

The Bumpy Road of Batten: A Beginner's Guide to Getting Programs & Services



Publication of Batten Disease Support and Research Association

WELCOME

NOTICE TO THE READER

This Batten Disease Handbook is compiled with information from many sources concerning the topics included. Families in the organization have also contributed specific situations that have been helpful in their own battle with Batten Disease.

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If medical or other expert assistance is required, the services of a competent professional should be attained.

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OUTLINE FOR PROGRAMS AND SERVICES

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The Bumpy Road of Batten: A Beginner's Guide to Getting Programs & Services

You have just been faced with life-altering information that your child has Batten Disease. Any parent would feel overwhelmed and devastated by the news that your child is not going to be “normal.” As if the trips to doctor after doctor and hospital after hospital haven't been enough, now you face the frustrating challenge of navigating through a government system that can be virtually impossible. Where do you start? What do you need? MR/DD what? These are only a few of the phrases that parents may find themselves uttering when trying to attempt this task. It is my hope that this guide will help you better “plot a course” into getting necessary services for your child with Batten Disease.

INSURANCE

Health insurance seems to be a luxury these days. As we're faced with a world where insurance premiums are at an all-time high, how in the world do we find and afford coverage for a sick child? Many parents think that they have to quit their jobs just to receive coverage for their child. This is not the case. While many parents choose to take drastic measures to ensure the best coverage for their child, there are other programs available. These programs allow families to continue supporting themselves *and* maintain affordable health insurance coverage for their families.

Medicaid

Medicaid is a government health insurance program for low-income families. While most people on Medicaid live below the federal poverty level, the government and Medicaid are finding ways

to fund Medicaid and make it more accessible for working families. Medicaid is a health insurance program that is run by the federal government at an overall level, but is administered in its own way by each state. So, while the funding for Medicaid is provided by the federal government, each state determines how to spend the money and what types of programs Medicaid may be responsible for.

If your family is below the Federal Poverty Level (FPL), you are most likely eligible for Medicaid Assistance. The 2009 FPL for a family of four is \$22,050 within the 48 contiguous states and the District of Columbia. This means that a family with four total people in the household cannot make more than \$22,050 a year. If this is the case for your family, contact your local health department or county social service agency and ask about applying for Medicaid.

Medicaid can be called many different things depending on your state of residency. For example, in California, Medicaid is referred to as Medi-Cal. In Pennsylvania, Medicaid is called Medical Assistance. You can find out the contact information for your state's Medicaid office by doing a simple internet searching using your state and "Medicaid" in the search bar. Just as each state calls Medicaid something different, each state has a different agency that may run and administer the Medicaid program. In Ohio, Medicaid is administered through the Department of Job and Family Services, but in Utah, the Department of Health has responsibility over the program. To apply for Medicaid where you live, you'll want to contact these offices at the county level. This information can also be found in your local phone book.

If your family is above the FPL but still not making enough money to pay for medical bills or afford quality health insurance, there are still options available through Medicaid. Many states are now participating in a *Medicaid Spend-down Program*. It is sometimes referred to as *Medicaid under Medically Needy Spend-down Eligibility*. This program allows families to qualify for Medicaid assistance after they have spent a certain amount of money on medical bills. Each state runs their *Medicaid Spend-down Program* differently and the eligibility for the program can vary by state as well. Also, not all states currently have a *Medicaid Spend-down Program* available, so be sure to contact your local health department or social service agency to find out. If your state does participate, a family can sometimes earn up to 200% of the FPL and still be eligible for this program. This means that a family of four could earn up to \$44,100 a year and qualify for the *Medicaid Spend-down Program* in their state.

Here is a more specific example of how this program works. Let's say a child has various medical bills totaling up to \$10,000. This child only lives with one parent whose monthly income is \$3,000. Let's also say that the state this family lives in has a Medically Needy Income level for 2 people of \$300. Therefore, the family's monthly income is currently \$2,700 over the \$317 limit. Medicaid, under this program, would help the family by paying \$7,300 of the total \$10,000 in medical bills. The parent would still be responsible for the other \$2,700 in medical bills.

