

# How to apply for Social Security benefits for your child with Batten Disease

## Batten disease and financial burden

Batten disease is a genetic disease which can devastate a family. After receiving a Batten diagnosis, parents and families are affected in all areas of life. The care, medication, and equipment required for keeping your child healthy is incredibly expensive.

This can bring a massive financial burden upon a family. A child with Batten disease may need round-the-clock care, and one parent may need to leave work to provide that care. Medicine is expensive, and necessary supplemental care has a high cost. Social Security disability benefits are available to help families manage the costs caused by their child's disease.

## SSD or SSI?

Social Security provides two different programs for Disability - SSDI and SSI. SSDI, or Social Security Disability Insurance is intended to help injured workers who have accumulated a sufficient number of work credits, and doesn't apply in the case of Batten because Batten affects only children. SSI, or [Supplemental Security Income](#) is designed to benefit low-income individuals who haven't worked. Children are able to qualify for SSI benefits. SSI provides cash to meet basic needs for food, clothing, and shelter.

Household income will be evaluated on behalf of a child applying for SSI benefits. If you or your spouse do not meet the income guidelines, your child will be unable to qualify for SSI benefits. You can see a rough outline of the SSA's income limits online.

## How to qualify for disability payments

To qualify medically with Batten disease, a child must meet the Social Security Administration's medical eligibility requirements, which can be found in the Blue Book. This is the Disability Evaluation Under Social Security page on SSA's website, and disabilities that affect children are found in [Childhood Listings](#), part B, in Section 111.

For a child to medically qualify with Batten disease, he or she will need to experience the following:

- The child must have one minor motor seizure per week despite at least 3 months of prescribed treatment. This is called *nonconvulsive epilepsy*.
  - A simple motor seizure can look like loss of consciousness or alteration of awareness, such as a child staring into space or appearing to be "out of it."

- There can also be symptoms of automatism, which is purposeless and involuntary. Examples include lip-smacking, chewing, or walking. (111.03)
- The child is “behind” in motor function appropriate for his age involving 2 extremities.
  - In this context that means not being able to use a limb, hand, or foot at the same level as his peers.
  - This is called *motor dysfunction* and it must be persistent over time, despite treatment. This can mean disruption of age-appropriate daily activities such as fine and gross movements (using small muscles like fingers, or large muscles like legs.)
  - Motor dysfunction also applies to gait and station, which means how the child walks. Abnormal walking is a strong sign of a neurological disorder (111.06).

### **Alternative options**

Sometimes an illness' symptoms don't always align exactly with the terms listed in the Blue Book. There is another route you can take to receive benefits. If your medical records don't match a listed condition, your child may still be able to qualify for benefits by using RFC analysis.

An RFC, or Residual Functional Capacity analysis, evaluates how symptoms affect daily life and abilities. RFC analysis is also used for adults to determine their ability to hold a job, but with children suffering from Batten, the analysis will focus on how the child's medical condition affects his abilities to take part in normal, age-appropriate activities, like playing with others and going to school.

### **How to apply for benefits**

Don't hesitate to start an application for SSI benefits for your child, once you have your medical evidence. You'll need to make an appointment with your local SSA office and apply in person. You can find your local SSA office [here](#) on the website for Social Security Regions. Select your region and you'll be shown a list of locations within your state. Try to find the closest one to where you live.

Batten disease qualifies for a Compassionate Allowance, which is a way to speed up processing Social Security disability claims. This applies to applicants with such acute symptoms that their condition easily meets Social Security's definition of disability. What this means for you is that your child could be approved for benefits with Batten disease as quickly as 10 days after your apply, so long as your income qualifies. Social Security is designed to help families with disabilities and can be the financial help your family needs to focus on what's truly important: your child's health.