

## Florida

When a family or individual is faced with a progressive condition such as DM1 or DM2 they are often presented with additional financial expenses as well as loss of a steady income. This section attempts to gather financial resources that are available on a state level for persons living in the United States. By no means is this section complete; we invite you to share with us any resources you've identified.

This is an on-going project. We will add more resources as we gather them; please send us resources you know of that are not currently listed.

Please be advised that each organization has its own eligibility and application requirements. None of these organizations are affiliated with the Myotonic Dystrophy Foundation. We hope you will share your experiences with us – let us know if you are successful in finding a good resource to help your family.

### **Financial Resources**

<u>The ABLE Trust:</u> The Able Trust, also known as the Florida Endowment Foundation for Vocational Rehabilitation, is a 501(c)(3) public-private partnership foundation. Its mission is to be a key leader in providing Floridians with disabilities opportunities for successful employment. The Able Trust works with community organizations throughout the state to help thousands of Floridians with disabilities enter the workforce. The Able Trust youth programs provide career development and transition to many students with disabilities annually, helping to reduce the dropout rate and prepare young adults for life beyond high school. The Able Trust supports a diversity of projects, including on-the-job coaching, supported employment, job skills-training, job development, employer outreach, ADA facility compliance, skills evaluation and programs leading to employment. <u>http://www.abletrust.org/about-us</u>

<u>Able United:</u> ABLE United was established to encourage and assist people with disabilities to save private funds to support health, independence and quality of life. To qualify you must be a Florida resident with disease onset prior to 26 years old. An ABLE United account is a tax-free savings account for your future. The individual with a disability owns the account, but an authorized person may establish and help oversee the account. You can save up to \$14,000/year with help from family/caretakers, and it will not affect Medicaid coverage. http://www.fddc.org/sites/default/files/ABLE%20United%20Quick%20Start%20Guide\_WEB.pdf

<u>Agency for Persons with Disabilities:</u> The APD works in partnership with local communities and private providers to assist people who have developmental disabilities and their families. APD also provides assistance in identifying the needs of people with developmental disabilities for supports and services. They also provide support and resource for families and individuals in crisis, employment opportunities and support, self-advocacy training, and more. <u>http://apd.myflorida.com/customers/application/</u>



<u>Center for Child Development</u>: The Center for Child Development was designed to address the developmental and behavioral concerns that parents and other caregivers may have about newborns and children. They work together with you and your pediatrician or pediatric nurse practitioner to complete an in-depth look at your child's development. <u>http://www.centerforchilddevelopment.com/</u>

<u>Florida Department of Children and Families Cash Assistance Program</u>: The TCA program provides cash assistance to families with children under the age of 18 (or 19 if enrolled full time in school). The program helps families become self-supportive while allowing children to remain in their own homes. Pregnant women may also receive TCA, either in the third trimester of pregnancy if unable to work, or in the 9th month of pregnancy. Parents, children and minor siblings who live together must apply together.

The relative caregiver program is a subset of the TCA program that provides monthly cash assistance to relatives who meet eligibility rules and have custody of a child under age 18, who has been court ordered dependent by a Florida court and placed in their home by the Department of Children and Families. The monthly cash assistance amount is higher than the Temporary Cash Assistance for one child, but less than the amount paid for a child in the foster care program. <u>http://www.myflfamilies.com/service-programs/access-florida-food-medical-assistance-cash/temporary-cash-assistance-tca</u>

<u>Florida Developmental Disabilities Council:</u> The Florida Developmental Disabilities Council was established in 1971 to help plan individual and family-centered supports for persons with disabilities in Florida. The Council also guides the development and administration of services for people with developmental disabilities by planning and funding research, innovations, and programs designed to improve the quality of their lives. They provide access to Florida and National Resources, including financial resources, as well as community and educational opportunities. <u>http://www.fddc.org/</u>

