a national nonprofit whose work focuses on achieving family-centered care for all children and youth with special health care needs and/or disabilities. Their goal is to help families make informed decisions, advocate for improved public and private policies, and build partnerships among professionals and families. Questions/comments may be left on the web contact form on the web site.

**Fetal Alcohol Spectrum Disorders Center for Excellence**

(866) 786-7327

<http://www.fasdcenter.samhsa.gov/index.cfm>

The FASD Center strives to support the development and improvement of prevention, treatment, and care of Fetal Alcohol Spectrum Disorders. It provides leadership and facilitates collaboration at the national, state and community levels.

**First Signs, Inc.**

(978) 346-4380

<http://www.firstsigns.org/>

First Sign strives for the best developmental outcome for every child by promoting awareness regarding the most important aspects of development: social/emotional, communication, and behavior. Its goal is to increase early identification and intervention of children with developmental delays and disorders.

**Forward Face**

(212) 684-5860

<http://www.forwardface.org/>

Forward Face's mission is to help children with craniofacial conditions, and their families, find immediate support that helps empower them to successfully manage the craniofacial condition. Knowing the demands that craniofacial conditions place on the patient as well as the family, Forward Face provides comprehensive services: educational support, advocacy, networking, community organizing, and other forms of assistance, when necessary.

**Foundation Fighting Blindness, Inc.**

(800) 683-5555 or (410) 423-0600

<http://www.blindness.org/>

The Foundation Fighting Blindness funds research to discover the causes, treatments, preventive methods, and cures for Retinitis Pigmentosa, Macular Degeneration, Usher Syndrome, Stargardt Disease, and the entire spectrum of retinal degenerative diseases. It also has information and referral services for individuals, their families, and eye care professionals.

**Foundation for Faces of Children**

(617) 355-8299

<http://www.facesofchildren.org/>

The Foundation for Faces of Children is dedicated to improving the lives of children with craniofacial anomalies, including cleft lip and palate and other skull and facial defects. The Foundation concentrates its efforts on education, training, family support systems, and the dissemination of accurate and timely information. It also funds targeted research about the causes, treatments, and outcomes of these congenital conditions.

**Foundation for the Nager and Miller Syndromes (FNMS)**

(800) 507-3667

<http://www.nagerormillersynd.com/>

The Foundation for the Nager and Miller Syndromes (FNMS) is an international support group dedicated to helping those affected by these two similar genetic conditions which involve severe facial and limb anomalies, but does not typically affect intellect. FNMS serves as an information clearinghouse.

**Fragile X Research Foundation (FRAXA)**

(978) 462-1866

<http://www.fraxa.org/>

The Fragile X Research Foundation (FRAXA) supports scientific research aimed at finding effective treatments and a cure for Fragile X. FRAXA funds grants and fellowships at universities all over the world. The web site provides information on the symptoms, causes, diagnosis and treatment of Fragile X.

**Frank Porter Graham Child Development Center (FPG)**

(919) 966-2622

<http://www.fpg.unc.edu/>

The Frank Porter Graham Child Development Institute is one of the nation's oldest multidisciplinary institutes for the study of young children and their families. Research and education activities focus on child development and health, especially factors that may put children at risk for developmental problems.

**Gallaudet University**

(866) 454-3924 or (212) 257-6140

<http://www.gallaudet.edu/>

Gallaudet University is the only accredited liberal arts college for the deaf in the world. The college offers bachelor degree programs in 50 subject areas, masters programs in 13, and Ph.D. degrees in 3 areas. In addition to the college, a division of pre-college programs, a division of graduate study and research, and a division of institutional advancement now offer a wide range of services and information in the field of hearing impairments. Other programs include: continuing education, sign language and interpreter training, International Center on Deafness, the Deafness Research Institute, the University Library, Center for Assessment and Demographic Studies, and the National Information Center on Deafness.

### **Girl Scouts of the USA**

(800) 478-7248 or (212) 852-8000

<http://www.girlscouts.org/>

Girl Scouts of the USA does not have a separate program for girls with disabilities. Its goal for girls with disabilities is to make the troop and camp experience as much like that of other girls as possible. Regular activities such as camping, sports and recreation, arts, service, and leadership skills are adapted to suit the abilities of individual girls. The Girl Scouts organization publishes "Focus on Ability: Serving Girls with Special Needs," a leaders' guide for including girls with disabilities in the program. All basic program resources are available in Braille, large type, and audio formats.

### **Genetic Alliance**

(202) 966-5557

<http://www.geneticalliance.org/>

Genetic Alliance is a consortium of national voluntary organizations for individuals and families with genetic disorders. The Genetic Alliance promotes genetic education, provides technical assistance to its member organizations, encourages communication among support groups, publishes educational literature, represents the consumer viewpoint before private and government forums, and holds national conferences on topics timely and relevant to consumers and professionals.

### **Group B Strep Association (GBSA)**

<http://www.groupbstrep.org/>

The Group B Strep Association (GBSA) is a non-profit organization formed by a group of parents whose babies were victims of Group B Streptococcal (GBS), to educate the public about GBS infections during pregnancy, and to promote routine screening of mothers. GBSA publishes an educational pamphlet and acts as a support and informational group to parents of GBS babies, to the general public, and to the medical community. GBSA is no longer focusing on phone and postal advocacy. Focus is upon education via the website and email lists.

### **Guardians of Hydrocephalus Research Foundation (GHRF)**

(718) 743-4473

<http://www.ghrforg.org/>

The Guardians of Hydrocephalus Research Foundation (GHRF) conducts research in the area of hydrocephalus and disseminates information to professionals and families.

**Guillain-Barre Syndrome Foundation International**

(610) 667-0131

<http://www.gbs-cidp.org/>

The Guillain-Barre Syndrome Foundation International helps patients and families cope with this disorder. Providing support and assistance to Guillain-Barre Syndrome (GBS) patients and their families and committed to increasing knowledge and awareness in both the public and professional communities, the Foundation provides print information and educational opportunities, sponsors worldwide meetings, lectures and support groups, hosts the bi-annual GBS International Symposium and encourages new findings by awarding research grants for further study and experimentation.

**Hands and Voices**

(303) 492-6283

<http://www.handsandvoices.org/>

Hands and Voices provides families with information about different communication methodologies for children with hearing impairments. From American Sign Language to cochlear implants, Hands and Voices represents people from all different approaches to and experiences with deafness or hearing loss.

**Hear Now**

(866) 354-3254

<http://www.starkeyhearingfoundation.org/>

Hear Now is a national, nonprofit organization committed to making hearing aids accessible to low income individuals with hearing impairments. Hear Now recycles used hearing aids and accepts donations of new and used hearing aids. The Starkey Hearing Foundation took over the Hear Now program, but the program is still in operation.

**Hearing Loss Association of America (HLAA)**

(301) 657-2248

<http://www.hearingloss.org/>

The Hearing Loss Association of America was formerly know as Self Help for Hard of Hearing People, Inc. (SHHH). It educates people about hearing loss detection, management, prevention of further loss, and works to develop public and professional acceptance of the needs of hard of hearing people. HLAA operates a nationwide support network of chapters and groups that meet to learn about hearing loss and coping strategies.

**Helen Keller National Center for Deaf-Blind Youths and Adults (HKNC)**

(516) 944-8900

<http://www.hknc.org/>

The Helen Keller National Center for Deaf-Blind Youths and Adults (HKNC) is part of a consortium of groups serving people who are deaf-blind along with the National Technical

Assistance Consortium for Children & Young Adults Who are Deaf-Blind (NTAC). HKNC develops pamphlets, fact sheets, videos, newsletters, bibliographies, indexes and abstracts of articles on deaf-blindness and rehabilitation for both professionals and laymen and makes many available in Braille, large print, or on disk. HKNC is funded through an Act of Congress (the Helen Keller Act).

**Hemophilia and AIDS/HIV Network for the Dissemination of Information (HANDI)**

(212) 328-3700 or (800) 42-HANDI

<http://www.hemophilia.org>

The Hemophilia and AIDS/HIV Network for the Dissemination of Information (HANDI) is a resource center for coagulation disorders. It answers consumer's questions, provides quality educational publications, makes referrals to additional sources of assistance and responds to the needs of the entire community. It sponsors many activities in education and information, research, advocacy, and resource development. It also helps promote access to clinical trials and, through HANDI, offers many publications.

**HHT Foundation International, Inc. (HHTFI)**

(800) 448-6389

<http://hht.org/>

The HHT Foundation International, Inc. (HHTFI) is dedicated to providing information to parents and physicians about HHT. HHT, also known as Osler-Weber-Rendu Disease, is a rare genetic blood vessel disorder.

**Histiocyte Society**

(856) 589-6606

<http://www.histiocytesociety.org/>

The goals of the Histiocyte Society are to promote clinical and laboratory research into the histiocyte and histiocytic disorders, to standardize nomenclature and investigation, and to advance understanding of these conditions.

**Human Growth Foundation (HGF)**

(800) 451-6434

<http://www.hgfound.org/>

The Human Growth Foundation (HGF) is a voluntary, nonprofit organization dedicated to helping medical science better understand the process of growth. It is composed of concerned parents and friends of children with growth problems and interested health professionals. Its objectives are support of research, family education and service, public education, support of training for growth specialists, education of the medical profession, and parent-to-parent support/networking program.

**Huntington's Disease Society of America (HDSA)**

(800) 345-HDSA or (212) 242-1968

<http://www.hdsa.org/>

The Huntington's Disease Society of America is a national non-profit voluntary health agency that is dedicated to finding a cure for Huntington's Disease (HD) while providing both vital services to improve the lives of those affected by HD, and support and guidance for HD families through our national network of volunteer-based chapters and affiliates as well as through our newly created Centers of Excellence. They provide leadership, support and guidance to HD families.

**Hydrocephalus Association**

(888) 598-3789 or (415) 732-7040

<http://www.hydroassoc.org/>

The Hydrocephalus Association provides support, education, resources, and advocacy for families and professionals. It has many publications available, including a quarterly newsletter, fact sheets, and resource packets. The website features methods to order free publications, links, and physician directories.

**Immune Deficiency Foundation (IDF)**

(800) 296-4433

<http://primaryimmune.org/>

The Immune Deficiency Foundation (IDF) is a national organization for the promotion of research, medical training, and patient information on the primary immune deficiency disorders. IDF has developed programs and publications for patients, families and medical professionals. Patient support is available via website forums.

**Independent Living Research Utilization (ILRU)**

(713) 520-0232

<http://www.ilru.org/>

ILRU is a national center for information, training, research and technical assistance on independent living. It also has information on the ADA, community services and health of individuals with disabilities.

**Indiana Resource Center for Autism (IRCA)**

(812) 855-6508

<http://www.iidc.indiana.edu/irca>

The efforts of the Indiana Resource Center for Autism's (IRCA) are focused on providing communities, organizations, agencies, and families with the knowledge and skills to support children and adults in typical early intervention, school, community, work, and home settings. Some publications are available in Spanish.

**Infantile Scoliosis Outreach Program (ISOP)**

(866) 417-4873 or (303) 691-9339

<http://www.infantilescoliosis.org/>

The Infantile Scoliosis Outreach Program (ISOP) connects families to resources and information that can help them make the best choices possible in the care of their children. The ISOP site contains information, treatment, and research pertinent to progressive infantile scoliosis. ISOP

also hosts an online support group, where parents come together to share information and experiences.

**Institute of Education Sciences (IES)**

(800) USA-LEARN

(202) 219-1385

<http://www2.ed.gov/about/offices/list/ies/>

The mission of the Institute of Education Sciences (IES) is to provide rigorous evidence on which to ground education practice and policy. This is accomplished through the work of its four centers. The focus of these four centers is: evaluation, research, statistics, and special education. IES is a program of the U. S. Department of Education.

**Institute on Community Integration (ICI)**

(612) 624-6300

<http://ici.umn.edu/>

The Institute on Community Integration (ICI) is committed to improving the professional services and social supports available to individuals with disabilities and their families. It does this through interdisciplinary pre-service and in-service training, model programs and technical consultation activities, applied research, and information dissemination. ICI is a University Center for Excellence in Developmental Disabilities.

**Institute on Disability (IOD)**

(603) 862-4320

<http://www.iod.unh.edu/>

The Institute on Disability (IOD) offers articles, books, video tapes, and posters on how best to include persons with severe disabilities into typical schools and communities. Topics include education, family support, transition/adult life, and employment. IOD is a University Center of Excellence in Developmental Disabilities.

**International Association of Laryngectomees (IAL)**

(866) 425-3678

<http://www.theial.com/ial/>

The International Association of Laryngectomees (IAL) is a voluntary organization of over 200 local clubs. The purpose of the IAL is to assist these clubs in their efforts towards the total rehabilitation of the laryngectomee.

**International Fibrodysplasia Ossificans Progressiva Association (IFOPA)**

(407) 365-4194

<http://www.ifopa.org/>

The International Fibrodysplasia Ossificans Progressiva Association (IFOPA) is an organization for people with FOP and their families. Its goals are to share information, support medical research, and educate physicians and other interested individuals about FOP.

**International Foundation for Functional Gastrointestinal Disorders (IFFGD)**

(888) 964-2001 or (414) 964-1799

<http://www.iffgd.org/>

The International Foundation for Functional Gastrointestinal Disorders (IFFGD), is a nonprofit education and research organization. IFFGD addresses the issues surrounding life with gastrointestinal (GI) functional and motility disorders. Its goal is to increase the awareness of these disorders among the general public, researchers, and the clinical care community.

**International Hearing Society (IHS)**

(734) 522-7200

<http://ihinfo.org/lhsV2/Home/Index.cfm>

The International Hearing Society (IHS) establishes training and ethical standards for professionals who test hearing, and fit and sell hearing aids. Its qualification process outlines the educational, experience, and ethical requirements needed to become a member. IHS offers an independent, self-paced study course in hearing aid technology.

**International Rett Syndrome Foundation (IRSF)**

(800) 818-RETT (7388) or (513) 874-3020

<http://www.rettysyndrome.org/>

The International Rett Syndrome Association (IRSA) supports and encourages medical research into the cause and cure for Rett syndrome. It also provides information and emotional support to families of children with Rett syndrome.

**International Ventilator Users Network**

(314) 534-0475

<http://www.ventusers.org/>

International Ventilator Users Network (IVUN) is an affiliate of Post-Polio Health International. IVUN is a worldwide membership organization of long-term ventilator users, respiratory health professionals, and ventilatory equipment manufacturers and dealers working together to promote assisted ventilation at home. IVUN publishes Ventilator-Assisted Living, a quarterly newsletter. It also publishes an annual IVUN Resource Directory available on-line.

