

## Help is on the Way

### Mary Summers

Mary Castro Summers is a parent with three adult sons and her youngest was born with complex health needs. For the past thirty years, she has worked with the New England Regional Genetics Group, the FIRST project at the University of Massachusetts Medical School, Family Ties of Massachusetts and now at Franciscan Children in Brighton, MA. Mary has also been a member of Marcel's Way Committee for the past five years. In that capacity, she reviews applications for the Marcel's Way Family Fund at MitoAction. Mary has learned of the impact of mitochondrial disease and has assisted many families in finding local community resources to address their needs. She is passionate about community resource information sharing and making connections among families who support children and adults with special health care needs. She was personally supported by others and enjoys paying back those acts of kindness. Her motto in this work is "You may be caring for your loved one by yourself, but you should never feel alone".

Mitochondrial diseases are comprised of a wide range of issues, which affect individuals and families in different ways. Children with an underlying diagnosis of mitochondrial disease may present with poor growth, loss of muscle coordination, muscle weakness. Seizures are also seen frequently. Other issues include autism, vision and hearing problems, developmental delays, learning disabilities, heart, liver and kidney disease, gastrointestinal disorders and diabetes. Many individuals also have a weakened immune system, which combined with reduced physical structure to combat infections, means they are more likely to be hospitalized and potentially have more serious repercussions. Thyroid and/or adrenal anomalies, autonomic dysfunction, as well as dementia are risks of mitochondrial diseases.

One excellent resource, among others, is the Genetic and Rare Disease Information Center (888-205-2311). But families dealing with mitochondrial diseases have a broad range of needs including:

- Healthcare
- Emotional Support,
- Basic Needs
- Community Services

### Healthcare

*HealthCare/Insurance:* Healthcare is a broad conversation but one of the fundamental issues is access to health insurance. Families may have employer-sponsored health insurance, access through the Medicaid buy-in programs, or through state services that provide health insurance to families who can't afford it through other means. Medicaid should be at the top of the list if you have a child or are a person under the age of 65 with mitochondrial disease. In many states, Medicaid is available not only as a primary insurance, but as a secondary insurance. Typically, an individual would apply for Medicaid noting that family finances would not allow them to get Medicaid as a standard benefit. They would also fill out the disability eligibility form. Upon approval, this would provide access to Medicaid as a secondary insurance on a buy-in basis. Like commercial insurance, there is a premium. Some states also have premium assistance programs.

In Massachusetts, this program is called CommonHealth. The premium assistance program in Massachusetts not only covers the costs of the secondary, (CommonHealth) insurance, but it may also pick up some or all of a primary (commercial) insurance. My understanding is that the state would rather subsidize the cost of premiums of commercial insurance (the primary payer) than be the primary payer itself. So the state may cover costs that are not covered either because of the details of the commercial plan or because of annual limits. The only caveat is that services must be provided by a provider who accepts Mass Health insurance.

A most significant benefit is that MassHealth, as secondary insurance, will pick up block nursing or home care nursing. As individuals start to have more and more medical challenges, it's often necessary to have someone to come in, not only to do daily assessments but also to provide medical care. If an individual requires more than two skilled services, the state Medicaid program can assess for home care nursing. Unfortunately, while the state may approve home care nursing, the challenge is often finding available staff.

It is also essential to understand one's benefits and what is covered in terms of doctor visits, hospital stays, outpatient therapies, imaging services, laboratory services and medications. If one is receiving insurance through a commercial provider, (e.g., through an employer), it's important to take the opportunity to provide feedback to HR or personnel as to the kinds of services needed and the complexity of care required. Some commercial insurances may allow for a rider or a separate special policy to be added for expanded benefits. Communication is essential in order to identify options that may not be readily apparent either to the employee or the employer.

*In home services and DME:* Other important in-home services (in addition to visiting and block nurses) would include infusion services, short term therapies, and emotional/behavior health services. For example, in Massachusetts, the Children's Behavioral Health Initiative (CBHI) supports children who have emotional/behavioral challenges. A service provider comes into the home and works one-on-one with a child to address the emotional side of their challenges, as well as to provide behavioral support. CBHI also offers a parent mentor who supports the individual(s) in the parent role, helping them to work through the challenges that they may have in raising a child with significant health issues. A primary care physician can also be a strong ally when someone is too medically fragile to leave the home for services, whether physical, occupational, speech, feeding, etc.

