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: Distributed by: Children with Special Health Care Needs and Snohomish County Early Intervention Program. This newsletter provides physicians, nurse practitioners, primary health care providers, public health centers and community partners with current information regarding identification and management of special health issues for children. This issue was written by Gwen Glew, MD, MPH. Reviewed by Katherine Tekolste, MD, Louise Gane, MS, genetic counselor of the M.I.N.D. Institute, University of California-Davis, and Debra Lochner Doyle, MS, CGC, State Genetics Coordinator, WA State Dept. of Health Support from the Washington State Department of Health and the University of WA Center on Human Development and Disability

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

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**

3. Personal communication with Dr. Lisa Herzig regarding her study of providers caring for children with Down syndrome, September, 2014.


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
- Global Down Syndrome Foundation: http://globaldownsyndrome.org
- Down Syndrome Connect, an 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

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SNOHOMISH COUNTY SPECIAL NEEDS RESOURCES

- **For children birth through age 18**
  - Contact: Snohomish Co Early Intervention Program 425.388.7402
- **For children under age three:**
  - Contact: Snohomish Co Early Intervention Program 425.388.7402
- **WithinReach Family Health Hotline**
  - 1.800.322.2588, 1.800.833.6388 TTD www.withinreachwa.org
- **For children age three and older:**
  - Contact: Local school district

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<tr>
<td>Arlington</td>
<td>Susan Queirolo</td>
<td>360.618.6266</td>
<td>Darrington</td>
<td>Val Cook</td>
<td>360.436.2150</td>
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<tr>
<td>Edmonds</td>
<td>Debbie rothfus</td>
<td>425.431.7555</td>
<td>Everett</td>
<td>Laurie Cwikla</td>
<td>425.385.5264</td>
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<tr>
<td>Granite Falls</td>
<td>Nancie Wilder</td>
<td>360.283.4311</td>
<td>Index</td>
<td>Linda Tate</td>
<td>360.793.1330</td>
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<tr>
<td>Lake Stevens</td>
<td>Janet Rich</td>
<td>425.335.1520</td>
<td>Lakewood</td>
<td>Jim Roan</td>
<td>360.652.4501 #3029</td>
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<tr>
<td>Marysville</td>
<td>Cathy Fridrich</td>
<td>360.653.0825</td>
<td>Monroe</td>
<td>Joyce Wilson</td>
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<tr>
<td>Mukilteo</td>
<td>Belinda Kelly</td>
<td>425.356.1204</td>
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<td>Marian Sherwood</td>
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<td>Stanwood</td>
<td>Lynn Currey</td>
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<td>Sultan</td>
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<td>360.793-9801x125</td>
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![Children with Special Health Care Needs](image1)

![Snohomish County Early Intervention Program](image2)

![Snohomish Health District](image3)

![Washington State Department of Health](image4)