**Iron Disorders Institute**

<http://www.irondisorders.org/>

The Iron Disorders Institute is a national voluntary public interest organization. It provides information and support resources to those persons who have iron disorders, their families, and those who provide services to them. Some of the resources include a physician registry, public awareness, drug information, approval and warnings, advocacy to increase research funding, and publications.

**Jaw Joints and Allied Musculo-skeletal Disorder Foundation, Inc. (JJAMD)**

(617) 266-2550

<http://www.tmjoints.org/>

The Jaw Joints and Allied Musculo-skeletal Disorder Foundation, Inc. (JJAMD) networks with patients, the general public, health care professionals to achieve the goal of preventing these disorders.

**John F. Kennedy Center for Research on Human Development**

(615) 322-8240

<http://kc.vanderbilt.edu/site/default.aspx>

The mission of the John F. Kennedy Center for Research on Human Development is to conduct and support research, training, and information dissemination on behavioral, intellectual, and brain development. The Center's aims are to better understand human development, to prevent and solve developmental problems, and enable people with developmental disabilities to lead better lives.

**John Tracy Clinic**

(800) 522-4582 or (213) 748-5481

<http://www.jtc.org/>

John Tracy Clinic provides, worldwide and without charge, parent-centered services to young children with a hearing loss offering families hope, guidance and encouragement.

**Joubert Syndrome Foundation**

(410) 997-8084

<http://www.joubertfoundation.com/>

Joubert Syndrome Foundation is an international network of parents who share knowledge, experience, and emotional support. Joubert Syndrome Foundation offers a networking list, a newsletter, and a bi-annual parent conference. Formerly called the Joubert Syndrome Parents In Touch Network, Joubert Syndrome Foundation maintains a family registry and a research registry.

**Junior National Association of the Deaf (JR. NAD) [A Program of NAD]**

(301) 587-1788

<http://www.nad.org/>

Junior National Association of the Deaf (JR. NAD) was established to develop leaders among young deaf students.

**Juvenile Diabetes Research Foundation International (JDRF)**

(800) 533-CURE (2873)

<http://www.jdrf.org/>

The Juvenile Diabetes Research Foundation International (JDRF) is the world's leading nonprofit, nongovernmental funder of diabetes research. JDRF is the only major diabetes organization focused exclusively on research. Volunteers help define research priorities, select research grant recipients, lead advocacy efforts, and provide guidance to overall operations. Volunteers also help raise funds.

## **KAPLAN**

<http://www.kaplanco.com/>

Today, Kaplan Early Learning Company is a leading international provider of products and services that enhance children's learning. A leader in the field of early care and education, we bring to market innovative curriculums, cutting edge assessments, teacher resource materials and valuable professional development opportunities to early childhood and elementary school educators, caregivers and parents around the world.

## **Kennedy Institute of Ethics**

(202) 687-8099

<http://kennedyinstitute.georgetown.edu/>

The Kennedy Institute for Ethics is a comprehensive academic bioethics center. The Institute and its library serve as a resource for those who research and study ethics, as well as those who debate and make public policy. The Kennedy Institute is home to a group of scholars who engage in research, teaching, and public service on issues that include protection of research subjects, reproductive and feminist bioethics, end of life care, health care justice, intellectual disability, cloning, gene therapy, eugenics, and other major issues in bioethics.

## **Kids As Self Advocates (KASA)**

(888) 835-5669 - FV National Office

<http://www.fvkasa.org/index.php>

Kids As Self Advocates (KASA), a project of Family Voices, is a national, grassroots network created by youth with disabilities for youth, to educate society about issues concerning youth with a wide spectrum of disabilities and special healthcare needs. Some issues include living with special health care needs, health care transition issues, education, employment, and many more. KASA believes in supporting self-determination, creating support networks, and proactive advocacy for all youth with disabilities in our society. KASA's website contains resources, current events, and hosts a forum for youths.

## **L'Arche USA**

(503) 282-6231

<http://www.larcheusa.org/>

The L'Arche USA is an organization which sponsors communities where persons with developmental disabilities live with persons without disabilities in an inclusive community setting. It is part of L'Arche International.

## **Laurent Clerc National Deaf Education Center (NDEC)**

(800) 526-9105 or (202) 651-5051

[http://www.gallaudet.edu/clerc\\_center/information\\_and\\_resources/info\\_to\\_go.html](http://www.gallaudet.edu/clerc_center/information_and_resources/info_to_go.html)

The Laurent Clerc National Deaf Education Center (NDEC), known as "Info to Go," is a centralized source of accurate, up-to-date objective information on topics dealing with deafness and hearing loss in the age group of 0-21. It responds to a wide range of questions from the general public, deaf and hard of hearing people, their families, and the professionals who work with them. It also collects, develops, and disseminates information on deafness,

hearing loss, and services and programs related to children with hearing loss from birth to age 21.

**Learning Ally**

(866) 732-3585 or (609) 452-0606

<http://www.learningally.org/>

Learning Ally is the new name of Recording for the Blind and Dyslexic (RFB&D), an organization providing recorded textbooks, books on CD, and other educational and professional resources to individuals who cannot read standard print. Learning Ally offers more than 65,000 downloadable titles in all K-12 curriculum areas from the top U.S. school publishers.

**Leukemia & Lymphoma Society**

(800) 955-4572

<http://www.lls.org/>

The Leukemia & Lymphoma Society (the Society) is the world's largest voluntary health organization dedicated to funding blood cancer research, education, and patient services. The Society's mission is to cure leukemia, lymphoma, Hodgkin's disease, and myeloma, and to improve the quality of life of patients and their families. The Society's website provides information regarding patient services, advocacy, diseases, research, and free materials. The Society was formerly known as The Leukemia Society of America.

**Little People of America (LPA)**

(888) LPA-2001 or (714) 368-3689

<http://www.lpaonline.org/>

Little People of America (LPA) is a nonprofit organization that provides support and information to people of short stature and their families. Membership is usually offered to those people who are no taller than 4'10" as an adult. This organization assists dwarfs with their physical and developmental concerns resulting from short stature. LPA offers information on employment, education, disability rights, adoption of short-statured children, medical issues, clothing, adaptive devices, and parenting tips.

**Low Syndrome Association (LSA)**

(972) 733-1338

<http://www.lowesyndrome.org/>

The Low Syndrome Association (LSA) is an international, voluntary, nonprofit organization composed of parents, medical and educational professionals, friends, relatives, and others interested in Low Syndrome. This rare genetic condition affects males and results in multiple disabilities, including congenital cataracts, glaucoma, intellectual impairment, poor muscle tone, kidney problems, and others.

**Lupus Foundation of America, Inc.**

(202) 349-1155 or a Spanish information line is at (800)558-0231

<http://www.lupus.org/>

The purpose of Lupus Foundation of America, Inc. is to assist local chapters in their efforts to provide supportive services to individuals living with lupus, to educate the public about lupus, and to support research into the cause and cure of lupus. Through an extensive network of branches and support groups, volunteers provide the majority of services that link the Lupus Foundation to thousands of lupus patients and their families. Information resources available on request include free pamphlets, brochures, and articles for people seeking an understanding of lupus. Several books and other materials on lupus are for sale through Lupus Foundation of America, Inc.

**Lyme Disease Foundation, Inc. (LDF)**

(800) 886-5963

<http://www.lyme.org/>

The Lyme Disease Foundation, Inc. (LDF) is a nonprofit medical healthcare agency dedicated to finding solutions to tick-borne disorders. LDF believes no one group has answers to these diseases, and in order to find solutions, four key groups must work together: the public, scientists, government, and private businesses. LDF is national in scope, with strong ties in the international scientific community, working with grass-root groups across the world. LDF offers information to the general public and health professionals about Lyme disease. Services include medical and scientific education, patient support, and public information.

**MAGIC Foundation (Major Aspects of Growth Disorders In Children)**

(800) 362-4423

<http://www.magicfoundation.org/www>

The MAGIC Foundation (Major Aspects of Growth Disorders In Children) assists parents of children with medical disorders or congenital conditions affecting their growth by providing educational seminars, materials, and a networking system through which parents can communicate for emotional support. The MAGIC Foundation also develops and sponsors educational seminars for health care professionals who treat children on a daily basis to recognize growth failure in children to assist in the early detection of children suspected of having growth failure and referrals to the appropriate specialist for diagnosis. Online support groups are available in both English and Spanish.

**Malignant Hyperthermia Association of the United States (MHAUS)**

(607) 674-790 or (800) 986-4287

<http://www.mhaus.org/>

The Malignant Hyperthermia Association of the United States (MHAUS) offers support to people who have experienced malignant hyperthermia (MH) and their families. Malignant hyperthermia is a rare condition in which some patients react to certain general anesthetics by developing a high temperature and other signs. Malignant Hyperthermia (MH) may be fatal.

**Mental Health America (MHA)**

(800) 969-6642 or (703) 684-7722

<http://www.mentalhealthamerica.net/>

Mental Health America (formerly known as the National Mental Health Association) is a nonprofit dedicated to helping all people live mentally healthier lives. With more than 320 affiliates nationwide, it represents a growing movement of Americans who promote mental wellness for the health and well-being of the nation. It can provide information and referrals to a broad range of local services and support groups, as well as literature on various mental health issues. However, Mental Health America is unable to provide medical advice, legal advice, individual advocacy, or counseling.

**Maple Syrup Urine Disease Support Group (MSUD)**

(740) 548-4475

<http://www.msud-support.org/>

The Maple Syrup Urine Disease Support Group (MSUD) Family Support Group is a nonprofit organization which includes families and professionals worldwide. This growing organization continues to develop resources to meet the goals of support and education. Informed families and professionals can provide better care for the child with MSUD. Treatment has improved and the future continues to brighten for these children and their families.

**Mitsubishi Electric America Foundation (MEAF)**

(703) 276-8240

<http://www.meaf.org/>

The mission of the Mitsubishi Electric America Foundation (MEAF) is to contribute to a better world for all by helping young people with disabilities, through technology, to maximize their potential and participation in society. National grants are approved by the foundation's Board of Directors, in consultation with experts in the fields of disability and education, to benefit young people with disabilities throughout the country. By supporting an assortment of projects addressing the unique needs of people with disabilities, the foundation has helped to improve and enrich thousands of lives

**MUMS National Parent-to-Parent Network**

(877) 336-5333

<http://www.netnet.net/mums/>

MUMS National Parent-to-Parent Network is an international parent-to-parent organization for parents or care providers of a child with any disability, rare disorder, chromosomal abnormality, or health condition. MUMS supports parents with a networking system that matches them with other parents whose children have the same or similar condition. It matches families dealing with very rare syndromes or undiagnosed conditions. MUMS networks with other organizations which do matching, thus expanding the possibilities of finding a match. MUMS also connects parents with support groups dealing with their child's specific disability or assists them in forming a group.

**Muscular Dystrophy Association (MDA)**

(800) 572-1717

<http://www.mdaua.org/>

Muscular Dystrophy Association (MDA) is a voluntary health agency -- a dedicated partnership between scientists and concerned citizens aimed at conquering neuromuscular diseases that affect more than a million Americans. MDA combats neuromuscular diseases through programs of worldwide research, comprehensive medical and community services, and far-reaching professional and public health education. MDA's programs include a nationwide network of clinics, support groups, summer camps, and more. MDA's website features publications, such as a magazine, newsletter, and articles, and also features much of the information in Spanish.

**Myositis Association (TMA)**

(800) 821-7356 or (202) 887-0082

<http://www.myositis.org/template/index.cfm>

The mission of The Myositis Association (TMA) [formerly The Myositis Association of America (MAA)] is to improve the lives of those affected by inflammatory myopathies. We will seek out persons with inflammatory myopathies, provide a support network, act as a resource for patients and the medical community, advocate for patients, and promote research into the causes and treatment of the diseases.

**National Adrenal Diseases Foundation (NADF)**

(516) 487-4992

<http://www.nadf.us/>

The National Adrenal Diseases Foundation (NADF) is a non-profit organization dedicated to providing support, information, and education to individuals having Addison's disease as well as other diseases of the adrenal glands. NADF is committed to bringing information regarding these rare diseases into the public's awareness to facilitate early diagnosis and treatment. NADF sponsors support groups across the country allowing for an exchange of ideas and feelings by individuals who share a common illness. NADF members receive quarterly newsletters, educational materials, and access to a library of related information.

**National Alopecia Areata Foundation (NAAF)**

(415) 472-3780

<http://www.naaf.org/>

The mission of the National Alopecia Areata Foundation (NAAF) is to support research to find a cure or acceptable treatment for alopecia areata, to support those with the disease, and to educate the public about alopecia areata.

**National Alliance for Caregiving (NAC)**

(301) 718-8444

<http://www.caregiving.org/>

NAC is an organization which supports family caregivers. They also have information on a study done about rural caregivers.

**National Alliance for the Mentally Ill (NAMI)**

(703) 524-7600 or (800) 950-6264

<http://www.nami.org/>

The National Alliance for the Mentally Ill (NAMI) is dedicated to improving the lives of people with mental illness and their loved ones. NAMI and its local affiliates (1) link new families with experienced families; (2) share information about mental illness, coping strategies, and reading materials; and (3) advocate for improved public understanding, services, and research on mental illnesses in children and adolescents. NAMI has numerous publications available.

**National Amputation Foundation (NAF)**

(516) 887-3600

<http://www.nationalamputation.org/>

National Amputation Foundation (NAF) comprises amputee volunteers who offer their support to fellow amputees and their families, and provide the patient with the opportunity to relate to another person who has been through a similar experience. NAF provides legal counsel, vocational guidance and placement, social activities, liaison with outside groups, psychological aid, and training in the use of prosthetic devices.

**National Art Education Association (NAEA)**

(703) 860-8000

<http://www.arteducators.org/>

The National Art Education Association (NAEA) is a professional organization which focuses on issues related to art education. Members include: (1) elementary and secondary teachers; (2) artists and administrators; (3) museum educators, arts council staff, and university professors from throughout the United States; and (4) 66 foreign countries. NAEA's mission is to advance art education through professional development, service, advancement of knowledge, and leadership.

**National Arts and Disability Center (NADC)**

(310) 794-1141

<http://www.semel.ucla.edu/nadc>

The National Arts and Disability Center (NADC) is the national information dissemination, technical assistance, and referral center specializing in the field of arts and disability. NADC is dedicated to promoting the full inclusion of children and adults with disabilities into the visual-, performing-, media, and literary-arts communities. Its resource directories, annotated bibliographies, related links, and conferences serve to advance artists with disabilities and accessibility to the arts. NADC is a project of the University of California, at Los Angeles (UCLA), Tarjan Center for Developmental Disabilities (formerly University Affiliated Program). NADC's website is a free online resource offering information on such topics as: (1) assistive technology and the arts, (2) designing accessible programs for museums, (3) books/media about disability, (4) the Americans with Disability Act and the arts, and (5) designing accessible web pages for the Internet. NADC also provides research assistance in response to individual requests made via the website.

