The Neuromuscular Resource Guide

Atlantic Neuroscience Institute





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The Neuromuscular Resource Guide was created by the Atlantic Neuroscience Institute's team of social workers. We intend this guide be used by our patients and their caregivers to find resources that can be helpful in education about diagnosis, seeking support, and suggested next steps following a diagnosis.

This directory is a helpful guide on where to start and what resources are available. If you are seeking more comprehensive information, we the team of neurology social workers are available.

Please call us so that we can provide additional information and guide you to the appropriate resources and provide guidance.

Your Social Work Team

Victoria Veninata, LSW, MSW 908-522-3517 **Atlantic Neuroscience Institute** 908-522-2829

Janet LeMonnier, LSW, MSW 908-522-5159 **Glasser Brain Tumor Center** 908-522-5914

Atlantic Health System does not endorse or recommend any service listed in this directory and resources are referenced for informational purposes only. The information in this directory was most current available at the time of publication, however, some programs/services/contact information may change or become outdated. Please check with individual organizations to verify accuracy and availability of programs and services.

Social Work Services

Atlantic Health System Social Work

Our neuroscience social workers are licensed professionals who provide psychosocial services to patients and families facing the impact of a significant diagnosis and treatment. Each of the social workers bring specialized training and expertise to their roles.

Counseling Services

Our social workers provide short-term supportive counseling at no charge. They can help you enhance coping skills and discuss any fears, concerns and worries related to your diagnosis, treatment or medical decision making. The social workers are also here for caregivers and loved ones and can guide you through talking with your support system about your diagnosis and subsequent treatment. Counseling services are available at any point in your treatment.

Resources and Referrals for Practical Issues

Our social workers also serve as a liaison and advocate between patients, the health care system, and the community. Based on your specific needs, your social worker will help you identify and access appropriate resources for transportation, financial counseling assistance, employment issues, health insurance, and community and in-home supports.

If you do not have health insurance, or if you have concerns about being able to pay for your care, there are multiple federal and state programs that and provide financial benefits to individuals and families such as Social Security, Medicare, New Jersey State Temporary Disability benefits, Charity Care and Medicaid. Please contact one of our social workers to connect you to those resources.

Advance Care Planning

Advance care planning is the process that helps you express your goals, values, and wishes as they relate to your health care. Our social workers are available to answer your questions and help you to communicate your wishes to your family and to your health care team.

Community and Virtual Resources for Patients with Neuromuscular **Disorders and Caregivers**

This guide offers a variety of community resources to enhance your understanding of your diagnosis and provide resources to patients and their support network. We encourage you to discuss your needs with your doctor and social worker so they can better provide additional insight. Atlantic Health System provides this quide as a benefit to our patients but does not endorse any of these services.

RESOURCES AT A GLANCE

NJ 211 Dial 2-1-1 or 1-877-652-1148 nj211.org

NJ Find-A-Ride nifindaride.com

NJ Temporary Disability myleavebenefits.nj.gov

Mental Health Crisis Hotline Dial 9-8-8

General Resources for Neuromuscular Disorder **Patients**

Atlantic Neuroscience Institute Neuromuscular Disorders Program

At Atlantic Health System's Neuromuscular Disorders Program, neurological specialists provide expert, compassionate diagnosis, and treatment of conditions, such as amyotrophic lateral sclerosis (ALS) or Lou Gehrig's disease, chronic inflammatory demyelinating polyneuropathy, Guillain-Barre syndrome, diabetic neuropathy, myasthenia gravis, muscular dystrophies, mvositis, sciatica, and more.

 908-522-2829, Monday through Friday, 8:00am to 4:00pm 99 Beauvoir Avenue, Fifth Floor, Summit, NJ 07901 1125 Route 22, Suite 155, Bridgewater, NJ 08807 atlantichealth.org/neuroscience atlantichealth.org/conditions-treatments/neuroscience/ neuromuscular-disorders

American Brain Foundation

The American Brain Foundation promotes and invests in research across the whole spectrum of brain disease. American Brain Foundation links neurologists, patients, and caregivers to better understand the whole brain to make unique connections and find cures. Brain disease affects one in six people worldwide and includes a wide spectrum of diseases and disorders—from stroke and Alzheimer's to multiple sclerosis, epilepsy, traumatic brain injury, and more.