<u>Florida Optional State Supplementation (OSS) for Assisted Living:</u> This cash benefit is available to US Citizens who are legal Florida residents and aged 65 and older (or younger if blind or disabled). OSS provides financial assistance to low-income seniors/disabled that cannot live independently and therefore require residential care, either in an adult family care home (traditionally what most people think of as adult foster care home), an assisted living residence, or a mental health treatment center. Assistance comes in the form of a cash payment made directly to the individual that requires care or their legal guardian. It is intended for the room and board portion of the fees charged by the residence. Other assistance is available for care services. <a href="https://www.payingforseniorcare.com/longtermcare/resources/florida\_oss.html">https://www.payingforseniorcare.com/longtermcare/resources/florida\_oss.html</a>

<u>Florida Temporary Assistance for Needy Families:</u> TANF is a federally-funded grant program for families in need, whether due to disability, illness or otherwise. While this program typically requires ongoing work participation to receive benefits, recipients currently enrolled in the SSI program are not included in the TANF benefit calculation, and are excluded from work requirements. The amount of assistance you receive depends on circumstances and family size, changing on a case-by-case basis. The TANF program focuses on helping children to stay



in homes with their families, keeping families together, and helping needy parents to find jobs and remain with their children. <u>https://www.benefits.gov/benefits/benefit-details/1657</u>

<u>FSQAP Delmarva Foundation:</u> The Delmarva Foundation is contracted by the State of Florida's Agency for Health Care Administration (AHCA) to provide quality assurance for the State's Developmental Disabilities Services system. They work in partnership with the Agency for Persons with Disabilities (APD) at the central office as well as with each local Area office. The resource center includes family and provider resources, including links and resources to different disability groups and non-profits. <u>http://www.dfmc-florida.org/Public2/resourceCenter/individualsFamilies/links.html</u>

# **Autism-Related Resources**

<u>Abilities Unlimited:</u> Abilities unlimited provides tutoring, training, and behavioral supports for individuals with autism and related disorders. Social Skills Trainings are available to all children. Children are given an evaluation before they begin training. Therefore, the activities are customized to meet your child's needs. Children receive one-on-one coaching, and small group training. They use a variety of techniques including video modeling, peer mentoring, and role playing. The Services are child friendly, and parents' concerns are taken seriously. http://www.abilitiesunlimitedtherapy.com/home\_1.html

<u>Alternative Outcomes Behavioral Therapy:</u> Alternative outcomes provides therapy and other services to children with a range of disabilities, including autism. They provide services in several Central Florida regions including Orange, Osceola, Brevard, Seminole, and Lake Counties. <u>http://www.alternativeoutcomes.net/index.html</u>

<u>Applied Behavior Center for Autism:</u> The ABC for Autism was founded to establish a childguided, positive, and effective therapeutic environment for children with autism, related developmental disabilities, and learning challenges. The program uses ABA (applied behavior analysis) as the treatment methodology to help all clients reach their maximum level of independence and ability. With thorough assessments and considerate observation they are able to assist all children regardless of age, level of disability, or diagnosis. They have center locations in Longwood, Oviedo, and Winter Garden. They provide 1:1 therapy, in-center therapy, and more. <u>http://appliedbehaviorcenter.com/</u>

<u>The Arbor School of Florida:</u> The Arbor School offers a sensory-based curriculum ideal for children for those with High Functioning Autism, learning disabilities such as Dyslexia, and other unique abilities that do not have severe behavioral outbursts. All classrooms at The Arbor School are sensory based. Each class is set up to meet the needs of the students with bean bags, low tables for floor sitting, space to stand, quiet spaces, and natural lighting. The school provides education for children K-12. <u>http://www.arborschoolflorida.com/</u>

<u>Autism Society of Greater Orlando:</u> Serving families of Central Florida, the Autism Society provides information, social skills groups, social events, annual field trips, support, and more to families, friends, caretakers, and patients of the Autism Spectrum Disorder. <u>http://asgo.org/</u>



<u>CARD: Center for Autism and Related Disabilities at USF:</u> The Center for Autism & Related Disabilities at the University of South Florida is a community-based project that provides information and consultation to individuals diagnosed with autism spectrum disorders and related disabilities. CARD-USF offers instruction and coaching to families and professionals through a training and assistance model. They provide direct assistance to families, schools, and agencies, as well as support and community access. <u>http://card-usf.fmhi.usf.edu/services/index.html</u>

