

## Who is FIRST?

The Foundation for Ichthyosis & Related Skin Types, Inc.™ (FIRST) is a vibrant, growing foundation connected to its members and families by the special skin and unique management needs of individuals and families with ichthyosis and related skin types.

Our mission is to educate, inspire, and connect those touched by ichthyosis and related disorders through emotional support, information, advocacy, and research funding for better treatments and eventual cures.

FIRST provides information about ichthyosis through our [website](http://www.firstskinfoundation.org), [www.firstskinfoundation.org](http://www.firstskinfoundation.org), via [printed publications](#), our [quarterly newsletter](#), *Ichthyosis Focus* and through our lobbying and advocacy efforts. Our signature event, the [National Family Conference](#), provides attending families an opportunity to forge unforgettable connections with each other and to consult with leading medical experts. FIRST also hosts smaller one-day [Regional meetings](#).

FIRST officially launched a [Research Grant Program](#) in 2006. This program promotes and strengthens investigation into the causes, treatments, and potential cures for ichthyosis. Summaries of the many projects that have been funded by FIRST are available on our website.

Through its sponsorship of the [Ichthyosis Registry](#), the [Tele-Ichthyosis Program](#), and the [Frontiers in Ichthyosis Research Conference](#), FIRST enables connections among researchers and physicians and provides support for their efforts.

FIRST is governed by a volunteer Board of Directors and guided by a Medical & Scientific Advisory Board comprised of dermatologists, medical researchers and other health professionals. For more information, contact us by phone at 800.545.3286, visit our website at [www.firstskinfoundation.org](http://www.firstskinfoundation.org), or email at [info@firstskinfoundation.org](mailto:info@firstskinfoundation.org).

## How can you help?

I would like to support the important work of the Foundation for Ichthyosis & Related Skin Types, Inc.™

Enclosed please find my donation of \$ \_\_\_\_\_.

Name \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_

State \_\_\_\_\_ Zip \_\_\_\_\_

Phone \_\_\_\_\_

Email \_\_\_\_\_

- ☐ I have ichthyosis.
- ☐ I have a close relative with ichthyosis.
- ☐ I would like to become a member of FIRST.  
Please send me more information.



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# ICHTHYOSIS





## What is ichthyosis?

Ichthyosis is a family of genetic skin disorders characterized by dry, cracked, scaling skin that may be thickened or very thin. The prefix “ichthy” is taken from the Greek root for the word fish. Each year, more than 16,000 babies are born with some form of ichthyosis. Ichthyosis affects people of all ages, races and gender. The disease usually presents at birth, or within the first year, and continues to affect the patient throughout their lifetime.

The top layer of skin, called the *stratum corneum*, is made up of layers of flattened, dead skin cells. In normal skin, the stratum corneum renews itself at a constant rate; the cells on top are shed invisibly as new cells are generated. In some types of ichthyosis, there are too many cells being formed, and in other types, the natural shedding process is slowed or inhibited.

For more detailed information on the symptoms and implications of ichthyosis or a related skin type, visit our website at [www.firstskinfoundation.org](http://www.firstskinfoundation.org).

## What causes ichthyosis?

Ichthyosis is caused by a genetic defect which may have been spontaneous (due to a new mutation of a gene) or passed on through family inheritance. It is present at conception, although in some types of ichthyosis the symptoms do not become apparent until later in life; in other instances, it is obvious at birth that something is wrong with the baby's skin. The genetics of ichthyosis are discussed in much greater detail in “*Ichthyosis: The Genetics of Its Inheritance*,” a booklet available from FIRST.

## Is it contagious?

People with ichthyosis are frequently asked, “Is that contagious?” The answer is “No.” Ichthyosis is **definitely not contagious** because it is not caused by a bacteria, virus, or germs.

## Why is skin so important to us?

The skin is the primary deflector for the human body. It encases and protects our body from the external environment. The barrier that makes up the skin has many components, which include a barrier to excessive loss of body fluids or uptake of noxious chemicals in the skin. The skin is made up of many layers, but it is the outermost layer that provides the most protection and it is this layer where most ichthyosis patients have a defect.

## What are the different types of ichthyosis?



Most types of ichthyosis are extremely rare. Ichthyosis Vulgaris, (“vulgar” in Latin means common) is the most frequently seen type, occurring in approximately one in every 250 people. It often goes undiagnosed; because people who have

it think that they simply have severe dry skin and never seek treatment. X-linked Ichthyosis is only seen in males, and occurs in one out of every 2,000 to 6,000 people. Lamellar Ichthyosis, Congenital Ichthyosiform Erythroderma, and Epidermolytic Hyperkeratosis are other well-recognized forms of ichthyosis, and may occur in fewer than one out of 100,000 births. The rarest forms of ichthyosis include: Netherton Syndrome, Harlequin Ichthyosis, Trichothiodystrophy, and related disorders such as Hailey-Hailey Disease, Darier Disease, and Palmar Plantar Keratodermas. These forms of ichthyosis occur in less than one in 1,000,000 births.

If you have ichthyosis or a related skin type and have questions about your diagnosis or about the presence or absence of particular findings, we strongly recommend that you consult a dermatologist or geneticist who is familiar with these diseases. The Foundation can help you find these professionals.

## What are some of the problems associated with ichthyosis?

Besides the common scaling condition of the skin and depending on the severity, there may be associated psychological symptoms due to the abnormal appearance of the skin. Ichthyosis is disfiguring for most affected individuals. In addition to the numerous medical complications like dehydration, infections, chronic blistering, overheating, and rapid-calorie loss, patients with ichthyosis are subjected to psychological issues. Patients are often ostracized and concerns of isolation, low self-esteem, and depression are common due to the appearance of their visible, chronically shedding skin.



## Is there a cure for ichthyosis?

At present there is no cure for ichthyosis, however dedicated researchers and physicians have and continue to develop effective ways to help manage the disorder. FIRST supports research into the causes of ichthyosis through its Research Grant Program. Parents are also playing an important role in sharing treatment options with fellow parents and affected adults.



# Educate • Inspire • Connect