

FACES:

The National Craniofacial Association 1-800-332-2373

What is Nager Syndrome?

Nager Syndrome is a condition resulting from problems in the development of the first and second branchial arches. The first arches produce the nerves and muscles for chewing, the lower jaw, two of three bones in the middle ear, and a small part of the ears. The second arches produce the nerves and muscles of facial expression, one bone in the middle ear, most of the external ears, and parts of the bone above the larynx. Characteristics which may or may not be present in your child include:

- underdevelopment of the cheek and jaw area
- down-sloping of the opening of the eyes
- lack or absence of the lower eyelashes
- lack of development of the internal and external ear
- possible cleft palate
- underdevelopment or absence of the thumb
- shortened forearms and poor movement in the elbow

Why did this happen?

Because this is such a rare syndrome, it is difficult to conduct genetic research; however, some initial studies indicate that Nager Syndrome may be passed on from one parent via a dominant gene.

Will this happen to children I have in the future?

If it is true that the gene is dominant and is passed on from a parent, then the chances would increase of having another child with Nager Syndrome. Genetic testing is highly recommended.

What kinds of problems could my child have?

- possible limited range of arm motion
- stomach and kidney reflux
- temporary or long-term hearing loss -- hearing evaluations should be conducted at an early age
- Nager Syndrome does not affect intellect

Will my child need surgery?

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

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

New advances in procedures related to the treatment of symptoms of Nager 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

email: faces@faces-cranio.org

website: www.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.

The Foundation for Nager and Miller Syndromes
DeDe Van Quill
13210 SE 342nd Street
Auburn, WA 98092
(800) 507-FNMS (3667)
Outside of USA: 001-253-333-1483

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 Nager Syndrome. Twice a year, they publish a very informative newsletter.

National Health Law Program
1114 I Street, NW, Suite # 1105
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, Nager Syndrome shares facial characteristics with the following syndromes:*

- Miller Syndrome
- Genee-Wiedemann
- Treacher Collins
- Pierre Robin
- Franschetti-Klein