<u>Florida Autism Center:</u> The center serves the community with center-based ABA therapy throughout the state of Florida, with a wide variety of behavior analysts at every location. They provide treatment based on the basic principles of Applied Behavior Analysis, and has a specific focus on early intensive behavioral intervention, verbal behavior (language) training, and social skills training. Additionally, the Florida Autism Center can help your child learn to display basic "following directions" skills, self-care and daily living skills, and can give your child a strong foundation in skills that will be needed as he or she advances academically. <u>http://flautism.com/</u>

### **Caregivers and Respite**

<u>Best Buddies Florida</u>: This organization offers One-to-One Friendship, Integrated Employment and Leadership Development programs – positively impacting nearly 104,640 individuals with and without disabilities in Florida. They help promote friendship and community, as well as integrated employment and leadership development. They hold events, challenges, and walks for everyone and to raise funds. <u>https://www.bestbuddies.org/</u>

<u>Bright Feats</u>: Bright Feats provides information about local community services, offers support to families and helps businesses convey their unique services to the special needs community. They maintain a website with expanded directory information, articles, links to related blogs, calendar with upcoming local events and more. They also provide access to a directory of therapy providers, professional providers, educational resources, community resources, and medical resources. <u>http://brightfeats.com/</u>

<u>Buddy Cruise:</u> The Buddy Cruise is an annual event for families who have a member with Down syndrome or other developmental disabilities. The cruise provides a community opportunity for families, as well as resources and education. <u>http://buddycruise.org/pages/Default.aspx</u>

<u>CSI Caregiver Services</u>: This organization helps connects people in need of caregiving services to organizations and providers. They include services for the elderly, disabled, and pediatrics. They rigorously screen all caregivers prior to placement, and now has more than 5000 active caregivers throughout Tennessee and Florida. <u>http://www.csicaregiver.com/</u>

<u>Deliver the Dream</u>: Deliver the Dream helps families experiencing a serious illness or crisis in their lives by organizing monthly three-day, two-night retreats. Each family that attends has a family member, whether it's a child or a parent, living with an illness/crisis such as cancer, autism, a blood disorder, etc. The program invites up to 15 families, free of charge, to one of the



retreat locations to relax, enjoy time together, forge new friendships, and create new support groups with other families. <u>http://www.deliverthedream.org/</u>

<u>The Family Café:</u> The Family Café exists to provide individuals with disabilities and their families with an opportunity for collaboration, advocacy, friendship and empowerment by serving as a facilitator of communication, a space for dialogue and a source of information. The hold an annual, 3-day event in Florida full of information, question sessions, access to resources, networking sessions, and more. There is no registration fee, and the Café will aim to provide financial assistance wherever possible. <a href="https://familycafe.net/the-annual-family-cafe">https://familycafe.net/the-annual-family-cafe</a>

<u>The Florida Center for Inclusive Communities:</u> A part of the University of Southern Florida, this center focuses on providing access and resources for interdisciplinary pre-service preparation and continuing education, training and technical assistance, community services, research, and dissemination for individuals with disabilities. <u>http://flfcic.fmhi.usf.edu/</u>

<u>Florida Crossroads Magazi</u>ne: The mission of Florida Crossroads is to provide you with a publication that is informative, inspiring and creates an inclusive environment of support, understanding and acceptance. Think of Florida Crossroads as a place where special needs families meet life-changing opportunities. <u>http://www.floridacrossroadsonline.com</u>

<u>The Florida Youth Council:</u> The FYC is all about getting youth and emerging leaders involved in self-advocacy, peer mentoring and other activities that will improve the quality life for youth and emerging leaders with disabilities in Florida. The program empowers youth and emerging leaders to decide what issues are important to their generation, to express those issues in their state and local communities, and to develop strategies to solve them. All members are between the ages of 15-30, and they all have some form of disability. They meet monthly, and have an annual youth summit. <u>http://www.floridayouthcouncil.org/frequently-asked-questions/</u>

