



MYOTONIC  
DYSTROPHY  
FOUNDATION

## FINANCIAL RESOURCES FOR FAMILIES WITH DM

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 federal/national 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 state-specific resources when we have compiled them.

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.

### Government Resources

#### Social Security Administration

The Social Security Administration has two different programs that can help people with disabilities. The first program, Social Security Disability Insurance (SSDI), pays benefits to you and certain members of your family if you are "insured," meaning that you worked long enough and paid Social Security taxes. The second program, Supplemental Security Income (SSI), pays benefits based on financial need. SSI is a Federal income supplement program funded by general tax revenues (not Social Security taxes). It is designed to help aged, blind, and disabled people, who have little or no income and it provides cash to meet basic needs for food, clothing, and shelter.

For general information about both programs check here to visit the SSA website:

<http://www.ssa.gov/disability/> Use the screening tool on this web page to help you determine which program may be appropriate for your situation.

Application to either of these programs takes some time. Some people seek the assistance of family or friends to help them gather the paperwork while others seek the help of an attorney. You can do it yourself. A comprehensive book on the process is Nolo's *Guide to Social Security Disability: Getting & Keeping Your Benefits*.

Another free source of help is Rebecca Pursley. She has multiple sclerosis and wrote an excellent document, "SSDI Tutor," a document that coaches you throughout the detailed paperwork process. Rebecca can be reached by email ([rebecca047@comcast.net](mailto:rebecca047@comcast.net)) or phone (206-232-7890).

The 2012 MDF Conference included a presentation by Daniel E. Fortuno of the Benefits Education Center. Mr. Fortuno offered advice about successfully applying for SSDI benefits. His presentation can be found on the MDF website (<http://myotonic.org/community/annual-conference/program>) or you can contact him at: [www.benefitseducationcenter.com](http://www.benefitseducationcenter.com)

#### Medicare and Medicaid

Medicare is a Federal health insurance program for people 65 years or older, people under 65 years of age with certain disabilities, and people of all ages with End-Stage Renal Disease. Medicare pays for hospital and medical care for elderly and certain disabled Americans.

Medicaid is a means-tested health and medical services program for certain individuals and families with low incomes and few resources. Primary oversight of the program is handled at the federal level, but each state

establishes its own eligibility, scope of services, rate of payment for services, and administers its own Medicaid program.

Both programs are managed by the Centers for Medicare and Medicaid Services (CMS).

Many individuals who qualify for Medicaid based on disability also receive cash assistance under the Supplemental Security Income (SSI) program. In almost all states, SSI eligibility automatically qualifies an individual for Medicaid coverage. However, some states use more restrictive eligibility criteria than those used by the SSI program. This means that in those states (commonly referred to as 209(b) states) receipt of SSI does not guarantee eligibility for Medicaid. Individuals not receiving SSI but seeking coverage based on disability must demonstrate that they have an impairment that prevents them from performing "substantial gainful activity" for at least one year. Once a disability determination is made, the individual must then undergo an asset test and meet specific income requirements in order to be considered for Medicaid eligibility.

<http://www.cms.gov/>

#### Housing and Urban Development

HUD offices offer rental assistance programs such as privately-owned subsidized housing, public housing, and housing choice vouchers. Additional resources exist for senior citizens, persons with a disability, and persons living in a rural area. You may also want to contact your state housing authority or your local public housing agency.

[http://portal.hud.gov/hudportal/HUD?src=/topics/rental\\_assistance](http://portal.hud.gov/hudportal/HUD?src=/topics/rental_assistance)

#### Making Home Affordable

This is a mortgage relief program of the Department of the Treasury & Housing and Urban Development. The Program provides options for people unable to meet their current monthly mortgage payment.

