

USEFUL RESOURCES ESPECIALLY FOR KANSAS & MISSOURI

GOVERNMENT PUBLIC BENEFIT PROGRAMS

Medicare

http://www.medicare.gov

1-800-633-4227

Social Security

http://www.socialsecurity.gov

1-800-772-1213

LOCAL AND NATIONAL ASSISTANCE WITH PUBLIC BENEFITS

Legal Aid of Western Missouri

http://www.lawmo.org/offices.htm

Social Security Disability Legal Advocates

913-262-6555 800-444-8185

Missouri Protection and Advocacy Services

http://moadvocacy.org

Westport Cooperative Services

Medicare Assistance Program

http://westportcooperative.org/medicare.php

Westport Cooperative Services provides a program to help individuals understand and navigate Medicare. They also provide a Senior Companion program as well.

NATIONAL ASSISTANCE WITH HEALTH INSURANCE

Accredo Therapeutics: The A.C.C.E.S.S. Program ("Advocating for Chronic Conditions, Entitlements and Social Services (A.C.C.E.S.S.) is dedicated to helping find solutions to many of the social and economic problems that confront families facing chronic conditions. A.C.C.E.S.S. can assist you in navigating the often-complex maze of state and federal entitlement programs.") (888) 700-7010

Patient Advocate Foundation ("Patient Advocate Foundation is a national non-profit organization that seeks to safeguard patients through effective mediation assuring access to care, maintenance of employment and preservation of their financial stability relative to their diagnosis of life threatening or debilitating diseases.") (800) 532-5274

LOCAL HEALTH INSURANCE & ASSISTANCE PROGRAMS

Missouri Health Insurance Pool (provides insurance to those who have been denied) http://www.mhip.org/
800-821-2231

Mid America Assistance Coalition (helps make social service system more simple and efficient) http://maaclink.org/maac.htm

Phone: (816) 561-2727 / (877) 962-6222

CLAIM – Missouri State Health Insurance Assistance Program http://www.missouriclaim.org/
1-800-390-3330

Kansas Health Insurance Association http://www.khiastatepool.com/default.asp

AREA AGENCIES ON AGING (AAA)

Area Agencies on Aging are supported by federal and state tax dollars to provide the services listed below. Your local AAA agency may provide the following services, but please note that not all agencies provide the same services:

- Information and Referral
- Newsletters
- Nutrition sites
- Legal services
- Counseling/case management
- Medication management
- Health and educational programs
- CARE program
- Health and functional status assessment for long-term care

Kansas Area Agencies on Aging

Wyandotte-Leavenworth AAA

1300 North 78th Street, Suite #100 Kansas City, KS 66112-1540 913-573-8531 888-661-1444

Southeast KS AAA

1 West Ash Chanute, KS 66720-1010 620-431-2980 800-794-2440

Northeast KS AAA

526 Oregon Hiawatha, KS 66434-2222 785-742-7152 800-883-2549

Central Plains AAA

2622 W. Central, Suite 500 Wichita, KS 67203-3725 316-660-7298 800-367-7298

Southwest KS AAA

236 San Jose Avenue P O Box 1636 Dodge City, KS 67801-1636 620-225-8230 800-742-9531

South Central KS AAA

304 S. Summit Arkansas City, KS 67005 620-442-0268 800-362-0264

Northwest KS AAA

510 W 29th Street, Suite B P O Box 610 Hays, KS 67601-3703 785-628-8204 800-432-7422

East Central KS AAA

117 S. Main Ottawa, KS 66067-2327 785-242-7200 800-633-5621

Johnson Co AAA

11811 S Sunset Drive, Ste # 1300 Olathe, KS 66061-7056 913-715-8800 888-214-4404

Jayhawk AAA

2910 SW Topeka Blvd. Topeka, KS 66611 785-235-1367 800-798-1366

North Central Flint Hills AAA

401 Houston Manhattan, KS 66502 785-776-9294 800-432-2703

Missouri Area Agencies on Aging

AAA Region X/The Vantage Central Missouri AAA

Point - Joplin, MO 531 E. 14th Street Joplin, MO 64803 417-781-7562

Columbia, MO 1121 Business Loop 70 East, Suite 2A Columbia, MO 65201 800-369-5211 cmaaa@cmaa.net