<u>Nathaniel's Hope:</u> Nathaniel's Hope provides community-based activities to families of children with special needs to inspire hope. They have a buddy system, buddy break church system, an event called "make 'm smile" with over 40,000 participants and 2,000 kids with special needs. They also do caroling at Christmas, have a birthday club, and more celebratory events. http://www.nathanielshope.org/

## **Exercise and Outdoors**

<u>Dreamplex:</u> The Central Florida Dreamplex is a center for fitness and recreation designed specifically for families with special needs. The facility blends alternative therapy, adaptive sports and recreation activities, and group fitness classes for the whole family into one location. The facility boasts a 24' long traverse rock wall, an Exerbike gaming system, a GameCycle, and gymnastics equipment to make therapy fun! Our occupational therapy room focuses on sensory integration, utilizing Nintendo Wii games, the Timocco interactive game set, and a therapeutic listening program. The have summer and after-school programs, as well as adaptive programs. https://www.cfldreamplex.com/



<u>Florida Disabled Outdoors Association:</u> The Florida Disabled Outdoors Association (FDOA) is a non-profit organization that is working to enrich lives through accessible inclusive recreation. The FDOA has promoted accessible recreation to persons with disabilities as well as the general public through its hands-on recreation programs, newsletters, and community outreach and education. They have worked closely with many state groups to enhance the disability access to the outdoors, including U.S. Fish and Wildlife Service, Wildlife Refuges, the Department of Environmental Protection/Parks and Recreation, and more. They also organize and host numerous adventure outings for the disabled, including scuba diving, deep-sea fishing, canoeing, and hunting expeditions. https://www.fdoa.org/about-us

<u>Freedom Ride</u>: Freedom Ride is dedicated to enriching the lives and experiences of children and adults with disabilities in the Central Florida area through therapeutic horseback riding and related activities. Freedom Ride provides therapeutic horseback riding to children and adults with disabilities, including cerebral palsy, muscular dystrophy, multiple sclerosis, autism, developmental delay, attention deficit disorder, deafness and many emotional and learning disabilities. <u>http://www.freedomride.com/</u>

<u>Healing Touch Therapeutic Riding Center (St. Cloud):</u> The therapeutic riding program integrates the teaching of riding skills with therapeutic activities designed specifically for the individual rider with physical and cognitive disabilities. They hold multiple annual events, such as their Special Olympics, alongside their regular school and lesson programs. https://www.healingtouchtrc.org/home.html

## **Healthcare and Medicine**

<u>Achieve Pediatric Therapy:</u> Achieve Pediatric Therapy (APT) is a therapist owned private practice with two Orlando offices. They work with Florida Speech to provide collaborative occupational therapy, physical therapy and speech therapy services. The caring therapists serve children with special needs at their homes, daycares, and at our offices located in Waterford Lakes (East Orlando) and Dr. Phillips (Southwest Orlando). http://www.achievepediatrictherapy.com/main.aspx

<u>Bright Start Pediatrics:</u> Brightstart Pediatrics is a PPEC Center (Prescribed Pediatric Extended Care)-a nursing and therapy center for medically fragile infants and children up to five years of age. They provide pediatric nursing, physical, speech, and occupational therapies. They have centers across several different counties. <u>https://brightstartpeds.com/about/faq/</u>

<u>Central Florida Pediatric Therapy Foundation:</u> The facility blends alternative therapy, adaptive sports and recreation activities, and group fitness classes for the whole family into one location. They also offer access to resources such as Dreamplex and therapeutic horseback riding. <u>http://www.faithprojects.org/</u>

<u>Children First Healthcare System:</u> This system is a state-wide healthcare organization focused on providing excellent healthcare to those in need. They accept Medicaid and most major insurance companies. They provide education and resources alongside their medical services, which include nursing and in-home therapies, outpatient therapies, PPEC medical day cares,



# Care and a Cure

medical equipment and supplies, medical group home, and pediatric pharmacy. <u>https://www.childrenfirsthealthsystem.com/</u>

