



IMPROVING OPPORTUNITIES FOR ALL!

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wheeldogs.com

3rd International Rare Neuroimmunologic Disorders Symposium **Friday, July 18, 2008**

Self Advocacy: Navigating Government & Community Support Programs

ADVOCACY

Advocacy is a set of hands-on technical skills and practices needed to effectively press for change.

Advocacy is the foundation of active citizenship, a process through which ordinary people learn to participate in decision making at all levels.

Advocacy is identifying priorities, crafting a strategy, stepping forward, taking action, and achieving results which are critical steps to finding one's voice, making oneself heard, and shaping one's future.

Successful Advocacy is when people are empowered with the dignity and confidence to act and a world of possibilities opens up.

[Institute for Sustainable Communities, Advocacy and Leadership Center http://www.iscvt.org/what_we_do/advocacy_and_leadership_center/]

THINGS TO KNOW

Know what is available.

Know the rules.

Use the language they use.

No does not necessarily mean NO

If they say no, you are no worse off. Keep on trying.

Every dollar helps.

Ask for other resources

PROVIDERS:

Government:

- Social Security –SSDI, SSI
- Center for Medicare & Medicaid-Medicare, Medicaid
- State Medicaid Waiver Programs
- Vocational Rehabilitation Departments
- Disability Boards
- DBTAC
- AT Projects
- Housing Board-HUB
- Dept. Transportation
- US Dept of Justice
- Dept. of Agriculture-AgAbilityGrants
- DOL-Office of Disability Employment Policy

Community:

- EnableTechnologies
- CILs
- Easter Seals
- Variety clubs
- AARP
- TMA
- NSCIA
- AAPD
- Churches
- Foundations
- Equipment Exchanges

Other:

- Insurance-case management
- Trusts
- Grants
- Loans

TMA RESOURCES

Transverse Myelitis Association <http://www.myelitis.org/index.html>

TM Center at Johns Hopkins <http://www.hopkinsneuro.org/tm/>

Project Restore <http://www.hopkinsneuro.org/restore/>

Jim Lubin's disABILITY Information and Resources <http://www.makoa.org/index.htm>

MORE RESOURCES

Americans With Disabilities Act Information -Information and Technical Assistance on the Americans with Disabilities Act. <http://www.ada.gov/>

Centers for Medicare and Medicaid Services (CMS) - Learn about Medicare or Medicaid. <http://www.cms.hhs.gov/>

Computer/Electronic Accommodations Program (CAP) -Provides assistive technology and services to people with disabilities, Federal managers, supervisors, and IT professionals. <http://www.tricare.mil/cap/>

Department Of Justice Section 508 -Requires that Federal agencies' electronic and information technology is accessible to people with disabilities, including employees and members of the public. <http://www.usdoj.gov/crt/508/508home.html>

Department of Veterans Affairs -Federal Benefits for Veterans and Dependents. <http://www.va.gov/>

Disability and Emergency Preparedness Resource Center -Providing practical information on how people with and without disabilities can prepare for an emergency. <http://www.disabilitypreparedness.gov/>

Disability Rights online News -Civil Rights Division Disability Rights Section Newsletter. <http://www.ada.gov/disabilitynews.htm>

Fair Housing and Equal Opportunity (FHEO) -To create equal housing opportunities for all persons living in America by administering laws that prohibit discrimination in housing. <http://www.hud.gov/offices/fheo/index.cfm>

GovBenefits.gov -A one-step resource for Americans to learn if they are eligible to receive government benefits. http://www.govbenefits.gov/govbenefits_en.portal

Health and Human Services -Link to the Health and Human Services press release announcing a list of counties in which PPOs are currently available. <http://www.hhs.gov/news/press/2002pres/20020827att.html>

Low Income Home Energy Assistance Program -Assistance with paying utility bills. <http://www.acf.hhs.gov/programs/ocs/liheap/>

Medicare -The Official U.S. Government Site for People with Medicare. <http://www.medicare.gov/default.asp>

