

# Questions Kids Ask

First of all, “How do you say that long word?” Ick – thee – oh – sis

Have your parents told you that you were born with ichthyosis? Have you wondered what that is? Have kids been asking you about your skin? Does it make you feel embarrassed sometimes? If you answered yes to any of these questions, this page will help you learn more about Ichthyosis and how you can talk to other kids about it, too.

## **What is ichthyosis?**

Kids who have ichthyosis have very dry skin. Sometimes their skin can get so dry that it can crack and can hurt a lot. In order to keep their skin from getting too dry, kids have special lotions and creams that they put on their skin in the morning and at night. Sometimes, their skin might get dry enough that they might need some lotion during the day, too.

Because the skin is so dry, it can look very thick and it might look like it is bumpy. Not every child with ichthyosis will have the same kind of skin.

## **How do you get ichthyosis?**

Ichthyosis is not something that you can get from another person, like a cold. If you play with someone who has a cold, you might get a cold too, but ichthyosis is not like that. You were born with it and nobody can get it from you.

So if you were born with it, how did you get it in the first place? All of us have genes in our body. Genes tell our bodies what to do and how to grow and develop. We all get genes from our parents, half of them come from our mom and the other half comes from our dad. Sometimes these genes can be changed and can cause us to look different from other people. Ichthyosis is caused by two changed genes, and each one of them came from one of your parents. Your parents don't have ichthyosis because they only have one changed gene, and you have two.

When you get older, you may want to speak with a genetic counselor to learn more about how genes work.

## **Talking to Other Kids about Ichthyosis**

Sometimes other kids might ask you questions about ichthyosis. They might be a little bit afraid of what your skin looks like. If you can talk to them about ichthyosis, it will make them feel better about talking to you and playing with you. They might be wondering if they could get ichthyosis by being around you. If you tell them they cannot get ichthyosis from you, they might feel better.

They might also wonder how you got ichthyosis. If you tell them that you were born with ichthyosis, they might understand a little better that you are not sick and that you live with it every day.

Even though your skin might look different, that doesn't mean that you can't do everything that other people can do. You might get hot more easily and may need to take more breaks when you play, but you can run, play ball, and be outdoors just like all the other kids.

## **Learning More about Ichthyosis**

If you would like to learn more about ichthyosis, there is a group of caring people in Pennsylvania who run the “Ichthyosis Foundation” that can help you. You and your parents can contact them anytime with your questions, concerns, or ideas. They have lots of information and ways to help you, like new lotions and ways to contact other kids who have ichthyosis, too.



**Foundation for Ichthyosis & Related Skin Types, Inc.®**

2616 North Broad Street, Colmar, PA 18915 • Phone: 800-545-3286

Website: [www.firstskinfoundation.org](http://www.firstskinfoundation.org) • Email: [info@firstskinfoundation.org](mailto:info@firstskinfoundation.org)  
**Improve lives and seek cures for those affected with ichthyosis and related skin types.**