**National Association for Dually Diagnosed (NADD)**

(845) 331-4336 or (800) 331-5362

<http://www.thenadd.org/>

NADD is an association for persons with developmental disabilities and mental health needs. It provides professionals, educators, policy makers, and families with education, training, and information.

**National Association for Parents of Children with Visual Impairments (NAPVI)**

(617) 972-7441

<http://www.spedex.com/napvi/>

The National Association for Parents of Children with Visual Impairments (NAPVI) is a national organization that strives to serve families of children of all ages and ranges of visual loss, including those who are blind and have multiple disabilities and those with multisensory impairments (deaf/blindness). It is a non-profit organization whose membership includes parents, parent organizations, agencies, and other persons with common objectives -- to provide support and services to the parents of children with visual impairments.

**National Association of Councils on Developmental Disabilities (NACDD)**

202-506-5813

<http://www.nacdd.org/site/home.aspx>

The National Association of Councils on Developmental Disabilities (NACDD) is a national, member-driven organization consisting of 55 State and Territorial Councils. NACDD is the national voice of the Councils on Developmental Disabilities. Its purpose is to support Councils in implementing the Developmental Disabilities Assistance and Bill of Rights Act and in promoting the interests and rights of people with developmental disabilities and their families.

**National Association of Hospital Hospitality Houses, Inc.**

(800) 542-9730 (Hotline) or (828) 253-1188

<http://www.nahhh.org/>

National Association of Hospital Hospitality Houses, Inc. is a nonprofit corporation serving facilities that provide lodging and other services to patients and their families with medical emergencies. Facilities provide a homelike environment to persons who travel to be with a patient or to receive necessary outpatient care. NAHHH offers educational opportunities, serves as a network for information exchange, and provides assistance to groups interested in creating similar programs.

**National Association of the Deaf (NAD)**

(301) 587-1788

<http://www.nad.org/>

National Association of the Deaf (NAD) is the nation's oldest and largest non-profit organization safeguarding the accessibility and civil rights of 28 million deaf and hard of hearing Americans across a broad range of areas including education, employment, health care, and telecommunications. Primary areas of focus include grassroots advocacy and empowerment, policy development and research, legal assistance, captioned media, information and publications, and youth leadership.

**National Ataxia Foundation (NAF)**

(763) 553-0020

<http://www.ataxia.org/>

National Ataxia Foundation (NAF) serves patients with hereditary and sporadic ataxia, identifies persons at risk, educates the public and the medical community, offers moral support to affected families, makes referrals to medical and other direct service providers, and raises funds for research grants.

**National Brachial Plexus/Erb's Palsy Association, Inc.**

(920) 836-9955

[http://www.familyvillage.wisc.edu/lib\\_erbs.htm](http://www.familyvillage.wisc.edu/lib_erbs.htm)

The National Brachial Plexus/Erb's Palsy Association, Inc. provides support to families dealing with children with diagnosis of Brachial Plexus Injury and Erb's Palsy, as well as related symptoms of condition, such as Horner's Syndrome and developmental delays. The Association offers information, contacts, resources, parent matching, and assistance in developing chapters or support groups.

**National Brain Tumor Foundation (NBTF)**

(415) 834-9970

<http://www.brainumor.org/>

The mission of the National Brain Tumor Foundation (NBTF) is two-fold: (1) to provide patients and families the information they need to successfully cope with their illness and (2) to fund promising research that will result in more effective treatments and, eventually, a cure. Services include in-depth seminars and national/regional conferences, a national network of patient support groups, and a clearinghouse for patient inquiries. NBTF publishes a quarterly newsletter, a guidebook, and many other printed materials.

**National Cancer Institute/Cancer Information Service (NCI/CIS)**

(800) 422-6237 or (304) 599-1496

<http://www.cancer.gov/aboutnci/cis>

The Cancer Information Service (CIS) is a nationwide network of 19 regional field offices supported by the National Cancer Institute (NCI) of the National Institutes of Health. Through its toll-free phone service, the CIS provides accurate, up-to-date information on cancer to patients and their families, health care professionals, and the general public. CIS can provide specific information about particular types of cancer, as well as information on how to obtain second opinions and the availability of clinical trials. Each CIS office has access to the NCI database, which contains current treatment, early detection, and supportive care information. Through its outreach program, CIS serves as a resource for state and regional organizations by providing printed materials and technical assistance to cancer education programs, media campaigns, and community programs. CIS's offices are located at NCI-designated cancer centers and other health care institutions.

**National Captioning Institute (NCI)**

(703) 917-7600 (V/TTY)

<http://www.ncicap.org/>

National Captioning Institute is a nonprofit corporation whose primary purposes are to deliver effective captioning services and encourage, develop and fund the continuing development of captioning, subtitling and other media access services for the benefit of people who require additional access to auditory and visual information. As its resources permit and opportunities unfold with the development of new technology, NCI will support services to deaf, hard of hearing and other people who, for whatever reason, wherever situated and irrespective of their economic conditions, are limited in their ability to participate fully in the world of communications, heard, seen or written.

**National Center for Education Statistics (NCES)**

(202) 502-7300

<http://nces.ed.gov/>

The National Center for Education Statistics (NCES) is the primary federal entity for collecting and analyzing data that are related to education in the U.S. and other nations. NCES is located within the U.S. Department of Education and the Institute of Education Sciences. The purpose of the NCES' website is to provide clear, complete information about NCES' mission and activities, and to serve the research, education and other interested communities.

**National Center for Health Statistics**

(800) 232-4636

<http://www.cdc.gov/nchs/>

The National Center for Health Statistics (NCHS) compiles statistical information to guide actions and policies to improve the health of the American people. Information is also available in Spanish.

**National Center for Medical Rehabilitation Research (NCMRR)**

(301) 402-4201

<http://www.nichd.nih.gov/about/org/ncmrr/>

The National Center for Medical Rehabilitation Research (NCMRR) conducts and supports research to develop techniques and devices for medical rehabilitation to improve the quality of life and increase the independence of people with disabilities. One of its priorities will be to support research leading to improved technologies and techniques to reactivate muscles, nerves, and bodily functions impaired by injury, disease, disorder, or birth defect; and to improve prosthetic devices.

**National Center for Post-Traumatic Stress Disorder (PTSD)**

(802) 296-6300

<http://www.ptsd.va.gov/index.asp>

The National Center for Post-Traumatic Stress Disorder (PTSD) was created within the Department of Veterans Affairs to address the needs of veterans with military-related PTSD. Its mission is to advance the clinical care and social welfare of America's veterans through research, education, and training in the science, diagnosis, and treatment of PTSD and stress-

related disorders. This web Site also provides information on post-traumatic stress disorder in children.

**National Center for Students with Intensive Social, Emotional and Behavioral Needs--Project Reach**

(610) 758-6973

<http://www.lehigh.edu/projectreach/>

Project REACH is a National Center which works with students with intensive social, emotional, and behavioral needs. The project is a collaborative effort between Lehigh University and the University of California, Riverside. The central themes of the project are intervention-based assessment, ecologically and culturally responsive practices, and collaboration across systems of care. Information is available on the website for parents and teachers.

**National Center of Medical Home Initiatives**

(847) 434-4000

<http://www.medicalhomeinfo.org/>

The national Center of Medical Home Initiatives strives to create a medical model of delivering primary care that is accessible, continuous, comprehensive, family-centered, coordinated and culturally effective for children with special needs. It is a grant project of the federal Maternal and Child Health Bureau.

**National Center on Birth Defects and Developmental Disabilities (NCBDDD)**

(404) 639-3534

<http://www.cdc.gov/ncbddd/index.html>

The National Center on Birth Defects and Developmental Disabilities (NCBDDD) seeks to improve child development by preventing birth defects and developmental disorders and disabilities. NCBDDD also works to enhance the quality of life and prevent secondary conditions among people who are living with mental or physical disabilities.

**National Center on Disability & Access to Education (NCDAE)**

(435) 797-1981

<http://www.ncdae.org/>

The National Center on Disability and Access to Education (NCDAE) improves educational services for all students through distance learning technologies. The focus of the Institute for Disability Personnel Development and Distance Education is the needs of children under the age of 22 years, especially the shortage of qualified personnel. The Institute for Disability Access in Distance Education provides information to postsecondary institutions about new accessible distance education technologies and accessibility patches to existing technologies. A web-based contact form is at <http://www.ncdae.org/community/contact.cfm>.

**National Center on Physical Activity and Disability (NCPAD)**

(800) 900-8086

<http://www.ncpad.org/>

NCPAD is an information center concerned with physical activity and disability. It has information and resources for everyone ranging from guidelines to consider before starting any kind of exercise program to factsheets on many popular activities, games, recreational pursuits, and sports that have been adapted to allow people with disabilities to participate as fully as they wish, become as active as they wish.

**National Center on Secondary Education and Transition (NCSET)**

612-624-2097

<http://www.ncset.org/>

NCSET provides technical assistance and disseminates information for youth with disabilities and their families about opportunities after high school.

**National Center on Shaken Baby Syndrome (NCSBS)**

(801) 627-3399; (888) 273-0071

<http://dontshake.org/>

National Center on Shaken Baby Syndrome (NCSBS) is a resource center that provide support, information and referrals related to shaken baby syndrome to health professionals, as well as parents and the general public. The service offers printed and online information on shaken baby syndrome, some available in Spanish.

**National CFIDS Foundation**

(781) 449-3535

<http://www.ncf-net.org/>

The National CFIDS Foundation, Inc. was founded in February 1997 by two 14 year activists of the movement. The goals of the Foundation are to help fund medical research to expedite a treatment and eventual cure, to provide information, education, and support to those people who have Chronic Fatigue Immune Dysfunction (CFIDS) -- also known as Myalgic Encephalopathy (ME) and Chronic Fatigue Syndrome (CFS) -- and related illnesses such as Gulf War Illness. Formerly called the National Chronic Fatigue Immune Dysfunction Syndrome Foundation (NCF).

**National Collaborative on Workforce and Disability for Youth (NCWD/Youth)**

(877) 871-0744 or (877) 871-0665

<http://www.ncwd-youth.info/>

The National Collaborative on Workforce and Disability for Youth (NCWD/Youth) assists state and local workforce development systems to better serve all youth, including youth with disabilities and other disconnected youth. It offers a range of technical assistance services to state and local workforce investment boards, youth councils and other workforce development system youth programs. NCWD/Youth is a project of the U.S. Department of Labor's Office of Disability Employment Policy.

**National Consortium on Deaf-Blindness (NCDB)**

(800) 438-9376

<http://nationaldb.org/>

The National Consortium on Deaf-Blindness (NCDB) continues the technical assistance activities of the former National Technical Assistance Consortium for Children & Young Adults Who Are Deaf-Blind (NTAC). They provide information and technical assistance to families and agencies, as well as providing personnel training.

**National Chronic Fatigue Syndrome and Fibromyalgia Association (NCFSA)**

(816) 737-1343

<http://www.ncfsfa.org/>

The National Chronic Fatigue Syndrome and Fibromyalgia Association is a non-profit, voluntary organization formed to educate and inform the public, patients and their families, and health professionals about the nature and impact of chronic fatigue syndrome (CFGS) and related disorders, including chronic fatigue and immune dysfunction syndrome, chronic Epstein-Barr virus and myalgic encephalomyelitis.

**National Coalition for Cancer Survivorship (NCCS)**

(301) 650-9127 or (877) 622-7937

<http://www.canceradvocacy.org/>

The National Coalition for Cancer Survivorship (NCCS) is a national, survivor-led advocacy organization working exclusively on behalf of people with all types of cancer. NCCS works to empower cancer survivors, and advocates for policy issues that affect survivors' quality of life. Many of NCCS's publications are available in Spanish.

**National Cued Speech Association (NCSA)/Deaf Children's Literacy Project**

(800) 459-3529

<http://www.cuedspeech.org/>

The National Cued Speech Association (NCSA) and its Deaf Children's Literacy Project provide services and information about Cued Speech, a phonemic-based communication system. NCSA is a non-profit membership organization founded in 1982 to promote and support the effective use of Cued Speech. We raise awareness of Cued Speech and its applications, provide educational services, assist local affiliate chapters, establish standards for Cued Speech and certify Cued Speech instructors and transliterators. NCSA produces a newsletter and a journal, and hosts a national conference. NCSA provides direct support at regional and national levels in the areas of instruction, guidance, education, and professional training and certification; produces publications; and provides referral.

**National Diabetes Information Clearinghouse (NDIC)**

(800) 860-8747

<http://diabetes.niddk.nih.gov/about/index.aspx>

The National Diabetes Information Clearinghouse (NDIC), a service of the National Institute of Diabetes and Digestive and Kidney Diseases, at the National Institutes of Health, provides information about diabetes to people with diabetes and their families, health care professionals, and the public. NDIC responds to inquiries; develops, reviews, and distributes publications; and works closely with professional and patient organizations and government agencies to coordinate resources about diabetes.

**National Digestive Diseases Information Clearinghouse (NDDIC)**

(800) 891-5389

<http://digestive.niddk.nih.gov/about/index.aspx>

A service of the National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health (NIH), the National Digestive Diseases Information Clearinghouse (NDDIC) offers a number of free publications on digestive diseases such as Crohns, IBS, and Colitis.

**National Dissemination Center for Children with Disabilities (NICHCY)**

(800) 695-0285 or (202) 884-8200

<http://nichcy.org/>

The National Dissemination Center for Children with Disabilities (NICHCY) provides information on disabilities in children; programs and services for infants, children, and youth with disabilities; IDEA, the nation's special education law; and research-based information on effective practices for children with disabilities. NICHCY is a project of the Special Education Technical Assistance and Dissemination Network (TA&D), funded by the U.S. Department of Education, Office of Special Education and Rehabilitative Services (OSERS).

**National Down Syndrome Congress**

(800) 232-NDSC

<http://www.ndscenter.org/>

The NDSC is a national organization for families who have a member with Down Syndrome.

**National Down Syndrome Society**

(800) 221-4602

<http://www.ndss.org/>

This is a national organization for families who have a member with Down Syndrome.

**National Early Childhood Technical Assistance Center (NECTAC)**

(919) 962-2001

<http://www.nectac.org/>

The National Early Childhood Technical Assistance Center (NECTAC) supports the implementation of the early childhood provisions of the Individuals with Disabilities Education Act (IDEA). NECTAC helps states improve outcomes for young children and their families by strengthening service systems to ensure children with disabilities (birth through five) and their families receive high quality, culturally appropriate, and family-centered supports and services. NECTAC is a project of the Special Education Technical Assistance and Dissemination Network (TA&D), funded by the U.S. Department of Education, Office of Special Education and Rehabilitative Services (OSERS).