• 866-770-7570 National Office: 201 Chicago Ave, Minneapolis, MN 55415 americanbrainfoundation.org americanbrainfoundation.org/diseases/alsneuromuscular/

ALS Association

ALS is a progressive neurodegenerative disease. ALS Association strives to discover treatments and a cure for ALS, and to serve, advocate for, and empower people affected by ALS to live their lives to the fullest.

 800-782-4747; alsinfo@alsa-national.org National Office: 1300 Wilson Boulevard, Suite 600. Arlington, VA 22209 als.org

GBS|CIDP Foundation International

The GBS | CIDP Foundation International is a global nonprofit organization supporting individuals and their families affected by Guillain-Barre syndrome (GBS), chronic inflammatory demyelinating polyneuropathy (CIDP), and related conditions through a commitment to support, education, research and advocacy.

• 866-224-3301 National Office: 375 East Elm Street, Suite 101, Conshohocken, PA 19428 abs-cidp.org

Muscular Dystrophy Association (MDA)

MDA is the nonprofit health agency dedicated to curing muscular dystrophy, ALS, and related diseases by funding worldwide research. MDA funds research for promising treatments and provides families with high quality care.

 800-572-1717; resourcecenter@mdausa.org National Office: 161 N. Clark, Suite 3550, Chicago, IL 60601 mda.org

Myasthenia Gravis Foundation of America

The Myasthenia Gravis Foundation of America (MGFA) works to raise awareness for and support those living with myasthenia gravis (MG). MGFA strives to support promising research, improve time to diagnosis and care for MG, and raise awareness about MG through advocacy, communications, and education.

 800-541-5454; mgfa@myasthenia.org National Office: 290 Turnpike Road, Suite 5-315, Westborough, MA 01581 myasthenia.org

The Myositis Association

The Myositis Association aims to improve the lives of people affected by myositis, fund innovative research, and increase myositis awareness and advocacy. They offer support groups, a community forum, and educational resources.

• 800-821-7356 6950 Columbia Gateway Drive, Suite 370, Columbia, MD 21046 myositis.org

Health and Wellness

Community Health at Atlantic Health System

Atlantic Health System's health and wellness program is tailored to meet the needs of today's adults. Offerings are held at various locations throughout Northern NJ and virtually. They include health education programs, nutrition, exercise, life enrichment classes, health screenings, and more. Many programs are free; others may require a fee.

 844-472-8499 to ask about programming or request a monthly calendar of events atlantichealth.org/communityhealth

Chambers Center for Well-Being

Part of Atlantic Health System, the Chambers Center is a state-of-the-art personalized medicine program and wellness facility offering a comprehensive range of medical, preventative care, fitness, nutrition, spa, and therapeutic services to improve your overall well-being. We offer a supportive environment to adopt a proactive. holistic approach to health and wellness.

• 973-971-6301 435 South Street, Suite 160, Morristown, NJ 07960 chamberscenterforwellbeing.org

Centers for Disease Control (CDC)

Improving emotional well-being, social connectedness, and resiliency through research-based health promotion and prevention programs is critical to the population's health. The CDC offers educational information including articles, tips, and quizzes to build knowledge and enhance emotional health and well-being.

· cdc.gov/mentalhealth

MGFA's Living Your Best Life with MG Wellness **Strategies**

The Myasthenia Gravis Foundation of America has a webpage devoted to providing tips, inspiration, and resources to MG patients on topics such as daily living, exercise, and fitness, and more.

 myasthenia.org/Living-Your-Best-Life-With-MG/ Wellness-Strategies

In response to COVID-19, MGFA has created an MG Wellness Webinar Series to connect, educate, and empower MG patients, care partners, and medical professional. Registration is simple and free.

 myasthenia.org/Living-Your-Best-Life-With-MG/ Wellness-Strategies/Wellness-Series

MDA's Exercising with a Muscle Disease from Quest: MDA's Research & Health Magazine Spring 2009

This MDA (Muscular Dystrophy Association) magazine issue shares information on exercising with a muscle disease.

 mda.org/sites/default/files/MDA Quest Excercise Package 2009.pdf

Education

Muscular Dystrophy Association Community Education

A compilation of resources on neuromuscular diseases that can be accessed on the Muscular Dystrophy Association's website include disease fact sheets, MDS informational resources, and more.

mda.org/services/community-education

ALS Association Informational Factsheets

The ALS Association offers a compilation of informational factsheets and resources that discuss and address government benefits, caregivers, research, and more, along with resources for ALS patients and newly diagnosed individuals.