Something very similar to the *Medicaid Spend-down Program* but meant for people who have a quality private insurance through work, is receiving Medicaid as a Secondary Insurance. Having Medicaid as a Secondary Insurance allows a parent to stay at work, receive private insurance through their place of employment for the family, and have Medicaid pick up additional

expenses that a private insurance company may not normally cover. Most private insurances require a co-pay for doctor's visits, hospital visits and medication. By having Medicaid as a Secondary Insurance, parents do not have to pay the high co-pay associated with these services. Medicaid will pick up the remainder of the fees left behind after a private insurance is done paying. Again, Medicaid as a Secondary Insurance is based on income level and not every state may offer this option. However, this type of insurance can allow for your child to receive special services like occupational and physical therapy, a higher-quality wheelchair, and care from specialists that may have higher co-pays.

SCHIP

SCHIP stands for State Children's Health Insurance Program. All 50 states participate in this program that offers health insurance coverage for children whose families make too much money to qualify for Medicaid but not quite enough money to overcome the high cost of private health insurance. While this program does not provide insurance for the entire family, it does ensure that a child receives the coverage they need. A family of four can earn up to \$34,100 and still be eligible for SCHIP coverage. This service covers expenses like doctor's visits, immunizations, hospitalizations, emergency room visits and much more. For more information about your state's children's health insurance program, visit <http://www.insurekidsnow.gov>.

Tips for Private Insurance

Your private insurance company may pay for much more than you may think. Anybody who has ever tried to read their private insurance policy knows that it can be full of confusing and hidden terms and practices. There are a few things you should know about your private insurance when

requesting for services through them. The first thing that everyone should know is that your state has a government office dedicated to insurance companies called the State Insurance Commission. These are the state government bodies responsible for regulating insurers' and health plans' activities. For a listing of each state's insurance commission, visit www.patientrights.com/links/links7.htm.

You always want to be as knowledgeable about your insurance plan as possible. One way to help you better understand your insurance or file a claim is to ask for a case manager. This is a person who can remain your point-of-contact when dealing with all matters of your insurance company. This also saves you the time and trouble of having to tell your story over and over again to someone new every time you call. Especially in the case of a rare disease, educating one person within your insurance company to be your advocate will prove to be more helpful than having to inform different people little by little to get what you want.

Another thing to keep in mind is that “no” doesn't mean “no” when coming from insurance companies. “No” often means “ask again.” Insurance companies deny people, much like social security or Medicaid, as a means of keeping the bottom line low. If you're dedicated enough to ask again or go through the appeals process, your claim is more likely to be found in your favor. It is important to know that 9 out of 10 people whose claim is denied the first time give up on the process and never follow through with an appeal. Make sure you are that one person who has the stamina to follow through with your claim and the appeal and your request is likely to be granted.

WAIVER PROGRAMS

Waiver programs are specialized programs run through your state's Medicaid bureau. These programs are designed to help individuals stay in their homes and be cared for in their homes even though they require an inpatient or facility level of care. Waiver programs are meant to "waive" parents' income levels to allow a child to have these services. Waiver programs are very different from state to state and even differ based on a child's age and current health or well-being. Every state has waiver programs but each state's Medicaid department decides which other state department runs the services and how much funding they will get. For example, in Ohio, waiver programs are administered through our Department of Mental Retardation/Developmental Disabilities, Department of Job and Family Services, and the Ohio Department of Aging.

Some waiver programs are called CAP programs. CAP stands for Community Alternative Programs. These are the same programs as described above. These waivers are also sometimes referred to as HCBS or Home and Community Based Services waivers. Children with Batten Disease may qualify for more than one type of waiver. The two most common types of waivers that children with Batten may qualify for are waivers through the **Mental Retardation or Developmental Disabilities department** and a waiver for **children who are medically fragile**.

Waivers help pay for many different types of services and different waivers may pay for different things. These services may include a personal care assistant for your child, transportation to and from appointments, in-home nursing or physical therapy, respite, and many other services. Once a child is granted a waiver, Medicaid insurance is also granted with it. The type of insurance and what it will cover varies from state to state. Be sure to ask about insurance

options when your child is granted their waiver. It may be possible to choose from different plans or providers.

Unfortunately, Medicaid waivers have their downside as well. First of all, the process can be very long. Just to get through the initial screening can take a great deal of time. Even once a child is approved for waiver services, there is often times a waitlist. This can happen due to lack of funding and a large number of individuals in need of the services. Waiver services also have many different components and organizing care can be difficult. However, there are things you can do to make the process smoother for your child and your family.