Medicare Rights Center -The Medicare Rights Center has developed an easy-to-use chart which compares health plan options. <http://www.medicarerights.org/index.html>

National Assistance -State's protection and advocacy information. <http://www.imadapting.com/>

National Library of Medicine -Health information provided free. Accurate, up to date, private/confidential, drug information, health news, medical encyclopedia and dictionary. <http://medlineplus.gov/>

National Organization of Social Security Claimants' Representatives -An association of over 3,300 attorneys and paralegal's who represent Social Security and Supplemental Security Income claimants. <http://www.nosscr.org/>

Office of Disability Employment Policy. -Provides national leadership by developing and influencing disability-related employment policy as well as practice affecting the employment of people with disabilities. <http://www.dol.gov/odep/>

Social Security -Social Security Programs. <http://www.socialsecurity.gov/>

Social Security Disability Coalition -Free knowledge and support with a focus on reform of the Social Security Disability System. <http://groups.msn.com/SocialSecurityDisabilityCoalition>

Social Security-Medicare Prescription -Information to organizations about SSA's Medicare Outreach products. <http://www.socialsecurity.gov/medicareoutreach2/index.htm>

Social Security-Work -Employment Support For People with Disabilities. <http://www.socialsecurity.gov/work/>

State Health Insurance Assistance Providers (SHIP) -The best resources on Medicare in your state. <http://www.aapd.com/links/shipassist.html>

U. S. Access Board -Accessibility For People With Disabilities. <http://www.access-board.gov/>

US Census Bureau -The leading source of quality data about the nation's people and economy. <http://www.census.gov/>

US Department of Housing and Urban Development (HUD) -To increase home ownership, support community development and increase access to affordable housing free from discrimination. <http://www.hud.gov/>

The US Office of Personnel Management -To provide information on Federal Employment for People with Disabilities. <http://www.opm.gov/disability/>

WIA Section 188 Checklist -Designed to ensure meaningful participation of people with disabilities in programs and activities operated by recipients of financial assistance under the Workforce Investment Act of 1998 (WIA). <http://www.dol.gov/oasam/programs/crc/WIASection188DisabilityChecklist.htm>

INDEPENDENT LIVING
Independent Living USA

Links to centers for independent living. www.ilusa.com

Institute on Independent Living

The Institute serves self-help organizations of disabled people who work for equal opportunities, self-determination and self-respect. www.independentliving.org

National Foundations
American Kidney Fund

1-800-638-8299

Web Site: <http://www.kidneyfund.org>

- **Individual Grants Program** - treatment-specific expenses; transportation, over-the-counter medicines, medication co-payments, kidney donor expenses and other necessities such as dentures.
- **Pharmacy Grant Program** - qualified renal patients receive urgently needed medications, nutritional products, and durable medical supplies.
- **Disaster Relief Program** - funds to assist patients replace medications, food and household items and pay for necessities lost because of natural disasters.

Annenberg Foundation

Headquarters Office
Radnor Financial Center
Suite A-200
150 N. Radnor-Chester Rd.
Radnor, PA 19087
(610) 341-9066
Fax: (610) 964-8688
Web Site: <http://www.whannenberg.org/>

Education and youth is the primary focus. Of special importance to the foundation is K-12 public education, early childhood education in relation to public education at the primary level and child development and youth services. Grants are for program development and some pilot projects; contact should be initiated through a letter or email.

Annie E. Casey Foundation

701 St. Paul St.
Baltimore, MD 21202

(410) 547-6600

Email: webmail@aecf.org

Web Site: <http://www.aecf.org/>

Grants to improve the futures for kids at risk of poor outcomes, encompassing direct support services to vulnerable children and families, and in recent years has used major grant making to support demonstrations, evaluations, and advocacy aimed at helping large public systems, as well as nonprofit networks, to become more effective in their efforts on behalf of struggling families and at-risk kids

Association of Blind Citizens AT Fund

Web Site: http://www.blindcitizens.org/assistive_tech.htm

- Funds to cover 50% of the retail price of adaptive devices or software. Products must retail for a minimum of \$200 and maximum of \$6,000.
- Eligibility:
 - Family income of less than \$50,000 & cash assets of less than \$20,000.
 - Applicants must be legally blind
 - Applicants must be a U.S. resident
- Two grant periods per year - June 30th and December 31st
- One grant request per calendar year.
- All applications submitted via e-mail.
- Email request form to: atf@blindcitizens.org.