**National Early Childhood Transition, Research and Training Center (NECTC)**

(859) 257-2081

<http://www.hdi.uky.edu/SF/NECTC/>

The National Early Childhood Transition, Research and Training Centers' (NECTC) mission is to examine factors that promote successful transitions between infant/toddler programs, preschool programs, and public school programs for young children with disabilities and their families. The purpose of NECTC is to investigate and validate practices that enhance the early childhood transition process and support positive school outcomes for children with disabilities. Comprehensive strategies for improving transition and enhancing school readiness for young children with disabilities and their families will be shared with families and service providers at all levels via validated concepts, curricula, and tools embedded in a systems change model. Funding for NECTC comes from the U.S. Department of Education, Office of Special Education Programs.

**National Eating Disorders Association (N.E.D.A.)**

(800) 931-2237 or (206) 382-3587

<http://www.nationaleatingdisorders.org/>

The American Anorexia Bulimia Association, Inc. has joined with EDAP to become the National Eating Disorders Association (N.E.D.A.). N.E.D.A. is a national non-profit organization dedicated to increasing the awareness and prevention of eating disorders.

**National Eye Institute (NEI)**

(301) 496-5248

<http://www.nei.nih.gov/>

The mission of the National Eye Institute (NEI) is to conduct and support research, training, health information dissemination, and other programs with respect to eye diseases, visual disorders, mechanisms of visual function, preservation of sight, and the special health problems and requirements of individuals who are blind or have visual impairments. Publications include brochures for patients and the general public, fact sheets, and a science program for schools.

**National Federation of the Blind (NFB)**

(410) 659-9314

<http://www.nfb.org/>

The National Federation of the Blind (NFB) maintains information about Braille resources and tracks legislation affecting individuals who are blind. NFB represents people who are blind through advocacy and representation in discrimination cases. NFB products include books, articles, films and videocassettes, a monthly magazine, and a quarterly magazine.

**National Foundation for Ectodermal Dysplasias (NFED)**

(618) 566-2020

<http://www.nfed.org/>

The National Foundation for Ectodermal Dysplasia (NFED) is dedicated to (1) locating patients and providing them with support and information; (2) assisting the medical community in acquiring information about this rare disorder; (3) maintaining professional databases; (4) conducting educational meetings for families; (5) distributing financial assistance to families for dental care as funds become available; (6) printing educational materials; (7) assisting with research projects; and (8) providing scholarship programs.

**National Foundation for Facial Reconstruction (NFFR)**

(212) 263-6656

<http://www.nffr.org/>

The National Foundation for Facial Reconstruction (NFFR) is a non-profit, voluntary organization chartered in New York State in 1951 to aid the rehabilitation of individuals who have facial disfigurement. Its major purposes are: (a) to provide facilities for the treatment and assistance of individuals who are unable to afford private reconstructive surgical care; (b) to assist in the training and education of personnel engaged in reconstructive plastic surgery; (c) to initiate, stimulate, and encourage research in this field; and (d) to carry on a public education program to make more people aware of the problems of facial disfigurement and the treatment methods currently available. A library of books and films is also available to the public.

**National Fragile X Foundation (NFXF)**

(925) 938-9300

<http://www.fragilex.org/>

The National Fragile X Foundation (NFXF) is a nonprofit organization dedicated to education and research concerning children and families with X-linked mental retardation. NFXF's goal is to increase awareness, support research, aid families, and encourage collaboration among professionals involved with Fragile X Syndrome.

**National Gaucher Foundation (NGF)**

(800) 504-3189

<http://www.gaucherdisease.org/>

The National Gaucher Foundation (NGF) is a non-profit, tax exempt organization dedicated to supporting and promoting research into the causes of, and a cure for Gaucher Disease. The mission of the NGF is to find a cure for Gaucher Disease by funding vital research programs, to meet the ever-increasing needs of patients and families, as well as to promote community/physician awareness and educational programs.

**National Heart, Lung, and Blood Institute Information Center (NHLBI-IC)**

(301) 592-8573 or (800) 575-9355

<http://www.nhlbi.nih.gov/>

The National Heart, Lung, and Blood Institute Information Center (NHLBI-IC) was established in 1986 as a source of information on cholesterol, asthma, blood pressure, obesity, heart attack, and a variety of sleep-related disorders. The National Asthma Education Program, the National Cholesterol Education Program, and the National Heart Attack Alert Program have also been added. Services include dissemination of public education materials, programmatic and scientific information for health professionals, materials on worksite health, and response to information requests.

**National Hopeline Network**

(800) 784-2433

<http://www.hopeline.com/>

The National Hopeline Network 1-800-SUICIDE will connect callers - people who are depressed or suicidal, or those who are concerned about someone they love - automatically to a certified Crisis Center. Using the ANI (Automatic Number Identification) system, telephone calls are routed to the Hopeline Network affiliated Crisis Center nearest to where the person is when the call is placed. Crisis Center calls are answered by trained counselors 24 hours a day, seven days a week. In the event that the nearest Crisis Center is at maximum volume, the call is seamlessly rerouted to the next closest center. Callers should never encounter a busy signal or voice mail. People in crisis usually reach a trained counselor within two to three rings, or about 20 to 30 seconds, from the moment they dial 1-800-SUICIDE. Once the caller is engaged, a lethality assessment is done. Those who are not highly lethal are referred to locally available resources.

**National Human Genome Research Institute (NHGRI)**

(301) 402-0911

<http://www.genome.gov/>

The National Human Genome Research Institute (NHGRI) leads the National Institutes of Health's (NIH) contribution to the International Human Genome Project, which has as its primary goal the sequencing of the human genome. As this project nears successful completion, the NHGRI's mission has expanded to encompass a broad range of studies aimed at understanding the structure and function of the human genome and its role in health and disease.

**National Immunization Program (NIP)**

(800) 232-4636

<http://www.cdc.gov/vaccines/>

The National Immunization Program (NIP) is a part of the Centers for Disease Control and Prevention. As a disease-prevention program, NIP provides leadership for the planning, coordination, and conduct of immunization activities nationwide.

**National Industries for the Blind (NIB)**

(703) 310-0500

<http://www.nib.org/>

Incorporated as a 501C3 not-for-profit organization, National Industries for the Blind (NIB) enhances the opportunities for economic and personal independence of persons who are blind, primarily through creating, sustaining and improving employment.

**National Information Center for Educational Media (NICEM)**

(505) 998-0800 or (800) 926-8328

<http://www.nicem.com/>

The National Information Center for Educational Media (NICEM) maintains an international database of information about audiovisual and nonprint materials for academic, professional, vocational, technical, and corporate settings. Librarians, media specialists, curriculum planners, teachers, faculty, human resource professionals, researchers, and interested others can find information about media by consulting the NICEM database online and on CD-ROM. NICEM's

Audiovisual Database, the world's leading source of information for nonprint educational and training materials, including film, video, audio, CD-ROM, DVD, slides, filmstrips, kits and more.

**National Institute of Allergy and Infectious Diseases (NIAID)**

(301) 496-5717

<http://www.niaid.nih.gov/Pages/default.aspx>

The National Institute of Allergy and Infectious Diseases (NIAID) is a component of the National Institutes of Health (NIH). NIAID conducts and supports research that strives to understand, treat, and ultimately prevent the myriad infectious, immunologic, and allergic diseases that threaten hundreds of millions of people worldwide.

**National Institute of Arthritis and Musculoskeletal and Skin Diseases Information Clearinghouse (NIAMS Info Clearinghouse)**

(301) 495-4484; (877) 22-NIAMS

<http://www.niams.nih.gov/>

The National Institute of Arthritis and Musculoskeletal and Skin Diseases Information Clearinghouse (NIAMS Info Clearinghouse), at the National Institutes of Health, provides information about various forms of arthritis and rheumatic diseases, and bone, muscle, and skin diseases. NIAMS Info Clearinghouse distributes patient and professional education materials, and refers people to other sources of information.

**National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)**

(301) 654-3327 or (800) 860-8747

<http://www2.niddk.nih.gov/>

The National Institute of Diabetes and Digestive and Kidney Diseases conducts and supports research on many of the most serious diseases affecting public health. The Institute supports much of the clinical research on the diseases of internal medicine and related subspecialty fields as well as many basic science disciplines. Information also available in Spanish.

**National Institute of General Medical Sciences (NIGMS)**

(301) 496-7301

<http://www.nigms.nih.gov/>

The National Institute of General Medical Sciences (NIGMS) primarily supports basic biomedical research that is not targeted to specific diseases or disorders. Because scientific breakthroughs often originate from such untargeted studies, NIGMS-funded work has contributed substantially to the tremendous progress that biomedical research has made in recent years. The Institute's training programs help provide the most critical element of good research: well-prepared scientists.

**National Institute of Mental Health (NIMH)**

(301) 443-4513 or (866) 615-6464

<http://www.nimh.nih.gov/index.shtml>

The National Institute of Mental Health (NIMH) conducts and supports research nationwide on mental illness and mental health, including studies of the brain, behavior, and mental health services.

**National Institute of Neurological Disorders and Stroke (NINDS)**

(800) 352-9424 or (301) 496-5954

<http://www.ninds.nih.gov/>

The National Institute of Neurological Disorders and Stroke (NINDS) is one of 24 institutes that make up the National Institutes of Health (NIH). Its mission is to conduct, support, and coordinate research in the causes and prevention, diagnosis, and treatment of neurological disorders and stroke, and in the basic sciences relevant to these problems. Support of training for research careers is also a basic component of the mission. NINDS maintains an Office of Scientific and Health Reports (OSHR) whose services are available to both lay and professional users.

**National Institutes of Health (NIH)**

(301) 496-4000

<http://www.nih.gov/>

The National Institutes of Health (NIH) is the steward of medical and behavioral research for the Nation. Its mission is science in pursuit of fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to extend healthy life and reduce the burdens of illness and disability.

**National Institute on Deafness and Other Communication Disorders (NIDCD) Information Clearinghouse**

(800) 241-1044

<http://www.nidcd.nih.gov/Pages/default.aspx>

The National Institute on Deafness and Other Communication Disorders (NIDCD) conducts and supports biomedical and behavioral research and research training in the normal and disordered processes of hearing, balance, smell, taste, voice, speech, and language. It also conducts and supports research and research training related to disease prevention and health promotion; addresses special biomedical and behavioral problems associated with people who have communication impairments or disorders; and supports efforts to create devices that substitute for lost and impaired sensory and communication function. NIDCD maintains a clearinghouse that provides the following services: an information service; materials development and distribution; and a computerized database of reference materials. A publications catalog is available upon request.

**National Jewish Medical and Research Center (NJM&RC)**

(303) 388-4461 or (800) 222-5864

<http://www.nationaljewish.org/>

The National Jewish Medical and Research Center (formerly the National Jewish Center for Immunology and Respiratory Medicine) is a nonprofit institution dedicated to enhancing prevention, treatment, and cures through research, and to developing and providing innovative

clinical programs for treating patients regardless of age, religion, race, or ability to pay. It researches, treats, and offers press kits on the following diseases: asthma, chronic bronchitis, emphysema, tuberculosis, allergic conditions, interstitial lung disease, cystic fibrosis, chronic fatigue syndrome, vocal cord dysfunction, sleep-related breathing disorders, juvenile rheumatoid arthritis, and lupus (and other autoimmune diseases).

**National Kidney Foundation (NKF)**

(800) 622-9010 or (212) 889-2210

<http://www.kidney.org>

The National Kidney Foundation (NKF), a major voluntary health organization, is dedicated to preventing kidney and urinary tract diseases, improving the health and well-being of individuals and families affected by these diseases, and increasing the availability of all organs for transplantation.

**National Lead Information Center (NLIC)**

(800) 424-LEAD [5323] or (202) 566-0500

<http://www.epa.gov/lead/pubs/nlic.htm>

The National Lead Information Center (NLIC) provides the general public and professionals with information about lead hazards and their prevention. NLIC operates under a contract with the U.S. Environmental Protection Agency (EPA), with funding from EPA, the Centers for Disease Control and Prevention, and the Department of Housing and Urban Development.

**National Library of Medicine (NLM)**

(301) 496-6308 or (888) 346-3656

<http://www.nlm.nih.gov/>

The National Library of Medicine (NLM), on the campus of the National Institutes of Health in Bethesda, Maryland, is the world's largest medical library. The Library collects materials and provides information and research services in all areas of biomedicine and health care.

**National Library Service for the Blind and Physically Handicapped (NLS)**

888-657-7323

<http://www.loc.gov/nls/>

NLS is part of the Library of Congress. They have a free library program of recorded materials for persons who are blind or have physical disabilities.

**National Limb Loss Information Center (NLLIC)**

(888) 267-5669

[http://www.amputee-coalition.org/nllic\\_about.html](http://www.amputee-coalition.org/nllic_about.html)

The National Limb Loss Information Center, (NLLIC) is a resource center that provides comprehensive resources for people with limb loss, as well as their families, friends, and the health care professionals involved with their lives. It is operated by the Amputee Coalition of America (ACA).

**National Lymphedema Network (NLN)**

(800) 541-3259 or (510) 208-3200

<http://www.lymphnet.org/>

The National Lymphedema Network (NLN) is an internationally recognized non-profit organization founded in 1988 by Saskia R.J. Thiadens, R.N. to provide education and guidance to lymphedema patients, health care professionals and the general public by disseminating information on the prevention and management of primary and secondary lymphedema.

**National Marfan Foundation (NMF)**

(516) 883-8712 or (800) 8-MARFAN

<http://www.marfan.org/marfan/>

The National Marfan Foundation (NMF) has three main goals: (1) to provide accurate and timely information about this condition to patients, family members, and physicians; (2) to provide means for patients and relatives to share in experiences, to support one another, and to improve their medical care; and (3) to support and foster research. It sponsors an annual conference and local chapters meet periodically and offer a wide array of activities in support of the goals of the Foundation. NMF also publishes a newsletter and other informative materials on the Marfan Syndrome.

**National Mental Health Association (NMHA)**

(800) 969-6642 or (703) 684-7722

<http://www.nmha.org/>

The National Mental Health Association (NMHA) is a citizen volunteer advocacy organization dedicated to addressing all aspects of mental health and mental illnesses. It strives to be a force for social change through advocacy, prevention, information and referral, and public education.

**National Mental Health Consumer Self-Help Clearinghouse (NMHCSC)**

(800) 553-4539 or (215) 751-1810

<http://www.mhselfhelp.org/>

The National Mental Health Consumer Self-Help Clearinghouse (NMHCSC) encourages the development and growth of consumer self-help groups by providing individuals and groups with information, materials, help, and referrals for a wide range of technical assistance issues ranging from fundraising, publicity, and membership to advocacy/legal advice, disabilities concerns, and organizing consumer-run centers.