1. The day of your Medicaid intake should be the **WORST DAY** in your family's life. You want that intake worker to see how much work and stress your family deals with everyday. **DO NOT** take extra time that morning to straighten up, do the laundry, dust the furniture, brush the cat, etc. Your Medicaid waiver will get approved much quicker if your environment reflects the true nature of your request. My favorite story about a situation like this was from a mom who had totally forgotten that her Medicaid intake was that day. She hadn't showered, she was in sweat pants, and her house looked like a tornado had just gone through it. She said that her intake worker approved her almost immediately.
2. Become familiar and friendly with your caseworker or contact person. If you do get put on a wait list, this is the person who will be able to update you on your place on the list. Be sure to call them frequently to ask about your case and offer to help them by

3. You have the right to have a new caseworker assigned to you. If you feel like your caseworker is not doing anything to help you out, you can ask for a new one. Be sure to talk to their supervisor about what you have experienced with them and be sure to provide accurate details about the situation. This should only be reserved for caseworkers who are truly not doing their job. Be sure to take accurate notes during every conversation that includes names, titles, dates and times.

4. If you need immediate or emergency services while waiting on a Medicaid waiver decision, talk to your intake or caseworker. You may be able to get these emergency services even if you are denied full services in the end. If you are denied services from a Medicaid waiver, find out why you were denied and look into appealing the decision. Keep in contact with your intake worker to find out the reasons. If it's something that can be easily acquired, ask for an expedited hearing to appeal the decision. It is important to know that the appeal process is always time-sensitive, so call as soon as you get a denial letter and find out what your rights are to appeal.

5. If you are put on a wait list for services and your situation changes, you may request a reassessment of your needs to determine if your place on the wait list can change. For

SOCIAL SECURITY

Supplemental Security Income (SSI)

Caring for any special needs child is expensive. Children with Batten Disease require many special things that can take a toll on the family's finances. If your family has limited income resources and your child is under age 18, applying for Supplemental Security Income (SSI) through the Social Security Administration may be an option for you.

In order for a child to qualify for SSI, two things must be present. One, a child must have a disability. This disability could be physical, mental or emotional. The key thing to consider is that this disability must result in "marked and severe functional limitations" and seriously affect the child's daily activities and living skills. The disability must also be expected to last at least 12 months or result in death. The Social Security Administration has listed different categories of disability. The categories include everything from Neurological Impairment to Muscular

Disorders. A child with Batten Disease would qualify under many different categories because of the child's multiple disabilities.

While your child has this set of qualifications, the family's income also plays a part in determining SSI eligibility. Unfortunately, this is where many families become frustrated and are denied SSI benefits. All of a family's assets are considered when looking at SSI eligibility. If a family has too many cars, too much money in a retirement or savings account, or a savings account in the child's name, SSI benefits could be denied. If you are told you make too much money before applying, find out what the limitation is for your state. Make sure to ask if there are exceptions for things like child care or medication costs. Are they basing this financial figure on a family of four or a family of eight and where does your family fall? If you are on the borderline of the financial limitations, apply for SSI.

What if you are denied? The first thing you will want to do is call the Social Security Administration the same day you get your denial letter and inquire about the appeals process. If you don't understand why you were denied, make sure to talk with someone about this. If you are certain you should be granted SSI, ask about an expedited appeals process to ensure a speedy decision. Remember, everyone has the right to appeal their decision but the appeal process is often time sensitive. In fact, on a nationwide basis, an average of 70% of all Social Security disability claims are denied after the first application. You will need to take action right away! You will only have 60 days from the time of your denial to appeal the SSA's decision. For further information on Social Security appeals and determining disability, visit <http://www.disabilitysecrets.com>.

There is another program in place used to expedite claims that would pertain to a child with Batten Disease. Known as TERI, this is a way that Social Security can expedite claims for individuals with terminal illnesses. This is not something you will find on the Social Security Administration website, nor is it something a Social Security worker is likely to tell you about. When you fill out the application for benefits, make sure to tell the worker that your child has a terminal illness, and you would like the claim expedited under the TERI clause. Using the TERI process, Social Security can make decisions on cases in a matter of days, rather than weeks or months as it can be for all other applications. TERI is also an expedited process that can be used for Social Security Disability Insurance (see below).

It is possible that your child may be eligible to receive immediate benefits, even from the time of first filling out the application. Individuals, whose disability and income requirements will most likely result in a determination to receive SSA benefits, could receive immediate benefits under the “Presumptive Disability Payments” program. The worker processing your application will determine if you are eligible for these payments. If your decision comes back and the SSA finds that your child is not “disabled,” these presumptive payments do not have to be repaid. These types of payments are especially important if your family has recently experienced a sharp decline in income or your child has experienced a sharp increase in medical costs. These payments could last as long as 6 months while a decision is being made about your child’s disability and eligibility for benefits. If your child is not found eligible for SSA benefits for reasons other than disability, you may have to pay back the Presumptive Disability Payments

that you received. This scenario is highly unlikely since a Social Security worker carefully evaluates your case before granting these types of payments.

