

What is Miller Syndrome?

Miller Syndrome is a very rare genetic condition often referred to as “postaxial acrofacial dysostosis”. This disorder is characterized by distinctive craniofacial malformations that occur in association with limb abnormalities. Some facial characteristics include:

- underdeveloped cheekbones
- abnormally small jaw (micrognathia)
- cleft palate
- small, protruding “cup-shaped” ears
- drooping of the lower eyelids

Why did this happen?

Research is still being conducted; however, it is believed that Miller Syndrome is inherited as an autosomal recessive genetic trait. That means that it is passed on when both parents carry a recessive gene with the Miller Syndrome trait.

Will this happen to children I have in the future?

If both parents carry the gene, there is a good chance that other children would be born with Miller Syndrome.

What kinds of problems could my child have?

In addition to the craniofacial characteristics common to Miller Syndrome, your child may have the following problems:

- incomplete limb development

- webbing of fingers or toes
- absence of certain fingers and /or toes
- underdevelopment of the ulna (bones on the “pinkie” side) and the radius (bones on the thumb side) causing the forearms to appear unusually short
- Miller Syndrome does NOT affect intelligence

Will my child need surgery?

Several surgeries may be necessary depending on the severity of your child’s Miller Syndrome. Some which may be needed are:

- tracheostomy to help with breathing
- gastrostomy tube to assure proper nutrition
- craniofacial surgery to the jaw, ears, and eyes

New advances in procedures related to the treatment of symptoms of Miller Syndrome are constantly being made. Be an advocate for your child!

How do I get help for my child?

Your child should be treated by a qualified craniofacial medical team at a craniofacial center. Currently, FACES has information on many of these teams. This is by no means a comprehensive list of all the craniofacial teams. Please contact FACES for details.

Am I alone?

No! There are many families and organizations who will be glad to talk with you and help you with information and support. Don't forget books, videos, and websites. The listing below will get you started.

FACES: The National Craniofacial Association
Post Office Box 11082
Chattanooga, TN 37401
(800) 332-2373

website: www.faces-cranio.org

email: faces@faces-cranio.org

We provide financial support for non-medical expenses to patients traveling to a craniofacial center for treatment. Eligibility is based on financial and medical need. Resources include newsletters, information about craniofacial conditions, and networking opportunities.

Foundation for Nager and Miller Syndromes
DeDe Van Quill, Director FNMS
13210 SE 342nd Street,
Auburn, Washington 98092
U.S.A.

Phone: 800-507-FNMS-(3667)

Phone out of USA: 001-253-333-1483

Fax: 253-288-7679

Email: dede@fnms.net

Website: www.fnms.net

Excellent resource!! This is an international support group that serves as an information clearinghouse that links families together. They have an extensive library of resources and medical reports and is involved in a genetic research project working to locate the genes responsible for Miller Syndrome. Twice a year, they publish a very informative newsletter.

National Health Law Program
1101 14th Street, Suite # 405
Washington, DC 20005
(202) 289-7661

website: www.healthlaw.org

Provides extensive information on health care laws affecting families of children with special needs.

Children with Facial Difference: A Parent's Guide.

Written by Hope Charkins, MSW.

Excellent resource for parents to help them cope with medical, emotional, social, educational, legal, and financial challenges presented by facial differences of their children. Look for this book at your larger bookstore chains.

Available at: www.Amazon.com

The Craniofacial Center

Dr. Jeffery A. Fearon, MD, FACS, FAAP, Director
7777 Forest Lane, Suite C-700

Dallas, TX 75230

(972) 566-6464

Email: cranio700@gmail.com

Website: www.thecraniofacialcenter.org

Visit Dr. Jeffrey Fearon's informative website that is very lay friendly and easy to understand.

*** According to FNMS, Miller Syndrome shares facial characteristics with the following syndromes:*

- Nager Syndrome
- Genee-Wiedemann
- Treacher Collins
- Pierre Robin
- Franchetti-Klein