

# FACES: The National Craniofacial Association 1-800-332-2373

## What is Pierre Robin?

Pierre Robin is not a syndrome or a disease. It is usually referred to as **Pierre Robin Sequence**, although it is also known as “Pierre Robin Malformation Sequence”, “Robin Anomalad”, and “Cleft Palate, Micrognathia and Glossoptosis.” It is the name given to the following birth defects if they appear together:

- small lower jaw (micronathia)
- a tongue which tends to ball up at the back of the mouth and fall back towards the throat (glossoptosis)
- breathing problems
- horseshoe-shaped cleft palate may or may not be present

## Why did this happen?

Doctors do not know exactly why Pierre Robin occurs. They do not believe it is the result of anything the mother did or did not do during pregnancy. If the child only has Pierre Robin, it is thought to be a result of the positioning of the fetus in the early weeks of pregnancy.

## Will this happen to children I have in the future?

Pierre Robin does not tend to run in families. The chances of you having another child with Pierre Robin are very small.

## What kinds of problems could my child have?

In addition to the physical characteristics common to Pierre Robin, your child may have the following problems:

- feeding problems in infancy

- ear infections
- reduced hearing
- About 40% of infants with Pierre Robin have Stickler Syndrome and about 15% have Velocardiofacial Syndrome. FACES recommends genetic testing be done to determine if your infant has either of these associated syndromes. The Pierre Robin Network has excellent information concerning [genetic testing](#) for babies born with Pierre Robin Sequence.

## Will my child need surgery?

Depending on the severity of Pierre Robin, your child may have some or all of the following surgeries:

- surgery to repair the cleft palate
- special devices to protect the airway and aid in feeding
- surgery to improve breathing
- the small jaw associated with Pierre Robin usually grows out on its own during the first two years, and usually no surgery is necessary on the jaw.

**New advances in procedures to correct the problems common to Pierre Robin 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 that 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**

P.O. Box 11082

Chattanooga, TN 37401

(800) 332-2373

e-mail: [faces@faces-cranio.org](mailto:faces@faces-cranio.org)

website: [www.faces-cranio.org](http://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.

### **Pierre Robin Network**

Nancy Barry, Founder

3604 Biscayne - Quincy, IL 62305

(217) 224-0698

email: [info@pierrerobin.org](mailto:info@pierrerobin.org)

website: [www.pierrerobin.org](http://www.pierrerobin.org)

Internet Support group composed of parents who are networking together to offer support to each other. There is also an outreach committee available to talk to those without Internet access.

### **Cleft Palate Foundation (CPF)**

1504 E Franklin Street - Suite 102

Chapel Hill, NC 27514

(800) 24-CLEFT (242-5338)

(919) 933-9044

e-mail: [info@cleftline.org](mailto:info@cleftline.org)

website: [www.cleftline.com](http://www.cleftline.com)

Resources include 24-hour information phone, fact sheets on cleft lip and palate and Pierre Robin, brochures, and medical referrals.

### **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 present by facial differences of their children. Look for this book at your larger bookstore chains.

Available at: [www.Amazon.com](http://www.Amazon.com)

### **The Cleft Palate Story.** Written by Samuel

Berkowitz, DDS, MS, FICD.

Surgical procedures performed from birth to adolescence are treated in depth; helps parents to understand options and what to expect; appendices on financial assistance, agencies, support groups, and a glossary of terms.

Available at: [www.amazon.com](http://www.amazon.com)

### **National Health Law Program**

1444 I Street, NW - Suite 1105

Washington, DC 20005

(202) 289-7661

Website: <http://www.healthlaw.org>

Provides extensive information on health care law affecting families with children who have special health care needs.