

# **Social Security Benefits: Frequently Asked Questions for BDSRA Families**



**A Publication of Batten Disease Support and Research Association**

# **WELCOME**

## **NOTICE TO THE READER**

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**Social Security Benefits  
Frequently Asked Questions for BDSRA Families**

**1. What can the Social Security Administration do for my child?**

The Social Security Administration (SSA) is a federally run program to assist people financially. Most people recognize Social Security as a financial benefit that people receive from the government after retiring from their career. The SSA also helps those with disabilities receive financial assistance under two programs:

- a. Social Security Disability insurance (SSDI)
- b. Supplemental Security Income (SSI)

Both programs are applicable to children with Batten Disease depending on their age.

**2. What is the difference between Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI)?**

A child, under age 18, with Batten Disease, would be eligible for Social Security Benefits under the Supplemental Security Income (SSI) program. Under this program, a child is still reviewed for disability, but would not receive SSDI. SSDI “pays benefits to you and certain members of your family if you are “insured,” meaning that you worked long enough and paid Social Security taxes.” SSI “pays benefits based on financial need.” A child, over the age of 18, with Batten Disease, would be eligible for the Social Security Disability Insurance (SSDI) program.

**3. How will my child qualify for SSI Benefits?**

A child with Batten Disease undergoes a disability review to see if they qualify for SSI. One of the obvious limitations is that a child must not be working or earning more than \$900 a month. The child must also have a physical or mental condition that results in “marked and severe

functional limitations” and must seriously affect the child’s daily activities and living. The child’s condition must also have lasted or is expected to last at least 12 months or must be expected to result in death. The Social Security Administration has listed conditions that are applicable to children that would be considered “severe” and have “marked limitations” on their everyday living. A child with Batten Disease would fall under several categories. These categories include “Impairments of the Musculoskeletal System,” “Impairments that Affect Multiple Body Systems,” and “Neurological Disorders.” The most applicable impairment category for a child with Batten Disease is the “Impairments that Affect Multiple Body Systems” as this category specifically focuses on genetic diseases and chromosomal dysfunctions.

Even though a child with Batten Disease meets all of these criteria, the parents’ income and assets are still taken into consideration. You may be told that you make too much to qualify; however, depending on just how much you make, you may still want to apply. If you are on the income border, and are denied, you can appeal any decision made by the Social Security Administration. Along with income, families cannot maintain too many assets in the child’s name or their own name. Children cannot have savings accounts or trust funds in their names. As highly unfair as this is, it is a necessary part of applying for and being granted Social Security benefits.

The qualifications for disability under the SSDI program are the same. The income limitations are slightly different because of the child’s age (18 or over). Make sure to talk with your Social Security representatives about the pros and cons of each program for your child, if they are over age 18. It may be possible that a child could receive benefits under both programs.

#### 4. When should I apply for SSI?

You can apply for SSI benefits at any time. It may be best to apply when noticeable conditions occur to your child. If your child has a confirmed diagnosis of Batten Disease and marked vision impairment, apply for SSI. If your child has marked vision impairment and the onset of seizures, apply for SSI. If your child has problems with mobility and seizures, apply for SSI. Any combinations of factors that are interfering with your child's daily life are substantial enough to apply for SSI benefits and be seriously considered.

Let's not beat around the bush, applying for Social Security benefits is a difficult and tedious task. There are forms upon forms to complete and turn in. Not only do you as a parent have to complete forms, teachers and other caregivers may be asked to complete forms as requested by a Social Security Administration representative. The process is time-consuming and very detail oriented. It is important to keep *very good* records about your child's symptoms, medications, education history, doctor's and hospital visits, etc. as all of these things may come up while completing the forms or attending the interview.

You can download forms from the Social Security Administration website ([www.ssa.gov](http://www.ssa.gov)) and return them to your local Social Security office. You can also complete the application on the phone. If you're like me, you hate doing things over the phone or online without ever speaking to an actual person. If this is the case, you can make an appointment at your local Social Security Administration office to fill out the forms and talk to a representative. You may also want to ask what information you should bring to your interview.

Most importantly, a local Social Security Administration representative has NO CLUE what Batten Disease is. When answering any questions about a child's condition, be sure to include

the specific details of the disease and ALL of the symptoms that occur. For example, “Batten Disease is an inherited neurological disorder that is marked with vision loss, multiple types of seizures, loss of mobility, cognitive impairments in both memory and learning, loss of speech,” etc. The clearer you can paint the picture of Batten Disease, the easier it is for someone outside of our world to understand and more adequately assess your need.

It is also important to tell the Social Security Administration (SSA) worker that Batten Disease is a terminal illness. The SSA has special protocol for processing applications for individuals with a terminal illness. The process is called the TERI (**TER**minal **I**llness) process and can allow claims to be expedited in a matter of days, instead of a matter of weeks or months like other applications. The SSA does not make it a habit to tell people about the TERI process, so you’ll want to advocate for yourself and your child when completing the application.

