New York

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 Myotonic. 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

AHRC New York: ARHC focuses on meeting the needs of people living with disabilities in New York. They offer a wide range of services for every aspect of life, including respite services for caregivers, in-home support, community opportunities, educational resources, and work resources. They have summer camps, adult day services, family education and educational services, etc. https://www.ahrcnyc.org

Autism-Related Resources

AMAC: The Association for Metroarea Autistic Children helps to provide high-quality programs to people with autism, developmental disabilities and emotional disorders. They have individual programs for pre-school and school aged children, and offer programs in behavioral support, respite services, and autism-related needs such as speech therapy and more. They also offer weekend respite services, and a two-week summer camp. http://amac.org/
Caregivers and Respite

Camp Oakhurst: Camp Oakhurst offers summer camps, day respite, and year-round out-of-home respite for families of the disabled in NY. The camp is open to children and adults. http://nysh.org/

Sprout: Sprout provides a year-round travel program of vacations as well as a year-round program of day and evening cultural, social and art-related activities in New York City for people with developmental disabilities. They run an annual weekend-long music and arts festival for an average of 225 people with developmental disabilities complete with live bands, video screenings, interactive art projects, carnival games, and other entertainment. http://gosprout.org/

Housing

Disabled Homeowners’ Exemption (DHE): Provides a property tax exemption to disabled owners of 1, 2, and 3 family houses, condominiums, or cooperative apartments. http://www1.nyc.gov/site/finance/benefits/landlords-dhe.page

Disability Rent-Increase Exemption: DRIE is an exemption against future rent increases for eligible disabled persons living in rent-controlled, rent-stabilized, Mitchell-Lama and other eligible apartments. http://www1.nyc.gov/nyc-resources/service/1522/disability-rent-increaseexemption-drie-program

Scholarship and Education

Chair Scholars Foundation National Scholarships: 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/

John Lepping Memorial Scholarship: provides scholarships to disabled students seeking a higher education (college, etc.) Must live in NY, NJ, or PA (tri-state area). http://www.lepfoundation.org/applications