

ADULT RESOURCE GUIDE
Table of Contents



8085 Saltsburg Road
Pittsburgh, Pa 15239

(412) 793-8077

Adaptive Technology, Equipment and Care	2
Adaptive Vacations and Travel Help	3
Advocate for Yourself	4
Clinical Trials and Research	5
Depression	5
Diet and Nutrition	6
Disability Insurance and Financial	6
Employment	7
Genetics	8
Hospitals, Clinics and Specialty Centers	9
Hospice	9
Legislative	9
Medical Health Communities	10
Pharmaceutical-Medication	11
Pain Management	12
Support Groups and Educational Organizations	12

ADAPTIVE TECHNOLOGY, EQUIPMENT AND CARE

Able Data

1-800-227-0216

www.abledata.com

(Assistive technology products and rehabilitation equipment.)

Apple Accessibility

1-800-692-7753

www.apple.com/accessibility/

(Apple software offers resources for people with vision, hearing, physical, learning and language impairment.)

Assistive Technology Solutions

1-425-373-1315

www.assistivetechologiesolutions.com

(Assistive technology to help enhance independence.)

Canine Companions for Independence

1-800-572-2275

www.cci.org

(Highly trained, assistive dogs for people with disabilities. No charge.)

Comfort Keepers

1-800-387-2415

www.comfortkeepers.com

(Resource for agency to help with light housework, cooking and travel assistance.)

Family Village Accessibility

(On-Line Only)

www.familyvillage.wisc.edu

(Thousands of online products and resources, easy to use.)

Helping Hands- Monkey Helpers

1-617-787-4419

www.monkeyhelpers.org

(Monkey helpers for the disabled.)

Medic Alert Foundation International

1-888-633-4298

www.medicalert.org

(Manages personal health information, ID bracelets, necklaces and emergency response center.)

Muscular Dystrophy Family and Friends Foundation (MDFF)

Phone: (317) 923-6333 or (800) 544-1213

www.mdff.org

Provides adaptive equipment and emotional support to individuals and families affected by one of over forty neuromuscular diseases covered under our program.

Perfect Hearing Aids

1-888-801-5214

www.perfecthearingaids.com

(No exam needed, name brand hearing aids.)

The Arc

Phone: 301-565-3842

www.thearc.org

“Works to include all children and adults with cognitive, intellectual, and developmental disabilities in every community.”

Wheel Chair Network

1-412-586-6908

www.wheelchairnet.org

(Products and information.)

ADAPTIVE VACATIONS AND TRAVEL HELP

Access Able Travel Source

1-303-232-2979

www.access-able.com

(Information and resources for special needs travelers, rentals, transportation and guides.)

Access for Disabled

1-925-460-9001

www.accessfordisabled.com

(Air travel information.)

Accessible Journeys

1-800-846-4537

www.disabilitytravel.com

(Wheelchair vacations, tours, equipment rental, travel tips and more.)

Adaptive Adventures

1-877-679-2770

www.adaptiveadventures.org

(National mobile sports programs and events.)

Air Charity Network

1-877-621-7177

www.aircharitynetwork.org

(Free air transportation for people with special needs.)

Angel Flight America

1-877-858-7788

www.angelflightamerica.org

(Free flights for patients and families seeking distant medical treatment.)

Comfort Keepers

(On Line Only)

www.comfortkeepers.com

(Resource for information on Caregivers Agency, assist with transportation.)

Disabled Sports USA

1-301-217-0960

www.dsusa.org

(Nationwide sports rehabilitation programs, winter and summer programs.)

Friendship Ventures

1-800-450-8376
www.friendshipventures.org
(Camping and travel programs.)

National Sports Center for the Disabled
1-970-726-1540
www.nscd.org
(One of the largest outdoor therapeutic recreation agency, links and resources.)

Wilderness Inquiry
Phone: 1-800-728-0719
www.wildernessinquiry.org
Providing outdoor adventures for people of all ages, backgrounds, and abilities.

ADVOCATE FOR YOURSELF

Families USA
1-202-628-3030
www.familiesusa.org
(Healthcare advocacy network.)

In Need of Diagnosis, Inc.
1-888-894-9190
www.inod.org
(Provides information and support to those who have an undiagnosed illness, communication and exchange board.)

