

BACKGROUND

Timely reporting of health and developmental outcomes for extremely low birth weight (ELBW) infants is critical for prenatal counseling of parents, treatment decisions, and post-discharge planning and care. Follow-up data from multiple centers or specific regions permit assessments of large cohorts of infants and more precise estimates of outcome status.

STUDY GROUP GOALS

1. Evaluate growth, health, sensory, motor, and cognitive outcomes for ELBW infants.
2. Analyze center, region, and group data to enable trending and comparisons over time.
3. Identify opportunity to improve follow-up care for infants most at risk for severe disability.

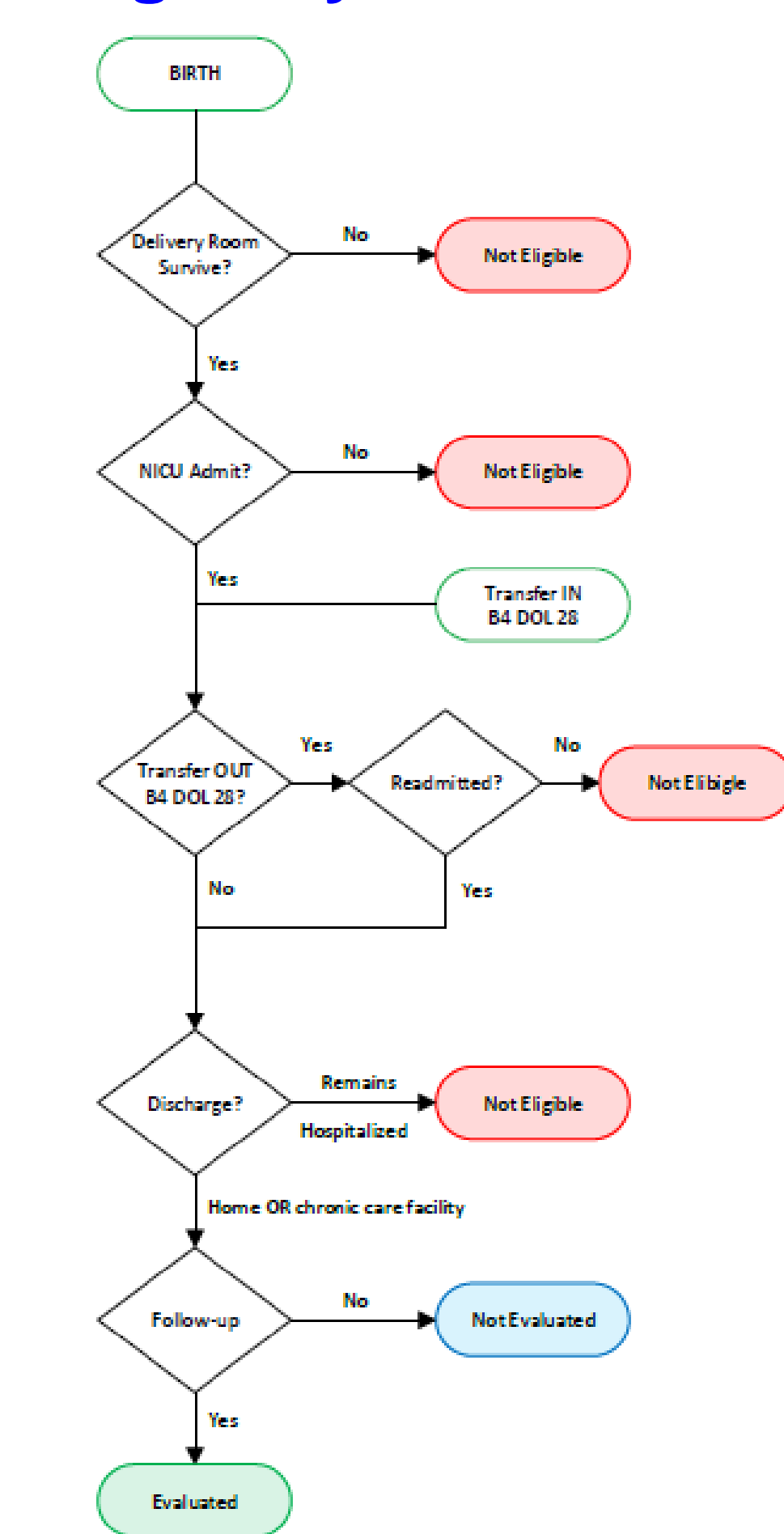
PARTICIPATING CENTER AIMS

1. Increase by 10% per year the rate of evaluated infants at 18-24 months' adjusted age.
2. Achieve and sustain a follow up rate of 85% or more.
3. Identify opportunities to improve post-discharge follow through care or outcomes or both for ELBW infants.