<http://www.makinghomeaffordable.gov/pages/default.aspx>

#### Women, Infants, and Children (WIC)

WIC focuses on protecting the health of low-income women, infants, and children up to age 5 who are at nutrition risk by providing nutritious foods to supplement diets, information on healthy eating, and referrals to health care. To see if you are eligible for WIC benefits, use this online tool:

<https://stars.fns.usda.gov/wps/pages/start.jsf>

#### Supplemental Nutrition Assistance Program (SNAP)

This program, operated by the United States Department of Agriculture, assists families in meeting their household expenses. By using SNAP benefits to purchase groceries, families can shift their budgeted grocery dollars to other uses.

<http://blog.usa.gov/post/26418735783/help-feed-your-family-through-the-snap-program>

#### Federal Income Tax Credit for the Elderly or Disabled

For more information on the federal income tax credit for certain elderly and disabled citizens, visit the Internal Revenue Service website [www.irs.gov](http://www.irs.gov).

#### 211.org

2-1-1.org provides free and confidential information and referral. Call 2-1-1 for help with food, housing, employment, health care, counseling and more. Services vary for each community. Find out if your community participates in this hotline by checking the website.

<http://www.211.org/>

#### Job Accommodation Network

The Job Accommodation Network (JAN) is the leading source of free, expert, and confidential guidance on workplace accommodations and disability employment issues. JAN provides free consulting services to individuals with physical or intellectual limitations to enhance their employability. JAN is one of several services provided by the U.S. Department of Labor's Office of Disability Employment Policy (ODEP). Services include one-on-one consultation about job accommodation ideas, requesting and negotiating accommodations, and rights under the Americans with Disabilities Act (ADA) and related laws. Although JAN

does not help individuals find employment, JAN does provide information for job seekers.

<http://askjan.org/index.html>

#### Regional ADA Technical Assistance Center

The ADA National Network provides information, guidance and training on the Americans with Disabilities Act (ADA), tailored to meet the needs of business, government and individuals at local, regional and national levels. The ADA National Network consists of ten Regional ADA National Network Centers located throughout the United States that provide local assistance to ensure that the ADA is implemented wherever possible. The Center is not an enforcement or regulatory agency, but a helpful resource supporting the ADA's mission to "make it possible for everyone with a disability to live a life of freedom and equality." Contact a regional office for help with issues related to any of the ADA titles – Employment, Public Entities, Public Accommodations, Telecommunications, or Miscellaneous Provisions.

<http://adata.org/contact-us>

#### Veterans Administration

The Veterans Administration healthcare system is for United States veterans without medical insurance. If veterans have lost their DD214, they can get it at this website: <http://www.archives.gov/veterans/military-service-records>. The VA website address is: <http://www.va.gov>

### **Resources Available from Other Non-Profit Organizations**

#### Muscular Dystrophy Association (MDA) website

An online guide, Financial, Legal, and Medical Issues, is a chapter from the MDA ALS Caregiver's Guide. Many of the resources are appropriate for any family dealing with a neuromuscular disease such as myotonic dystrophy. Topics in this chapter include financial assistance opportunities from government sources, private sources, help with healthcare and equipment costs, and organizing financial information and making decisions.

<http://mda.org/publications/mda-als-caregivers-guide/chapter-7>

#### Easter Seals Disability Services

Easter Seals is a national organization with offices throughout the country. The organization provides services, education, outreach, and advocacy to persons with disabilities. Services include support for caregivers, in-home services, employment & training, and medical rehabilitation (occupational therapy, physical therapy, speech and language pathology, audiology, early intervention and other therapies that help people learn the skills they need to live, learn, work and play in their communities). In some states the Easter Seals is regional and partners with another organization such as Goodwill.

The online document, *With Open Arms: Embracing a Bright Financial Future for You and Your Child* is a free PDF available from this page: [http://www.easterseals.com/site/PageServer?pagename=ntl\\_with\\_open\\_arms](http://www.easterseals.com/site/PageServer?pagename=ntl_with_open_arms). On the right sidebar of this page, <http://www.easterseals.com>, you can enter your zip code and locate the Easter Seals office closest to you.