Mid-America Regional Council

Kansas City, MO 600 Broadway, Suite 200 Kansas City, MO 64105-1659 816-474-4240

Care Connection for Aging

Services – Warrensburg, MO 106 W. Young P.O. Box 1078 Warrensburg, MO 64093 800-748-7826 & 660-747-3107 information@GoAging.org

Mid-East Area Agency on

Aging – Manchester, MO 14535 Manchester Road Manchester, MO 63011 636-207-1323 800-AGE-6060

Northwest MO AAA -

Albany, MO 211 South Polk Street P.O. Box 265 Albany, MO 64402 660-726-3800 888-844-5626 nwmoaaa@nwmoaaa.org

Southeast Missouri AAA

1219 N. Kings Highway, Suite 100 Cape Girardeau, MO 63701 573-335-3331 or 800-392-8771

Southwest MO, Office on

Aging – Springfield, MO 1735 South Fort Springfield, MO 65807 800-497-0822

FREE OR LOW COST MEDICAL CARE IN MO & KS

Kansas City Free Health Clinic

http://www.kcfree.org/

Jaydoc Free Health Clinic - University of Kansas Medical Center

http://www.jaydocfreeclinic.org/

Swope Health Services

http://www.swopeparkwayhc.org/Clinics/Swope Clinic Locations.aspx

KC Northland CARE / Metro Care

http://www.metromedkc.org/northland-care-metrocare

WyJo Care Medical Society of Johnson & Wyandotte Counties msjwc@msjwc.org

Sites to find free or low cost medical care throughout KS and MO

http://www.freemedicalcamps.com/vcitv.php?stateid=MO

http://www.needymeds.org/free clinics.taf? function=list&state=ks

HOW TO PREPARE FOR YOUR MEDICAL APPOINTMENTS

http://www.ahrq.gov/questionsaretheanswer

MEDIC ALERT BRACELETS

https://www.medicalert.org/

http://www.medicassist.com/

http://www.laurenshope.com/aboutus.aspx

http://www.americanmedical-id.com/extras/reimbursement.php

MEDICATION ASSISTANCE PROGRAMS

GENERAL RESOURCES

Benefits CheckUp - NCOA's Online Screening Service http://www.benefitscheckup.org (prescription drugs, health care, utilities and other needs)

Partnership for Prescription Assistance - 1-888-477-2669 https://www.pparx.org/Intro.php (prescription assistance)

RxAssist - http://www.rxassist.org/default.cfm - (comprehensive data base of patient assistance programs, medical assistance cards and prescription assistance)

Needy Meds - http://www.needymeds.com - (no-cost prescription medications)

Cost Containment Research Institute - http://www.institute-dc.org (free and low cost prescription drugs)

UneedPSI - 1-800-336-7741 http://www.uneedpsi.org (health insurance premium, pharmacy copayment and copayment waiver assistance

KANSAS RESOURCES

Kansas Health Insurance Association: http://www.khiastatepool.com/default.asp

MISSOURI RESOURCES

Missouri Health Insurance Pool (provides insurance to those who have been denied) http://www.mhip.org/ 800-821-2231

CLAIM-Missouri State Health Insurance Assistance Program: http://www.missouriclaim.org/ 1-800-390-3330

Kansas City Free Health Clinic: http://www.kcfree.org/

Swope Health Services: http://www.swopeparkwayhc.org/Clinics/Swope Clinic Locations.aspx

SPECIFIC DRUG ASSISTANCE

Mestinon: Valeant Patient Assistance Program (administered through RxHope) 1-800-511-2120, www.rxhope.com Timespan (time release pyridostigmine), Mestinon Syrup (pyridostigmine syrup) and Prostigmin (neostigmine).