Social Security Disability Insurance (SSDI)

Some children with Batten Disease may be eligible to receive Social Security Disability Insurance, or SSDI benefits. These benefits are eligible to children, over age 18, whose parent is either:

- Receiving Social Security retirement or disability benefits; or
- Have died and worked long enough under Social Security.

Social Security must determine that your child was disabled before the age of 22. The criteria used to determine disability is the same criteria used to determine adult disability. The payments made to the child are all based on a parent's earnings and contribution into the Social Security System. The needed medical information is the same as a child under age 18 applying for SSI benefits. Under the SSDI program, only the child's income and assets are considered when approving the child for benefits. The adult "child" can continue to receive benefits as long as he/she is disabled. Your child does not need to have worked to receive this type of benefit since it is based on the parent's contributions.

A child receiving SSDI benefits can receive Medicare as a health insurance. Medicare is only available after having received benefits for two years. However, based on your child's income

level, Medicaid should be available immediately. Talk with your Social Security representative or Medicaid case manager to discuss the benefits of switching your health insurance to Medicare, when the time comes.

It is also important to know that a child may receive both SSI and SSDI benefits at the same time. If this is the case, the benefits need to be monitored very closely. Because SSI payments are based on income and assets, the amount of money received from SSDI payments contributes to the total income of an individual and could result in a loss of SSI benefits. More importantly, if an adult “child” receiving benefits loses their SSI, they may be in jeopardy of also losing their Medicaid insurance. A loss of these benefits affects individuals who need the medical benefits more than the cash benefits that SSDI may provide.

Congress did pass a law to protect the Medicaid benefits of a disabled adult “child” receiving SSDI benefits to ensure that their Medicaid benefits would not be lost. An individual who receives SSDI benefits that are high enough to cause a loss in SSI benefits may be able to retain their Medicaid if they:

- Are unmarried or married to another beneficiary who is receiving disabled adult “child” benefits;
- Lost benefits for SSI after July 1, 1987, because of an increase in their SSDI benefits;
- Had a special need before the age of 22; and
- Would be currently eligible for SSI benefits if it wasn't for the SSDI benefits.

RESPITE CARE

Let's face it, even the most loving and caring parents of a child with Batten Disease need a break every once in awhile. Whether it's time to spend with your other children, time to spend as a couple, or care needed when parents may not be able to be there for their child, respite becomes a familiar term to parents with special needs children. Not to be confused with private-duty nursing care, respite care is a short-term care option to give parents time away. Sometimes respite is provided while parents are out of the home, but it can also be provided when a parent is in the home. Respite can be as informal as having a relative come over to watch your child while you take some time for yourself, or can be as formal as hiring a respite care worker who is professionally trained to watch after your child while you are not at home.

Getting respite care can be a challenge. While most states' Medicaid programs will pay for respite, most private insurance companies will not, or at least not right away. And while most states' Medicaid programs agree to pay, they may not have money in their budgets to pay at that moment in time. I have known several parents to encounter the familiar phrase, "Yes, we'll grant you respite. Unfortunately, we don't have the funds in our budget to pay for respite right now." You may also be fortunate enough to be granted respite and have the funds to pay for a worker, but then have the daunting task of finding your own respite worker to care for your child.

The first thing to do is ask your insurance company, whether private or state-funded, if respite care is covered under your policy. It may be a service provided under the mental health section of your insurance coverage. This type of care may also be labeled as "skilled nursing care," "home health aides," or "attendant care." There are a few key differences to be aware of when

looking at these labels. Some skilled nursing care requires a patient to have certain medical conditions in order to receive services. For example, your child may need to have a feeding tube, tracheostomy, or some other complex medical condition in order to receive this type of service. You may be able to get your doctor to write a note of medical necessity for this highly skilled level of care, if you and your doctor believe this is necessary. It is also important to know that the level of skill, education, and experience may be different for each of these labels. It may also differ just based on the agency you go through to find a worker. You have the right to ask a nursing provider agency what their requirements are for hiring these para-professionals. Important things to ask include: “Do they need CPR and first-aid certification?”; “What is the highest level of education they need to have completed?”; “Can they administer medications to my child?” Be sure to look into multiple agencies to find the agency that best suits your needs and your family’s needs.