Durable medical equipment is another essential medical service and it is important to understand what insurance will cover there as well. Examples of durable medical equipment are wheelchairs, walkers crutches, braces; lifts, elevators, and ramps; and bath safety equipment. If the product is not covered by insurance, reach out to the employer or the insurance company to discuss coverage. Additionally, Easter Seals runs programs throughout the country that take durable medical equipment that's no longer needed and refurbish it. The refurbished equipment is offered to those with limited financial resources, typically through some kind of state program in conjunction with Easter Seals. It could be something as simple, though lifesaving, as a bed rail. Other examples are outgrown wheelchairs and bath equipment.

Regarding ramps, it may be necessary to speak with a qualified individual to determine if a ramp is feasible. In addition, Home Depot has a foundation that has helped thousands of

families build ramps at their home. Other charities may provide similar services. Vocational high schools are another possible resource as is Easter Seals.

Stairlifts may be really helpful in the home and in some cases, can be rented if a long term need is not anticipated. There is likely to be a delivery/pick up fee as well as monthly rental charges. Again, check with insurance to see if coverage is available.

Lighting and sound devices are also helpful for someone with limited movement or limited vision or with sensitivity to sounds. Review home accessibility including things like kitchen counters and appliances. Consider bathroom accommodations such as bath chairs, a roll-in shower or bathtubs that have a door.

*Medication:* Both prescription and over-the-counter drugs are essential to dealing with many of the medical challenges that come with mitochondrial disease. Over-the-counter (OTC) medications are sometimes covered by Medicaid, based on an approved list. Other medical supplies for which assistance might be available are incontinence products, either through primary or secondary insurance or Medicaid.

MitoAction has received numerous requests from families hoping for financial assistance to help to pay for compounded cocktails. MitoAction considers each request but the overarching concern is what happens to access to the compound cocktail once the one-time grant has been used. Mito suggests that families also look to other nonprofits and work with their physician to see if it can be covered by insurance.

More and more commercial insurance plans are covering alternative therapies such as homeopathic and natural remedies, acupuncture, meditation, yoga and mindfulness. Frequently these services are available at a very low cost in the community, at hospitals and, if age appropriate, at senior centers.

*Other Services and therapies:* Outpatient services and therapies like OT, PT, speech or feeding therapies are often essential for patients with challenges, particularly around stamina. While hospital inpatient service may be once or twice a day, once discharged, patients don't receive services at the same frequency. In addition, children may get OT, PT or speech therapy in school, but it may not take into account all of the child's needs, such as lack of endurance that emerges from the medical condition. As always, speak with child's primary care physician or the metabolic specialist to get a prescription for services and present that to insurance. Some state Medicaid programs cover a certain number of visits per year which can be increased with additional letters of justification provided by the physician.

All health insurance in the United States is supposed to offer parity or an equal level of services for both medical conditions and mental health issues. In addition to private practice resources, a physician can often direct you to community resources, which may be more affordable. Do not let any stigma, real or perceived, keep you from seeking help. Those who take care of children or other family members with complex needs, must also take care of themselves. And those with mitochondrial disease or other complex medical conditions also need resources and a safe space to deal with their emotional challenges. Often children/adults do not discuss their emotional issues with their parent/caregiver because they don't want to add to the parent's burden, or can't sort out what they're feeling.

A broad resource that is now available nationwide is National Family Voices [familyvoices.org](http://familyvoices.org), which is an organization established by families of children and adult members who have complex medical needs. They help others identify resources in their own states. Every state has a Family Voices chapter that serves as the Family to Family Health Information Center. An interactive map on the Family Voices website directs the user to local information and resources.

### **Emotional Support:**

Emotional/mental health is a priority for both the patient and the caregiver(s). When the emotional needs of an individual are addressed, they have more energy to address their daily needs and to enjoy and see the joys in life. Peer support for both caregivers and patients can be a tremendous help. Finding others who understand the challenges lets an individual know that they are not alone, provides new ideas, and offers an outlet. Although everyone's situation is unique, everyone can learn from each other's experiences, feelings, resources and outlooks. For families of children with special needs up to age 22, contact the local Parent to Parent network, which you can find through the web site, [p2pusa.org](http://p2pusa.org). Another excellent resource are Centers for Independent Living, which are consumer-controlled, community-based, cross-disability, nonresidential private nonprofit agencies that are designed and operated within a local community by individuals with disabilities and provide an array of independent living services. Their website is [ILRU.org](http://ILRU.org). These organizations have federal and state funding and can offer practical advice, counseling and assistance related to community living, governments and community resources, job training, support services and opportunities. Organizations such as MitoAction are another tremendous resource for both information and support.