<u>Children's Medical Services:</u> Children's Medical Services is a collection of special programs for eligible children with special needs. They have a variety of services for expecting moms, newborn babies, infants and toddlers, school-aged children, adolescents and young adults. All services are provided by highly qualified physicians, nurses, social workers and other health care providers around the state. Their programs fall into several categories, including child protection and safety, information, early intervention and child development, and newborn screening for expectant parents. <u>http://www.floridahealth.gov/alternatesites/cms-kids/families/families.html</u>

<u>Children's Medical Services Manage Care Plan:</u> Florida's Children's Medical Services Managed Care Plan (CMS Plan) provides children with special health care needs a family-centered, comprehensive, and coordinated system of care. The CMS Plan is designed to serve children under age 21 whose serious or chronic physical or developmental conditions require extensive preventive and ongoing care. Each member has a coordinator to assist them and their family through the healthcare system, and members has access to and receive a wide range of quality medical care through the state. <u>http://www.floridahealth.gov/programs-and-services/childrens-health/cms-plan/about/index.html</u>

<u>The Felice Center</u>: The center focuses on speech, language, occupational therapy and physical therapy. They offer additional services such as communication screenings, progress monitoring with the family, formal assessments, rehabilitation, and more. They accept most major insurances. <u>http://felicecenter.com/index.php</u>

<u>Florida HATS:</u> FloridaHATS is a program of Florida Department of Health, Children's Medical Services. Their mission is to ensure successful transition from pediatric to adult health care for all youth and young adults in Florida, including those with disabilities, chronic health conditions or other special health care needs. They provide information, resources, health toolkits, and access to healthcare and professionals to ensure everyone gets quality healthcare. <u>http://www.floridahats.org/about-us/</u>

<u>Florida Health Finder:</u> This government website helps individuals to find the appropriate medical resources and professionals for them based on their health conditions and needs. It also includes information and education about health and resources. <u>http://www.floridahealthfinder.gov/index.html</u>

<u>Joyful Music Therapy:</u> Music Therapy is an established health profession in which music is used within a therapeutic relationship to address physical, emotional, cognitive, and social needs of individuals. After assessing the strengths and needs of each client, the qualified music therapist provides the indicated treatment including creating, singing, moving to and/or listening to music. They provide music lessons, family music lessons, musical theater, early childhood class, summer programs, and more. <u>http://www.joyfulmusictherapy.com/</u>

<u>Kidz Therapy Zone:</u> Kidz Therapy Zone offers comprehensive sensory-based services for clients and their families living with Sensory Processing Disorder, attention deficit disorders



(ADD and ADHD), autistic spectrum disorders, anxiety disorders, emotional and behavioral disorders, sensory-based learning disorders, and other developmental issues. They offer home, school, and clinic based therapy, developmental screenings, clinical evaluations, individualized treatments plans and therapy, consultations, therapy, and more. <u>http://www.kidztz.com/</u>

<u>Lighthouse Central Florida:</u> Lighthouse offers an optimal blend of proven rehabilitation training and real world application to help individuals of all ages, who live with any degree of vision loss, adjust to their reality with grace and confidence so that they can remain active, productive members of our community. They also help to mitigate the costs of vision care. https://lighthousecfl.org/OurMission

<u>Vision Specialists of Central Florida:</u> This optometric practice offers eye exams, assistance for patients with developmental disorders, strokes, athletes, children, and more. <u>http://drmarcsherman.com/</u>

## Housing

<u>Disability Rights Florida: Public Housing:</u> This resource provides information and access to public housing for low income citizens, including the elderly and disabled. Housing varies from single-family homes to apartments for the elderly, and the day-to-day management of public housing is done by Public Housing Agencies. The webpage includes information about how to apply, and who is eligible.

http://www.disabilityrightsflorida.org/resources/disability\_topic\_info/assistance\_vouchers

## Miscellaneous

<u>Be an Angel Therapy Dogs Ministry Inc.</u>: This organizations provides a variety of pre-arranged venues for volunteer members to join them in animal-assisted activities. These activities include, but not limited to visits to nursing homes, assisted living venues, hospitals, libraries, schools, behavioral centers, detention centers, homeless children's church, special needs children and adult activities and visits to domestic violence shelters. Their motto is "Turn that frown upside down!" <u>http://beanangeltherapydogs.org/</u>