Medical Notebook/FCIC
1-888-878-3256
www.pueblo.gsa.gov
(Federal citizens information center.)

National Family Caregivers Association
Phone: 301-942-6430 or 800-896-3650
www.nfcacares.org
Dedicated to supporting and improving the lives of America's family caregivers.

National Patient Advocate Foundation
1-800-532-5274
www.npaf.org
(Legislative and policy reform information.)

Patient Advocate Foundation
1-800-532-5274
www.patientadvocate.org
(Advocates/mediates as a liaison between patient's insurance, employer and creditors.)

Well Spouse Association
800-838-0879 732-577-8899
www.wellspouse.org
Focuses on "the needs of spouses caring for a chronically ill and/or disabled husband, wife, or partner."

CLINICAL TRIALS AND RESEARCH

Government Clinical Trails

(On Line Only)

www.clinicaltrials.gov

(Information about federally and privately supported clinical research.)

National Institutes of Health

1-301-496-4000

www.nih.gov

(Information on health resources and clinical trails.)

National Organization for Rare Disorders

1-800-999-6673

www.raredisease.org

(Provides information on diseases and conditions.)

NLM Gateway

<http://gateway.nlm.nih.gov/gw/Cmd>

(National Institutes of Health website that allows users to locate the latest research abstracts on medical topics)

U.S. Food and Drug Administration (FDA)

1-888-463-6332

www.fda.gov

(Information on clinical trials, product safety, drugs, diseases and more.)

World Health Organization

(On-Line Only)

www.who.int

(Health topics and publications.)

DEPRESSION

Center for Coping

1-516-822-3131

www.coping.com

(Helps with the difficulties of medical problems, stress, depression, anxiety, bereavement, family, relationships and more.)

Depression Anonymous

1-502-569-1989

www.depressedanon.com

(Therapeutic resources for depressed individuals of all ages. 12 step program.)

Mental Help Net

(On-Line Only)

www.selfhelpgroups.org

(Promotes mental health and wellness education and advocacy.)

DIET AND NUTRITION

For My Diet

(On Line Only)

www.formydiet.com

(Information on inborn errors of metabolism, fatty acid disorders and other metabolic conditions.)

Medline Plus Herbal Remedies

(On Line Only)

www.medlineplus.com

(Healthcare related, drugs and supplement information.)

NIH Office of Dietary Supplements Consumer Information Page

(On Line Only)

www.ods.od.nih.gov

(Supplement use, safety and recommendations.)

Solace Nutrition

1-888-876-5223

www.solacenutrition.com

(Nutritional products designed for individuals living with chronic disease.)

Epic 4 Health

1-800-866-0978

www.epic4health.com

(Q-Gel, Coenzyme Q10, Alpha-Lipoic Acid, L-Carnitine and much more.)

DISABILITY INSURANCE AND FINANCIAL

Center for Medicare and Medicaid Services

(On Line Only)

www.cms.hhs.gov

(Government health insurance supplement.)

Department Of Veterans Affairs

1-800-827-1000

www.va.gov

(Veteran benefits, information and assistance.)

Disability Resources

(On Line Only)

www.disabilityresources.org

<http://www.fodsupport.org/insurance.htm>

(By State, promote, awareness, availability and accessible information.)

GovBenefits.gov

www.govbenefits.gov

Locate federal and state benefits you might be eligible for.

Medicare

1-800-633-4227

www.medicare.gov

(Government health insurance supplement.)

Medicare, Medicaid and Medicaid Waiver Programs

<http://www.geocities.com/HotSprings/Villa/1029/medicaid.html>

List of waiver-covered services by state:

<http://cms.hhs.gov/medicaid/1915c/regular.pdf>

<http://cms.hhs.gov/medicaid/1915c/model.pdf>

National Association of Insurance Commissioners (NAIC)

www.naic.org

Locate insurance commissioners for all 50 states. Mission includes protecting the public interest and facilitating the “fair and equitable treatment of insurance consumers.”

National Network of American’s With Disabilities Act Center

1-800-949-4232

www.adata.org

(Information, referrals, resources and training on ADA.)

Social Security/SSI

1-800-772-1213

www.ssa.gov

(Disability benefits, Office of Public inquiries.)

Social Security and Disability

(On Line Only)

www.socialsecurityanddisability.com

(Resource links on eligibility, discrimination, long term and insurance.)