### **Basic Services and Needs/Government programs**

Food. Housing. Transportation. Key resources here include Social Security, whether it's SSI or SSDI, SNAP, sometimes called food stamps, and the Department of Transitional Assistance in your state.

SSI is Supplemental Security Income and it's a way to bring some funding into a family even if a person who has never worked or has a very short work history. It provides monthly benefits to people with limited income and resources who are disabled, blind, or age 65 or older. Disabled would likely include those with a complex medical situation that impacts their ability to go to work. It may also be used for children who have special health care needs.

In considering an application for SSI, note that for children under the age of 18 (i.e., up to the 18<sup>th</sup> birthday) family financial assets are considered the child's assets. Once a child turns 18, they (or someone on their behalf) can file for SSI and the only assets that are counted are the assets in the name of the child, now young adult. There are asset limitations though. Currently, the applicant cannot have more than two thousand dollars with their name attached to it. This includes bank accounts, savings bonds, and brokerage accounts, which includes bonds (e.g., savings bonds). If someone gives you savings bonds in the child's name, when that child becomes a young adult, that would be counted towards their limit

Even if the applicant is close to the limits that are listed on the Social Security website (and would only get a few dollars monthly), it pays to apply because once approved (i.e., the

individual has a medical condition that makes them eligible for SSI), that individual is automatically enrolled in Medicaid in their state. Benefits vary by state but for a child applicant, the money provided may be enough to provide additional flexibility for adult caregivers; for adult applicants, it is supplemental income if, because of a medical condition, they can work only limited hours or not at all.

SSDI is Social Security Disability Insurance. It's a completely different program for those who have more than 10 quarters of documented work – meaning they've paid into Social Security through payroll deductions. SSDI covers someone who is no longer able to work. SSDI is a complicated system and it's worth going in and visiting the local Social Security office, if possible. Note again, that being approved for SSDI is an automatically qualifier for Medicaid (in your state). There may be other programs specific to state of residence that can assist families with dependent children.

SNAP (familarly known as food stamps) provides assistance based on family income and family size and the number of members of the household who would avail themselves of the kinds of foods that are available through food stamps. WIC (which stands for women, infants and children is a supplemental nutrition program specifically for pregnant and postpartum women with children under the age of five.. Some states have surplus food programs as well as other resources focused on hunger and nutrition though there are fewer government direct-to-consumer programs. Food banks and food pantries are typically the best options for families in need for food.

Housing assistance is more complicated because programs will vary both within and among states. Section 8 vouchers (which can help reduce housing costs) may be available on a federal or state level that can help to reduce the cost of housing to a family but waiting lists for Section 8 housing are very long. Despite this, if housing is an issue, it makes sense to get the list. Section 8 housing also covers adults with special health care needs who are utilizing services such as SSI or SSDI. Other options include public (government) housing and housing that is designated as “affordable housing.” All of these programs have income and other restrictions. Adult Foster Care offers a home-based environment for adults who needs others to care for their needs. The name of the program (and methods of payment) will vary by state. Multi-generational homes may be a good option for some people, with benefits such as support for the disabled and the disabled individual being able to contribute to the household in some way.

Transportation services will also vary by state and may include transportation for both medical and non-medical services. In many states, Medicaid has a benefit that pays medical transportation or reimburses Medicaid recipients for transport to medical appointments. Care coordinators or other staff members at a physician's office or hospital can help arrange necessary transportation, including cabs, wheelchair vans, stretcher car or ambulance. Different states also require different documentation and reimbursement could be denied if proper documentation is not in place.

There also may be programs that provide reduced ticket prices for local and regional public transportation as well as government-support vans and carpools. In addition, there may be financial assistance available for a wheelchair van or a vehicle that is more accessible for the patient (new or used). Charitable organizations may also be able to provide financial assistance or additional resources and guidance, including where to look for a used vehicle. Some families use “Go Fund Me” pages – though that is a very personal decision.