Find out the specific steps that your insurance company requires in applying for and obtaining this service. A letter of necessity may be required from a health professional like a doctor or counselor or a professional in the field of Batten Disease like one of our staff members or Medical Advisory Board members. Be sure to think of all the times when you would have needed or liked to have had a respite care worker in your home. Think about how many hours a day, week, or month would be enough to give you a needed break. If there are more specific hours of the day that you need care, like after school, be sure to include those in your request. The application can vary depending on your insurance company, so be sure to read the application carefully and follow all guidelines as requested. As always, any decision made can always be appealed. If you are unhappy, look into your insurance company’s appeal policy and

take the necessary steps. Remember, they may have denied you to make you go away even if you have a very valid claim. While appealing may be a little extra work, it could be enough to get you the decision you want.

So now you've been granted respite care. If you were granted this service from the state, you must go through the department under which this service is being funded. The respite care may be from the Department of Developmental Disabilities or possibly through the Department of Mental Retardation, or maybe through the Department of Health. Contact them to see what respite care provider agencies they recommend and reimburse. The same can be said about a private insurance company. If your private insurance company has a list of recommended providers, start by contacting them to get a worker in your home. Parents may also have the option to find their own respite care worker. If a friend or family member has experience taking care of your child, they may be able to become certified through the state to become a respite care worker. Not too much is required to make this happen. In most cases a person will fill out paperwork, participate in required trainings like CPR, First-Aid, or Ethics trainings, and have a criminal background check performed. The department under which the respite is being funded should be able to give you more information.

As parents, you have the right to choose the best person to care for your child. If a worker is assigned to you without your say but you do not like the care your child is receiving, you have the right to request a new worker. Many families have requested worker after worker until finding one that was the best fit for them. These are all things to consider while going through the process.

There may also be respite funding available through your local Child Abuse Prevention program. Studies have shown that children with special needs are more likely to be victims of abuse. In 2006, Congress enacted the Lifespan Respite Care Act. This Act was created to “assist states in coordinator state and federal funding streams and approve access to respite for all families regardless of age or disability.” Currently, there is not sufficient funding to really support or help run the Lifespan Respite Care Act. There are a few states that have found the funding to fully support the program. With funding from the Lifespan Respite Care Act and Child Abuse Prevention programs, respite will most likely become a readily available service to families who have children with disabilities. Talk to your local congressman or senator about advocating for funding for this Act in your state.

There are other places to consider when looking for respite care funding. Look to your state’s Developmental Disabilities Council for funding. You can also look at local charitable organizations for programs and services funding. These private charitable organizations include Rotary and Lions’ clubs, Moose and Elk Lodges, and other fraternal types of organizations. It may also be of your benefit to ask your church or religious organization if they would be able to help you pay for respite care. Be sure to look into summer camps for children with developmental and other disabilities. These can be found through your local Easter Seals, Epilepsy, or Blindness Foundations. Many times the only qualification is seizure activity, visual impairment, or other disabilities.

A few key things to remember about respite care:

1. Contact your insurance provider to ask about the service first. Remember, it may be a service provider under the mental health portion of your policy.
2. Consider how much time you would like in terms of hours a day, hours a month, days a week, days a month, etc. You also have the right to appeal any decision granted to you.
3. Research your provider agencies carefully. If you are unhappy with a respite care worker, you have the right to request a new one. Ask about a family member or friend being hired as your respite care worker if this applies to you.
4. Never feel guilty for using respite care. Every parent needs time for themselves to rebuild their strength and stamina. You are doing what you need to do to be a better parent for your child.

PROGRAMS FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS

Some states have special programs available for children with unique medical conditions, like a child with Batten Disease. **Not every state offers this type of program** and finding these programs can be difficult to nearly impossible. If your state does offer this type of program, they may provide services like case management, respite, help finding medical equipment, genetic counseling, treatment options, etc. These programs may be based on income, or may be available to all citizens, regardless of age, income, or diagnosis.

When inquiring about this program in your state, it may be listed under many different names and run by any of the state's different departments. One common name used to refer to these programs includes "CSHCN" or Children with Special Health Care Needs." Another label may be a bureau or department for "Children with Medical Handicaps." Yet another title may include

something like, “Program for Medically Fragile Children.” With so many different names and titles, it’s no wonder that a parent may not know where to look.

