



## WHAT IS SYNDACTYLY?

Syndactyly, one of the most common congenital hand anomalies, is an abnormal connection of fingers or toes to one another—the digits are “webbed,” and have failed to separate normally during development. It most commonly involves the middle and ring fingers. In about 50% of cases, both hands are involved. Syndactyly may occur alone, or with other anomalies as part of a syndrome.

**Does syndactyly cause my baby any pain?** Typically, syndactyly is not painful. However, in some very severe cases, in which the nails might grow into the joined fingertips, minor infections and wounds can cause some discomfort.

**What are the different types of syndactyly?** Syndactyly may occur in different forms. *Complete syndactyly* occurs when the digits are joined all the way to their tips, while in *incomplete syndactyly*, the digits are joined only for part of their length. *Simple syndactyly* means that the digits are joined by the skin and soft tissue only, while *complex syndactyly* means that the bones of the digits are fused together.

**Who gets syndactyly?** Syndactyly can occur in any newborn infant. Overall, syndactyly occurs in approximately one out of 2500 newborns. In up to approximately 40% of cases, there is a family history of syndactyly. If syndactyly occurs alone, it is inherited as an autosomal dominant condition; that is, the children of an affected individual will have a 50% chance of having syndactyly. However, syndactyly is not the same from one generation to the next, and can be more or less severe than in the affected parents. Syndactyly is more common in Caucasians than in other ethnicities, and affects boys twice as often as girls.

**What causes syndactyly?** When the hands and feet are developing in the womb, they start out as flat “paddles” that then normally separate into five digits. Syndactyly occurs when there is a failure of this separation process. This may be caused by a genetic abnormality or by environmental influences.

### What are the main issues related to syndactyly?

The primary issue in syndactyly is function of the hand and digits. Syndactyly causes limitation of function, because the involved digits cannot move completely independently. In very severe cases, with multiple digits involved in complex syndactyly, there can be problems with infections and skin breakdown.

**Are there other problems that occur commonly with syndactyly?** Some children with syndactyly will have other congenital abnormalities or syndromes. Syndactyly may occur as part of several different syndromes.



The Helping Hands People<sup>SM</sup>

[www.nfsus.org](http://www.nfsus.org)

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Find **Syndactyly Family Support** on Facebook to connect with other families affected by Syndactyly.

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National Foundation for  
**SYNDACTYLY**  
RESEARCH, SUPPORT AND EDUCATION

*“Talking with other parents was a huge help. After going through it, I feel I was able to help other parents deal with Syndactyly as well! Everyone is so supportive.”*

-Alisha Hill

## WHAT IS NFS ?

The **National Foundation for Syndactyly Research, Support, and Education** is a charitable, tax-exempt, 501(c)(3) organization organized to fund research, support, and education. The foundation serves as a resource to connect families touched by Syndactyly and other related hand abnormalities with other families, facilities for treatment, and board certified hand physicians who specialize in Syndactyly treatment. We provide research grants to investigate the causes and best practices in treatment as funding permits.

The National Foundation for Syndactyly Research, Support, and Education was founded in 2012 by Linwood and Karen Gray who, as parents, were touched by Syndactyly in 1979 with the birth of their son and again in 2012 with the birth of their grandson.



## RESEARCH

The National Foundation for Syndactyly Research, Support, and Education was organized to help fund research into the causes and prevention of Syndactyly. Despite the advances in modern medicine, little if any research funding is dedicated to Syndactyly largely because it is not a life threatening affliction. It is however, a fairly common congenital defect that has no known preventative measures, and is only treated today by surgical intervention.



Annually, as our fund-raising allows, we offer competitive grants to other Scientists, Universities, and Physicians who also seek progress in the understanding and treatment of Syndactyly and other hand related abnormalities. The Scientific Advisory Council reviews applications for funding research and makes recommendations to the Board of Directors for grant funding.

The National Foundation for Syndactyly has now been listed in the Disease InfoSearch, a trusted resource for more than 7,000 diseases and the organizations dedicated to them. Our participation in Disease InfoSearch makes National Foundation for Syndactyly's information more widely available to individuals affected by Amniotic Band Syndrome, Polydactyly, Polysyndactyly, Syndactyly and Symbrachydactyly.

### **What is the treatment for babies with syndactyly?**

While every patient is treated individually, with treatment plans made specifically for him or her, some generalizations are possible. Syndactyly is treated surgically, with an operation that separates the digits using skin from the digits and, sometimes skin grafts from the arm or lower abdomen to cover the separated fingers. When the small finger or thumb is involved, this operation is done at about six months of age, to avoid distortion of the adjacent ring or index finger with growth, since the thumb and small finger are shorter than their neighboring digits. Otherwise, syndactyly release is often performed at an older age, ranging from 12 months to 3 years. Before this age, the incidence of wound healing complications and skin graft failures is significantly higher. In special cases with very complex syndactyly—or *complicated* syndactyly—such as in Apert's syndrome, surgery may begin earlier, and multiple procedures may be required in a staged sequence to achieve separation of all the digits.

**What sorts of specialists will be involved in my baby's care?** At the very least, your child will be treated by the hand surgeon and a certified hand therapist. In addition, a geneticist and developmental pediatrician are usually involved in the care of babies with Syndactyly.

**Other Common Hand Abnormalities** Polydactyly literally means "extra digits." There may be an extra thumb, small finger, or, less commonly, an extra digit in the central part of the hand. Polydactyly is one of the most common congenital hand anomalies.



## FAMILY SUPPORT & EDUCATION



One of our objectives is to connect families with Board Certified Hand Surgeons. Here's what other families are saying about NFS family support.

*"Understanding you are not alone. When making decisions on surgery, therapy, etc.; knowing you're moving in the right direction."*

**-Kelly Conlon Meyer**

*"Sharing stories and photos helps to provide more of an understanding with Syndactyly."*

**-Victoria Munoz**