

# Ichthyosis Disability Benefits

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Ichthyosis refers to a group of related genetic skin disorders. Each disorder is usually marked by cracked, flaky, or scaly skin, but symptoms and severity can vary greatly. Ichthyosis can also open the door for infections. Unfortunately, this means a lot of time and money spent on seeking out the best possible treatments. If you or a family member has ichthyosis and you're experiencing financial difficulty, you may be eligible to receive Social Security Disability benefits to help offset these costs.

The Social Security Disability application process is notoriously long and complicated. However with the correct research and support, you and your family members will be able to receive the benefits you need. The following information will serve as a starting point for this research and will prepare you to begin the process of applying for disability benefits.

## Is Ichthyosis a Disability?

Because the term “disability” is subjective, the Social Security Administration (SSA) has established an official definition of the term. This is to provide applicants with a general idea as to what types of individuals will qualify for disability benefits. This definition is split up into two parts, one for adult applicants (older than 18) and one for child applicants (younger than 18).

The SSA will consider an adult to be disabled if:

- He or she cannot do work that they did prior to becoming disabled; and
- He or she has a physical or mental health condition that prevents them from learning to do other types of work; and
- His or her condition has lasted—or is expected to last—at least one year or result in death.

The SSA will consider a child to be disabled if:

- He or she is not working a job that the SSA considers to be 'substantial work'; and
- He or she has a physical or mental condition (or a combination of conditions) which causes “marked and severe functional limitations.” This means that the condition(s) very seriously limits the child’s activities; and
- The condition has lasted, or is expected to last, at least one year or result in death.

To qualify for disability benefits, all applicants must meet the definition of disability that applies to their age group. If an applicant does not meet this definition, he or she will not qualify.

## Disability Benefit Programs

There are several disability benefit options available, depending on the applicant's age, finances, and employment. The two programs we will discuss are Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI).

Adults who have extensive employment history will likely find that SSDI benefits best suit their needs. SSDI is funded by the Social Security taxes that workers all over the United States contribute throughout their careers. To qualify, applicants must have earned an income and paid Social Security taxes for a significant amount of time.

Children and adults with little work experience will likely find that SSI benefits are the more appropriate option. SSI benefits have no work, age, or tax requirements. Instead, eligibility for SSI is based solely on an applicant’s income and financial resources. To qualify, you must fall within the specific financial limits that have been set by the SSA. In the case of a child applicant, the SSA will evaluate a portion of the parents’ income to determine eligibility. This is called deeming.

Learn more about SSI and deeming for child applicants at:  
<http://www.socialsecurity.gov/ssi/text-child-ussi.htm>.

## Medical Eligibility

The SSA uses an official guidebook of disabling conditions to determine an applicant's medical eligibility. This guidebook, called the blue book, is published online and is divided into separate sections for adults and children. Each listing contains the medical criteria for a specific condition or group of conditions.

For both adults and children, the SSA will evaluate skin disorders based on the following information:

- The onset, duration, frequency of flare-ups, and prognosis; the location, size, and appearance of lesions; history of exposure to toxins, allergens, or irritants, familial incidence, seasonal variation, stress factors, and the ability to function outside of a highly protective environment.

Ichthyosis specifically will be evaluated under blue book listing 8.02 for adults and blue book listing 108.02 for children. Both listings require that applicants must provide medical evidence that demonstrated the following:

- Extensive skin lesions that persist for at least 3 months despite continuing treatment as prescribed.

See the complete listings at:

<http://www.ssa.gov/disability/professionals/bluebook/AdultListings.htm>. Navigate between the adult listings and the childhood listings using the menu options in the upper left-hand corner.

## The Application Process

An adult applicant can begin the Social Security Disability application process on the SSA's website or in person at a local Social Security office. Children on the other hand must attend an in-person interview with an SSA representative. Both children and adults will have to complete several different forms. It is important that you fill these out completely and accurately. Any missing information can result in the delay or the denial of your claim.

After submitting your initial application, it may be several months before you receive a decision. If your claim is denied, do not panic or give up. You can appeal this decision within 60 days of receiving your notice of denial. Although being denied is not ideal, the appeals process will provide you with the opportunity to build a stronger claim. Note that many more applicants are approved during the appeals process than during the initial application.

*This information was contributed by Molly Clarke of Social Security Disability Help Blog and is not affiliated with the Social Security Administration.*

*This information is provided as a service to patients and parents of patients who have ichthyosis. It is not intended to supplement appropriate medical care, but instead to complement that care with guidance in practical issues facing patients and parents. Neither FIRST, its Board of Directors, Medical & Scientific Advisory Board, Board of Medical Editors, nor Foundation staff and officials endorse any treatments or products reported here. All issues pertaining to the care of patients with ichthyosis should be discussed with a dermatologist experienced in the treatment of their skin disorder.*



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Skin Types

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***Improve lives and seek cures for those affected by ichthyosis and related skin types.***

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