These types of programs are often recommended by a child’s doctor or nurse. It may also be something recommended by a local children’s hospital or even a child’s school. To find these programs, you may first want to contact your child’s pediatrician, or local children’s hospital. Within the children’s hospital, ask to speak to a social worker or someone in the social services department. You can also call your local Health Department or local Department of Social Services to see if your state participates in this type of program.

As stated earlier, the program’s eligibility may or may not be dependent on a family’s income. Parents might be able to pay a percentage of the fee based on their income or may be able to participate in a spend-down program, much like Medicaid. However, in some cases, the services may be completely free to any family regardless of income. Since these programs vary widely from state to state, it is important to ask questions and get as much information as possible before deciding to accept services.

NON-GOVERNMENT ORGANIZATIONS

Getting assistance from the government can be a very frustrating process. Fortunately, there are other organizations to turn to for help. The school can be a great asset to a child with Batten Disease and their family. Many families run into roadblocks when trying to get help from the school, but if you can get these people on your side, you will have a win-win situation. Never be afraid to ask your child’s teachers and principal for recommendations about a good physical

therapist, equipment manufacturer, or summer day camp. If they don't know of something specific, they may be able to point you in the right direction.

Staying in contact with your local children's hospital may also prove to be a great resource. You may be able to rent certain equipment from the hospital that may be hard to find somewhere else. Many children's hospitals offer community-based supports and services for children they see frequently. Again, this can be a great resource to locate an occupational therapist, an exercise or play group, or help finding respite. Even if your child has not been to the children's hospital in quite some time, asking if these services are available is still a good idea.

Many children's hospitals are beginning to provide Palliative Care services to children with life-limiting illnesses. Unlike Hospice, Palliative Care still allows parents and families to seek out treatment, while receiving supports from nurses, social workers, chaplains, and doctors. Palliative care really takes a look at the "quality" of a child's life and helps to enhance that quality in many different ways. A child with Batten Disease is more than qualified for services through a Palliative Care program. Contact your local children's hospital to see if they have a Palliative Care program available in your area.

Think about all the different types of organizations that may be available to your child. Some of these organizations may include your local Foundation Fighting Blindness or other visually impaired organization for individuals or your local Epilepsy Foundation. Organizations that your child may not have a diagnosis for but the symptoms are very similar may also be able to help you out. This might include a Cerebral Palsy foundation or Autism Society. While these diseases

really have nothing to do with your child's disease, many of the resources that they provide or have knowledge about may be very suitable for your child. It never hurts to ask or inquire. If they can't help you, they may be able to find someone that can. Another popular organization is the Easter Seals. This is an organization that helps people of all ages with any type of disability. They have locations all over the state and provide everything from equipment donation to respite services. Your local United Way chapter can help you find resources in your community as well. They keep a very thorough database of the services and organizations in your area that meet your needs. BDSRA also has a thorough database of services and organizations in your state.

As you can see, the road to getting services for your child can be a difficult one to manage. It will take perseverance and determination. Remember, you may not get exactly what you want the first time, every time. Getting these programs and services will be a life-long fight. The more knowledgeable you are about your rights and your child's rights and the more confident you are in your demands, the more likely you are to get what you ask for. It will be a hard journey, but remember to stay strong and keep advocating for what you need.

HELPFUL WEBSITES

If you have questions about any of the information in this publication, please consult the following websites for additional information about some of the topics discussed.

1. Social Security Administration
 - a. <http://www.ssa.gov>
2. Center for Medicaid and Medicare Services
 - a. <http://www.cms.hhs.gov/>
3. Information on Waiver Programs
 - a. <http://www.cms.hhs.gov/MedicaidStWaivProgDemoPGI/>
4. National Easter Seals
 - a. <http://www.easterseals.org>
5. National Epilepsy Foundation
 - a. <http://www.epilepsyfoundation.org>
6. Foundation Fighting Blindness
 - a. <http://www.blindness.org>
7. United Way of America
 - a. <http://www.unitedway.org>
8. Reference Information about Programs for Children with Special Health Care Needs
(Note: not every state is listed)
 - a. Ohio—<http://www.odh.ohio.gov/odhPrograms/cmh/cwmh/bcmh1.aspx>
 - b. Utah—<http://health.utah.gov/cshcn/>
 - c. Minnesota—<http://www.health.state.mn.us/divs/fh/mcshn/index.htm>