Social Security Rights

(On Line Only)

www.yoursocialsecurityrights.com

(Information and resource links.)

EMPLOYMENT

Disabled Business Persons Association

1-619-594-8805

www.disabledbusiness.org

(Connects entrepreneurs with disabilities with mentors to help with self employment and small business.)

The Employer Assistance and Recruiting Network

1-800-327-6669

www.earnworks.com

(Free service, offers assistance to employment service providers and jobseekers with disabilities.)

Equal Opportunity Employment Commission

1-800-669-4000

www.eeoc.gov

(EEOC enforces federal civil rights law regarding job discrimination.)

The Job Accommodation Network (JAN)

1-800-526-7234

www.jan.wvu.edu

www.jan.wvu.edu/sbses

(Free consulting service to increase employability of people with disabilities, also link to small business and self employment services.)

Job Enable

(On-Line Only)

www.jobenable.com

(Online job bank for people with disabilities and potential employers.)

One Stop Career Centers

1-877-872-5627

www.careeronestop.org

(Explore careers, education, training, resumes, job search and more. Find a center near you.)

US Department Of Labor

1-866-633-7365

www.dol.gov

(Resources for entrepreneurs with disabilities and career center.)

GENETICS

Center for Disease Control

1-800-232-4636

www.cdc.gov

(Information on diseases and conditions.)

Duke Center for Human Genetics

1-919-684-2063

www.chg.duke.edu

(Research, study, study participate and education of inherited diseases.)

Gene Test

1-206-616-4089

www.geneclinics.org

(Genetic information and testing.)

Genetic Alliance

(800) 336-4363

www.geneticalliance.org

International coalition of individuals, professionals and genetic support organizations that work together to enhance the lives of those impacted by genetic conditions.

Hereditary Disease Foundation

1-212-928-2121

www.hdfoundation.org

(Research in genetics to understand inherited diseases.)

National Human Genome Research Institute

(On Line Only)

www.genome.gov

(Government grant program to study genetic components of complex disorders.)

National Society of Genetic Counselors

(On Line Only)

www.nsgc.org

(Consumer information: Find a genetic counselor in your area.)

UCSD Biochemical Genetics

(On Line Only)

<http://biochemgen.ucsd.edu/>

(Biochemical genetic lab services.)

HOSPITALS, CLINICS AND SPECIALTY CENTERS

For more information, please contact The United Mitochondrial Disease Foundation directly:

1-412-793-8077 or toll free 1-888-317-8633

Email: info@umdf.org

Operating hours: 8:00 a.m. – 5:00 p.m. Eastern Standard Time

HOSPICE

Crisis, Grief and Healing

1-301-670-1027

www.webhealing.com

(Internet interactive grief website, discussion board.)

Living with Loss Magazine

1-888-604-4673

www.bereavementmag.com

(Hope and healing for the body, mind and spirit.)

National Association Homecare and Hospice

1-202-547-7424

www.nahc.org

(Representing the interests and concerns of homecare agencies, hospice, aids and organizations.)

National Hospice and Palliative Care Organization

1-800-658-8898 Help-Line

www.nhpco.org

(Advocates, promoting access to hospice and palliative care, resource links and education.)

LEGISLATIVE

House of Representatives

1-202-224-3121

www.house.gov

(Website for the United States House of Representatives. Find you State Representative.)

Office of Senator

1-202-224-3121

www.senate.gov

(Website for the United States Senate. Find your State Senator.)

National Conference of State Legislatures

1-202-624-5400

www.ncsl.org

(Serves the legislators and staff. State and federal issues.)

MEDICAL HEALTH COMMUNITIES

E Medicine

(On-Line Only)

www.emedicine.com

(Clinical references continually updated.)

Health Finders

(On-Line Only)

www.healthfinder.gov

(Encyclopedia of over 1600 health topics, services and information.)

Health Line

(On-Line Only)

www.healthline.com

(Health search engine and medical information.)

Med Help

(On-Line Only)

www.medhelp.org

(Answers to medical questions, research information on drugs and health topics.)

Med Line Plus

(On-Line Only)

www.medlineplus.com

(Health and drug information, helps answer health questions.)

National Rehabilitation Information Center

(On-Line Only)

www.naric.com

(Disability and rehabilitation oriented information with over 70,000 articles.)

