

## **NINDS Parry-Romberg Information Page**

Synonym(s): Progressive Hemifacial Atrophy

### **What is Parry-Romberg Syndrome?**

Parry-Romberg syndrome is a rare disorder characterized by slowly progressive deterioration (atrophy) of the skin and soft tissues of half of the face (hemifacial atrophy), usually the left side. It is more common in females than in males. Initial facial changes usually involve the tissues above the upper jaw (maxilla) or between the nose and the upper corner of the lip (nasolabial fold) and subsequently progress to the angle of the mouth, areas around the eye, the brow, the ear, and the neck. The deterioration may also affect the tongue, the soft and fleshy part of the roof of the mouth, and the gums. The eye and cheek of the affected side may become sunken and facial hair may turn white and fall out (alopecia). In addition, the skin overlying affected areas may become darkly pigmented (hyperpigmentation) with, in some cases, areas of hyperpigmentation and patches of unpigmented skin (vitiligo). Parry-Romberg syndrome is also accompanied by neurological abnormalities including seizures and episodes of severe facial pain (trigeminal neuralgia). The onset of the disease usually begins between the ages of 5 and 15 years. The progression of the atrophy often lasts from 2 to 10 years, and then the process seems to enter a stable phase. Muscles in the face may atrophy and there may be bone loss in the facial bones. Problems with the retina and optic nerve may occur when the disease surrounds the eye.

### **Is there any treatment?**

There is no cure and there are no treatments that can stop the progression of Parry-Romberg syndrome. Reconstructive or microvascular surgery may be needed to repair wasted tissue. The timing of surgical intervention is generally agreed to be the best following exhaustion of the disease course and completion of facial growth. Most surgeons will recommend a waiting period of one or two years

before proceeding with reconstruction. Muscle or bone grafts may also be helpful. Other treatment is symptomatic and supportive.

### **What is the prognosis?**

The prognosis for individuals with Parry-Romberg syndrome varies. In some cases, the atrophy ends before the entire face is affected. In mild cases, the disorder usually causes no disability other than cosmetic effects.

### **What research is being done?**

The NINDS supports research on neurological disorders such as Parry-Romberg syndrome with the goal of finding ways to prevent, treat, and cure them.

### **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 on the next page will get you started.

# The Romberg's Connection

The Romberg's Connection is an international support group made up of over 500 individuals and families whose lives are affected by Romberg's Syndrome. We have come together to offer our strength, courage, support and friendship to one another. Visit our website at <http://therombergsconnection.com/>

## Romberg's Connection

Theresa Hildebrand  
10622 South Parkside  
Chicago Ridge, IL 60415  
(708)4253496  
Email: [rombergs@hotmail.com](mailto:rombergs@hotmail.com)  
Website: <http://therombergsconnection.com/>

## FACES: The National Craniofacial Association

P.O. Box 11082  
Chattanooga, TN 37401  
(800) 332-2373  
Email: [faces@faces-cranio.org](mailto:faces@faces-cranio.org)  
Website: <http://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.*

## Epilepsy Foundation

8301 Professional Place  
Landover, MD 20785  
Email: [contactUs@efa.org](mailto:contactUs@efa.org)  
Website: <http://epilepsyfoundation.org/>  
Tel: 301-459-3700 or 800-EFA-1000 (332-1000)  
Fax: 301-577-2684

## Parry-Romberg Syndrome Resource, Inc.

317-566-8149  
Website: <http://prsresource.com>  
Email: [prsresource@comcast.net](mailto:prsresource@comcast.net)

National Organization for Rare Disorders (NORD)  
P.O. Box 1968  
(55 Kenosia Avenue)  
Danbury, CT 06813-1968  
Email: [orphan@rarediseases.org](mailto:orphan@rarediseases.org)  
Website: <http://rarediseases.org/rare-diseases/parry-romberg-syndrome/>  
Tel: 203-744-0100 Voice Mail 800-999-NORD (6673)  
Fax: 203-798-2291

Prepared by:  
Office of Communications and Public Liaison  
National Institute of Neurological Disorders and Stroke  
National Institutes of Health  
Bethesda, MD 20892

*NINDS health-related material is provided for information purposes only and does not necessarily represent endorsement by or an official position of the National Institute of Neurological Disorders and Stroke or any other Federal agency. Advice on the treatment or care of an individual patient should be obtained through consultation with a physician who has examined that patient or is familiar with that patient's medical history.*