CancerCare

1-800-813-HOPE (4673)

http://www.cancer.org/get_help/assistance/index.php

Breast Cancer:

Linking A.R.M.S.[™]: Limited financial assistance for hormonal and oral chemotherapy, pain and anti-nausea medication, lymph edema supplies and durable medical equipment.

Children (ages 18 and under; all cancers):

Limited financial assistance for homecare, childcare, transportation, medication and co pays.

Challenged Athletes Foundation

11199 Sorrento Valley RD, STE C
San Diego, CA 92121

Director of Programs, Jill Prichard

(858) 866-0959

Email: Jill@challengedathletes.org

Web Site: <http://www.challengedathletes.org>

Eligibility:

- Disability within the International Paralympic Committee (IPC) classifications. http://www.paralympic.org/release/Main_Sections_Menu/index.html.
- Must demonstrate a financial need.

Education World Grants

Web Site: http://www.education-world.com/ew_grants/index.shtml

40 Education Grants through the "Grants for Educators" program. These grants are funded through utilization of the Education World VISA Card and will be awarded in \$250 and \$500 amounts. Education World is dedicated to improving the practical usage of technology and the Internet.

George A Ramlose Foundation, Inc.

PO Box 550

Sterling, MA 01564

(978) 368-8264

Preference to applications received from organizations in close proximity to one of the Directors (for monitoring purposes): James Fisher, President, is from South Carolina Grants accepted during July 1 – Aug 31 of each year

Hear Now Starkey Hearing Foundation

6700 Washington Ave.

South Eden Prairie, MN 55344

800-648-4327 (48 contiguous states)

Web Site: <http://www.sotheworldmayhear.org>

- Provides hearing aids for individuals with limited financial resources and limited family support.
- \$100 processing fee for each application.
- Fee is non-refundable income based, and must attempt other funding.

Joni and Friends - Christian Fund for the Disabled - Up to \$2500

Contact: Karen Johnson

CFD Coordinator,

Email: kjohnson@joniandfriends.org

Fax: (818) 707-2391

- Online application at http://www.joniandfriends.org/CFD_Application.pdf
- Grants of up to \$2,500 nationally, as well as churches and other Christian organizations.

Mitsubishi Electric America Foundation

1560 Wilson Blvd.

Suite 1150

Arlington, VA 22209

(703) 276-8240

FAX: (703) 276-8260

Web Site: <http://www.meaf.org/about.html>

A small foundation, the mission of the MEA Foundation is to contribute to a better world for us all by helping young people with disabilities, through technology, to maximize their potential and participation in society. Starfish Grants are approved by the Board of Directors, in consultation with experts in the fields of disability and education, to benefit young people with disabilities throughout the country.

Modest Needs Foundation

150 W. 22nd St. 5th Floor

NY, NY 10011

Web Site: <http://www.modestneeds.org/help/grants/>

Apply on website, proof of need required.

Three (3) Grants:

- Self-Sufficiency Grant (short-term emergency)
- Back-to-Work Grant (small, work-related)
- Independent Living Grant (small, irregular)

NEC Foundation of America

(516) 753-7021

Web Site: <http://www.nec.com/company/foundation/index.html>

NEC Foundation makes cash grants to nonprofit organizations and programs with national reach and impact in one or both of the following:

- science and technology education, principally at the secondary level, and/or
- the application of technology to assist people with disabilities.

They have a terrific web site with everything you'll need to determine eligibility.