Cyclosporine: Novartis Patient Assistance Program 1-800-245-5356 - Sandimmune (cyclosporine) and Neoral (cyclosporine) <u>www.abbotpatientassistancefoundation.org</u> or Abbott Labs - Gengraf, Abbot Patient Assistance Foundation 1-800-222-6885

CellCept: Roche Pharmaceuticals 1-877-757-6243 or Genetech: Patient Access Program http://www.gene.com/gene/products/access/ 1-888-422-2377

Mytelase: (ambenonium chloride): Sanofi-Synthelabo 1-800-446-6267

Prednisone: Express Scripts (866) 699-8239, http://www.xubex.com/

DISCOUNT PRESCRIPTION CARDS

http://www.caprxcard.org

http://www.familywize.org

http://www.themedicineprogram.com

http://www.togetherrxaccess.com

EMPLOYMENT & DISABILITY ADVOCACY RESOURCES

Vocational Rehabilitation (specializes in employment and training services that can assist you in becoming employed)

http://www.dese.mo.gov/vr/vocrehab.htm 1-877-222-8963

Job Accommodation Network

JAN is the leading source of free, expert, and confidential guidance on workplace accommodations and disability employment issues. Working toward practical solutions that benefit both employer and employee, JAN helps people with disabilities enhance their employability, and shows employers how to capitalize on the value and talent that people with disabilities add to the workplace." http://www.askjan.org

(800)526-7234 (Voice)

WITH OFFICES IN KS & MO

The Whole Person

The Whole Person Inc. provides a variety of community-based, consumer-driven services to people with disabilities to promote consumer control and choice of services, self-direction, empowerment, independence, self-reliance, self-help, self-advocacy and integration into the community. http://www.thewholeperson.org 800-878-3037

Coalition for Independence

The Mission of the Coalition for Independence is to facilitate positive and responsible independence for people with disabilities by acting as an advocate for individuals with disabilities, providing services and promoting accessibility and acceptance.

http://www.cfi-kc.com

866-201-3829

Disability Rights Center of Kansas

The Disability Rights Center of Kansas (DRC), formerly Kansas Advocacy & Protective Services (KAPS), is a public interest legal advocacy agency empowered by federal law to advocate for the civil and legal rights of Kansans with disabilities. DRC is the Official Protection and Advocacy System for Kansas and is a part of the national network of federally mandated and funded protection and advocacy systems. As such, DRC advocates for the rights of Kansans with disabilities under state or federal laws (ADA, the Rehabilitation Act, Federal Medicaid Act, Kansas Act Against Discrimination, etc.)

http://www.drckansas.org/default.asp

877-776-1541

APARTMENT COMPLEXES WITH DISABILTY ACCESS

http://www.apartmentguide.com/apartments/Missouri/Kansas-City/disability-access-4ia/

http://www.apartmentcities.com/Kansas-City-Apartments/Kansas-City/feature-af06/Disability Access

TRANSPORTATION ASSISTANCE – KS & MO

KUMC – Transportation Handbook for Individuals with Disabilities in Greater Kansas City area

http://www.alliedhealth.kumc.edu/programs/ot/documents/PDF/transportation.pdf

Share-a-Fare Program through Kansas City Metro Bus System

http://www.kcata.org/rider guide/share a fare

Additional Transportation Options in KS

http://www.apta.com/resources/links/unitedstates/Pages/KansasTransitLinks.aspx#a2

TALKING BOOKS IN KS & MO

KS – Talking Books –through KS Library system

http://www.kslib.info/talking

KU's Audio Reader Program - for residents of KS and Western MO

http://reader.ku.edu/

Audio-Reader

1120 west 11th St.

P.O. Box 847 785 864 4600 Lawrence KS 66044 800 772 8898

Wolfner Library for the Blind and Physically Handicapped

Missouri residents are served by **Wolfner Library for the Blind and Physically Handicapped**, PO Box 387, 600 W. Main, Jefferson City, MO 65102-0387. Contact Wolfner Library by calling toll-free, (800) 392-2614 (within Missouri) or 573-751-8720 (within the Jefferson City area). You may e-mail the library at wolfner@sos.mo.gov

EMERGENCY HOME EVACUATION PLAN

Home Evacuation Guide specific to the needs of senior adults and individuals with disabilities

http://www.nyredcross.org/?nd=disaster_safety_guide_for_seniors_and_people_with_disabilities

IN-HOME MEDICAL EQUIPMENT

Coalition for Independence

http://www.cfi-kc.com/cfi/Services/DME/DMEInventory.aspx

Muscular Dystrophy Association

http://www.mda.org/local/?postalcode=64132&submit=find

MDA's local office provides access to equipment loans and other services which may be of interest to an individual living with MG.

