

Social Security Disability: Applying with Phenylketonuria

Living with Phenylketonuria (PKU) can put a significant financial strain on a family, as they seek the best treatment, adhere to the strict diet, and take time away from work to care for their loved one. To address this, the Social Security Administration (SSA) provides financial assistance to qualifying individuals in the form of Social Security disabilities. Understanding the application process and eligibility requirements for these benefits with PKU will help you successfully file your claim.

Disability Programs

The Social Security Administration oversees two distinct disability programs: Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI). <http://www.disability-benefits-help.org/content/social-security-programs>

SSDI is intended for disabled workers and their families. It's funded through payroll taxes, meaning applicants have to present a sufficient work history and have paid into the system over the course of their employment. The criteria are as follows:

- The individual must be disabled.
- The individual is a working adult under 65 years old OR their parent receives SSDI benefits.
- The individual has accumulated work credits according to their yearly earnings, demonstrating they have paid Social Security taxes for a number of years.

SSI is a needs-based benefit program that pays stipends to the elderly and to disabled people with low income. Instead of employment history or tax credits, SSI is awarded based on financial limits set by the SSA, like income and the value of resources you own.

For a child under 18, the parent or guardian of a child with a disability will go through the parental deeming process where the eligibility will be based on part of a parent's finances.

Medical Eligibility

The SSA will only consider you eligible for benefits if you meet specific medical criteria for your condition. This information is kept in a guidebook, called the Blue Book, of technical medical criteria for disabling health conditions. The Blue Book has sections for adults and children.

PKU is named in the blue book under the listing 10.01 (110.01 for children) Congenital Disorders that Affect Multiple Body Systems. In order to qualify under this listing, you'll need lab analysis confirming your diagnosis and showing that your case is severe enough that you are unable to work or, if applying for a child, they are kept from performing and developing at age-appropriate levels.

<http://www.disability-benefits-help.org/disabling-conditions/phenylketonuria-and-social-security-disability>

If you're unable to meet the listing for PKU, you can also qualify under an associated condition. Since PKU can lead to significant intellectual disability, you may be eligible under listing 12.05 (112.05 children) – Intellectual Disability. This requires one of the following:

- Dependence upon others for personal needs and an inability to follow directions

- A valid verbal, performance, or full scale IQ of 59 or less
- A valid verbal, performance, or full scale IQ of 60 through 70 and a physical or other mental impairment imposing an additional and significant work-related limitation of function
- A valid verbal, performance, or full scale IQ of 60 through 70, resulting in at least two of the following:
 1. Marked restriction of activities of daily living; or
 2. Marked difficulties in maintaining social functioning; or
 3. Marked difficulties in maintaining concentration, persistence, or pace; or
 4. Repeated episodes of decompensation, each of extended duration.

The childhood requirements are slightly adjusted according to age.

You may also qualify under 11.02 or 11.03 (111.02 or 111.03 for children), the epilepsy listings, if you suffer from seizures as a result of PKU. These must continue despite treatment.

The Application Process

Prepare for the application by gathering all the medical and financial information you'll need. You should include:

- Record of any hospitalizations or medical visits
- Lab analysis confirming your diagnosis
- Treatments received
- Doctor's note and statements from other professionals about your case
- Employment or financial documentation for either SSDI or SSI

To begin, schedule an interview with an SSA representative or begin filling out the forms online. While adults can choose either route, applications for children can only be done in person.

Be prepared to wait for several months for a decision, but you will likely be busy during this time presenting your case and supplying necessary information to disability examiners. No need to worry, you will receive back payments for any amount of time you were disabled prior to being approved.

Remember that the SSA denies many first time applications, but these people often still qualify for benefits through a separate appeal. You may appeal within 60 days of receiving the denial. The appeals process is different than the initial application, but there are many attorneys and disability advocates who can help you.

They are experts in the application process and only take payment if you qualify. These representatives can help during the preparation for the application and when it comes to interaction with Disability Determination Services.

The application process may seem complicated and troublesome, but many families find the benefits received to be very helpful in allowing them to lead more productive lives. By familiarizing yourself with the requirements and application steps, you are well on your way to securing Social Security disability benefits.