The Robert Wood Johnson: Faith In Action Program

Faith in Action Program

The Robert Wood Johnson Foundation

P.O. Box 2316

Princeton, NJ 08543-2316

(877) 324-8411

Email: grants@interfaithcare.org

Deadlines: October 1, 2000; February 1, 2001; June 1, 2001; October 1, 2001

Web Site: <http://www.rwjf.org/>

An initiative to support faith-based volunteer care giving projects, offers start-up grants, most for \$35,000 each, and technical assistance to help communities organize new Faith in Action coalitions. Grants are made to coalitions established by faith congregations (including churches, temples, synagogues, mosques, and other groups with religious missions), as well as by other volunteer organizations or social or health service provider agencies that can demonstrate the participation of faith denominations in the proposed program. Applications are

welcome from those who wish to create a new coalition, as well as from existing interfaith coalitions that wish to develop a Faith in Action program.

<http://www.rwjf.org/grant/cfp-faith-in-action.htm>

Ronald McDonald House Charities

Attn: Grants Manager

One Kroc Drive

Oak Brook, IL 60523

(630) 623-7048

Web Site: <http://www.rmhc.com/grant/index.html>

makes grants to other not-for-profit organizations whose programs help children in need – most interested in organizations that directly benefit children with consistent and effective management, clear goals and objectives, a broad base of funding support, a demonstrated ability to respond to the needs of specific groups of children in a manner that yields measurable results.

Verizon Foundation

1-800-360-7955 - Do not send paper mail

Email: Verizon_Foundation@verizon.com

Web Site: <http://www.verizon.com/foundation>

Committed to supporting programs and projects that create innovative e-solutions, help bridge the digital divide, foster basic and computer literacy and help enrich communities, educate our citizens and create a skilled workforce.

Medical Assistance Grants from United HealthCare Announced

The [United Healthcare Children's Foundation](#) is offering support to meet the needs of children across the United States with assistance grants for medical services not fully covered by health insurance. Parents and caretakers across the country will be eligible to apply for grants of up to \$5,000 for healthcare services that will help improve their children's health and quality of life. Examples of the types of medical services covered by UHCCF grants include speech therapy, physical therapy, and psychotherapy sessions; medical equipment such as wheelchairs, braces, hearing aids, and eyeglasses; and orthodontia and dental treatments.

Any child 16 years old or younger living in any UnitedHealthcare region of the United States (all 50 states) and in need of financial assistance for healthcare services will be considered eligible for a grant. Families must meet economic guidelines, reside in the US, and be covered by a commercial health insurance plan.

Visit United Healthcare's website to learn more about these grants.

Wheelchair Foundation

Wheelchair Foundation World HQ

3820 Blackhawk Road

Danville, California 94506

(877) 378-3839 Toll Free - North America

(925) 791-2340

Fax: (925) 791-2346

Email: info@wheelchairfoundation.org

- Used wheelchairs.
- Submit written request.
- Specific details on the website.

Resources for Individual Consumers- That might fund assistive technology

Able Project

Email: info@ableproject.org

productlisting@ableproject.org

Phone: (408) 263-8000

Fax: (408) 273-6660

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

Able Project's mission: "To provide a network where people with disabilities and their loved ones can easily research, compare, locate and obtain mobility and assistive products, thereby helping them to lead more independent lives." They have a "Giving Program" that solicits donated products that are provided free of charge to low-income elderly and children with no insurance or funding.

Bellows Fund .

This program is available only through UCP affiliates. The annual income generated from the Charitable Fund is utilized to purchase assistive technology equipment for individuals with disabilities. Under the Bellows Program, each UCP affiliate receives an annual notice in November or December, indicating that affiliate's allocation of Bellows Program funds for the entire year. The amount is based on a formula set by the UCP Board of Trustees. An application for each grant must be submitted by the affiliate for review and approval by the UCP Bellows Committee in order to receive the funds. http://www.ucp.org/ucp_general.cfm/1/11365.

