

FALL/WINTER 2015

KITSAP COUNTY CHILD HEALTH NOTES



Promoting partnerships between primary health care providers, families & the community to support early identification of children with special needs and comprehensive care within a primary care Medical Home

Distributed by: Kitsap County Medical Home Leadership Network

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Down Syndrome

"My doctor was so helpful when he told me my baby would be able to do pretty much everything I hoped he would be able to do in life, even though he had Down syndrome. That was an extreme relief."-----Rebecca Partridge, MD, mother of a child with Down syndrome.

Down syndrome (DS) is the most common cause of intellectual disability and the most common chromosomal condition diagnosed in the United States. Each year, about 6,000 babies born in the United States have DS. Approximately 83,000 children and adolescents with DS are living in the United States.¹

Individuals with DS are at greater risk for a number of health concerns including heart defects, hearing, vision and thyroid abnormalities, and obstructive sleep apnea. Between 1 and 10% of those with DS also qualify for the diagnosis of autism.²

The American Academy of Pediatrics (AAP) updated their comprehensive health supervision guidelines for the care of children and young adults with Down syndrome in 2011:

<http://pediatrics.aappublications.org/content/128/2/393.full.pdf>² Are you following these guidelines?

According to a recent survey, 72% of providers could not correctly answer a quiz question about new AAP Guidelines for the care of children with Down syndrome.³ This is what often gets missed:



Hearing screening: The AAP recommends hearing screening at birth and at 1 month, hearing testing at 6 months, and annually from 1 to 21 years of age.



Vision screening: The AAP recommends eye exams (especially to look for cataracts) once between birth and 1 month, and once between 1 month and 1 year. After that, ophthalmologic exams are recommended annually from 1 to 5 years, every 2 years from 5 to 13 years, and every 3 years from 13 to 21 years, looking for cataracts, strabismus, and nystagmus in particular.



Thyroid screening: The AAP recommends thyroid screening as part of the newborn screen, once during the newborn period to 1 month, at 6 months, 12 months, and annually from 1-21 years.

Major Changes to AAP Guidelines in 2011:

- The AAP **added** a new recommendation, sleep apnea screening, by age 4 years.
- The X-ray to rule out atlanto-axial instability was **subtracted** in the 2011 update.
- Individuals with DS are at increased risk for obesity as they age.⁴ Special DS growth charts have been developed, but the use of them is controversial now as fitness standards have changed. Some suggest using DS *height* curves, but standard *weight* curves. The 2011 AAP recommendation is to use standard curves for both height and weight.²

References/ National Resources

1. CDC Website: statistics about Down syndrome. <http://www.cdc.gov/ncbddd/birthdefects/DownSyndrome.html> Sept. 2014.
2. The American Academy of Pediatrics Clinical Report—Health Supervision for Children with Down Syndrome by Marilyn Bull and the Committee on Genetics. *Pediatrics* 2011; 128: 393-406; <http://pediatrics.aappublications.org/content/early/2011/07/21/peds.2011-1605.full.pdf>
3. Personal communication with Dr. Lisa Herzig regarding her study of providers caring for children with Down syndrome, September, 2014.
4. Hickey F, Hickey E, Summar KL. "Medical update for children with Down syndrome for the pediatrician and family practitioner." *Advances in Pediatrics* 2012 59 (1): 137–57. doi:10.1016/j.yapd.2012.04.006. PMID 22789577.
5. The Intellectual and Developmental Disabilities Toolkit by the Vanderbilt Kennedy Center for Research on Human. Development. <http://www.cmhnetwork.org/news/toolkit-idd-mental-health-challenges>. The IDD Toolkit offers health care providers best-practice tools and a wealth of information regarding specific medical and behavioral concerns of adults with IDD including resources for patients and families.
6. [*Understanding a Down Syndrome Diagnosis*](#), a booklet from The Joseph P. Kennedy, Jr. Foundation. Reviewed by representatives of national medical and Down syndrome organizations and available in both print and digital formats.

Regional Clinical Resources

- [Virginia Mason Down Syndrome Clinic](#), by Dr. Rebecca Partridge. Dr. Partridge is the mother of a child with Down syndrome. She is also Board certified in Pediatric Emergency Medicine and a primary care provider who sees patients in Issaquah and at University Village. Call (425) 557-8000 for an appointment or to arrange a phone consultation.
- The [Neurodevelopmental Clinic at Seattle Children's Hospital](#) has staff (Darcy King, ARNP, and fellow, Lisa Herzig) with special interest in Down syndrome. Call (206) 987-2000 and ask for the Neurodevelopmental scheduler for an appointment.

Professional and Parent Groups

- National Down Syndrome Society: <http://www.ndss.org>
- Global Down Syndrome Foundation: <http://globaldownsyndrome.org>
- *Down Syndrome Connect*, a NIH-sponsored national registry for those with Down syndrome to keep families informed of opportunities to participate in studies as they become available. <https://dsconnect.nih.gov>

Highly Recommended Books for Families

- [Babies with Down Syndrome: A New Parent's Guide](#) by Susan J. Skallerup. Published 11/15/2012.
- [The Down Syndrome Transition Handbook Charting Your Child's Course to Adulthood](#) by Jo Ann Simons. Published 3/28/2010.
- [Mental Wellness in Adults with Down Syndrome: A Guide to Emotional and Behavioral Strengths and Challenge](#) by Dennis McGuire and Brian Chicoine. Published 7/28/2006.

Kitsap County Special Needs Resources			
➤ For children under age 3:	Holly Ridge Center (360) 373-2536 or (800) 449-1660 5112 NW Taylor Road Bremerton, WA 98312		
➤ For children age 3 to 21:	Local School District Office of Special Education		
	Bainbridge Island 206-842-2907	Central Kitsap 360-662-1040	North Mason 360-277-2111
	Bremerton 360-473-1008	North Kitsap 360-394-2604	South Kitsap 360-443-3625
➤ Family Support:	The U.P.S.I.D.E. – Down Syndrome Support Group of Kitsap County Sharon Dommermuth (360) 308-0187, theupside@comcast.net		