STUDY GROUP METHODS

Eligible infants were born 1/1/14 – 12/31/16 with birth weight (BW) 401 to 1000 grams (inclusive) or gestational age (GA) 22 weeks 0 days to 27 weeks 6 days surviving until hospital discharge. Data were collected using standardized tools at the time of the 18 - 24 months' corrected age follow-up visit. Participating centers contributed to the VON VLBW database, and were affiliated with a Follow-up

Eligibility Flowchart



Clinic in which the Bayles Scales of Infant Development (BSID) were used for neurodevelopmental assessment. All collected data was de-identified. Center participation was voluntary and open annually. Each center was responsible for determining the need for IRB review and patient consent. Centers were not identified in group reports.

The Extremely Low Birth Weight Infant Follow-up Study Group: Supporting Follow-Through and Outcomes Assessment Birth Year Cohorts 2014-2016

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Follow-up clinics have a critical role in the follow-through of prematurity related morbidities that impact infant growth, health and neurodevelopment.

Table 1: Health after discharge.

	Evaluated Infants	
	Median	IQR
Support after discharge	79%	(73,95)
• Oxygen	33%	(18, 46)
• Respiratory Medication	48%	(27, 63)
• Oral Feeding Support	25%	(13, 33)
• Speech Support	42%	(30, 65)
• Motor Support	64%	(46, 88)
Medical re-hospitalizations	36%	(27, 41)
Surgical procedures	30%	(24, 40)

Figure 1: Support after discharge.

