

FACES: The National Craniofacial Association 800-332-2373

What is Freeman-Sheldon Syndrome?

Freeman-Sheldon Syndrome is a very rare genetic condition. Characteristics include:

- A small mouth which looks like the person is whistling
- A flat face
- Club feet
- Contracted muscles of the joints of the fingers and hands
- Underdeveloped nose cartilage

Why did this happen?

Little is known about why Freeman-Sheldon syndrome occurs. Doctors do know it is a genetic condition which can run in some families. There is nothing that the mother did or did not do during pregnancy that caused this condition.

Will this happen to children I have in the future?

Since so little is known about this syndrome, your best course would be to receive genetic counseling. Freeman-Sheldon syndrome can follow either a dominant or recessive inheritance pattern.

What kinds of problems could my child have?

In addition to the physical characteristics common to Freeman-Sheldon Syndrome, your child may have the following problems:

- A squinting eye
- Drooping upper eyelids

- Scoliosis (lateral curvature of the spine)
- During infancy, vomiting and feeding problems which usually improve with age
- Hearing loss
- Difficulty walking

Will my child need surgery?

Depending on the severity of Freeman-Sheldon Syndrome, your child may have some or all of the following procedures:

- Orthopedic or plastic surgery to correct the hands, feet, and/or mouth
- Craniofacial surgery to reshape the frontal bone and increase eyelid openings
- Physical therapy to improve hand function
- Physical therapy to improve the ability to walk
- Repositioning of the thumb to improve hand function
- Speech therapy

New advances in procedures to treat Freeman-Sheldon 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 web sites. 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

e-mail: faces@faces-cranio.org

We provide financial support for nonmedical 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.

Freeman-Sheldon Research Group Inc. (FSRG)
FORMERLY Freeman-Sheldon Parent Support Group
FSRG Outreach Department

C/O WVPTI

ATTN: Pat Haberbosch

1701 Hamill Avenue

Clarksburg, WV 26301

(800)281-1436 in WV only

(304) 624-1436

website: www.fsrgroup.org

e-mail: phaberbosch@aol.com

Excellent Resource!!! This organization offers information on Freeman-sheldon syndrome, peer support, registry, and link between researchers and families. Resources include newsletter, membership directory, telephone "helpline", and pamphlets.

National Health Law Program

1444 I Street; 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