

# FACES:

The National Craniofacial Association 1-800-332-2373

## What is Stickler Syndrome?

Stickler Syndrome is a group of hereditary conditions characterized by a distinctive facial appearance, eye abnormalities, hearing loss, and joint problems. Stickler Syndrome may be the most common tissue disorder in the United States. Overall, the estimated prevalence of Stickler Syndrome is about 1 in 10,000 persons.

People with Stickler Syndrome have the following characteristics:

- some degree of cleft palate
- cataracts and/or retinal detachment at early age
- a flat face
- a small jaw
- skeletal abnormalities

## Why did this happen?

Doctors believe it is the result of a mutation of the genes during fetal development. Three genes have been identified as causing Stickler Syndrome: COL11A1, COL11A2 (non-ocular), and COL2A1 (75% of Stickler cases). Other genes may also cause Stickler but have not yet been identified.

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

Stickler Syndrome tends to run in families. There is a 50% chance of passing it on to future children if you carry the trait.

## What kinds of problems could my child have?

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

- joint pain
- Scoliosis

- hearing loss
- mitrovalve prolapse
- It is recommended that children with Stickler Syndrome avoid contact sports, and that the child be immediately seen by the doctor if there is any head injury.

## Will my child need surgery?

Depending on the severity of the Stickler syndrome, your child may need some or all of the following surgeries:

- repair to the cleft palate
- surgery to correct retinal detachment and/or to remove cataracts
- corrective dentistry due to the small jaw
- regular hearing and eye exams

**New advances in procedures and information dealing with Stickler Syndrome are constantly changing. 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  
P.O. Box 11082  
Chattanooga, TN 37401  
(800) 332-2373

email: [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.*

### Stickler Involved People

15 Angelina  
Augusta, KS 67010  
(316) 259-5194

email: [sip@sticklers.org](mailto:sip@sticklers.org)

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

*Excellent resource! SIP is a network whose purpose is to educate and give support to people affected by Stickler Syndrome. Be sure to ask about the book, Stickler-The Elusive Syndrome, written by Wendy Hughes, which explains the condition in lay-friendly, positive terms.*

### Stickler Involved People College Scholarship

Dr. and Mrs. Stickler have generously donated the start-up money for a fund to provide high school seniors, who have a diagnosis of Stickler Syndrome, with a four year scholarship.

Scholarship applications for graduating high school seniors are on our website. Deadline is June 15. The winner will be announced at the Annual Stickler Syndrome Conference.

website: <http://www.sticklers.org>

### *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.*

Website: [www.Amazon.com](http://www.Amazon.com)

### Stickler Syndrome Web Site

<http://ghr.nlm.nih.gov/ghr/disease/sticklersyndrome>

*This United States National Library of Medicine site answers many of the genetic questions regarding Stickler.*