 als.org/navigating-als/living-with-als/informationalfactsheets

National Institute of Health - National Institute of Neurological Disorders and Stroke

Learn about neurological and neurodevelopment disorders from NINDS. NINDS shares information about clinical trials, education, and support resources.

ninds.nih.gov/health-information

Help at Home

Home Health Services

While Medicare and other insurances may cover some home care services, such as help after surgery or hospitalization. This is usually ordered by a physician for short-term support and requires that a person meet specific criteria to medically qualify. Generally, nurses, therapists, or aides provide one to two hours of services each week. Most insurances do not cover ongoing or long-term home care to assist with personal care and supervision. This is called "custodial care," and therefore this is often an out-of-pocket expense.

Home Care Association of New Jersey

Provides a directory of member home care agencies throughout New Jersey.

• 732-877-1100 411 North Avenue East, Cranford, NJ 07016 homecarenj.org

Atlantic Visiting Nurse

· Serves Essex, Morris, Somerset, Sussex, Union, and Warren Counties in NJ and Pike County in PA 973-379-8400, Referrals 973-379-8472 atlantichealth.org/visitingnurse

Visiting Nurse Association of Northern New Jersey

Serves Morris, Hunterdon, Sussex & Warren Counties

• 800-938-4748 vnannj.org

Private Pay

Home care can enable individuals to remain at home as opposed to moving into assisted living or a skilled nursing facility. Home care can help enable people to remain at home instead of choosing to live in a facility. When an individual requires personal care and supervision, this is called "custodial care," and it is an out-of-pocket expense. The average cost of private pay home care services in NJ is \$35-40/hour and most agencies have a daily minimum of 4 consecutive hours. Ask your medical team or social worker for a more comprehensive list of home care providers.

Additional resources to help pay for home care include:

- · Long Term Care Insurance policy that covers home care services
- Applying for social service programs, such as Medicaid
- Veteran's Aid & Attendance pension benefit available to Veterans or spouses who meet financial criteria

Private Care Agencies

Commission on Accreditation for Home Care (CAHC) New Jersey

- CAHC-accredited agencies go beyond the basic requirements of a health care service firm to undergo lengthy review and annual monitoring by experienced RN Field Nurse Surveyors. Visit cahcusa.org or call 201-880-9139 for names of accredited agencies.
- · Atlantic Private Care (affiliated with Atlantic Health System) 973-540-9000 atlanticprivatecare.com
- Alvita Home Care 212-273-0490 alvitacare.com
- · Bayada Home Health Care 973-867-3000 bayada.com
- Brightstar Home Care 973-898-0800 (Morris), 908-322-8200 (Westfield) brightstarcare.com
- · Claddagh Home Care 973-598-9732 claddaghhomecare.com
- Executive Care 201-489-4899 executivehomecare.com
- · HomeWell Senior Care 201-487-9220 homewellseniorcare.com
- SAGE Eldercare 908-273-8400 sageeldercare.org
- · Senior Home Care Services 973-538-4357 seniorhomecareservices.com
- · Seniors in Place 973-376-1600 seniorsinplace.com
- The Senior Company 973-355-6336 theseniorcompany.com
- TrueVine 732-821-7618 truevinehealthcare.com
- Synergy Home Care 973-394-5638 synergyhomecare.com
- · Victory Care Givers 908-441-6625 victorycaregivers.com

Home Safety

FireAvert

FireAvert is an effective way to protect a home from dangerous fires. Products for gas or electric stoves and microwaves install in less than ten minutes and requires no professional skill. FireAvert syncs to the sound of the smoke alarm, including Nest alarms, and will automatically shut off the power or gas when your smoke alarm sounds.

· fireavert.com

Medical Alert Systems

Many companies offer systems that provide pendants or wrist units that the wearer can push to connect them with emergency services if they need help. These are helpful for individuals who live alone or are at risk for falling. These systems are often an out-of-pocket expense (may be covered by Medicaid) but provide a sense of security. Some companies offer specialized services that can assist with health monitoring, such as medication dispensing systems, fall detection, or GPS monitoring.