Carolina Children's Charity

811 St. Andrews Blvd.

Charleston, South Carolina 29407

Tele: 843-763-2640

Fax: 843-763-2642

awards financial grants to Lowcountry children with birth defects and/or childhood diseases from birth through 18 years of age.

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

Carolina Sunshine grants wishes to children between 3 and 18 years old with life threatening illnesses. Wishes are granted every month at the Board meeting. <http://www.carolinasunshine.org/>

Children's Hopes and Dreams Foundation

280 Route 46
Dover, NJ 07801
(973) 361-7366

Any child 5-17 with chronic or life threatening condition/illness.

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

Disabled Children's Relief Fund

PO Box 7420
Freeport NY 11520

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

Provides disabled children with assistance to obtain wheelchairs, orthopedic braces, walkers, lifts, hearing aids, eyeglasses, medical equipment, physical therapy, and surgery. Blind, Deaf, Amputees, and children with Cerebral Palsy, Muscular Dystrophy, Spastic Quadriplegia, Encephalitis, Rheumatoid Arthritis, Spina Bifida, Down's Syndrome, and other disabilities receive assistance. DCRF focuses special attention on helping children throughout the U.S. that do not have adequate health insurance, especially the physically challenged.

Fairygodmother Foundation

213 West Institute Place, Suite 509

Chicago, Illinois 60610

Phone: (312) 573-0028

Fax: (312) 573-0047

Email: info@fairygodmother.org

Fairygodmother Foundation is a national 501(c)(3) organization that grants wishes to adults (18 and older) facing terminal illness.

Morrison Knudsen Corporation Foundation

One Morrison Knudsen Plaza

Boise Idaho 83729

(208) 386-8100

helps economically troubled employees and the "impoverished in communities where MK conducts business or has business opportunities." Makes gifts to individuals and non-profit organizations

Special People in Need Foundation (S.P.I.N.)

Gary Kline, Special People in Need

500 West Madison Street, Suite 3700

Chicago, Illinois, 60661

(312) 715-5000

Email: jpeter@wilvaine.com

Provides grants and scholarships twice a year to help people with disabilities, with emphasis on enabling the person to engage in meaningful, productive or beneficial activity that might otherwise not be possible. Emphasis is on a strong showing of need.

Foundation Grants to Individuals Online

For a membership fee, you can search through detailed descriptions of close to 4,800 foundations and public charities that fund students, artists, researchers, and other individual grantseekers. You get quarterly updates, and daily search tips. \$9.95 for one month, adding months as needed

<http://gtionline.fdncenter.org/learnmore/index.html>

The FAQ section of the Foundation Center has a good section on “Where can I find information on grants to individuals?”

<http://foundationcenter.org/getstarted/faqs/html/indiv.html>

The Institute on Disabilities at Temple University

Good list of civic groups that fund assistive technology for individuals.

http://www.temple.edu/instituteondisabilities/publications/assistive/foun_civ_2.htm

Excellent list of foundations and disability-specific organizations

http://www.temple.edu/instituteondisabilities/publications/assistive/foun_civ.htm

A good list of wish granting foundations (usually for life-threatening illnesses) can be found at <http://www.familyvillage.wisc.edu/general/wish-grant-orgs.html>

Project Walk® is internationally recognized as a pioneer in exercise-based recovery for people with spinal cord injuries; providing hope, improved quality of life and a chance for life beyond a wheelchair. <http://www.projectwalk.org>

ADL Foundation/ Mobility Aids for the Uninsured The mission of the ADL Foundation is to provide mobility by loaning out mobility aids to those that are qualified. Those who are uninsured or have been turn down by Medicare / Medicaid for an Electric Power chair, Scooter or need a ramp built, so they can get in and out of their homes! FOUNDATIONS GOAL: Our goal, is to raise the necessary funds to purchase new or used mobility aids, or for batteries, tires, and parts needed to repair a donated unit to get it back in working order, to loan them out to qualified recipients! <http://www.adlfoundation.org> or email adlfoundation@yahoo.com

Thank you all for this opportunity and special thanks to