**National Mental Health Information Center (NMHIC)**

(800) 789-2647 or (240) 221-4021

<http://www.mentalhealth.samhsa.gov>

The NMHIC is part of the Substance Abuse and Mental Health Services Administration (SAMHSA), under the U.S. Department of Health and Human Services. The Information Center provides resources, publications, and information on a myriad of mental health topics, including dually diagnosed disabilities. Anyone can call their toll-free numbers to have a mental health question answered. Information is also available in Spanish.

**National Minority AIDS Council (NMAC)**

(202) 483-6622

<http://www.nmac.org/>

The National Minority AIDS Council provides training, technical assistance, conference information, and treatment information on the topics of HIV and AIDS. It targets community-based organizations, health departments, and national AIDS organizations and businesses.

**National Mucopolysaccharidosis Society, Inc. (MPS)**

877-MPS-1001

<http://www.mpssociety.org/>

The National Mucopolysaccharidosis Society's (MPS) goal is to ultimately find a cure for mucopolysaccharidoses (MPS) and mucopolipidoses (ML) disorders. MPS will achieve this goal by supporting research, providing support to individuals and their families affected by an MPS or ML disease, promoting public and professional awareness, and significantly increasing participation by regions.

**National Niemann-Pick Disease Foundation, Inc. (NNPDF)**

(877) 287-3672; (920) 563-0930

<http://www.nnpdf.org/>

The National Niemann-Pick Disease Foundation, Inc. (NNPDF) is an international, voluntary, nonprofit organization made up of parents, medical and educational professionals, friends, relatives, and others who are committed to finding a cure for Niemann-Pick disease.

**National Organization for Albinism and Hypopigmentation (NOAH)**

(800) 473-2310 or (603) 887-2310

<http://www.albinism.org/>

The National Organization for Albinism and Hypopigmentation (NOAH) is a U.S. based nonprofit, tax-exempt organization that offers information and support to people with albinism, their families, and the professionals who work with them. NOAH is operated by its members on a volunteer basis and is funded primarily by dues and contributions of its members. NOAH has also received grants from foundations and organizations for specific projects.

**National Organization for Disorders of the Corpus Callosum (NODCC)**

(714) 747-0063

The National Organization for Disorders of the Corpus Callosum (NODCC) is for professionals, parents and individuals with an interest in corpus callosum disorders. It seeks to promote the understanding and acceptance of individuals with these disorders through research, education, advocacy and networking. The organization has information about corpus callosum disorders, publishes materials, coordinates an annual conference, and creates a community of support for families and professionals.

**National Organization for Rare Disorders (NORD)**

(203) 744-0100 or (800) 999-6673

<http://www.rarediseases.org/>

The National Organization for Rare Disorders (NORD) acts as a clearinghouse for information about rare disorders and networks families with similar disorders for mutual support. NORD also promotes research, accumulates and disseminates information about orphan drugs and devices, provides technical assistance to newly organized support groups, and educates the general public and medical professions about diagnosis and treatment of rare disorders.

**National Organization of Mothers of Twins Clubs (NOMOTC)**

(248) 231-4480

<http://www.nomotc.org/>

The National Organization of Mothers of Twins Clubs (NOMOTC) is comprised of local clubs across the United States. The basic purposes of the organization are research and education. Local clubs meet monthly to discuss twin care and other topics of interest to parents of multiples. NOMOTC publishes a brochure, "Your Twins and You" and a newsletter, "MOTC's Notebook."

**National Organization of Parents of Blind Children (NOPBC)**

(410) 659-9314

[http://www.nfb.org/nfb/Parents\\_and\\_Teachers.asp](http://www.nfb.org/nfb/Parents_and_Teachers.asp)

The National Organization of Parents of Blind Children (NOPBC) facilitates the sharing of experience and concerns among parents of blind children; provides resources and support for parents and their children; and helps parents gain an understanding of blindness through contact with blind adults. NOPBC conducts seminars and workshops, information/referral and literature about blindness and the education of the blind.

**National Organization on Disability (NOD)**

202-293-5960

<http://www.nod.org/>

NOD works to expand the participation and contribution of individuals with disabilities in all aspects of life.

**National Organization on Fetal Alcohol Syndrome (NOFAS)**

(202) 785-4585 or (800) 66NOFAS

<http://www.nofas.org/>

The National Organization on Fetal Alcohol Syndrome (NOFAS) is dedicated to eliminating birth defects caused by alcohol consumption during pregnancy and to improving the quality of life for all those affected by FAS/FAE. NOFAS takes a multicultural approach to prevention and healing among individuals, families, and communities. NOFAS sponsors a series of national and regional conferences and seminars, community-based public awareness campaigns, a FAS curriculum for medical and allied health students, teen leadership and peer education programs, and a FAS information clearinghouse. NOFAS has both Spanish language publications and Spanish-speaking staff.

**National Patient Air Transport HELPLINE**

(800) 296-1217

<http://www.patienttravel.org/>

National Patient Travel HELPLINE provides information about all forms of charitable, long-distance medical air transportation and provides referrals to all appropriate sources of help available in the national charitable medical air transportation network. The HELPLINE is staffed live 9am to 5pm Eastern Time, Monday thru Friday. After hours help is available within 10 minutes of leaving an after-hours message marked urgent.

**National Pediatric & Family HIV Resource Center (NPHRC)**

(973) 972-0410 or (800) 362-0071

<http://www.womenchildrenhiv.org/>

The National Pediatric & Family HIV Resource Center at University of Medicine and Dentistry of New Jersey is a non-profit organization that serves professionals who care for children, adolescents, and families with HIV infection and AIDS. Founded in 1990, the Center offers education, consultation, technical assistance, and training for health and social service professionals. Professionals caring for children and youth with HIV infection and their families need access to the most current scientific information, as well as to innovative approaches to meeting families' health and social service needs. The multi-generational impact of HIV disease and the ethnic and cultural influences on families demand creative and knowledgeable program responses from the professionals.

**National Professional Development Center on Autism Spectrum Disorders**

(888) 718-7303

<http://autismpdc.fpg.unc.edu/autismpdc/>

The National Professional Development Center on Autism Spectrum Disorders is a multi-university center to promote the use of evidence-based practice for children and adolescents with autism spectrum disorders. The Center operates through three sites that include the FPG Child Development Institute at the University of North Carolina at Chapel Hill, the M.I.N.D. Institute at University of California at Davis Medical School, and the Waisman Center at the University of Wisconsin at Madison. The National Professional Development Center on Autism Spectrum Disorders is a project of the Special Education Technical Assistance and Dissemination Network (TA&D), funded by the U.S. Department of Education, Office of Special Education and Rehabilitative Services (OSERS).

**National Resource Center for Special Needs Adoption (NRC for Special Needs Adoption)**

(248) 443-0306

<http://www.nrcadoption.org/>

The National Resource Center for Special Needs Adoption (NRC for Special Needs Adoption) provides training, technical assistance and materials for professionals related to permanency planning, adoption, and post legal adoption services for children with developmental disabilities, special health and emotional needs, as well as children who are older, siblings who need one family to adopt them and who are members of a racial or ethnic minority group.

Spaulding for Children provides therapeutic foster care, adoption and post legal adoption services to children with special needs and their families who reside in Southeastern Michigan.

**National Resource Center for Traumatic Brain Injury (NRC TBI)**

(804) 828-9055

<http://www.neuro.pmr.vcu.edu/>

The mission of the National Resource Center for Traumatic Brain Injury (NRC TBI) is to provide relevant, practical information for professionals, persons with brain injury, and family members. Many of its products were developed by nationally recognized experts. NRC TBI has more than 20 years of experience developing intervention programs, assessment tools, and investigating the special needs and problems of people with brain injury and their families.

**National Resource Center for Youth Services (NRCYS)**

(918) 660-3700

<http://www.nrcys.ou.edu/>

The National Resource Center for Youth Services (NRCYS) focuses on youth who are at-risk, transition to independent living, diversity, team-building, and conflict management. It serves child welfare professionals and professionals who work with adolescents and their families.

**National Resource Center on Domestic Violence (NRCDV)**

(800) 537-2238

<http://www.nrcdv.org/>

The National Resource Center on Domestic Violence (NRC) provides comprehensive information and resources, policy development, and technical assistance to enhance the community response to and prevention of domestic violence. NRC coordinates information and resource development and dissemination with the three Special Issue Resource Centers . While a particular focus of the resource network is to support and expand the capacity of community-based and state domestic violence organizations, they also work closely with the federal, state and local government agencies, policy leaders, the media, and other individuals and organizations involved in responding to or preventing domestic violence.

**National Reye's Syndrome Foundation (NRSF)**

(800) 233-7393

<http://www.reyessyndrome.org/>

The National Reye's Syndrome Foundation (NRSF) is a citizen group that generates a concerted, organized lay movement to eradicate Reye's Syndrome. Its programs focus on three main areas: public awareness, medical research, and service to individuals and families affected by Reye's Syndrome. NRSF disseminates literature to the lay community and medical professionals, such as brochures, awareness bulletins, and emergency room posters.

**National Runaway Switchboard (NRS)**

(773) 880-9860 or (800) 344-2785

<http://www.1800runaway.org/>

National Runaway Switchboard (NRS) is a non-profit volunteer organization whose mission is to provide crisis intervention and referrals for youth and families through national and local telephone switchboards, as well as advocacy and educational services on the problems of youth. NRS also offers "Home Free," a free transportation service for qualified runaway youth who wish to return to their families. Call 1-800-621-4000 for service.

**National Scoliosis Foundation (NSF)**

(781) 341-6333 or (800) 673-6922

<http://www.scoliosis.org/>

The National Scoliosis Foundation (NSF) is a patient-led nonprofit organization dedicated since 1976 to helping children, parents, adults, and health-care providers to understand the complexities of spinal deformities such as scoliosis. Severe scoliosis impacts the quality of life, putting pressure on the heart, diminishing lung capacity, and limiting physical activity. We are involved in all aspects of scoliosis support, whether the issue is early detection through screening programs, treatment methods, pain management, or patient care. Our focus is on promoting public awareness, providing reliable information, fostering ongoing research in the field, and educating and nurturing the community of those affected by scoliosis. We also provide comprehensive education and support for patients and healthcare professionals through videos, books, brochures, local chapters, conferences, and postural screening training sessions.

**National Secondary Transition Technical Assistance Center (NSTTAC)**

(704) 687-8606

<http://www.nsttac.org/>

The National Secondary Transition Technical Assistance Center (NSTTAC) assists states to build capacity to support and improve transition planning, services, and outcomes for youth with disabilities. NSTTAC is a project of the Special Education Technical Assistance and Dissemination Network (TA&D), funded by the U.S. Department of Education, Office of Special Education and Rehabilitative Services (OSERS).

**National Spasmodic Torticollis Association (NSTA)**

(800) 487-8385 or (714) 378-9837

<http://www.torticollis.org/>

National Spasmodic Torticollis Association (NSTA) increases awareness of Spasmodic Torticollis (ST), provides support services for individuals who are afflicted with ST and their caregivers, and creates effective advocacy through teaching the public, the government, and the medical community about ST, and the need for research toward a cure. NSTA offers support and information to people with spasmodic torticollis and their families through services which include a quarterly magazine, a toll-free help line, an annual conference, and support groups in many states.

**National Spinal Cord Injury Association (NSCIA)**

(301) 214-4006 or (800) 962-9629

<http://www.spinalcord.org/>

The mission of the National Spinal Cord Injury Association (NSCIA) is to improve the quality of life for individuals with spinal cord injury. NSCIA runs the National Spinal Cord Injury Resource Center (NSC IRC). Publications include fact sheets and a resource directory.

**National Stuttering Association (NSA)**

(212) 944-4050 or (800) 937-8888

<http://www.nsastutter.org/>

The National Stuttering Association (NSA) is a self-help organization run by, and for, people who stutter. NSA provides information on all aspects of stuttering to people who stutter and the general public. NSA publishes a monthly newsletter, offers pamphlets and article reprints, and provides a speech pathology referral service. See also [www.westutter.org](http://www.westutter.org).

**National Tay-Sachs & Allied Diseases Association, Inc. (NTSADA)**

(617) 277-4463 or (800) 906-8723

The National Tay-Sachs & Allied Diseases Association, Inc. (NTSADA) provides general information on Tay-Sachs, Canavan, and 40 other related genetic disorders. NTSADA provides information and support services to individuals and families affected, as well as the public. NTSADA provides public and professional education, genetic screening, family services, advocacy, and research.

**National Technical Assistance Center for Children's Mental Health (NTACCMH)**

(202) 687-5000

[http://gucchd.georgetown.edu/programs/ta\\_center/index.html](http://gucchd.georgetown.edu/programs/ta_center/index.html)

The National Technical Assistance Center for Children's Mental Health (NTACCMH) at the Georgetown University Center for Child and Human Development, formerly called the CASSP, emphasizes the development of systems of care for children and their families, community-based service approaches, cultural competence, services for special populations of high-risk youth, and strategies for financing services. Policymakers, administrators, service providers, and families interested in finding out about services in their state for children and adolescents who have serious emotional disturbances can contact them. They will be put in touch with a state child mental health person or with someone who can inform them about state or local services for children and adolescents with a serious emotional disturbance.

**National Technical Institute for the Deaf (NTID) at RIT**

(585) 475-6400

<http://www.ntid.rit.edu/>

The National Technical Institute for the Deaf (NTID), a college of Rochester Institute of Technology, provides technical and professional post-secondary education to deaf and hard of hearing students. Staff research in audiology, speech therapy, educational methods, and vocational training and placement is reported in professional journals, as well as in publications of the Institute. Sign language interpreter training, teaching internships, and workshops for employers, educators, and rehabilitation professionals are offered both on and off campus.

**National Tourette Syndrome Association**

<http://tsa-usa.org/>

The mission of national Tourette Syndrome Association is to identify the cause of, find the cure for and control the effects of Tourette Syndrome. We offer resources and referrals to help people and their families cope with the problems that occur with TS. We raise public awareness and counter media stereotypes about TS.

**National Vitiligo Foundation (NVF)**

(513) 541-3903

<http://nvfi.org/>

The National Vitiligo Foundation (NVF) offers a wealth of current, accurate, and easy to understand information about vitiligo. It strives to enable people with this disease to make the best choices for themselves and their families, and to serve as a one-stop resource for both the medical and scientific community.

