



## Social Security Disability Help

### How to Apply for Social Security Disability Benefits with Myotubular Myopathy

Myotubular myopathy is a genetic condition which causes muscle weakness and underdevelopment in muscles associated with movement. The condition can often be a struggle with basic physical activities, such as walking or sitting. In many cases, these individuals also have trouble breathing on their own, which can be life threatening without proper care.

Living with, and treating Myotubular myopathy often requires plenty of extra care and assistance—the cost of which can really add up. Fortunately, the Social Security Administration (SSA) provides disability benefits to qualifying individuals so that they have access to the necessary treatments and their loved ones can afford to take time away from work to help.

#### Disability Programs

The SSA oversees two of the largest disability assistance programs in the United States:

- Social Security Disability Insurance (SSDI); and
- Supplemental Security Income (SSI).

SSDI is funded through Social Security taxes and available to workers who have paid these taxes. Because of this, the program is geared towards adults under age 65 who have worked for a number of years. An applicant is considered eligible when they've earned enough work credits, which are based on your yearly earnings.

Families of eligible workers who are disabled may also receive some SSDI payments. In order to qualify, you will need to present a record of your employment over a period of many years (around ten).

SSI, on the other hand, is a benefit program for individuals who have considerably limited finances. To be eligible, you must either be over age 65 or be disabled, and you must meet the SSA's financial parameters to be considered low income. The SSA judges this by evaluating your total income and the value of resources that you own.

Because there is no work requirement, children often qualify for SSI over SSDI. In the case of a child, a parent or guardian would go through the parental deeming process where the SSA looks at a portion of their income to determine eligibility.

#### Medical Requirements for Benefits

Besides these program requirements, the SSA also requires that anyone applying for disability benefits meet specific medical criteria as well. The SSA publishes a guidebook filled with specific requirements for all disabling health conditions called the Blue Book. <http://www.disability-benefits-help.org/glossary/social-security-blue-book>

If you wish to receive disability benefits from the SSA, you will need to match your case with the corresponding listing in the Blue Book. The Blue Book is divided into separate sections for adult and child listings.

While you won't find Myotubular myopathy named in the Blue Book, the SSA will assess your case according to similar listings or listings associated with your symptoms. The most common listings are:

- Section 1.02 (Adult) or 111.06 (Child) - Major Dysfunction of a Joint due to any Cause
- Section 11.17A - Degenerative Disease not Listed Elsewhere

Section 1.02 requires:

- At least one major, weight-bearing joint be affected, causing an inability to move about well; or
- At least one major peripheral joint in each upper extremity is involved, preventing you from performing fine and gross movements well.

In the Childhood listing (111.06), there must be proof of:

- Poor motor function for age level in at least two extremities; and
- Deficient gait and station; and



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- Poor fine and gross movements, which disrupt daily age-appropriate activities.

To qualify under section 11.17A, the applicant must show significant disorganization of motor function in at least two extremities, causing trouble with movement.

If you're unable to meet any of these listings, you may also qualify under listings of associated symptoms. For example, individuals with the condition who require breathing assistance in the form of a tracheostomy or ventilation may be able to meet section 3.02 (or 103.02 for children) – Chronic Pulmonary Insufficiency. This listing takes into account one's height and breathing ability.

### **The Application Process**

There are two ways to begin the application, which consists of several forms. You may complete the forms online or you may work with a representative from the SSA. Applications for children can't be completed online and must be done during an interview with an SSA representative. <http://www.disability-benefits-help.org/content/application-process>

Before you begin filling out the forms, make sure to have all of the necessary medical and technical information required of you:

- Work information if applying for SSDI benefits
- Financial documents if applying for SSI benefits
- Doctor's notes
- Record of hospitalizations and treatments received
- Lab results confirming your condition
- In the case of a child, statements from teachers and therapists about the effects of Myotubular myopathy on the child.

You stand a better chance of being approved for benefits if you can be more detailed about how Myotubular myopathy affects your daily life and ability to work. You will need more than a diagnosis.

As the SSA makes its decision, you will likely be contacted regarding presenting your claim or receiving an assessment from an examiner. The entire process can take a considerable amount of time, so you will want to begin right away. In the case of SSDI, you are not permitted to receive benefits for the first five months of being disabled. That said, you may receive back payments for all the time that you have been disabled.

If your application is denied, you are entitled to a separate appeal, as long as that appeal is submitted within 60 days of receiving the denial. Because many applications are denied upon initial review, this is how many people receive Social Security disability benefits.

To ensure your application is complete and ready to be approved, you may want to hire a disability advocate to represent you. These specialists know all the ins and outs of the application process and will help you prepare and even present your claim to Disability Determination Services. They typically only take pay once you have been approved.

Social Security Disability payments can help you pay directly for treatment for Myotubular myopathy, or can be used to supplement your income and pay for daily expenses. This is particularly helpful when you have to take time off work due to the condition. These benefits can be well worth the effort required to complete the application process.