- Ask your medical team or social worker for a more comprehensive list.
- ADT Emergency Panic Button 1-800-521-1729 adt.com
- LifeAlert 1-800-360-0329 lifealert.com
- · LifeStation Medical Alert System 1-866-398-8474 lifestation.com
- · MedicalCare Alert 1-855-272-1010 medicalcarealert.com
- Mobile Help Medical Alert System 1-800-992-0616 mobilehelp.com
- Philips Lifeline Also offers medication dispensing system. 1-855-600-6127 lifeline.philips.com
- · Walgreens Ready Response Multilingual monitoring services available 1-866-310-9061 walgreensreadyresponse.com

Home Modifications

Home modification organizations have a goal to create safe and accessible homes to patients with physical needs. These companies can help make changes in the home such as adding grab bars, ramps, and stair chair lifts.

- Back Home Safely 973-219-4147 backhomesafely.com
- 101 Mobility 973-447-3975 for Northern New Jersey or 888-258-0652 for a different service area 101mobility.com
- · Able Care 800-310-1196 able-care.com

Assistive Devices

The goal of assistive devices is to improve functionality in one's daily routine from grips on toothbrushes or utensils to a sock aide to help with dressing. Ask your medical team or social worker for suggestions on gadgets that can create a positive change to your daily routine.

Medical Equipment

Power Wheelchair

Power wheelchairs and scooters enable riders to steer themselves more easily at home or in the community. Medical insurance requires patients to go for a clinic evaluation for approval. The process can generally take three months and the power wheelchair or scooter will only be provided after the clinic evaluation. You can find information about cost and details from Medicare's website or by calling your insurance provider

- · medicare.gov/Pubs/pdf/11046-Medicare-Wheelchair-Scooter.pdf
- You can reach out to the following locations for a clinic evaluation:
 - Kessler Saddle Brook 201-368-6000
 - JFK Edison 732-321-7000 x 65812
 - NuMotion 855-873-6660

AtHome Medical

AtHome Medical, an affiliate of Atlantic Health System, is a provider of durable medical equipment including home oxygen, respiratory equipment, home enteral equipment, sleep therapy devices, wheelchairs, specialty beds and support surfaces.

• 1-800-287-0643 200 The American Road, Morris Plains, NJ 07950 athomemedical.org

AECDC – Health Equipment Loan Program (HELP)

This program lends medical equipment such as walkers, shower seats, wheelchairs, etc. at no cost for as long as needed to individuals with limited finances. A minimal, refundable deposit is required depending on the type of equipment that is being loaned.

• 732-296-9922 222 Livingston Avenue, New Brunswick, NJ 08901 aecdc.org

Goodwill Home Medical Equipment

Non-profit organization provides refurbished durable medical equipment to anyone, with priority given to those with limited resources for getting such equipment due to lack of health insurance or coverage of specialized equipment.

• 609-812-2210 300 Benigno Boulevard, Bellmawr, NJ 08031 goodwillhomemedical.org

Pluckemin Presbyterian Church Medical **Equipment Ministry**

Pluckemin Church loans gently used medical equipment (such as wheelchairs, walkers, crutches, recliners, hospital beds, etc.) at no charge for those in need. Supplies are donated by the community for the community.

908-396-6057 279 Rt. 202-206, PO Box #402, Pluckemin, NJ 07978 ppch.org

Ask JAN

The Job Accommodation Network (JAN) provides free, expert, and confidential guidance on workplace accommodations and disability employment.

• 800-526-7234 askjan.org

Food and Nutrition

Feeding America

Offers an online listing of food banks and links to food assistance programs.

• 800-771-2303 feedingamerica.org

FoodPantries.org

Online listing of food pantries and soup kitchens throughout the country.

· foodpantries.org

Support

ALS Association Support Groups

The Greater NY ALS Association Chapter leads support groups in New Jersey along with telephone and virtual support groups.

als-ny.org/index.php?page=for patients&sub=support

MGFA Support Groups

MGFA-sanctioned Support Groups can offer support. resources, and educational programming as well as social and recreational activities. Share your story, learn from local professionals, and obtain information or "life hacks" to help you manage your MG and symptoms so you can live a better quality of life. Support groups can be found with the "Find a Support Group Near You" function.

