

DECEMBER, 2000

ADAMS COUNTY CHILD HEALTH NOTES:

Adams County Child Health Notes is distributed by Adams County Interagency Coordinating Council (ICC) and Adams County Health District. This newsletter provides physicians and nurse practitioners with current information regarding identification and management of special health issues for children. Contributing agencies and programs include: Adams County ICC - Adams County Health District - Department of Health - Children With Special Health Care Needs Program (Contract #N08400) - Univ. of Washington - Center on Human Development and Disability - Whatcom County Medical Home Team. Additional Child Health Notes are available at <http://depts.washington.edu/medhome/>.



For additional information on evaluation of children's growth and Marfan syndrome, see:

- Assessment of Abnormal Growth Curves. American Family Physician; July 1998. (available at <http://www.aafp.org>)
- Tall Stature. Alpert BS. Pediatrics in Review. 19(9):303-5, Sept 1998.
- Health Supervision for Children with Marfan Syndrome. AAP Committee on Genetics. Pediatrics. 98(5):978-982, Nov 1996.

ASSESSMENT OF TALL STATURE: WHEN TO CONSIDER MARFAN SYNDROME

Marfan syndrome is a connective tissue disorder that affects the skeletal system, the heart and the eyes. Recent research has demonstrated that Marfan Syndrome results from defects in a gene on chromosome 15. Changes in this gene affect the production of fibillin, a connective tissue protein.

Affected individuals are typically tall, slender and have hypermobile joints; Additional physical findings may include:

- **Skeletal:** scoliosis; chest wall abnormalities; long, slender fingers; a thin, narrow face; micrognathia; arm span greater than body height (ratio greater than 1.05); decreased upper to lower body segment ratio for age
- **Cardiac:** mitral valve prolapse, aortic dilatation, aortic valve insufficiency, aortic aneurysm
- **Eye:** myopia, lens dislocation

Marfan syndrome is inherited in an autosomal dominant manner. A child has a 50-50 chance of inheriting the disorder from an affected parent. In about 25 percent of cases, Marfan syndrome represents a new mutation. In the United States the incidence of Marfan syndrome is approximately 1 per 10,000.

Assessment of tall stature in childhood includes serial growth measurements. In more than 90% of children with increased height, the etiology is familial. The rate of growth is normal in familial tall stature. In Marfan syndrome and other conditions where the cause of increased height is pathological, the rate of linear growth is generally accelerated.

When tall stature is a concern:

- Review family history for Marfan syndrome or related symptoms
- Provide careful assessment of skeletal, cardiac, and eye findings. It is often appropriate to refer for detailed cardiac and eye examinations.

Consider referral for genetics evaluation when the family history is positive and/or when physical findings suggest Marfan syndrome.

REGIONAL RESOURCES

- University of Washington Genetics Resource Line 1-800-562-4363
Telephone consultation for health and social service professionals
- Children's Hospital and Regional Medical Center
Medical Genetics Clinic Contact the Medical Genetics office
Medical Genetics Outreach Clinics (206) 526-2056

ADDITIONAL RESOURCES

Marfan Syndrome

- National Marfan Syndrome Foundation - www.marfan.org
- Canadian Marfan Association - www.marfan.ca

ADAMS COUNTY RESOURCES FOR DEVELOPMENTAL SCREENING AND ASSESSMENT

- **For children under age three:** Contact: Adams County Health District
Phone: 659-3317 or 488-2031
- **For children age three and older:** Contact: Local school district

District:	Phone	Fax	District:	Phone	Fax
Othello School	488-4682	488-5876	Ritzville School	659-0232	659-0927
Lind School	677-3481	677-3463	Washtucna School	646-3237	646-3249

SPECIAL NEEDS INFORMATION AND RESOURCES:

- **Local:** Adams County Health District 659-3317 or 488-2031
- **Regional:** Children's Hospital and Regional Medical Center
Health Professional Hotline (800) 293-2462
Parent Resource Line (877) 526-2500
- Infant Toddler Early Intervention Program www.wa.gov/shs/iteip/iteip.html
- **National/Internet:** AAP Developmental and Behavioral Pediatrics www.dbpeds.org/
American Family Physician www.aafp.org
American Academy of Child and Adolescent Psychiatry www.aacap.org.htm
Family Village www.familyvillage.wisc.edu/
Family Voices www.familyvoices.org

**The first Parent Night was held at Othello Community Hospital on November 13th. Jennifer Newhouse with Columbia Basin Parent to Parent led the meeting. The parents in attendance requested meeting every other month for a chance to talk about issues that concern them with their special needs children. The next meeting is scheduled for January 8th. If you have parents you believe would be interested in attending these meetings please refer them to the Health District for further information.*

Adams County Health District
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Ritzville, WA 99169