Points To Remember About Ichthyosis

- Ichthyosis is a group of skin disorders with symptoms that include dry skin, itching, and redness, cracking, and scales on the skin.
- For most people, the disease is caused by one or more mutated (changed) genes you received from your parents.
- While there is currently no cure for ichthyosis, treatments, such as creams, lotions, and some medications can help manage the symptoms.
- You can do some things to help relieve symptoms, such as taking baths, keeping your home cool, and wearing clothing that does not irritate the skin.

What is ichthyosis?
Ichthyosis is a group of skin disorders. It leads to dry, itchy skin that appears scaly, rough, and red. The symptoms can range from mild to severe. Ichthyosis can affect only the skin, but sometimes the disease can affect internal organs, too.

Who gets ichthyosis?
Anyone can get ichthyosis. The disease usually runs in families; however, some people can be the first in a family to develop ichthyosis.

What are the types of ichthyosis?
There are several types of ichthyosis. Doctors may determine the type of ichthyosis you have by identifying the:

- Changed gene that caused the disorder.
- How it is passed down in your family by looking at your family tree.
- Symptoms, including how bad they and which organs they affect.
- Age when symptoms first appeared.
What are the symptoms of ichthyosis?

The symptoms of ichthyosis can range from mild to severe. The most common symptoms include:

- Dry skin.
- Itching.
- Redness of the skin.
- Cracking of the skin.
- Scales on the skin that are white, gray, or brown.

Depending on the type of ichthyosis, other symptoms may include:

- Blisters that can break, leading to wounds.
- Hair loss or fragile hair.
- Dry eyes and difficulty closing eyelids.
- Inability to sweat because skin scales clog the sweat glands.
- Difficulty hearing.
- Thickening of the skin on the palms of the hands and soles of the feet.
- Tightening of the skin.
- Difficulty flexing some joints.
- Open wounds from scratching itchy skin.

What causes ichthyosis?

Changes to one or more genes cause all of the inherited types of ichthyosis. Genes carry information that determines which features are passed to you from your parents. We have two copies of our genes—one from each parent. You may get this changed gene from one or both parents, or the gene might stop working properly on its own.

Some people get ichthyosis because they have another medical condition or experience a side effect from a medication.

Is there a test for ichthyosis?

There is no one test for ichthyosis. Health care providers usually diagnose the disorder by:
• Asking about your family and medical history, including any skin disorders.
• Doing a physical exam, which includes looking at your skin, hair, and nails.
• Performing a skin biopsy to examine the tissue under a microscope.
• Ordering a genetic test to see if you have a changed gene.

How is ichthyosis treated?

Although there is currently no cure for ichthyosis, the goals of treatment include reducing the redness of the skin, thickness of the scales, and itching. Treatments can include:

• Using creams, lotions, or ointments on moist skin to help trap moisture in the skin and relieve dryness and scaling.
• Taking long baths to soften and release scales.
• Taking a type of medication that can decrease scaling.
• Using prescription creams or ointments.

Who treats ichthyosis?

You may see one or more of the following health care providers:

• Dermatologists, who specialize in conditions affecting the skin, hair, and nails.
• Clinical geneticists, who diagnose and treat children and adults with genetic disorders.
• Ophthalmologists, who treat disorders and diseases of the eye.
• Genetic counselors, who counsel and educate people on their genetic health.
• Audiologist, who diagnoses and treats hearing and balance problems.
• Nurse educators, who specialize in helping people to understand their overall condition and to set up their treatment plans.
• Pediatricians, who diagnose and treat children.
• Primary care physicians, who diagnose and treat adults.

Living with ichthyosis

The following self-care tips may help you manage the disease, improve your health, and enjoy a better quality of life:

• Take baths to add more moisture to the skin and help remove the scales before applying lotions, creams, or ointments.
• Keep your environment cool, especially if you cannot tolerate heat, have reduced sweating, or have a lot of itching.
• Use a humidifier to help keep moisture in the air and keep the skin from drying out as much.
• Wear loose-fitting clothes made from materials such as cotton, which may be less irritating to the skin.
• Use laundry detergents designed for sensitive skin that do not contain a lot of dyes or perfumes.
• Find a supportive community or join an online support group focused on ichthyosis. Some people may find it helpful to speak to a mental health professional about coping with the disorder.

For more info

U.S. Food and Drug Administration
Toll free: 888-INFO-FDA (888-463-6332)
Website: https://www.fda.gov

Drugs@FDA at https://www.accessdata.fda.gov/scripts/cder/daf. Drugs@FDA is a searchable catalog of FDA-approved drug products.

Centers for Disease Control and Prevention, National Center for Health Statistics
Website: https://www.cdc.gov/nchs

American Academy of Dermatology
Website: https://www.aad.org

Foundation for Ichthyosis and Related Skin Types, Inc.
Website: https://www.firstskinfoundation.org

National Registry for Ichthyosis and Related Disorders
Website: https://depts.washington.edu/ichreg/ichthyosis.registry

If you need more information about available resources in your language or other languages, please visit our webpages below or contact the NIAMS Information Clearinghouse at NIAMSInfo@mail.nih.gov.
  • Asian Language Health Information
  • Spanish Language Health Information