 800-541-5454; mgfa@myasthenia.org myasthenia.org/Community-Resources/Support-Groups-MG-Friends

Caregiver Resources

Thomas Glasser Caregivers Center at Overlook Medical Center

Recognizing that healthy self-care is an important part of the ability to care for someone else. The Thomas Glasser Caregiver Center provides support in a variety of ways. Located just behind the hospital's information desk and lobby, the center offers visitors a quiet space for respite and privacy as well as a place where caregivers can take a break from the bedside to reflect and rest, yet still be close to their loved ones. The center features guiet areas for conversations, computers and business equipment, a kitchenette filled with beverages and snacks, a resource library, as well as massages and healing touch services provided by licensed therapists. Visitors can receive counseling and support from staff members, as well as learn about support groups, classes and lectures for caregivers.

• 908-522-6348 atlantichhealth.org

Statewide Respite Care Program

This NJ program provides respite care services to relieve their unpaid caregivers of stress arising from the responsibility of providing daily care. Services can include home health aides, medical or social adult day care, or a short-term stay in a skilled nursing facility. To learn more about the program's eligibility requirements, contact the NJ Aging & Disability Resource Connection.

• 877-222-3737 adrcnj.org

ALS Association's Support for Caregivers

The ALS Association devotes a webpage specifically to offering caregiver resources, such as tips and hints, coping mechanisms, self-care suggestions, support groups, and more.

· als.org/navigating-als/for-caregivers

Muscular Dystrophy Association's Guide for **Caregivers**

An online booklet (pdf) that is meant to guide and act as a resource for caring for someone who has a neuromuscular disease, created by the Muscular Dystrophy Association.

• mda.org/sites/default/files/Guide-For-Caregivers-2018.

GBS|CIDP Foundation International's A **Handbook for Caregivers**

A quide created and offered as a pdf by GBS|CIDP Foundation International meant to aid caregivers, family members, and friends of patients with Guillain-Barre syndrome, CIDP, and more.

• gbs-cidp.org/wp-content/uploads/2012/07/A-Handbook-for-Caregivers.pdf

Caregivers Connections – DOROT

DOROT offers a telephone-based support group for those who have difficulty going to a meeting due to their caregiving responsibilities or access to transportation.

 877-819-9147 or 212-769-2850 dorotusa.org

NJ Self Help Clearinghouse

Resources to find local support groups in your area for a variety of topics

• 800-367-6274 njgroups.org

Well Spouse Association – Support for Spousal Caregivers

The Well Spouse Association advocates for and addresses the needs of individuals caring for a chronically ill and/or disabled spouse/partner. Website offers information and directory of local support groups for spousal caregivers.

• 800-838-0879 or 732-577-8899 wellspouse.org

Caregivers Coalitions of the United Way of **Northern New Jersey**

Coalitions facilitate education, access to resources, advocacy, and support for those caring for older adults, individuals with disabilities or mental illness. Coalitions offer monthly meetings, educational seminars, special events and caregiver socialization. In Morris, Suburban Essex, Somerset, Sussex, and Warren Counties. Pathways for Caregiving guidebook available in print and online.

· unitedwaynnj.org

Veteran's Administration – Caregiver Support Line Education Calls

Offers supports for caregivers of veterans of all eras. Visit website and contact the NJ VA Caregiver Support Coordinator to learn more about available resources.

- 855-260-3274 National VA Caregiver Support Line
- 973-676-1000 ext. 3085 NJ VA Caregiver Support Coordinator caregiver.va.gov

Counseling Services

A new medical diagnosis and the changes that ensue may cause some people, and their loved ones, to struggle with issues such as depression, anxiety, grief and loss, negative self-image, cognitive impairment, and other mental health issues. Counseling resources are available to help individuals and their loved ones address emerging mental health concerns, or emotional issues they have faced throughout their lives.

Unless indicated, the following agencies accept most insurance and/or offer services on a sliding scale based on income. We also invite you to speak with your social worker regarding counseling referrals tailored to your specific needs.

- ** Indicates Spanish speaking counselors are available.
- ** Indica que hay consejeros de habla hispana disponibles.

Atlantic Health Behavioral Health

Sessions available in-person at Atlantic Health System locations, or virtually

All insurances accepted

• 908-522-4800 atlantichealth.org/conditions-treatments/behavioralhealth

Psychology Today Directory **

This website, sponsored by Psychology Today magazine, provides a directory of therapists with descriptions provided by the professionals themselves. The site enables users to narrow down their choices by language, desired location, specialty, gender, as well as types of insurance accepted or other payment methods available.

· psychologytoday.com/us

Medicare **

Find psychologists, psychiatrists and clinical social workers who accept Medicare.

