

## Resources for Kentucky Children with Down Syndrome

52 Weeks of Public Health Spotlight: Down Syndrome Awareness Month



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**FRANKFORT, Ky.** (October 25, 2017) – October is Down Syndrome Awareness Month. As part of the 52 Weeks of Public Health campaign, the Kentucky Department for Public Health (DPH) within the Cabinet for Health and Family Services (CHFS) is raising awareness about the genetic disorder and the resources available to Kentucky children dealing with learning and development delays.

Down syndrome, a genetic disorder caused by a defect of the chromosomes impacting the genetic information that makes each person unique. Every year in Kentucky approximately 66 babies are born with Down syndrome, a rate that equates to about 11.6 cases per 10,000 live births.

There are three different types of Down syndrome with Trisomy 21 being the most common type. Most people have two copies of each chromosome in each of cell, however, people with Trisomy 21 have three copies of chromosome 21 in every cell.

Translocation Down syndrome and Mosaic Down syndrome are two additional types of the disease, but are extremely rare. With these conditions, an extra whole or partial copy of chromosome 21 is attached to another chromosome in every cell or some, but not all cells has an extra copy of chromosome 21.

Common physical features of individuals with Down syndrome include a flattened face, almond-shaped eyes that slant up, a short neck, small ears, a tongue that tends to stick out of the mouth,

tiny white spots on the eye, small hands and feet, a single line across the palm of the hand, poor muscle tone or loose joints, and short height. These physical characteristics may be less pronounced in individuals with Mosaic Down syndrome.

"Most people know that mothers over 35 years old are at higher risk of having a baby with Down syndrome. However, most babies with Down syndrome actually have mothers who are younger than 35 because births among younger women are more common," says Monica Clouse, MPH, Principal Investigator for the Kentucky Birth Surveillance Registry. "Women who are concerned about Down syndrome should talk to their doctor about whether to get genetic counseling before becoming pregnant."

Each person with Down syndrome is unique having different personalities, abilities, and needs. In Kentucky, there are several organizations throughout the state that are committed to supporting families and individuals with Down syndrome.

- The Down Syndrome Association of Central Kentucky is based in Lexington and provides services to families in Central and Eastern Kentucky.
- <u>Down Syndrome of South Central Kentucky</u> is based in Bowling Green and provides services to families in South Central Kentucky.
- Green River Area Down Syndrome Association is based in Owensboro and covers western Kentucky.
- **Down Syndrome of Louisville** is based in Louisville and covers counties surrounding Louisville and Elizabethtown.
- The Council on Developmental Disabilities is based in Louisville and provides statewide services to individuals with developmental disabilities.
- <u>The Down Syndrome Association of Greater Cincinnati</u> supports families in Northern Kentucky.

The Kentucky Department for Public Health maintains a <u>Birth Surveillance Registry (KBSR)</u> that tracks information relating to Down syndrome as well as other birth defects. For more information about Down syndrome, visit the <u>Department for Public Health website</u>.

Interested in learning more about healthy Kentucky lifestyle? Through our 52 Weeks of Public Health campaign, the Kentucky Department for Public Health will spotlight public health issues as well as highlight services and resources available to Kentuckians statewide. Follow us on Facebook for your weekly tip.