#### Andre Sobel Grants

The Andre Sobel River of Life Foundation (ASRL) helps with urgent expenses to allow single parents to stay at their child's bedside during catastrophic illness. The Andre Sobel River of Life Foundation works through a network of five pediatric hospitals that help families access ASRL assistance funds, typically within 24 hours. If your child is being treated at one of these centers, please contact your child's social worker directly for more information on how to obtain aid from the foundation's program, or e-mail ASRL at [info@andreriveroflife.org](mailto:info@andreriveroflife.org). <http://andreriveroflife.org/for-families-and-social-workers/partners>

#### HealthWell Foundation Grants

The HealthWell Foundation provides financial assistance to eligible individuals to cover coinsurance, copayments, health care premiums and deductibles for certain medications and therapies. If you've been prescribed a medication and your insurance company covers it, but you still cannot afford the coinsurance or copayment required, HealthWell Foundation may be able to help by paying for part of your medication costs. Also, if you are eligible for health insurance, but cannot afford the insurance premium, the Healthwell Foundation may be able to help with your insurance premium.

<http://www.healthwellfoundation.org/>

#### Patient Access Network Foundation

The Patient Access Network Foundation (PANF) facilitates access to medical treatment for patients with chronic or life-threatening illness. PAN is dedicated to overcoming financial and other barriers to treatment, and works efficiently and collaboratively to help patients receive prescribed treatments and the care that best meets their needs. Since October 2004, PAN has awarded hundreds of millions of dollars in co-payment assistance to patients in need.

<http://www.panfoundation.org/fundingapplication/index.php?3>

#### Patient Advocate Foundation Co-Pay Relief Program

The Patient Advocate Foundation (PAF) Co-Pay Relief Program (CPR) provides direct financial support for pharmaceutical co-payments to insured patients, including Medicare Part D beneficiaries, who financially and medically qualify.

<http://www.copays.org>

#### National Association for the Terminally Ill Assistance

The applicant must have been diagnosed with a terminal illness with a life expectancy of two years or less. This program will help with day-to-day living expenses, including rent, mortgage, groceries, utilities, or bills for up to 90 days. Each family is evaluated on a case-by-case basis. There is also a specific program for families of those suffering from cancer with a life expectancy of 2 years or less.

<https://www.caring4cancer.com/go/cancer/financial/help-with-costs/DisplayProgram.aspx?Source=PAP&ProgramId=74>

#### University Centers for Excellence in Developmental Disabilities

University Centers for Excellence in Developmental Disabilities (UCEDD) is a national network of 67 universities that assist individuals with developmental disabilities, their families, professionals, and students through education, training, community services, and early intervention. These university centers work with people with disabilities and members of their families, state and local government agencies, and community providers on projects that provide training, technical assistance, service, research, and information sharing, with a focus on building the capacity of communities to sustain all their citizens, and enhancing quality of life.

<http://www.aucd.org/template/page.cfm?id=24>

#### Alternatives in Motion Grants

This organization provides funding to people who need assistance to purchase a wheelchair.

<http://www.alternativesinmotion.org/chair>

#### Elsie S. Bellows Fund Grants

The United Cerebral Palsy (UCP) Elsie S. Bellows Fund is a national program operated by UCP that provides funds to individuals with disabilities for assistive technology equipment. Individuals are recommended by UCP affiliates. UCP affiliates submit an application on behalf of an individual to the UCP national office. Applications are reviewed for funding by the Bellows Committee. Assistive technology equipment is defined as "any piece of equipment, or product system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain or improve functional capabilities of individuals with disabilities."

<http://www.ucp.org/affiliates/benefits-of-affiliation/bellows-fund>

#### Grottoes of North American Humanitarian Foundation

The Humanitarian Foundation believes that children with special needs should live as fully and as independently as possible. They are committed to helping to alleviate suffering and improve quality of life by providing dental care for those who might otherwise go without. Eligibility includes all children under 18 years of age with a neuromuscular disease.

<http://www.hfgrotto.org>

#### Canine Companions

Canine Companions for Independence® provides highly-trained assistance dogs for children and adults with disabilities, free of charge.

