**Congenital Diaphragmatic Hernia and Social Security Disability Benefits**

Congenital Diaphragmatic Hernia (CDH) is a condition characterized by the malformation of a child’s diaphragm. Typically, the diaphragm separates the organs in the chest from the organs in the abdomen. In a child born with CDH, the weakened or non-existent diaphragm allows the intestines to move upward into the chest cavity. This can cause serious health problems and, unless treated properly, can be life-threatening.

Having a child born with CDH can be scary and overwhelming. You want to do everything in your power to ensure that your child is healthy and happy. Unfortunately, doing so can take a certain degree of financial stability. For families that don’t have the means to pay expensive medical bills, caring for a child with CDH can be financially devastating.

If your child has been born with CDH or if you are expecting a child with CDH, you may qualify for financial assistance in the form of Social Security Disability (SSD) benefits. Before you apply however, it is very important that you understand the basics of SSD benefits. A single mistake on your child’s application can result in a denial. The following information will provide you with everything you need to know to get your child the benefits he or she needs.

**Overview**

Although the SSA offers benefits from two different programs, children will only qualify for one type of benefit on his or her own record. This type of benefit is called Supplemental Security Income—or SSI. To qualify for SSI, the applicant’s parents or guardians will be required to meet strict financial requirements. In addition to these financial requirements, the child applicant must meet the official definition of disability and will also have to meet very specific medical criteria.

**Technical and Financial Eligibility**

Essentially, SSI is a welfare-type program that provides financial assistance to blind, disabled, or elderly individuals who earn very little income. To qualify for SSI, applicants cannot exceed very specific financial limits. Because children do not earn income, the SSA will determine a child’s eligibility based on a portion of a parent or guardian’s income. This process is called parental deeming.


**Definition of Disability**

If your family meets the SSI technical and financial eligibility requirements, your child will then be evaluated to determine whether or not he falls under the official definition of disability. This definition is comprised of these three standards:
• Your child is not working a job considered to be substantial work. A child with CDH will typically meet this requirement because his or her condition is present at birth and will require the most medical intervention while he or she is not yet old enough to hold a job.

• Your child has a physical and/or mental condition that causes severe functional limitations. The severity of a child’s defect will determine whether or not he or she meets this standard.

• Your child’s condition is expected to last at least one year or result in death. A child with CDH will meet this standard if his or her condition will require ongoing treatment and or hospitalization. He or she might also meet this standard if they experience significant complications or residual symptoms after receiving treatment.

If your child meets all three of these requirements, the SSA will consider him or her to be disabled.

Medical Eligibility

If your family meets the SSI financial requirements and falls under the SSA’s definition of disability, your child will then be evaluated based on strict medical requirements. These requirements are typically listed in the SSA’s blue book. The blue book is a list of disabling conditions and medical symptoms that can potentially qualify a person for SSD benefits.

Although CDH is not listed in the blue book, your child may qualify under the listing for Fryns Syndrome. To meet this listing your child’s condition must have required surgery at birth. Additionally, you will have to submit diagnostic medical imaging to prove the extent of your child’s CDH. This may include the following:

• Chest and abdominal radiographs
• Cranial ultrasound examination
• Echocardiogram
• Renal ultrasound

Fortunately, the listing for Fryns Syndrome is included among the Compassionate Allowance Listings (CAL). This means that the SSA recognizes the severity of this condition and will expedite the processing of your child’s claim so that he or she can qualify for benefits in as little as ten days. Typically, it can take anywhere up to four months to receive benefits.

To access the complete listing for Fryns Syndrome, visit the following page: https://secure.ssa.gov/apps10/poms.nsf/lnx/0423022951.

Starting the Application Process

To complete the SSI application process on behalf of your child you will have to submit two different forms and participate in an interview with an SSA representative. The required forms include the Child Disability Report and the Application for Supplemental Security Income. These can be completed at the time of your scheduled interview.
Because most children are born with CDH, attending an in-person interview may be out of the question for most parents. For this reason, the SSA also allows interviews to be conducted over the phone. To schedule your interview, call the following number: 1-800-772-1213. Because CDH often qualifies for Compassionate Allowance processing, you should receive a decision in the weeks following your interview.

Although the application for SSI can be stressful, it is often a necessary step toward gaining the financial assistance you need for your child. For more information visit Social Security Disability Help or contact Molly Clarke at mac@ssd-help.org.