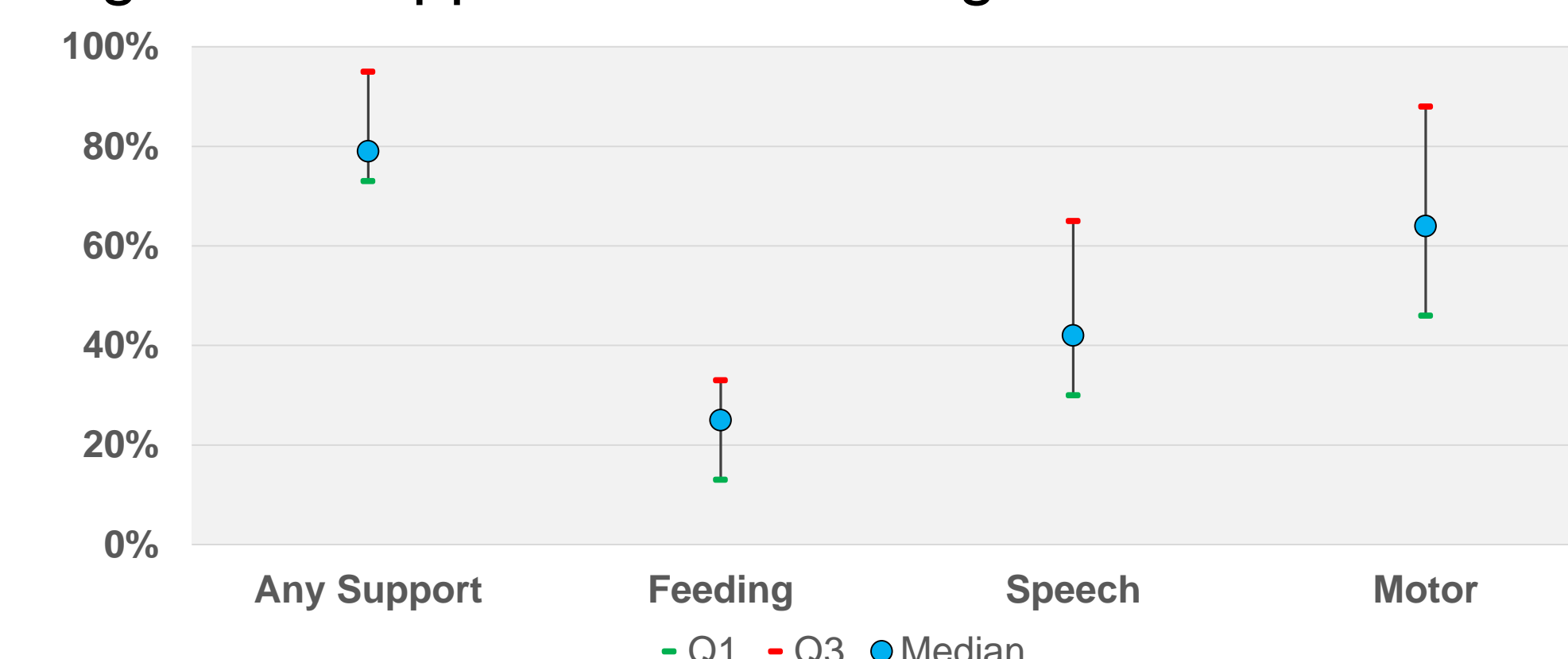
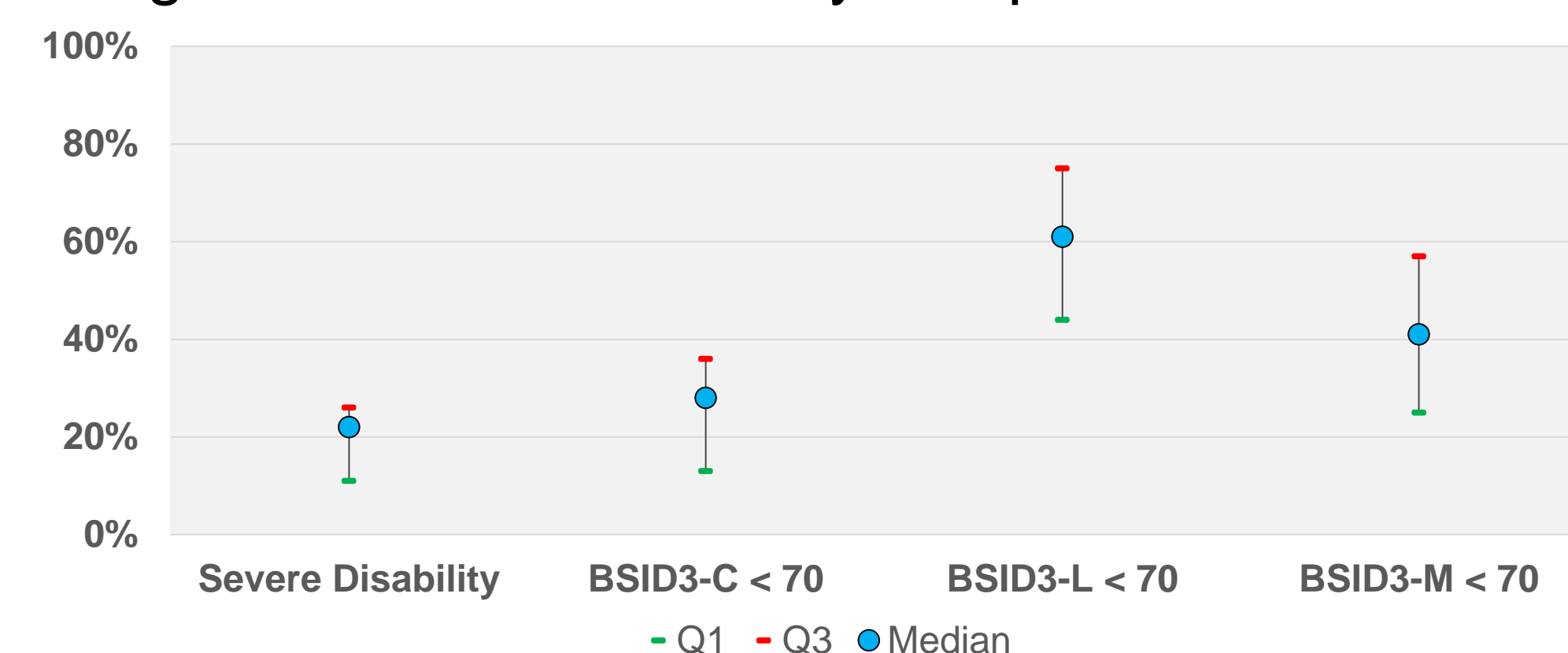


Table 2: Severe Disability at follow-up.