## Community Services

Community services covers areas such as education, job training and support, socialization, and recreation. These will vary community to community as will available resources (government and nonprofit) to support these activities and programs.

Special education services are important for children with special health care needs from the age of three to 21 or 22, (depending on the state). The goal is to help children access the highest level of quality education that they can in the least restrictive environment.

IEPs (Individualized Education Plans) and 504 Plans are typically required in order to receive services. The main difference is that IEP plans are for students who require specialized instruction; students with 504 plans don't require specialized instruction but do require other types of accommodations. Another difference is that 504 plans can follow the student into college and into the workforce. There is a lot of information online about the distinctions between the programs.

Other federal laws and state regulations support families as well. Every state has PTI or Parent Training and Information Centers. These are federally funded programs that can help families learn more about specific disabilities, parental and child rights under the law, and other resources such as support groups and educational specialists.

Typically, local districts provide services, providing either an integrated classroom setting or small, substantially separate classroom settings depending on the child's needs. If that is not adequate for the child, there are also what are known in Massachusetts as collaborative schools. The collaborative schools in Massachusetts are small, mostly separate programs that service children from multiple communities. These schools allow children to have greater access to more individualized teaching services. Tuition costs are typically covered by the local school district.

Interventional health care plans map out what the school needs to do specifically for a child in order for them to access their health and educational services. An individualized health care plan ensures that a child can be safe and healthy while at school. The community resources noted earlier can help with this.

Job training and support and transition to adulthood and adulthood services should be a part of a child's school planning starting at age 14 or 16 (depending on the state). Planning should include attention to a child's interests and vocational needs; skills they have and would like to develop; opportunities to develop those skills with an eye toward gainful employment, whether part time or full time; and support that may be needed to ensure success in the workplace. There are a number of different vehicles for support, including schools, community programs, and developmental disability agencies, with support including things like job coaching or interview prep, as well as support on the job.

Socialization is another essential aspect of caring for individuals with special medical needs. It is crucial that the individual has meaningful opportunities to be engaged with family, friends and a community. Parents and caregivers can think about what interests the individual has and then look for activities that foster socialization. For example, if someone

loves animals, maybe there is a way to volunteer at an animal shelter, work at a pet shop, or provide dog walking services.

Recreation and physical activity, where appropriate, also afford opportunities for socialization and adaptive equipment may be available through state and local resources. For example, in Massachusetts, the Department of Conservation and Recreation hosts an annual event in the Boston area where they bring in about 50 different types of adaptable bicycles and allow people to ride along the Charles River, to try them. DCR also offers accessible kayaking, hiking, and ice sleds. There are similar opportunities in the arts through local resources and a national organization called VSA, (Very Special Arts)

Charities/nonprofit organizations offer a range of financial and other support to individuals with special needs, including many wish programs in addition to the well-known Make a Wish. These programs let families to be thoughtful and creative about what their child needs, whether it's a large screen television for a visually-impaired individual or accessible playground equipment. Many of these programs, however, only help those up to age 18. Organizations that may be able to help include the Knights of Columbus, the Jaycees, Kiwanis, the Lion's Clubs, the Masons. Parents to parent groups and Family Voices (a national grassroots network organization) can also be invaluable.

Personal Care: In addition to skilled nursing, individual may need personal care attendants. Most states through their Medicaid programs provide funding for "an extra pair of hands" to support the activities of daily living, including feeding, bathing, dressing, etc.. Private insurance may also offer some coverage for personal care attendants. With PCAs, parents need to be very specific about the best way to work with the child and break what may seem to be obvious tasks into steps that work for the child.

Note: Background on Marcel's Way Family Fund. The goal of the program is to offer a helping hand in the way of direct financial support to those who suffer from some aspect of mitochondrial disease. Through a fairly simple application process on the MitoAction website, individuals with a diagnosis of mitochondrial disease or are seeking testing to definitively determine that diagnosis, can apply to MitoAction for up to \$500. Currently, there is a one-time award with a \$500 cap. Marcel's Way has funded or helped to fund items such as specialized stroller, a folding wheelchair and iPads (for communication and educational activities) as well as services such as medications, travel for medical diagnosis and/or care, utility bills and accessibility needs.