#### **5. When my child turns 18, will they lose their SSI?**

When a child turns 18, their SSI will be reevaluated. A parent’s assets and income level are no longer a factor when considering the child’s disability and whether they qualify for SSI benefits. The medical disability criteria is slightly different for an adult than it is for a child, but for a child with Batten Disease, qualifying for SSI benefits once they reach 18 should not be an issue since the disease has most likely progressed since first receiving SSI benefits. This review process generally begins in the one year period that begins on your child’s 18<sup>th</sup> birthday. *Remember, a child that was not eligible for Social Security benefits prior to their 18<sup>th</sup> birthday, may become eligible for benefits once they turn 18.*

A child over age 18, but disabled before age 22 (like a child with Batten Disease) may be eligible for Social Security Disability Insurance (SSDI) benefits based on the parents' Social Security earnings record. In order for this child to receive these types of benefits, one of the child's parents must:

- a) be receiving Social Security retirement or disability benefits or;
- b) have died and worked long enough under Social Security.

If you have a question about what types of benefits your child may be eligible for, please contact your local Social Security Administration office and speak to a representative. Remember, if your child is under the age of 18, they are only eligible for SSI benefits. Once a child turns 18, a child may be eligible for different types of benefits depending on the situation.

#### **6. Can the amount of money I receive from SSI ever change?**

Things can happen to a family's situation at any moment. If there is a change to your family's income level and your child is under 18, your child's SSI benefits may be reassessed. This can happen both in a positive and negative way. For example, if one parent loses their job and the family's total income decreases, a child's SSI payments may increase. On the other hand, if a parent receives a raise or has an increase in income for whatever reason, a child may lose some or all of their SSI benefits. The entire process is so delicate and unfortunately the slightest bump can throw the whole thing off course. Keeping careful track of finances is very important in a family where a child receives SSI benefits.

It is also important to know that a child in one state can be paid a significantly different amount in SSI benefits than a child with the same impairments living in another state. There is a

baseline of social security benefits that each state must pay as provided by the Federal government. It is then up to the state whether or not they choose to pay extra into their social security program. If a family moves to another state, the SSI benefits will most likely be reassessed. This may also explain why benefits received in a state of former residence are different from the benefits received in the state of current residence.

**7. It is obvious to me that my child qualifies for benefits, can I get money right away?**

It is possible for your child to start receiving immediate SSI benefits if the Social Security worker feels that your income level is SSI eligible and your child's disability will be found valid in the determination process. The program, called "Presumptive Disability Payments," allows your child to receive immediate payments while a decision is being made. These payments may continue for up to 6 months while a decision is being made. If a decision is made in which your child is determined not to be disabled, these payment do not have to be repaid.

**8. If I receive SSI, do I still need to apply for Medicaid?**

When a child is granted SSI, Medicaid is generally granted with it. In some states Medicaid is started automatically, while in other states, it must be applied for separately. This is especially good for parents who may not have the best insurance for a child with special medical needs. This is also good for a parent who needs multiple types of services like respite, in-home nursing, or other specialized types of care that a private insurance may be unwilling or uneager to pay for.

It is important to know, however, that a child's Medicaid benefits are also income-dependent, and while a parent's income may allow their child to still be SSI eligible, the income for that

month may be too much for Medicaid benefits. You will want to talk with your SSA representative to find out the details of receiving Medicaid with your SSI payments, and the income limitations for both programs.

#### **9. My child was denied SSI/SSDI benefits, now what?**

In your denial letter, it should state the reason for your denial. If the denial is due to too much income, there may be nothing you can do short of making drastic family financial changes. In this case, the amount of money provided by SSI may not be worth terminating employment or giving up large amounts of savings. However, if anything ever changes in the matters of the family's income level, you may want to reapply for SSI at that time. Also, when a child turns 18 and the family's income level is no longer considered when evaluating a child's eligibility for SSI benefits, applying for SSI again is a good idea. It is important to remember that the appeals process is time-sensitive. If you want to appeal a decision, you will want to make the phone call the same day you receive your denial letter. Make sure to also ask about an expedited appeals process. If you have a unique financial situation or hardship, this process could get your child benefits quicker.

If your denial is for something other than income, find out exactly what it is for. Talk with your Social Security representative about the denial letter and get a thorough explanation of the circumstances surrounding the initial denial. Just like a court decision, a Social Security benefits decision can also be appealed. Correcting any mistakes or misinformation on the application and resubmitting it may lead to a decision in your favor. Additionally, as the condition progresses and your child's symptoms become worse or new symptoms surface, your child's disability becomes more apparent. If this is the case, reapply for SSI and include these

new circumstances in the application. Keeping old Social Security applications on file may aid in the ease of completing of a new application.

Finally, treat the Social Security Administration (SSA) representative with respect and kindness. It can be very easy to transfer your frustrations as a parent with a sick child onto a third party like an SSA representative. However, if you can win this person over, they may be more likely to aid you in your application process or even expedite the process to get a decision faster. Getting this person on your side will only help your case.

**As always, if you have questions about anything in this publication, please contact Amy Kirk, Coordinator of Family Services, BDSRA at 1-888-379-2546 or by email: [kirka@bdsra.org](mailto:kirka@bdsra.org).**