<u>Disability Rights Florida: Service Animals:</u> This webpage provides information about service animals for the disabled. It has information about types of animals, and the rights of people who have service animals in relation to housing, travelling, public access, and transportation. It also includes a definition of a service animal and the support an animal must provide to be licensed as a service animal.

http://www.disabilityrightsflorida.org/resources/disability\_topic\_info/service\_animals

<u>FL SAND:</u> Sand is the Florida Self-Advocates network, which is an independent 501©3 organization that was formed to expand the self-advocacy movement in Florida. It works with the support of local grassroots, legislative platforms, local business and communities, and raising awareness and promotes inclusion for all. They have local groups in every county of the



state which advocate for change in their individual communities, as well as the overall organization. They also have a scholarship available to participate in self-advocacy and leadership training and opportunities. <u>https://www.flsand.org/</u>

# **Scholarships and Education**

<u>The Academy of Ability:</u> The Academy of Ability is a private, non-profit school for children with physical and learning disabilities. The education program offers a specialized curriculum developed to meet not only the educational needs of the students but also fosters the development of life skills essential for a more involved and independent life. They strive to develop an individualized program of instruction to meet each child's needs and challenge each student to advance to meet his or her potential. The Academy of Ability participates in the McKay Scholarship program. They are an equal opportunity school and offer entrance to students independent of their ethnic, race, or religious preferences. Located in Orlando. <a href="http://www.academyofability.org/">http://www.academyofability.org/</a>

<u>CECO</u>: The Conductive Education Center of Orlando offers a special needs school day kindergarten through 12th grade, summer camp, early intervention ages 6 months to 4 years old and walking challenge program. Conductive Education is a unique, holistic educational approach to help children with Cerebral Palsy and other motor disabilities achieve their greatest level of independence through physical and cognitive activities. <u>https://www.ceco.org/</u>

<u>Chair Scholars Foundation National Scholarships</u> This foundation provides financial assistance for college to physically challenged students. The National Scholarship Program provides eligible high school seniors and college undergrads up to \$20,000 for tuition to attend the Edinboro University in Pennsylvania or the University of Tampa, in Florida. http://www.chairscholars.org/

<u>The de Moya Foundation Vocational/Technical Program Scholarship:</u> Awarded to students with documented disabilities who wishes to attend a vocational/technical certificate program. <u>http://demoyafoundation.com/scholarships/vocational-technical-program-scholarship/</u>

<u>The First Academy:</u> The First Hope, a program for special needs children, is a unique approach to teach children with disabilities. Classes are at a 2:1 student:teacher ratio for all Inclusion and Transitions+ Programs, except Transitions+ Intermediate and Secondary which is 4:1 student:teacher ratio — with a goal of independence. This program is available to children age 3 to grade 12 who are diagnosed with Autism Spectrum Disorder, PDD, Asperger's Syndrome, Down Syndrome, Language Delays, Fragile-X Syndrome, Sensory Processing Disorder, Developmental Delay, Severe Learning Disability and other Developmental Disabilities. https://thefirstacademy.org/academics/first-hope/



# **Transportation and Equipment**

<u>Angel Flight Southeast:</u> Angel Flight Southeast is a volunteer pilot organization that provides free air transportation to medical facilities for citizens who are financially distressed or otherwise unable to travel on public transportation. They provide flights to life-saving medical appointments for patients from Florida, Puerto Rico, the U.S. Virgin Islands, and the Bahamas. http://www.angelflightse.org/

<u>Florida Commission for the Transportation Disadvantaged:</u> The Transportation Disadvantaged Program is a coordinated state-wide effort which groups riders together for a shared ride service. Transportation services are available in all 67 Florida counties for those who are eligible and have no access to transportation. Federal, State and Local agencies join together to provide necessary transportation to medical appointments, employment, educational and other life sustaining services. <u>http://www.fdot.gov/ctd/index.htm</u>