Pub Med

(On-Line Only)

www.pubmed.com

(Biomed literature citations and abstracts.)

The Right Health

(On-Line Only)

www.righthealth.com

(Answers to common health concerns.)

PHARMACEUTICAL-MEDICATION INFORMATION

Daily Med

(On-Line Only)

www.dailymed.com

(Medication safety information, links to discount prescriptions.)

Drug Information On-Line

(On-Line Only)

www.drugs.com

(Provides free advice on more than 24,000 prescription drugs.)

International Academy of Compounding Pharmacists

www.iacprx.org

“A compounding pharmacist prepares customized prescription medication to meet individual patient needs.”

Includes pharmacist location finder.

UMDF Note: Because some patients are prescribed a “vitamin cocktail” or need their meds in liquid form, they may wish to locate a compounding pharmacist who can custom-mix their supplements.

The Medicine Program

573-996-7300

www.themedicineprogram.com

NeedyMeds.com

www.needymeds.com

“Provides information about patient assistance programs which provide no cost prescription medications to eligible participants.” Programs listed for specific medications.

Pharmaceutical Research and Manufacturers of America (PhRMA)

1-202-835-3400

www.pharma.org

(Discovering and development of new medicines.)

Pharmacy Web

(On-Line Only)

www.pharmweb.net

(Patient information on drugs, medicines, diseases, conditions and more.)

Ross.com

www.ross.com/reimbursement/default.asp

Links for Medicare/Medicaid coverage, including nutritional & internal products, by state.

RX List

(On-Line Only)

www.rxlist.com

(Drug index for prescription drugs, medications, disease, conditions, medical dictionary and terms.)

Safe Medication/American Society of Health Systems Pharmacists

1-301-657-3000

www.safemedication.com

(Helping people use medication safely and effectively.)

Patient Assistance

(On-Line Only)

www.patientassistance.com

(Non-profit, helping uninsured patient get free medicine and/or save money on prescriptions.)

PAIN MANAGEMENT

American Academy of Pain Management

(On-Line Only)

www.aapainmanage.org

(Resource links for patients.)

American Chronic Pain Association, Inc.

1-800-533-3231

www.theacpa.org

(Peer support, education, awareness, newsletters and phone networking.)

American Pain Foundation

1-888-615-7246

www.painfoundation.org

(Information, advocacy and support.)

Chronic Pain Outreach

(On-Line Only)

www.chronicpain.org

(Spreading the message of chronic pain, articles and resource links.)

SUPPORT GROUPS AND EDUCATIONAL ORGANIZATIONS

Digestive

Cyclic Vomiting Syndrome

1-414-342-7880

www.cvsaonline.org

(Networking, support, education and newsletter.)

International Foundation for Functional Gastrointestinal Disorders

1-888-964-2001

www.iffgd.org

(Education, research, support, information and assistance.)

Irritable Bowel Syndrome Self Help and Support

(On-Line Only)

www.ibsgroup.org

(Support and advocacy.)

Oley Foundation, Inc.

1-800-776-6539

www.oley.org

(Provides information and psychosocial support for home nutrition support-intravenous or tube feedings.)

Endocrine

American Autoimmune Related Diseases Association

1-800-598-4668

www.aarda.org

(Support, advocacy and education on any type of autoimmune disease.)

American Diabetes Association

1-800-DIABETES

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

Chronic Fatigue Immune Association

1-704-365-2334

www.cfids.org

(Advocacy, information and encouragement.)

Endocrine Web

(On-Line Only)

www.endocrineweb.com

(Largest site for diabetes, osteoporosis, thyroid, parathyroid and other endocrine disorders.)

Immune Deficiency Foundation

1-800-296-4433

www.primaryimmune.org

(Support, education, newsletter, handbook and videotapes.)

National Fibromyalgia Association

1-714-921-0150

www.fmaware.org

(Education, patient assistance, support and group directory.)

Cardiac/Cardiovascular

American Heart Association

1-800-242-8721

www.americanheart.org

(Prevention, education, advocacy, diseases of the heart.)

Mended Hearts

1-214-360-6149

www.mendedhearts.org

(Networking, support for all heart diseases.)

Hearing or Loss of Hearing

Hearing Loss Association of America

1-301-657-2248 (V)

1-301-657-2249 (TTY)

www.hearingloss.org

(Support, information, education, advocacy and referrals.)