MEDICATION REMINDERS

http://www.imedicalapps.com/2010/09/iphone-android-blackberry-medication-reminder-app

ORGANIZATIONS THAT PROVIDE VOLUNTEERS FOR IN-HOME REPAIRS FOR OLDER ADULTS

Jewish Family Services (open to everyone) Help @ Home Program http://www.jfskc.org/wp-content/uploads/2011/01/H@H-9-11.pdf

Shepherd's Center Minor Home Repair http://www.sckck.org 913-281-8908

CAREGIVING SUPPORT

Well Spouse Association

http://www.wellspouse.org

National Alliance for Caregiving

http://www.caregiving.org

Turning Point, The Center for Hope and Healing

http://www.turningpointkc.org/index.aspx

Strength for Caring, a Place for Caregivers

http://www.strengthforcaring.com

National Family Caregivers Association

http://www.thefamilycaregiver.org/index.cfm

Handbook for Long Distance Caregivers

http://www.caregiver.org/caregiver/jsp/content/pdfs/op 2003 long distance handbook.pdf

Caring from a Distance

http://www.cfad.org

CaringBridge

http://www.caringbridge.org/about

ON-LINE SUPPORT GROUPS

http://www.dailystrength.org - - click on "Support Groups"

http:/www.mdjunction.com/myasthenia-gravis - - also click on "forums"

http:/www. health.groups.yahoo.com/group/maddysmgsupport/

http://www.groups.google.com/health,groups.yahoo.com/group/MGC7HT3

LOCAL SUPPORT GROUPS

The MGA sponsors patient support group meetings which provide MG patients and their caregivers with a resource to better understand and cope with the disease. Most meetings feature a special presentation and present an opportunity for informal sharing of information among attendees. The MGA has several support group location besides in the Kansas City metro area:

- Lawrence, KS
- Wichita, KS
- St. Joseph, MO

- North Kansas City, MO
- Columbia/Jefferson City, MO
- Springfield, MO

For more information about support groups, please contact the MGA at 816-256-4100 or mgakc@sbcglobal.net.

MYASTHENIA GRAVIS ASSOCIATION OF KS & MO

The MGA not only provides support groups, but a wide array of services to individuals living with MG in KS and MO. These services are:

- Quarterly newsletters
- Information and referral
- MG-knowledgeable neurologists recommended by members

- MGA staff support at the MG Clinic at the University of Kansas Medical Center and by appointment at Neurological Consultants/Dr. Michael Schwartzman's office.
- MGA website at mgakc.org and Facebook page at facebook.com/mgakc
- Awareness and educational events throughout the year 2 walks for awareness and annual meeting

For more information, please contact the MGA at 816-256-4100 or mgakc@sbcglobal.net.

MORE WEBSITES OF INTEREST

CaringBride provides websites that connect people experiencing a significant health challenge to family and friends, making each health journey easier. http://www.caringbridge.org/about

Myasthenia Gravis Association of Kansas & Missouri - http://www.mgakc.org

Myasthenia Gravis Foundation of America - http://www.myasthenia.org

Muscular Dystrophy Association (put myasthenia gravis in search box) - http://www.mda.org

Magazine of the MDA - http://www.quest.mda.org

<u>National</u> Center for Biotechnology Information http://www.ncbi.nim.nih.gov/pubmed?term=myastheniagravis

U.S. National Library of Medicine - http://www.nim.nih.gov

American Academy of Neurology - http://www.aan.com

Neurology Now Magazine - http://www.journals.lww.com/neurologynow/default.aspx