Severe Disability	Evaluated Infants	
	Median	IQR
Severe Disability	22%	(11, 26)
• Impaired vision	3%	(0, 3)
• Impaired hearing	5%	(0, 6)
• Unable to walk with support	22%	(9, 31)
• Cerebral Palsy	36%	(13, 50)
• BSID III < 70 Cognitive	28%	(5, 19)
• BSID III < 70 Language	61%	(44, 75)
• BSID III < 70 Motor	41%	(25, 57)
• Too severely delayed to complete	4%	(0, 5)

Figure 2: Severe disability components.



DATA FORM HEALTH

VERMONT OXFORD NETWORK - Infant Follow-Up - HEALTH STATUS REPORT

ELBW Infant Follow-Up Report for Center

Table 6: Support After Discharge¹

	2016		2014-2016		
	Cases	N %	Cases	N %	
Support After Discharge	21	100	36	45	80
Yes	0	21	0	9	45
No	0	21	0	0	0
Unsure	0	21	0	0	0
Support (1)	0	21	0	0	0
Tracheostomy	1	21	5	1	36
Ventilator	11	21	52	19	36
Oxygen	2	21	10	5	36
Gastrostomy	1	21	5	1	36
Nasogastric Feeds	0	21	0	0	0
Apnea or Cardio-Respiratory Monitor	13	21	62	21	36
Pulse Oximetry	11	21	52	16	36
Respiratory Medication	7	21	33	14	36
Oral Feeding Support	7	21	33	16	36
Speech Support	7	21	33	16	36
Motor Support	13	21	62	24	36

1: An infant could have one or more types of support.

CENTER REPORT HEALTH STATUS

VERMONT OXFORD NETWORK - Infant Follow-Up - HEALTH STATUS REPORT

ELBW Infant Follow-Up Report for Center

Table 6: Support After Discharge¹

2016

2014-2016

Cases N % Cases N %

Support After Discharge

Yes 21 100 36 45 80

No 0 21 0 9 45 20

Unsure 0 21 0 0 0 0

Support (1)

Tracheostomy 1 21 5 1 36 3

Ventilator 11 21 52 19 36 53

Oxygen 2 21 10 5 36 14

Gastrostomy 1 21 5 1 36 3

Nasogastric Feeds 0 21 0 0 0 0

Apnea or Cardio-Respiratory Monitor 13 21 62 21 36 58

Pulse Oximetry 11 21 52 16 36 44

Respiratory Medication 7 21 33 14 36 39

Oral Feeding Support 7 21 33 16 36 44

Speech Support 7 21 33 16 36 44

Motor Support 13 21 62 24 36 67

DATA FORM DEVELOPMENT

VERMONT OXFORD NETWORK - Infant Follow-Up - DEVELOPMENTAL STATUS REPORT

ELBW Infant Follow-Up Report for Center

Table 15: Severe Disability

	2016		2014-2016			
	Cases	N %	Cases	N %		
Severe Disability (1)	3	21	14	11	45	24
Impaired Vision	0	3	0	0	11	0
Impaired Hearing	2	3	67	3	11	27
Unable to Walk with Support	0	3	0	1	11	9
Cerebral Palsy	0	3	0	3	11	27
Any BSID - III Composite Score < 70	2	3	67	10	11	91
BSID - III Cognitive < 70	0	3	0	4	11	36
BSID - III Language < 70	1	3	33	5	11	45
BSID - III Motor < 70	1	3	33	6	11	55
Too Severely Delayed to Complete BSID	0	3	0	0	11	0

CENTER REPORT SEVERE DISABILITY

VERMONT OXFORD NETWORK - Infant Follow-Up - DEVELOPMENTAL STATUS REPORT

ELBW Infant Follow-Up Report for Center

Table 15: Severe Disability

2016

2014-2016

Cases N % Cases N %

Severe Disability (1)