[http://www.cci.org/site/c.cdKGIRNqEmG/b.3978475/k.3F1C/Canine\\_Companions\\_for\\_Independence.htm](http://www.cci.org/site/c.cdKGIRNqEmG/b.3978475/k.3F1C/Canine_Companions_for_Independence.htm)

## **Awards for Young Persons and Students**

### Smart Kids with Learning Disabilities Youth Achievement Award

This \$1,000 award recognizes the strengths and accomplishments of young people with learning disabilities and ADHD. It is given annually to a student 19 or younger for demonstrating initiative, talent and determination resulting in a notable accomplishment in any field—including art, music, science, math, athletics or community service. Honorable Mentions are also awarded.

<http://www.smartkidswithld.org/award>

### The VSA Arts Playwright Discovery Award

The VSA Playwright Discovery Program invites middle and high school students to take a closer look at the world around them, examine how disability affects their lives and the lives of others, and express their views through the art of playwriting. Playwrights may write from their own experience or about an experience in the life of another person or a fictional character. Scripts can be comedies, dramas, or musicals. Young playwrights with and without disabilities are encouraged to submit a script. Entries may be the work of an individual student or a collaboration by a group of up to five students.

[http://www.kennedy-center.org/education/vsa/programs/playwright\\_discovery.cfm](http://www.kennedy-center.org/education/vsa/programs/playwright_discovery.cfm)

### International Young Soloists Award

Since 1984, the VSA International Young Soloists Program has identified talented musicians who have a disability. The VSA International Young Soloists Award is given annually to outstanding musicians from the United States and the international arena. The award provides an opportunity for these emerging musicians to each earn a \$5,000 award and a performance in Washington, D.C.

[http://www.kennedy-center.org/education/vsa/programs/young\\_soloists.cfm](http://www.kennedy-center.org/education/vsa/programs/young_soloists.cfm)

### Joyce Walsh Junior Disability Awards

The Junior Award for the Handicapped was established in 1983 as the official project of the Junior Division under the leadership of Joyce Walsh, Junior Counselor. The annual competition is open to any Junior instrumentalist or vocalist who is mentally or physically disabled.

<http://www.mfmc.net/scholarships.html#joyce>

## **Scholarships for Students**

### 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 college or university of their choice.

<http://www.chairscholars.org/index.php/apply-for-a-scholarship>

### Lawrence Medeiros Scholarship

This scholarship provides financial assistance for college to high school seniors who have a chronic disorder.  
[www.Adirondackspintabkiller.com](http://www.Adirondackspintabkiller.com)

### P. Buckley Moss Endowed Scholarship

The P. Buckley Moss Endowed Scholarship is awarded to one or more high school seniors with financial need, with certified language-related learning differences and artistic talent, who plan a career in the visual arts.

<http://www.mosssociety.org/page.php?id=69>

### Patient Advocate Foundation Scholarships for Survivors

The purpose of these scholarships is to provide support to individuals under the age of 25 who have been diagnosed with or treated for cancer and/or a chronic/life threatening disease within the past 5 years. Applicants must apply via postal mail and include all required information in its entirety when submitting an application. Due to the increasing demand for scholarships, incomplete applications will not be forwarded to the Scholarship Review Committee for consideration.

<http://www.patientadvocate.org/index.php?p=69>

### Anne Ford and Allegra Ford Thomas Scholarships

The Anne Ford and Allegra Ford Thomas Scholarships offer financial assistance to two graduating seniors with documented learning disabilities (LD) who are pursuing post-secondary education.

<http://www.ncl.org/about-us/learning-disability-scholarships-awards/anne-ford-allegra-ford-scholarships>

#### Through the Looking Glass Scholarships

These scholarships provide financial assistance for college to high school seniors based on the following criteria: academic performance, community activities and service, letter of recommendation and an essay describing the experience of growing up with a parent with a disability.

<http://www.lookingglass.org/scholarships>

#### Anne and Matt Harbison Scholarship

Each year a \$1,500 scholarship is awarded to one high school senior with a certified language-related learning difference who is pursuing post-secondary education. Nominations are made by a P. Buckley Moss Society member (brief letter from nominator stating relationship is optional).