**National Youth Advocacy Coalition (NYAC)**

(202) 319-7596 or (800) 541-6922

<http://www.nyacyouth.org/>

The National Youth Advocacy Coalition (NYAC) is the only national organization focused solely on improving the lives of gay, lesbian, bisexual, and transgender (GLBT) youth through advocacy, education, and information. NYAC advocates for and with GLBT youth through the collaboration of a broad spectrum of community-based and national organizations. Through this partnership, NYAC seeks to end discrimination against GLBT youth and ensure their physical and emotional well-being. NYAC's Bridges Project provides information resources, technical assistance, and referrals to GLBT youth and their allies.

**National Youth Employment Coalition (NYEC)**

(202) 659-1064

<http://www.nyec.org/>

The National Youth Employment Coalition (NYEC) is a nonpartisan national organization dedicated to promoting policies and initiatives that help youth succeed in becoming lifelong learners, productive workers and self-sufficient citizens. NYEC strives to improve the capacity and effectiveness of youth-serving organizations to affect youth development through employment, education and training.

**National Youth Leadership Network (NYLN)**

(866) 480-6565

<http://www.nyln.org/>

National Youth Leadership Network (NYLN) is dedicated to advancing the next generation of disability leaders. NYLN promotes leadership development, education, employment, independent living, and health and wellness among young leaders. It fosters the inclusion of young leaders with disabilities into all aspects of society. The phone number is for youth leaders only (866) 480-6565 ext.2.

### **NECTAC**

(919) 962-2001

<http://www.nectac.org/default.asp>

NECTAC is the national early childhood technical assistance center supported by the U.S. Department of Education's Office of Special Education Programs (OSEP) under the provisions of the Individuals with Disabilities Education Act (IDEA). NECTAC serves Part C-Infant and Toddlers with Disabilities Programs and Part B-Section 619 Preschool Programs for Children with Disabilities in all 50 states and 10 jurisdictions to improve service systems and outcomes for children and families.

### **Neuro-Developmental Treatment Association, Inc. (NDTA)**

(800) 869-9295 (toll-free)

<http://www.ndta.org/>

The Neuro-Developmental Treatment Association, Inc. (NDTA) is an advanced therapeutic approach practiced by experienced Occupational Therapists, Physical Therapists, and Speech-Language Pathologists. This hands-on approach is used in working with people who have central nervous system insults that create difficulties in controlling movement. Therapists using NDT treatment have completed advanced training in NDT and work closely with individuals with neurological challenges (e.g. cerebral palsy, stroke, head injury), helping them to become as independent as possible.

### **Neurofibromatosis, Inc. (NF, Inc.)**

630-627-1115 or 1-800-942-6825 toll free

Neurofibromatosis, Inc. (NF, Inc.), is a nonprofit organization made up of independent state and regional chapters, providing support and services to families affected by Neurofibromatosis (NF). NF, Inc. provides coordinated educational support; works with clinical and research programs; and promotes national, state, and local community involvement. NF, Inc. offers free information about neurofibromatosis to families and individuals; identifies local support groups; refers to local medical resources; encourages research; and educates legislators of NF family needs. It produces a newsletter, booklets, and a video. NF, Inc. also hosts a camp for children with NF and conferences.

### **NICHCY**

(800) 695-0285 or (202) 884-8200

<http://nichcy.org/>

NICHCY is the National Dissemination Center for Children with Disabilities serving the nation as a central source of information on disabilities in infants, toddlers, children, and youth with disabilities; IDEA, the nation's special education law; and research-based information on effective practices for children with disabilities. NICHCY is a project of the Special Education Technical Assistance and Dissemination Network (TA&D), funded by the U.S. Department of Education, Office of Special Education and Rehabilitative Services (OSERS).

### **NISH**

(571) 226-4660 or (866) 633-7365

<http://www.nish.org/>

NISH assists community rehabilitation programs nationwide to expand job opportunities for persons with significant disabilities by securing federal contracts through the AbilityOne Program for its network of community-based, nonprofit agencies. NISH was formerly called National Industries for the Severely Handicapped.

**NIMAS Technical Assistance Center**

(781) 245-2212

<http://aim.cast.org/>

The National Instructional Materials Accessibility Standard (NIMAS) guides the production and electronic distribution of digital versions of textbooks and other instructional materials so they can be more easily converted to accessible formats, including braille and text-to-speech. The NIMAS Technical Assistance Center works with key stakeholders such as states, school boards, and publishers to raise awareness of the benefits of accessible materials. It also advises stakeholders on the efficient production and distribution of NIMAS-compliant materials. NIMAS Technical Assistance Center is a project of the Special Education Technical Assistance and Dissemination Network (TA&D), funded by the U.S. Department of Education, Office of Special Education and Rehabilitative Services (OSERS).

**North American Riding for the Handicapped Association (NARHA)**

(800) 369-7433; (303) 452-1212

<http://www.pathintl.org/>

North American Riding for the Handicapped Association (NARHA) is a membership association that promotes equine activities for individuals with physical, emotional, and learning disabilities. There are more than 650 NARHA centers in North America providing equine-assisted activities and therapy for people with various disabilities of all ages. NARHA's website features a list of riding centers, articles, products for sale, conference information, a section for independent equestrians, and more.

**Northwestern University Prosthetics-Orthotics Center for Research and Education (NUPOC)**

(312) 503-5700

<http://www.nupoc.northwestern.edu/index.html>

NUPOC is dedicated to the improvement of the quality of life for persons who use prostheses and orthoses. NUPOC develops new concepts and devices that improve the quality, cost-effectiveness, and delivery of P&O fittings, while enhancing knowledge about human interactions with these systems. Rehabilitation engineering research, including studies of human gait and motion analysis, is conducted in a medical environment that fosters direct clinical interactions and applications. NUPOC offers education for individuals who wish to become professional prosthetists and orthotists.

**OASIS@MAAP**

<http://www.aspergersyndrome.org/>

The Online Asperger Syndrome Information and Support (OASIS) center has joined with MAAP Services for Autism and Asperger Syndrome to create a single resource for families, individuals,

and medical professionals who deal with the challenges of Asperger Syndrome, Autism, and Pervasive Developmental Disorder / Not Otherwise Specified (PDD/NOS). This is an online resource.

**Obsessive Compulsive Foundation, Inc. (OCF)**

(617) 973-5801

<http://www.ocfoundation.org/>

The Obsessive Compulsive Foundation, Inc. (OCF) is a voluntary nonprofit organization composed of people with Obsessive Compulsive Disorder (OCD), their families, friends, professionals, and other concerned individuals. OCF is dedicated to early intervention in controlling and finding cures for OCD, and for improving the welfare of people with this disorder. OCF also has Spanish-language publications and a bilingual staff member.

**Office of Rare Diseases (ORD)**

(301) 402-4336

<http://rarediseases.info.nih.gov/>

The goals of the Office of Rare Diseases (ORD) are to stimulate and coordinate research on rare diseases and to support research to respond to the needs of patients who have any one of the more than 6,000 rare diseases known today.

**Office of Rare Diseases (ORD)--Genetic and Rare Diseases Information Center**

(888) 205-2311

At the Office of Rare Diseases (ORD) at NIH you can find information on more than 6,000 rare diseases, including current research, publications from scientific and medical journals, completed research, ongoing studies, and patient support groups. Established by the National Human Genome Research Institute and the Office of Rare Diseases, the Genetic and Rare Diseases Information Center employs experienced information specialists to answer questions from the general public, including patients and their families, health care professionals, and biomedical researchers. Note: The Center does not give medical advice, provide treatment or diagnose illness. Telephone operation is Monday - Friday, 12 P.M. to 6 P.M. Eastern Standard Time; E-mail or Fax (will be answered within 5-10 working days); and By U.S. Mail (will be answered within 5-10 working days).

**OHSU Center on Self-Determination**

503 494-8311

<http://www.ohsu.edu/oidd/CSD/>

The Center on Self-Determination identifies, develops and shares approaches that promote the self-determination of people with disabilities and ongoing health conditions. The Center works closely with consumer groups, organizations, schools and agencies to develop model programs and public policies that support self-determination. It focuses on disability and health issues, research and training. The Center also produces materials and conducts training for professionals and community organizations.

**Oley Foundation (OF)**

(518) 262-5079 or (800) 776-OLEY (6539)

<http://www.oley.org>

The Oley Foundation (OF) is a non-profit organization affiliated with the clinical nutrition division of Albany Medical College. It was established to address the special needs of those involved in Home PEN. PEN (parenteral and enteral nutrition) is used when a person suffers from a severe, chronic gastrointestinal disease that impairs food intake, digestion, and absorption leading to malnutrition. The person receives primary nutrition through intravenous (parenteral) feedings or through tube feedings directly into the digestive tract (enteral). All of this can be done at home with training.

**Organic Acidemia Association, Inc. (OAA)**

(763) 559-1797

<http://www.oaanews.org/>

The Organic Acidemia Association (OAA) encourages consistent communication and support among families and professionals dealing with organic acidemias and related rare metabolic disorders. OAA is a referral, networking, and clearinghouse information center.

**Osteogenesis Imperfecta Foundation, Inc. (OI Foundation)**

(800) 981-2663

<http://www.oif.org/>

The Osteogenesis Imperfecta Foundation, Inc. (OI Foundation) seeks to improve the quality of life for individuals affected by OI through research to find treatments and a cure, education, awareness, and mutual support.

**Oxalosis and Hyperoxaluria Foundation (OHF)**

(212) 777-0470 or (800) OHF-8699

The Hyperoxaluria and Oxalosis Foundation (OHF) disseminates information to physicians to help make available and standardize treatment plans. Research is supported by tracking patients and by fund-raising. Also available are a network and newsletter to provide support and information on current treatment options.

**Parents' Action for Children**

(888) 447-3400

<http://www.parentsaction.org/>

Formerly, I am Your Child Foundation, Parents' Action is a national non-profit dedicated to advancing the interests of families and young children. Parents' Action for Children develops parent education materials, connects parents with one another, and fights for issues such as early education, health care, and high quality and affordable child care.

**Parent Advocacy Coalition for Educational Rights (PACER Center)**

(800) 537-2237 or (952) 838-9000

<http://www.pacer.org/>

PACER Center is a national center focused on providing resources to expand opportunities and enhance the quality of life of children and young adults with disabilities and their families. It has numerous statewide projects, which include the Parent Training and Information Center (PTI) for the state of Minnesota. The following are some of PACER Center's national projects. Technical Assistance Alliance for Parent Centers (the Alliance) - PACER is the national coordinating office for consultation and technical assistance for over 100 federally funded parent centers across the country under the Individuals with Disabilities Education Act (IDEA).

**Parents as Teachers National Center, Inc. (PAT)**

(314) 432-4330

<http://www.patnc.org/>

Parents as Teachers (PAT) is a national award-winning non-profit parent education and family support organization. Through a network of local programs, the Parents as Teachers National Center develops curriculum, trains, and certifies parent educators to work with parents to provide them with parenting support and information on their developing child.

**Parents of Galactosemic Children, Inc. (PGC)**

(866) 900-7421

<http://www.galactosemia.org/>

Parents of Galactosemic Children, Inc. (PGC) is a national, non-profit, volunteer organization whose mission is to provide information, support, and networking opportunities to families affected by galactosemia.

**Pathways Awareness Foundation (PAF)**

(800) 955-2445

<http://www.pathwaysawareness.org/>

The Pathways Awareness Foundation (PAF) is a not-for-profit organization dedicated to education for and about children with movement difficulties, to education and empowering parents, to advocate the extreme importance of early intervention and the significance of the inclusion of children with physical challenges into our community schools. PAF believes that through early detection, intervention and increased public awareness, children with physical challenges can look forward to a brighter future.

**Perkins School for the Blind**

(617) 924-3434

<http://www.perkins.org/>

Perkins School for the Blind is committed to helping children and adults who are blind, visually handicapped, deafblind, and multihandicapped reach their greatest possible independence.

**Phoenix Society for Burn Survivors (Phoenix Society)**

(800) 888-2876 or (616) 458-2773

<http://www.phoenix-society.org/>

A self-help organization for burn survivors and their families, the Phoenix Society for Burn Survivors (Phoenix Society) works to ease the psychosocial adjustment of severely burned

persons during and after hospitalization so that they can return to normal lives within their communities.

**Pierre Robin Network, Inc. N.F.P.**

(217) 224-7480

<http://www.pierrerobin.org/>

The Pierre Robin Network organization is made up of parents, relatives, caregivers, adults with Pierre Robin Syndrome (PRS) and professionals who have an interest in PRS. The group provides support and information online, including a glossary and information sheets, bulletin board, and email listserver. For those not online, they have a welcome packet. The Pierre Robin Network also offers "buddy" parents to those seeking specific information or personal contact.

**Prader-Willi Syndrome Association (USA)**

(800) 926-4797 or (941) 312-0400

<http://www.pwsausa.org/>

Prader-Willi Syndrome Association (USA) is dedicated to serving individuals affected by Prader-Willi Syndrome, their families, and interested professionals. To provide information, education, and support services to its members, Prader-Willi Syndrome Association (USA) offers a toll-free telephone number for information and referrals; publications and audiovisual presentations about Prader-Willi Syndrome; an annual national conference for families and professionals; a nationwide network of local chapters, parents, and professionals; research funding to expand knowledge and treatment options; and representation on the international level. Products include books, handbooks, information packets, educational materials, videos, brochures, and a bimonthly newsletter.

**President's Committee for People with Intellectual Disabilities**

(202) 619-0634

<http://www.acf.hhs.gov/programs/pcpid/index.html>

This committee advises the US President on issues affecting people with intellectual disabilities and their families.

**Prevent Blindness America**

(847) 843-2020 or (800) 331-2020

<http://www.preventblindness.org/>

Prevent Blindness America, also known as the National Society to Prevent Blindness, works to prevent blindness through public and professional education, community service programs, and vision research. It works through a network of affiliates, division, chapters, and branches. Community programs concentrate on health education and often provide free screening for the public.

**Project Participate**

(303) 315-2318

<http://www.projectparticipate.org/>

Project Participate provides families, educators, administrators, and therapists with simple strategies to increase the active participation of students with disabilities in school programs. Supported by a U.S. Department of Education grant (H324M980258), Project Participate facilitates team collaboration and promotes the appropriate uses of technology in the classroom.

**Prosthetics Research Laboratory and the Rehabilitation Engineering Research Program**  
(312) 238-6500

<http://www.feinberg.northwestern.edu/depts/repoc/>

The Prosthetics Research Laboratory and the Rehabilitation Engineering Research Program are dedicated to the improvement of prostheses and orthoses, to the improved fitting and manufacturing processes for prosthesis/orthosis systems, and to the improved basic understanding of human interactions with these systems. The research, applied and technical in nature, is conducted in a medical environment that fosters direct clinical interactions and applications.

