



MPS and ML SOCIAL SECURITY BENEFITS

Community Liaison, SSA
www.disability-benefits-help.org

MPS and ML symptoms can range from dwarfism to intellectual disability or vision problems. When these traits present themselves more severely, an individual with any combination of these affects may be unable to work and earn a living, or function at age-appropriate levels.

You may be eligible for disability benefits from the Social Security Administration (SSA). These benefits can pay for therapy or for your daily expenses, making room for a much better quality of life. While the application process can require much time and effort, understanding the eligibility requirements and application process is beneficial in receiving the financial support you deserve.

Applying for Social Security Disability (SSI) and Social Security Workers with Disabilities (SSDI) can be a difficult, frustrating, and long process. The process can be expedited if all medical, and pertinent legal information has been gathered before the application time. If you are having difficulties, and need direction, contact the National MPS Society.

Compassionate Allowance is recognized by the SSA and is designed to put the application on a “fast track” by defining specific conditions that “obviously meet disability standards.” These conditions include many types of cancer, as well as other chronic, and often terminal, afflictions (including several MPS/ML disorders). If an applicant is suffering from any of the conditions on the Compassionate Allowances list, their application is fast-tracked because it is presumed that a disability exists with this person. This expedites the application process and assists people suffering from serious conditions by awarding benefits in a timely manner when they need them most. The MPS/ML disorders currently on the list are MPS I, II, III, and ML Type II. Investigating your disorder on the Compassionate Allowance list will exponentially secure an earlier decision by the SSA.

There are instances where applicants with these disorders have been denied. **Do not give up or become discouraged.** These programs are designed to increase “quality of life”. Often, the SSA reviewers have not heard of MPS or ML. It will become your responsibility to advocate for yourself, or your loved one. Ensure you include all of your key stakeholders to provide letters of support. Stay resolute and treat everyone involved in the process, with respect.

Disability Benefit Programs

The SSA provides two financial assistance options to those with MPS.

The first, SSDI, provides benefits to working adults when a prolonged medical condition keeps them from working. SSDI is funded by Social Security taxes and available only those who have paid Social Security taxes for a significant amount of time.

In order to qualify for SSDI, you will need to have a record of employment. This record will show that you have not only paid Social Security taxes, but also you have earned the required number of work

credits needed for qualification. Work credits are based on yearly earnings and applicants can earn up to four credits each year.

Those who may not be eligible for SSDI may qualify for Supplemental Security Income (SSI) instead. This program requires that its applicants meet certain financial restrictions, showing they demonstrate financial need. SSI is beneficial for elderly applicants over age 65 or children who may not have been able to work long enough to qualify for SSDI benefits. The SSA evaluates applicants based on portions of their income and the value of resources they own. In the case of a child, the SSA will evaluate parts of a parent's finances under the assumption that the child also shares in these funds, called the parental deeming process. Parents' income and resources will not be used in the determination process once the individual with MPS turns 18. <http://www.disability-benefits-help.org/ssi/qualify-for-ssi>

Medical Eligibility

The SSA has a guidebook of conditions it considers disabling called the Blue Book. Applicants must demonstrate that their condition fits a listing of requirements in the Blue Book for a known disability. If the applicant can't meet a listing, they can also match an associated symptom or complication in severity to receive benefits.

Because MPS affects children from birth and there is no cure, the most common way to qualify for one of these conditions is by meeting Blue Book listing 110.08 – A Catastrophic Congenital Disorder. This listing is met when:

- Death is expected within the first months of life; or
- There is very serious interference with development or functioning.

Usually, the condition has affected many regions of the body.

Those with MPS may also qualify under listings of associated symptoms, such as:

- 12.05 – Intellectual Disability (112.05 for children)
- 4.06 – Symptomatic Congenital Heart Disease (104.06 for children)
- 100.00 – Growth Impairment
- 1.02 – Major Dysfunction of a Joint (due to any cause) (101.02 for children)
- 2.10 or 2.11 – Hearing loss treated or not treated with cochlear implant (102.10 or 102.11 for children)

Applicants with MPS also are eligible for an expedited application process called compassionate allowances, which seeks to pay benefits to those with very severe and obvious disabilities. Compassionate allowances enable individuals to qualify based on minimal medical evidence.

The Application Process

The application can be completed online or with a representative from the SSA. Applications for children must be completed in person and can't be submitted online, however an adult can choose either method. <http://www.disability-benefits-help.org/content/application-process>

Before you begin, gather all medical and technical documentation needed for each step of the process. This includes:

- Medical records
- Lab results
- Doctor's notes
- Hospitalizations
- Treatments received
- If you're applying for SSDI, you will need to present a sufficient record of employment.
- If you are applying for SSI, you will need financial information to demonstrate you meet the income and resource limits.

The turnaround time for a decision from the SSA is usually a few months. During that time, you will be asked to present your claim and possibly attend evaluations from examining doctors. It may be helpful to hire representation to help you prepare all the required information and present it to the SSA in a way that improves your chances of qualifying. Disability advocates and attorneys are specialists when it comes to the application process and know the best way for you to qualify according to your specific conditions.

In the event your claim is denied, you may appeal the decision. The appeal is a separate process than the application and can be completed online within 60 days of the denial.

Knowing how to navigate the application process before you begin seeking Social Security disability benefits will increase your chances of correctly submitting a claim and eventually being approved for the financial assistance your family deserves. The relief the benefits provide can greatly improve quality of life for families dealing with MPS.

Additional Resources are listed below and include: Compassionate Allowance List of disorders, are available through the SSA website, both the SSA home website address, and subsequent MPS and ML condition list links.

Resources:

Social Security Administration

<https://www.ssa.gov/compassionateallowances/index.htm>

Compassionate Allowance Website

<https://www.ssa.gov/compassionateallowances/index.htm>

Compassionate Allowance List

<https://www.ssa.gov/compassionateallowances/conditions.htm>

MPS I Effective Dates: 12/03/2018-Present DI 23022.415

<https://secure.ssa.gov/apps10/poms.nsf/lnx/0423022415>

MPS II Effective Dates: 12/03/2018 – Present DI 23022.410

<https://secure.ssa.gov/apps10/poms.nsf/lnx/0423022410>

MPS III Effective Dates: 12/03/2018 – Present DI 23022.495

<https://secure.ssa.gov/apps10/poms.nsf/lnx/0423022495>

ML Type II (I Cell Disease) Effective Dates: 08/10/2012 - Present DI 23022.775

<https://secure.ssa.gov/apps10/poms.nsf/lnx/0423022775>