<http://www.mossociety.org/page.php?id=30>

#### Bryon Reisch Scholarships

The Bryon Reisch Paralysis Foundation's (BRPF) goal is to find a cure for paralysis through funding the latest in medical research and to provide assistance to those that suffer from neurological disorders. Research grants benefit spinal cord injuries, stroke victims, people diagnosed with ALS, Alzheimer's, Parkinson's and other neurological disorders. The BRPF works within the paralysis community providing charitable grants to help make life easier for people suffering from paralysis. Equally important, the BRPF provides scholarships to individuals suffering from paralysis or families with a parent dealing with a neurological disorder.

<http://www.brpf.org/Index.html>

#### American Association on Health and Disability Scholarships

Each applicants must be enrolled as full time undergraduate student or as part time or full time graduate student as well as have a documented disability and provide documentation of his/her disability. Preference is given to students majoring in public health, disability studies, health promotion or a field related to disability and health.

The mission of the American Association on Health and Disability (AAHD) is to contribute to national, state, and local efforts to promote health and wellness in people with disabilities and identify effective intervention strategies that reduce health disparities between people with disabilities and the general population. AAHD accomplishes its mission through research, education and advocacy at the national, state and community level.

<http://www.aahd.us/initiatives/scholarship-program/>

#### Foundation for Science and Disability Graduate Student Grant Fund

The Foundation for Science and Disability (FSD) was founded in 1975 as a non-profit organization to promote the integration of scientists with disabilities into all activities of the scientific community and of society as a whole and to promote the removal of barriers that hinder the success of students with disabilities in the pursuit of scientific careers. The Student Award Program of FSD helps to increase opportunities in science, engineering, mathematics, technology, and pre-medical/dental areas for graduate or professional students with disabilities.

FSD has established a Science Graduate Student Grant Fund, which is available to fourth year undergraduates (who are disabled and have been accepted to a graduate or professional school in the sciences) and graduate science students who have a disability. Awards of \$1000 each are made to qualified college or university students with a disability in any field of mathematics, science, medicine, technology, or engineering. Awards are given for an assistive device or instrument, or for other special needs.

<http://www.stemd.org/>

### **Scholarships Related to Autism**

#### Schwallie Family Scholarships

In 2008, the Organization for Autism Research (OAR) introduced the Schwallie Family Scholarship Program to support qualified individuals with autism or Asperger Syndrome residing in the United States pursuing

post-secondary education. OAR will present awards of \$3,000 each across three categories: 1) Four-year undergraduate college or university; 2) Two-year undergraduate college, and; 3) Trade, technical or vocational school. All scholarships are one-time awards.

<http://www.researchautism.org/news/otherevents/scholarship.asp>

## **Miscellaneous**

### Paul G. Hearne/AAPD Leadership Awards

Each year the American Association of People with Disabilities (AAPD) recognizes those outstanding emerging leaders with disabilities who exemplify leadership, advocacy, and commitment to the broader disability community. Two candidates emerging as leaders in the cross-disability civil rights movement will each receive \$10,000 to help them continue their progress and further connect their work with AAPD's national outreach.

<http://www.aapd.com/what-powers-us/leadership-awards/>

### Ford Mobility Motoring Program

The Ford Motor Company provides a cash reimbursement for the cost of installing adapt-to-driving aids on new vehicles from Ford or Lincoln Mercury.

<https://www.fordmobilitymotoring.com>

### GM Mobility Program

General Motors provides a cash reimbursement for the cost of installing adaptive driving aids on new purchases from General Motors.

<http://www.gmmobility.com/>

### Mobility by Volvo

Volvo provides a cash reimbursement for the cost of installing adaptive driving aids or alert hearing devices on new purchases of Volvo vehicles.

[http://www.volvocars.com/us/sales-services/sales/volvo\\_mobility\\_program/pages/default.aspx](http://www.volvocars.com/us/sales-services/sales/volvo_mobility_program/pages/default.aspx)

### Toyota Mobility Program

Toyota provides a cash reimbursement for the cost of installing adaptive driving aids on new purchases of Toyota vehicles.