**Protection and Advocacy for Assistive Technology (PAAT) Program**

202-245-6493

<http://www2.ed.gov/programs/paat/>

The Protection and Advocacy for Assistive Technology Program is often called the PAAT Program. It provides protection and advocacy services to assist individuals with disabilities of all ages in the acquisition, utilization or maintenance of assistive technology services or devices.

**Prune Belly Syndrome Network, Inc. (PBSN)**

<http://www.prunebelly.org/>

The Prune Belly Syndrome Network, Inc. provides support for those who have Prune Belly, their families, friends, and the health care professionals who treat them. Here you will find a collection of information about Prune Belly Syndrome which is also known as Eagle-Barrett Syndrome.

**Recovery, Inc.**

(866) 221-0302

<http://www.lowselphelpsystems.org/>

Recovery, Inc. is a community mental health organization that offers systematic training in a self-help method for controlling temperamental behavior and handling anxiety, depression, and fears. Groups are open to anyone aged 18 years or older. There is no required fee to attend a group meeting although a voluntary contribution is collected at the end of each meeting. Recovery, Inc. was founded in 1937 by Abraham A. Low, M.D. a neuropsychiatrist. There are more than 700 groups meeting throughout the United States, Canada, and overseas.

**Reflex Sympathetic Dystrophy Syndrome Association of America (RSDSA)**

(203) 877 3790 or (877) 662-7737

<http://www.rds.org/index2.html>

The Reflex Sympathetic Dystrophy Syndrome Association of America (RSDSA) is a national nonprofit organization that promotes public and professional awareness of RSD, educates those afflicted with the syndrome, their families, friends, insurance and healthcare providers on the disabling pain it causes, and raises funds for research into the causes, treatment and cure of RSD.

**Registry of Interpreters for the Deaf, Inc. (RID)**

(703) 838-0030

<http://www.rid.org/>

The Registry of Interpreters for the Deaf (RID) is a membership organization of professional interpreters. Its primary purpose is to initiate, sponsor, promote, and implement policies and activities that will further the profession of interpreting. The major focus is certifying interpreters and translators. RID provides information to the general public about finding interpreting services and using them effectively. Information is also provided about careers in interpreting, professional development, and job opportunities.

**Rehabilitation Engineering and Assistive Technology Society of North America (RESNA)**

(703) 524-6686

<http://www.resna.org/>

Rehabilitation Engineering and Assistive Technology Society of North America (RESNA) is an association of people with a common interest in technology and disability. RESNA also works on issues related to testing standards and accreditation programs.

**Rehabilitation Research and Training Center on Workplace Support**

(804) 828-1851

<http://www.worksupport.com/>

This center identifies factors that help or inhibit businesses in hiring persons with disabilities. and is designed to study: (1) return to work strategies for persons who become disabled while employed; (2) key components of effective disability management programs; (3) financial tax credits to encourage hiring, retention, and advancement; (4) the impact of work support interventions on employment and advancement; (5) employer perceptions of obstacles to hiring and retaining; and (6) the significance of structural changes in the American economy on people with disabilities.

**Research and Training Center for Children's Mental Health (RTCCMH)**

(813) 974-4661

<http://rtckids.fmhi.usf.edu/>

The Research and Training Center for Children's Mental Health (RTCCMH) started in 1984 to address the need for improved services for children with serious emotional disturbances and their families. RTCCMH receives funding from the National Institute on Disability and Rehabilitation Research, and the Center for Mental Health Services. It conducts research; synthesizes and disseminates existing knowledge; provides training and consultation; and serves as a resource for policymakers, researchers, parents, and advocates.

**Research and Training Center on Community Living (RTC)**

(612) 624-6328

<http://rtc.umn.edu/main/>

The Research and Training Center on Community Living (RTC) collects and disseminates national data on residential and related services for people with developmental disabilities. It has conducted studies related to community living for persons with developmental disabilities and has developed a national database from the results of this research. RTC staff are involved in research and technical assistance in areas related to integrated community living, including recreation and leisure services, augmentative communication, social relationships, and self-determination and self-advocacy. Information dissemination is primarily done through a range of publications, direct response to requests for information, and technical assistance. A complete listing of publications and prices is available upon request.

**Research and Training Center (RTC) on Early Childhood Development**

(828) 255-0470

<http://www.researchtopractice.info/>

The Research and Training Center (RTC) on Early Childhood Development seeks to promote and enhance the healthy development of infants, toddlers, and preschoolers with or at risk for developmental delays or disabilities. The RTC was established to create a bridge between research evidence and early childhood intervention practices. The website is designed to be useful for parents, therapists, early childhood educators and early interventionists, as well as researchers. The website includes information about effective practices based on research.

**Research and Training Center on Family Support and Children's Mental Health**

(503) 725-4040

<http://www.rtc.pdx.edu/>

The Research and Training Center on Family Support and Children's Mental Health is dedicated to promoting effective community-based, culturally competent, family-centered services for families and their children who are, or may be affected by mental, emotional or behavioral disorders. This goal is accomplished through collaborative research partnerships with family members, service providers, policy makers, and other concerned persons.

**Research and Training Center on Independent Living (RTC/IL)**

(785) 864-4095

<http://www.rtcil.org/>

The mission of the Research and Training Center on Independent Living (RTC/IL) is to enable people with disabilities to control their lives and live independently through product research and development that facilitates the work of independent living centers (ILCs), consumer organizations, and policy makers. Consumer empowered teams determine the need and provide input for research and development over the course of each project. RTC/IL expanded its services in 1993 to underserved populations--groups of people with disabilities whose independent living needs are not being addressed. These groups include: people with chronic psychiatric disabilities, people with acquired brain injury, people with cognitive and intellectual

disabilities; and people from culturally diverse backgrounds with disabilities. Outreach to underserved populations is a priority.

**Rubinstein-Taybi Parent Group**

(888) 447-2989

[http://www.rubinstein-taybi.org/html/united\\_states.html](http://www.rubinstein-taybi.org/html/united_states.html)

The Rubinstein-Taybi Parent Group offers support to parents of children with the syndrome. Resources for parents include a list of families with children with Rubinstein-Taybi. Rubinstein-Taybi Parent Group is expanding and currently working on organizing regions within the USA.

**Scleroderma Foundation (SF)**

(978) 463-5843

<http://www.scleroderma.org/>

The Scleroderma Foundation (SF) provides education and support for persons with scleroderma and their families. SF is dedicated to raising funds for research, seeking the cause and cure of scleroderma, and increasing public awareness of the condition. SF provides printed information, physician referrals, peer counseling, and health care information. In addition, it conducts medical information meetings and sponsors a patient education seminar annually.

**Scottish Rite, Southern Jurisdiction RiteCare Childhood Language Program (RiteCare)**

(202) 232-3579 or (800) 776-2766

<http://scottishrite.org/>

The Scottish Rite of Freemasonry, Southern Jurisdiction's RiteCare Childhood Language Program has over 160 clinics, centers, or programs in 35 states, Puerto Rico, and the District of Columbia. Treatment is available to preschool children and those in the early grades who have difficulty speaking, reading, or understanding the spoken or written word. Freemasonry (or Masonry) is the oldest and largest fraternity in the world. One of Freemasonry's objectives is "to make good men better" by teaching those virtues recognized as part of a better life, i.e. brotherhood, morality, justice, tolerance, citizenship, education, and freedom of ideas, religious choice, and expression.

**Selective Mutism Foundation, Inc.**

<http://www.selectivemutismfoundation.org/>

Selective Mutism Foundation, Inc. is a support organization for parents and families of children and adults with selective mutism, a disorder in which children do not speak in social situations for more than 1 year. These children understand spoken language, have the ability to speak, and may speak to their parents and a few others.

**Share and Care Cockayne Syndrome Network, Inc.**

(703) 727-0404 or (865) 435-9777

<http://cockaynesyndrome.net/>

The Share and Care Cockayne Syndrome Network, Inc. is a network of parents and professionals who deal with Cockayne Syndrome. It offers information and emotional support for those dealing with this syndrome.

### **Shriners Hospitals for Children**

(813) 281-0300

<http://www.shrinershq.org/>

The Shriners Hospitals for Children (Shriners Hospitals) is a network of pediatric specialty hospitals, founded by the Shrine, where children under the age of 18 receive medical care absolutely free of charge. There are 18 orthopedic Shriners Hospitals, three Shriners Hospitals dedicated to treating children with severe burns, and one Shriners Hospital that provides orthopedic, burn, and spinal cord injury care. Shriners Hospitals are located throughout North America with 20 in the United States and one each in Mexico and Canada. There is never a charge to the patient, parent, or any third party for any service or medical treatment received at Shriners Hospitals.

### **Sidran Institute**

(410) 825-8888

<http://www.sidran.org/>

The Sidran Institute is a national nonprofit organization devoted to education, advocacy, and publications related to the early recognition and treatment of trauma-related stress in children and the understanding and treatment of adults with trauma-generated conditions. The Sidran Institute delivers professional training, provides information and resources, and publishes books and tapes about the effects of traumatic stress.

### **Signing Exact English Center (SEE Center) for the Advancement of Deaf Children**

(562) 430-1467

<http://www.seecenter.org/>

The Signing Exact English Center (SEE Center) for the Advancement of Deaf Children is a nonprofit organization that works with parents and educators of hearing impaired children. SEE Center: (1) promotes early identification and intervention; (2) promotes development of improved English skills; (3) promotes understanding of principles of Signing Exact English; (4) provides information to parents; and (5) fosters the positive development of self concept in the deaf child.

### **Sjögren's Syndrome Foundation (SSF)**

(800) 475-6473 or (301) 530-4420

<http://www.sjogrens.org/>

The Sjögren's Syndrome Foundation (SSF), is a 501(c)(3) tax-exempt national voluntary health agency. Founded in 1983, the SSF provides patients practical information and coping strategies that minimize the effects of Sjögren's syndrome. In addition, SSF is the clearinghouse for medical information and is the recognized national advocate for Sjögren's syndrome. It's mission is to: educate patients and their families about Sjögren's syndrome; increase public and professional awareness of Sjögren's syndrome; and encourage research into new treatments and a cure.

### **Small Business and Self-Employment Service (SBSES)**

(800) 526-7234

<http://askjan.org/>

The SBSES is a service of the Office of Disability Employment Policy of the U.S. Department of Labor, which provides information, counseling, and referrals about self-employment and small business ownership opportunities for people with disabilities. SBSES is located at the Job Accommodation Network.

### **Sotos Syndrome Support Association (SSSA)**

(888) 246-7772

<http://www.sotossyndrome.org/>

Organized in 1988, the Sotos Syndrome Support Association (SSSA) is made up of families, physicians, genetic counselors, and health care agencies throughout the United States. SSSA has a research library with over 160 published articles available to members. There are audio and video tapes of previous conferences available for purchase. Many families have mentioned how helpful the list of members and addresses has been in keeping in touch with other families in their region or whose children have similar strengths and weaknesses.

### **Special Connections**

<http://www.specialconnections.ku.edu/>

The Special Connections site connects teachers to strategies that help students with special needs be successful across the general education curriculum. Teacher tools for implementing best practices, case study materials, resources, and online collaboration are provided in modules focusing on instruction, assessment, behavior plans and collaboration.

### **Special Olympics**

(202) 628-3630

<http://www.specialolympics.org/>

Special Olympics is a nonprofit, international program that provides year-round training and athletic competition for more than one million athletes with mental retardation in nearly 150 countries. Training and competition are available in 22 official sports and more than 140,000 qualified coaches train Special Olympic athletes. Each state has a Special Olympics office.

### **Specialized Training of Military Parents (STOMP)**

(800)-5-PARENT (V/TTY) or (253) 565-2266

<http://www.stompproject.org/>

STOMP (Specialized Training of Military Parents) helps military families who have children with special education or health needs. It provides information about parent rights and responsibilities in achieving special education services for military children world-wide. It also provides information about networking with military and civilian resources. STOMP is a project of Washington PAVE, and it is funded by the Office of Special Education Programs of the U.S. Dept. of Education.

**Sturge-Weber Foundation (SWF)**

(973) 895-4445; (800) 627-5482

<http://www.sturge-weber.com/>

The Sturge-Weber Foundation (SWF) offers information and support to persons with the syndrome and their families. SWF seeks to increase public awareness, offer support, and facilitate and fund research on Sturge-Weber Syndrome, Port Wine Stains, and Klippel-Trenaunay. It also produces publications, a newsletter, hosts annual meetings & conferences, and has videos available.

**Stuttering Foundation of America**

(800) 992-9392 or (901) 452-7343

<http://www.stutteringhelp.org/>

The Stuttering Foundation provides free online resources, services and support to those who stutter and their families, as well as support for research into the causes of stuttering. We are the largest - and the first - nonprofit charitable organization in the world working towards the prevention and improved treatment of stuttering, reaching over a million people annually. We also offer extensive educational programs on stuttering for professionals.

**Substance Abuse and Mental Health Services Administration (SAMHSA)**

(240) 276-2130

<http://www.samhsa.gov/>

The Substance Abuse and Mental Health Services Administration (SAMHSA), formerly the Alcohol, Drug Abuse, and Mental Health Administration (ADAMHA), was established by Congress as the principal federal agency concerned with the prevention, control, and treatment of alcoholism, drug abuse, mental illness, and the promotion of mental health. The three ADAMHA research institutes -- the National Institute on Drug Abuse (NIDA), the National Institute on Alcohol Abuse and Alcoholism (NIAAA), and the National Institute of Mental Health (NIMH) -- have been placed under the auspices of the National Institutes of Health (NIH).

**Summer Solutions: Advisors on Camps & Trips**

(800) 729-7090

<http://summersolutions.com/>

Summer Solutions offers parents free information, advice, and brochures on summer camps nationwide. Camps are for all children, however, some do have services for milder disabilities, especially ADD/LD. Camp fairs are held in several states during the winter months. Check the website for dates and locations.

**Support Organization for Trisomy 18, 13 and Related Disorders (SOFT)**

(585) 594-4621; (800) 716-7638

<http://www.trisomy.org/>

Support Organization for Trisomy 18, 13 and Related Disorders (SOFT) is a network of families and professionals dedicated to providing support and understanding to families involved in the issues and decisions surrounding the diagnosis and care in Trisomy 18, 13 and related chromosomal disorders.

**TASH Equity, Opportunity and Inclusion for People with Disabilities**

<http://tash.org/>

TASH is an international leader in disability advocacy. Founded in 1975, TASH advocates for human rights and inclusion for people with significant disabilities and support needs – those most vulnerable to segregation, abuse, neglect and institutionalization. TASH works to advance inclusive communities through advocacy, research, professional development, policy, and information and resources for parents, families and self-advocates. The inclusive practices TASH validates through research have been shown to improve outcomes for all people.