National Association of the Deaf

1-301-587-1788 (V)

1-301-587-1787 (TTY)

www.nad.org

(Legal rights, advocacy, information and education.)

Kidney and Liver

National Kidney Foundation

1-800-622-9010

www.kidney.org

(Public education, newsletters, patient education, diets and more.)

American Liver Foundation

1-800-465-4837

www.liverfoundation.org

(Prevention, support, advocacy, chapters and more.)

Metabolic and Mitochondrial

Fatty Acid Oxidation Support Group

1-517-381-1940

www.fodsupport.org

(Support, networking and information.)

Genetic Alliance

1-202-966-5557

www.geneticalliance.org

(Weekly bulletins, newsletters and resources.)

Association of Glycogen Storage Disease

(On-Line Only)

www.agsdus.org

(Support, awareness and research.)

Organic Acidemia Association, Inc.

1-703-497-1216

www.oaaneews.org

(Support, education, information and networking.)

Mitochondrial Disease Action Committee

1-888-648-6228

www.mitoaction.org

(Support, education and advocacy.)

Mitochondrial Medicine Society

(On-Line Only)

www.mitosoc.org

(Represents international group of physicians.)

United Mitochondrial Disease Foundation

412-793-8077 or toll free 1-888-317-8633

www.umdf.org

Email: info@umdf.org

Web Crawler

(On-Line Only)

www.webcrawler.com

Search: mitochondrial disorder and/or disease

(Over a dozen links for mitochondrial information.)

Neurological and Neuro-Muscular

American Stroke Association

1-888-478-7653

www.strokeassociation.org

(Support groups, magazine, information and referrals.)

Dysautonomia Foundation, Inc.

1-212-279-1066

www.familialdysautonomia.org

(Supports medical treatments, research, awareness and social services.)

Dystonia Medical Research Foundation

1-800-377-3978

www.dystonia-foundation.org

(Movement disorder support, treatments and research.)

Epilepsy Foundation

1-800-332-1000

www.epilepsyfoundation.org

(Research, advocacy and education.)

Multiple Sclerosis Association of America

1-800-532-7667

www.msaa.com

(Support, education, information, referrals and more.)

Muscular Dystrophy Association (MDA)

1-800-572-1717

www.mda.org

(Supports research, self help groups, on line chat sessions, education and more.)

National Aphasia Association

1-800-922-4622

www.aphasia.org

(Support, education and advocacy.)

National Ataxia Foundation

1-763-553-0020

www.ataxia.org

(Support and research.)

National Dysautonomia Research Foundation

(On-Line Only)

www.ndrf.org

(Information, medical network and discussion forums.)

National Institute of Neurological Disorders and Strokes

1-800-352-9424

www.ninds.nih.gov

(Research and development into neuro diseases.)

National Migraine Association

(On-Line Only)

www.migraine.org

(Research and information, migraine overview.)

National Multiple Sclerosis Society

1-800-344-4867

www.nationalmssociety.com

(Funds research, support groups, provides information and education.)

National Stroke Association

1-800-787-6537

www.stroke.org

(Prevention, treatments, rehabilitation, family support and research.)

Neuropathy Association

1-212-692-0662

www.neuropathy.org

(Support, newsletter, information and referrals.)

Neuro Talk

(On-Line Only)

www.neurotalk.psychcentral.com

(Provides message board for dozens of different neuro and neuro-muscular diseases.)

United Cerebral Palsy Association, Inc.

1-800-872-5827

www.ucp.org

(Local programs include support, referral, advocacy and information.)

We Move/Life in Motion

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

“the Internet's most comprehensive resource for movement disorder information and the hub of movement disorder activities on the web.”

Visual/Loss of Sight

Foundation Fighting Blindness

1-800-683-5555

www.blindness.org

(For people affected by retinitis pigmentosa and other retinal degenerative diseases.)

National Association for Visual Handicapped

1-415-775-6284

www.navh.org

(Provide low vision services, visual aids and training, support and education.)

National Federation of the Blind

1-410-659-9314

www.nfb.org

(Advocacy, education, research and programs for independence and self confidence.)

Retinitis Pigmentosa International

1-818-992-0500

www.rprinternational.org

(Support, information and research.)