<http://www.toyotamobility.com/>

### Chrysler Automobility Program

Chrysler provides a cash reimbursement for the cost of installing adaptive driving aids on new purchases from Chrysler motors.

<http://www.chryslerautomobility.com/>

## **For Professionals and their Affiliations**

### Facilitation Awards for Scientists and Engineers with Disabilities

The National Science Foundation encourages scientists and engineers with disabilities to participate fully in all of its programs. This announcement describes opportunities for physically disabled persons to facilitate their work by providing special equipment or assistance needed in conjunction with NSF-supported projects. This announcement covers all projects supported by NSF in science and engineering research or education, including fellowships.

[http://www.nsf.gov/funding/pgm\\_summ.jsp?pims\\_id=5516](http://www.nsf.gov/funding/pgm_summ.jsp?pims_id=5516)

### Access for Athletes Grants

Access for Athletes — Challenged Athletes Foundation's® (CAF) flagship provides funding grants for equipment such as sports wheelchairs, handcycles, mono skis and sports prosthetics, and resources for training and competition expenses directly to physically challenged individuals.

[http://www.challengedathletes.org/site/c.4nJHJQPqEiKUE/b.6449453/k.E830/Access\\_for\\_Athletes.htm](http://www.challengedathletes.org/site/c.4nJHJQPqEiKUE/b.6449453/k.E830/Access_for_Athletes.htm)

### Musicians Foundation Financial Assistance

The Musicians Foundation helps professional musicians by providing emergency financial assistance in meeting current living, medical and allied expenses.

<http://www.musiciansfoundation.org/>

#### Singers Financial Aid

Any individual who has derived his/her primary income as a professional singer for 5 years or more may qualify for services. Requests for assistance must be emergency in nature and made by singers who have dire financial needs. All services provided are confidential.

<http://www.singers.org/programs.html>

#### Writers Emergency Assistance Fund

The mission of the Writers Emergency Assistance Fund is to help established freelance writers who, because of advanced age, illness, disability, a natural disaster, or an extraordinary professional crisis are unable to work. A writer need not be a member of ASJA to qualify for a grant. However, applicants must establish a record of past professional freelance nonfiction writing over a sustained period of years, which means qualifications generally similar to those of ASJA members. WEAFF does not award grants to beginning freelancers seeking funding for writing projects, nor does it fund works-in-progress of any kind.

<http://www.asja.org/for-writers/weaff/>

#### American Dental Association Foundation Relief Grant Program

The purpose of the ADA Foundation Relief Grant Program is to provide financial assistance to dentists and their dependents who, because of accidental injury, a medical condition, disability or advanced age, are unable to meet basic living expenses.

<http://www.ada.org/applyforassistance.aspx#relief>

#### Elks National Foundation Emergency Educational Fund Grants

The Emergency Educational Grant program provides financial assistance to children of deceased or totally disabled Elks, who wish to obtain or further their college education.

<http://www.elks.org/enf/scholars/eefgrants.cfm>

### **Parents and Caregivers**

#### Federal Income Tax Deduction for Child and Dependent Care Expenses

The U.S. government offers a federal income tax credit for a portion of the expenses incurred in caring for a child or disabled dependent. For more information on the Child and Dependent Care Credit, see Publication 503, Child and Dependent Care Expenses. You may download these free publications from

<http://www.irs.gov> or order them by calling 800-TAX-FORM (800-829-3676).

<http://www.irs.gov/uac/Ten-Things-to-Know-About-the-Child-and-Dependent-Care-Credit>

#### Jay and Rose Phillips Caregiver Award

The Phillips Caregiver Award acknowledges and honors a caregiver's contribution that is vital to the independence and quality of life of a person with a disability. The Phillips Caregiver Award is administered by the Courage Center, with funding made possible by the Jay and Rose Phillips Family Foundation.

<http://www.couragecenter.org/ContentPages/phillipsawards.aspx>