Impaired Vision 0 3 0 0 11 0

Impaired Hearing 2 3 67 3 11 27

Unable to Walk with Support 0 3 0 1 11 9

Cerebral Palsy 0 3 0 3 11 27

Any BSID - III Composite Score < 70 2 3 67 10 11 91

BSID - III Cognitive < 70 0 3 0 4 11 36

BSID - III Language < 70 1 3 33 5 11 45

BSID - III Motor < 70 1 3 33 6 11 55

Too Severely Delayed to Complete BSID 0 3 0 0 11 0

RESULTS

For 2014-2016, there were 7,878 ELBW infants born at Study Group centers. Of these, 6,019 infants were eligible for follow-up and 2,917 (48%) were evaluated. The median center follow-up rate increased over this period from 47% to 55%. Of evaluated infants, 10% weighed < the 3rd percentile and 20% weighed < the 10th percentile at follow-up: 9% had a head circumference (HC) < the 3rd percentile and 17% a HC < the 10th percentile (WHO Growth Data).

Of evaluated infants, 79% received some type of support between discharge and follow-up. Of these, 25% received oral feeding support, 42% speech support and 64 % motor support. (Table 1, Figure 1) Of evaluated infants 36% were re-hospitalized at least once between discharge and follow-up. Of these re-hospitalizations, 77% were for a respiratory illness. Surgical procedures were performed for 30% of evaluated infants. Of these surgeries, 26% were for tympanostomy tubes and 21% were inguinal hernia repairs.

Of evaluated infants, 8% had cerebral palsy (CP); 22% had a BSID Cognitive score ≤ 84, 40% a Language score ≤ 84 and 26% a Motor score ≤ 84. Severe disability (SD), defined as any of bilateral blindness, hearing loss requiring amplification, any BSID score < 70, CP, or inability to walk with support, occurred in 22% of assessed infants (center IQR;11%,26%). Of infants with SD, 36% had CP, 28% a BSID Cognitive score < 70, 41% a BSID Motor score < 70 and 61% a BSID Language score < 70. (Table 2, Figure 2) The percent of infants with SD increased with decreasing BW or GA.

CONCLUSIONS

Center follow-up rates vary widely. Severe disability remains highest among infants of lowest birth weight and gestational age.

FUTURE DIRECTIONS

1. Improve the overall rate of follow-up.
2. Focus follow-through and follow-up effort on infants born 22-24 weeks gestational age.
3. Transition to assessment using the Bayley-4.
4. Link patient level data between ELBW Nightingale data and follow-up data.

Akron Children's Hospital
Ascension- St Joseph's Hospital
Aurora Baycare Medical Center
Baptist Memorial Hospital for Women
Baystate Medical Center
Beth Israel Deaconess Medical Center
CHOC Children's Hospital
CHOI at OSF St. Francis Medical Center
Cape Fear Valley Medical Center

Children's Hospital U. Mississippi Health Care
Children's Hospital of Wisconsin
Children's Hospital & Clinics, Minneapolis
Cone Health Women's Hospital
Connecticut Children's Medical Center
Dartmouth Hitchcock Medical Center
Driscoll Children's Hospital
Eastern Maine Medical Center
Golisano Children's SW Florida

Goryeb Children's Hospital
Helen Devos Children's Hospital
Henry Ford Hospital
IRCCS Ospedale Maggiore di Milano
KK Women's & Children's Hospital
Massachusetts General Hospital
Mercy San Juan Medical Center

PARTICIPATING CENTERS for BIRTH YEAR COHORTS 2014-2016

Mississippi Baptist Health Systems
New Hanover Regional Medical Center
Oklahoma U Health Sciences Center
Providence Tarzana Medical Center
Rainbow Babies & Children's Hospital
Randall Children's Hospital Legacy Emanuel
Rocky Mountain Hospital for Children

St. Barnabas Medical Center
St. John Hospital & Medical Center
Sunnybrook Health Sciences Centre
Tufts Medical Center
UCSF Benioff Children's Hospital SF
UMass Memorial Health Care
USA Children's and Women's Hospital
University Hospital San Antonio
University of Illinois at Chicago

University of Iowa Children's Hospital
University of Louisville Hospital
University of Vermont Children's Hospital
Vidant Medical Center
Wake Medical Center
Women & Infants Hospital
Women's Hospital
Yale-New Haven Children's Hospital
Yale-New Haven at Bridgeport Hospital