**Technical Assistance Alliance for Parent Centers (TA ALLIANCE)**

(888) 248-0822

<http://www.parentcenternetwork.org/national/>

The Technical Assistance Alliance for Parent Centers (The ALLIANCE) is an innovative partnership of one national and six regional parent technical assistance centers. The ALLIANCE National Center supports Parent Centers through standardized publications, unified data collection, national conferences and institutes, webinars, a monthly e-newsletter, management and nonprofit expertise, and other resources. The ALLIANCE National Center is a project of the Special Education Technical Assistance and Dissemination Network (TA&D), funded by the U.S. Department of Education, Office of Special Education and Rehabilitative Services (OSERS).

**Technical Assistance Center on Positive Behavioral Interventions and Supports (PBIS)**

(541) 346-2505

<http://www.pbis.org/>

The TA Center on Positive Behavioral Interventions and Supports (PBIS) was established to give schools capacity-building information and technical assistance for identifying, adapting, and sustaining effective school-wide disciplinary practices. on a large scale with high durability and effectiveness. The Center is a project of the Special Education Technical Assistance and Dissemination Network (TA&D), funded by the U.S. Department of Education, Office of Special Education and Rehabilitative Services (OSERS).

**Technical Assistance Center on Social Emotional Intervention for Young Children (TACSEI)**

(813) 974-6100

<http://www.challengingbehavior.org/>

The Technical Assistance Center on Social Emotional Intervention for Young Children (TACSEI) is a continuation and expansion of the work of the Center for Evidence-Based Practice, Young Children with Challenging Behavior. TACSEI gives decision makers, caregivers and service providers an enhanced awareness and understanding of, and ability to use evidence-based practices for improving the social-emotional outcomes for young children with, or at risk for, delays or disabilities. TACSEI uses the widely endorsed Pyramid Model framework for promoting social-emotional competence and addressing challenging behavior as the conceptual model to deliver this important information.

TACSEI is a project of the Special Education Technical Assistance and Dissemination Network

(TA&D), funded by the U.S. Department of Education, Office of Special Education and Rehabilitative Services (OSERS).

**Technical Assistance on Transition and the Rehabilitation Act (TATRA)**

(800) 537-2237

<http://www.pacer.org/tatra/>

PACER's Technical Assistance on Transition and the Rehabilitation Act (TATRA) project was funded by the Rehabilitation Services Administration (RSA) to provide technical assistance to six Rehabilitation Act Parent Training Projects. These projects are part of RSA initiatives to inform individuals with disabilities and their families about Rehabilitation Act and vocational rehabilitation and independent living services, to enable them to improve and expand employment goals and outcomes. TATRA offers a variety of services that help the RSA parent training projects achieve their goals. These services include individual technical assistance plans, ongoing information and referral, an annual conference, teleconferencing, and collaborative activities with other organizations such as the National Center on Secondary Education and Transition (NCSET) and the National Council on Independent Living (NCIL).

**Telecommunications for the Deaf (TDI)**

(301) 589-3786

<http://tdiforaccess.org/>

Telecommunications for the Deaf (TDI) is a national special interest nonprofit advocacy and consumer organization. TDI serves as a clearinghouse for technology and information services in the field of visual telecommunications and information. TDI provides consultation on policy, program development, and implementation; program evaluation; technology standards for telecommunications relay services; 9-1-1 emergency services; public awareness training on deaf culture; and how to use a TTY. Use Relay (800) 735-2258.

**The National Council on Independent Living**

<http://www.ncil.org/>

NCIL advances independent living and the rights of people with disabilities through consumer-driven advocacy.

**Think First National Injury Prevention Foundation**

(800) THINK56

<http://www.thinkfirst.org/home.asp>

The Think First National Injury Prevention Foundation offers educational programs for grades 1-3 (Think First for Kids) and teenagers (Think First for Teens).

**Trace Research and Development Center**

(608) 262-6966

<http://trace.wisc.edu/>

The Trace Research and Development Center is funded by the Department of Education to serve as the Rehabilitation Engineering Research Center (RERC) on the topic of information

technology access and telecommunication access. Trace Center conducts research to make every day technologies accessible and useable for those with disabilities.

**Transition Coalition**

(785) 864-0686

<http://www.transitioncoalition.org/transition/>

Transition Coalition provides research-based transition training to school districts, regions and states.

**Treatment and Education of Autistic and related Communication handicapped Children (Division TEACCH)**

(919) 966-2174

<http://www.teacch.com/>

TEACCH seeks to generate knowledge; to integrate clinical services with relevant theory and research; and to disseminate information about theory, practice, and research on autism through training and publications locally, nationally and internationally.

**Tourette Syndrome Association (TSA)**

(718) 224-2999

<http://www.tsa-usa.org/>

Tourette Syndrome Association (TSA) is a national nonprofit whose mission is to identify the cause of Tourette Syndrome (TS), find a cure, control the effects of TS, and serve everyone affected by TS. TSA maintains physician referral listings by state and medical referrals in other countries. TSA produces a variety of brochures and films, as well as public service announcements available for local placement.

**Trips Inc. Special Adventures**

(800) 686-1013

<http://www.tripsinc.com/>

Trips Inc. Special Adventures provides travel outings to adults of various abilities in a safe, respectful, and fun atmosphere. Trips are designed for people with developmental disabilities and special needs who require staff assistance for a safe and enjoyable vacation. They offer the ratio of travelers to chaperones of 1 to 3 or 4.

**Tuberous Sclerosis Alliance (TS Alliance)**

(301) 562-9890 or (800) 225-6872

<http://www.tsalliance.org/>

The Tuberous Sclerosis Alliance is the national volunteer organization for families and individuals with tuberous sclerosis. They encourage research, provide family support and have links to local groups.

**United Brachial Plexus Network (UBPN)**

(866) 877-7004

<http://www.ubpn.org/>

The United Brachial Plexus Network (UBPN) is devoted to providing information, support, and leadership for families and those concerned with brachial plexus injuries worldwide. Available resources include: (1) an extensive website; (2) online registry; (3) various outreach and awareness programs; and (4) Outreach, and in-depth publication.

**United Cerebral Palsy (UCP)**

(800) 872-5827

<http://www.ucp.org/>

United Cerebral Palsy (UCP) and its nationwide network of affiliates strive to ensure the inclusion of persons with disabilities in every facet of society. The national office provides key services for its affiliates, information and referral service, legislative advocacy, technology initiatives, and research. Direct services for people with disabilities and their families are offered through UCP affiliates across the U.S. Services may include: therapy, assistive technology training, early intervention programs, individual and family support, social and recreation programs, community living, state and local referrals, employment assistance and advocacy.

**United Leukodystrophy Foundation (ULF)**

(815) 895-3211 or (800) 728-5483

<http://www.ulf.org/>

The United Leukodystrophy Foundation (ULF) provides patients and families with information about leukodystrophy and all genetic white matter disorders, and assists them in identifying sources of medical care, social services, and genetic counseling. It also promotes and supports research, coordinates a communication network among affected families, and promotes public awareness. Publications include booklets, videos, and article reprints.

**United Mitochondrial Disease Foundation (UMDF)**

(888) 317-UMDF (8633)

<http://www.umdf.org/>

The United Mitochondrial Disease Foundation's mission is to promote research and education for the diagnosis, treatment and cure of mitochondrial disorders and to provide support to affected individuals and families.

**U.S. Association of Blind Athletes (USABA)**

(719) 866-3224

<http://www.usaba.org/>

United States Association for Blind Athletes (USABA) is dedicated to developing athletic competition for blind and visually impaired athletes and encourages participation regardless of age or degree of impairment.

**U.S. Census Bureau**

(800) 923-8282 or (800) 877-8339

<http://www.census.gov/>

The U.S. Census Bureau is a general purpose statistical agency which collects, tabulates, and publishes a wide variety of statistical data about the people and economy of the United States. The Census Bureau publishes most of its information (all of its publications, for example) online via internet and makes it free to users.

**U.S. Paralympics**

(719) 866-2030

<http://usparalympics.org/>

U.S. Paralympics is a division of the U.S. Olympic Committee that was created to focus efforts on enhancing programs, funding and opportunities for persons with physical disabilities to participate in Paralympic sport. The mission of U.S. Paralympics is to be the world leader in the Paralympic movement and to promote excellence in the lives of persons with physical disabilities. The Paralympic Games are the second largest sporting event in the world, conceding top honors only to the Olympics. The multi-sport competition showcases the talents and abilities of the world's most elite athletes with physical disabilities.

**VSA arts**

(800) 933-8721 or (202) 628-2800 or (202)737-0645

<http://www.vsarts.org/>

VSA arts (formerly Very Special Arts) is an international organization that creates learning opportunities through the arts for people with disabilities. The organization offers arts-based programs in creative writing, dance, drama, music, and the visual arts implemented primarily through its affiliate network in 39 states and the District of Columbia, international affiliates in 67 countries. VSA arts also publishes educational program resources for use in classroom environments geared towards utilizing arts-based curricula to increase disability awareness, encourage expression, improve learning, and grow self-esteem.

**Vestibular Disorders Association (VEDA)**

(503) 229-7705 or (800) 837-8428

<http://www.vestibular.org/>

The Vestibular Disorders Association (VEDA) is a support and information organization for people with balance and inner ear problems. It provides information about vestibular disorders; has a support network for people with dizziness and balance disorders; educates the public and health professionals about vestibular disorders; and supports research and clinical activities.

**Westat**

(301) 251-1500

<http://www.westat.com/>

Westat performs research studies in a wide range of programs and subject areas, including education. It has many products, including the Annual Report to Congress on the Implementation of the Individuals with Disabilities Education and Act, which is funded by the U.S. Department of Education, Office of Special Education Programs (OSEP).

**Wheelchair Sports, USA (WSUSA)**

(636) 614-6784

<http://www.wsusa.org/>

Wheelchair Sports, USA (WSUSA) organizes and governs wheelchair sports in the United States. Its activities are directed by the National Wheelchair Athletic Committee, which maintains rules on wheelchair athletics, records rule changes, maintains records, selects sites for national championship meets, sanctions meets, and promotes wheelchair sports. The organization believes in the positive psychological aspects of a rehabilitation program of competitive sports, and hopes that the media attention gained from sponsoring meets will serve to educate the public. WSUSA offers sports in the following: archery, athletics, shooting, swimming, table tennis, weight-lifting and fencing. WSUSA also has two team sports. They are quad rugby and basketball. Membership is available for a fee.

**Williams Syndrome Association (WSA)**

(248) 244-2229

<http://www.williams-syndrome.org/>

The Williams Syndrome Association, Inc. (WSA) is a national organization currently providing support and information to over 3500 families. WSA is dedicated to helping individuals with Williams syndrome to reach their full potential by providing them and their families with the most current information available regarding medical guidelines and educational techniques. It works to increase public and professional awareness and understanding, disseminate the most timely and accurate information, and actively support research into all aspects of Williams Syndrome.

**Wilson's Disease Association**

(330) 264-1450 or (888) 264-1450

<http://www.wilsonsdisease.org/>

The Wilson's Disease Association is a nonprofit self-help and advocacy group whose main purpose is to give aid and support to the victims of Wilson's Disease & related diseases and their families. Wilson's Disease is a rare genetic disorder characterized by excess storage of copper in the body tissues, particularly in the liver, kidneys, brain, and corneas of the eyes. The Wilson's Disease Association fosters research, disseminates information, and provides direct financial aid to patients. Its biannual newsletter contains information on current research, pertinent legislation, and advocacy activities.

**World Arnold Chiari Malformation Association (WACMA)**

(610) 353-473

<http://www.pressenter.com/~wacma/>

Staffed by volunteers, the World Arnold Chiari Malformation Association is committed to providing support, current information, and understanding to those affected by the Arnold Chiari malformation and syringomyelia. It is also our goal to raise the awareness of, and educate the medical community as to the complex nature of this disease and how it affects the lives of those who have it. With the help of our members from around the world we hope to be

able to provide further research into the areas of symptoms, diagnosis, treatment and outcomes related to ACM and syringomyelia.

**Wrightslaw Yellow Pages for Kids**

<http://www.yellowpagesforkids.com/>

At Wrightslaw, our mission is to provide parents, advocates, educators, and attorneys with accurate, up-to-date information about special education law and advocacy so they can be effective catalysts. Wrightslaw Yellow Pages for Kids is an on-line directory of several resources available for individuals with disabilities and their families. The directory is organized by state making it a great, easy to use resource.

**Wrightslaw**

<http://www.wrightslaw.com/>

At Wrightslaw, our mission is to provide parents, advocates, educators, and attorneys with accurate, up-to-date information about special education law and advocacy so they can be effective catalysts.

**Yale Child Study Center**

(203) 785-2540

<http://medicine.yale.edu/childstudy/index.aspx>

The Yale Child Study Center of the Yale Developmental Disabilities Clinic offers comprehensive, multidisciplinary evaluations for children with social disabilities, usually focusing on the issues of diagnosis and intervention. It also conducts research projects on autism, AS, and other PDDs.

**Zero to Three- National Center for Infants, Toddlers, and Families**

<http://www.zerotothree.org/>

ZERO TO THREE is a national, nonprofit organization that informs, trains, and supports professionals, policymakers, and parents in their efforts to improve the lives of infants and toddlers.

## Training Projects Funded Under IDEA

### **Increasing the Number, Competence, and Resources of Early Interventionists in Areas of Shortage Through Distance Learning (*INCREAS-DL*)**

Grant No. H325K090120      Funding Year (2010-2013)

**Project Director:** Lee Ann Jung

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Lexington, KY 40506-0001

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#### ABSTRACT

**Purpose:** This project will address the critical shortage of special education instructors in rural Kentucky by training 24 part-time students in an alternate certification program that will lead to Interdisciplinary Early Childhood Education Certification.

**Method:** The program will integrate training and field-based practice opportunities delivered via innovative distance education formats. Coursework that focuses on early intervention service delivery will be included, as well as an emphasis on a primary service provider model. Much of the field-based learning experiences will take place within the scholars' current employment, allowing them to work toward certification without having to interrupt job responsibilities, thus maintaining the current availability of service in Appalachian Kentucky. Particular emphasis will be placed on recruiting applicants from Appalachia, the area experiencing greatest shortage and least opportunity for certification.

#### **PREPaRE: Preparing Related Services Personnel for Rural Employment**

##### **Project co-directors:**

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**Purpose:** Department of Rehabilitation Sciences, Divisions of Physical Therapy and Communication Sciences Disorders, at University of Kentucky in collaboration with the Department of Occupational Therapy at Eastern Kentucky University, received a 4 year, \$738,559 grant from the U.S. Department of Education for personnel development to help alleviate the regional shortage of highly qualified personnel in occupational therapy, physical therapy, and speech-language pathology who are able and willing to work collaboratively in early intervention and schools in rural areas.