· medicare.gov

Bergen County

Jewish Family Service of Northern New Jersey ** **Teaneck**

JFS offers counseling for clients of all ages as well as case management, assessment, and wellness services for seniors.

• 201-837-9090 jfcsnnj.org/mental-health-services

Essex County

Family Connections - Caregiver Connections Program **

Orange

Program offers Essex County caregivers in-home counseling and connection to community resources and supports.

• 973-675-3817 familyconnectionsnj.org

Family Service League **

Bloomfield

Payment: Sliding scale, dedicated to serving lowerincome individuals and families. Insurance is not accepted.

• Phone: 973-746-0800, ext. 301 familyserviceleague.org

Main Street Counseling **

West Orange

• 973-736-2041 mainstreetcounseling.org

Mental Health Association of Essex and Morris, Inc. **

Montclair

Payment: Accepts Medicaid/Medicare only, does not accept private pay

• 973-509-9777 mhainspire.org

Jewish Family Service of MetroWest NJ Florham Park

JFS offers counseling for clients of all ages as well as case management, assessment, and wellness services for seniors.

• 973-765-9050 ifsmetrowest.org

Hunterdon County Hunterdon Health **

Fleminaton

Part of Hunterdon Health system

• 866-424-2060 hunterdonhealth.org/services/hunterdonbehavioralhealth

Jewish Family Service of Somerset, Hunterdon, and Warren Counties

Somerville

JFS offers counseling for individuals of all ages, and support groups for seniors and caregivers.

• 908-725-7799 jewishfamilysvc.org

Middlesex County

Middlesex County Office of Human Services Division of Addictions and Mental Health Planning

New Brunswick

Provides information and referral services for behavioral health, mental health, and addictions programs.

• 732-745-3280 middlesexcountynj.gov

Jewish Family Services of Middlesex County Milltown or Monroe Twp

Provides a range of counseling, support groups and multi-services for seniors

• 732-777-1940 or 609-395-7979 ifsmiddlesex.org

Monmouth County

Monmouth County Office of Mental Health Human Services Building

• 732-431-7200 co.monmouth.nj.us

Mental Health Association of Monmouth County Shrewsbury

Mental Health Association promotes mental health as a critical component of overall wellness, including prevention services for all, early identification, and intervention for those at risk, integrated care, and treatment for those who need it, with recovery as the goal.

• 732-542-6422 mentalhealthmonmouth.org

Morris County

Jewish Family Service of MetroWest NJ

Florham Park

JFS offers counseling for clients of all ages as well as case management, assessment, and wellness services for seniors.

• 973-765-9050 ifsmetrowest.org

Mental Health Association of Morris County ** **Parsippany**

Payment: Accepts Medicaid/Medicare only, does not accept private pay

• 973-334-3496 mhainspire.org

New Bridge **

Parsippany

This agency offers counseling and psychiatric services for individuals of all ages. For seniors, New Bridge provides in-home professional counseling to homebound seniors and individuals with physical difficulties in Morris County.

• 888-746-9333 newbridge.org

Ocean County Caring Family Community Services ** Jackson, NJ

• 732-780-2799 caringfamily.org

Passaic County

Jewish Family Service of Clifton-Passaic **

Passaic

JFS offers counseling for clients of all ages as well as case management, assessment, and wellness services for seniors.

 973-777-7638, Ext. 151 ifsclifton.org

New Bridge

Haskell

This agency offers counseling and psychiatric services for individuals of all ages.

• 888-746-9333 newbridge.org

Somerset County

Jewish Family Service of Somerset, Hunterdon, and Warren Counties

Somerville

JFS offers counseling for individuals of all ages, and support groups for seniors and caregivers.

• 908-725-7799 jewishfamilysvc.org

Richard Hall Community Health & Wellness Center **

• 908-725-2800 co.somerset.nj.us/government/human-services/ mental-health

Family & Community Services of Somerset County **

Bound Brook

Virtual and in-person support services

• 732-356-1082 fcssomerset.org

Sussex County **Jewish Family Service of MetroWest NJ**

Florham Park

JFS offers in-home and office-based counseling, case management and support groups to older adults in southern Sussex counties.

• 973-765-9050 ifsmetrowest.org

Tri-County Behavioral Care **

Stanhope, Sparta, and Denville

• 973-691-3030 tcbllc.org

New Bridge

Sparta

This agency offers counseling and psychiatric services for individuals of all ages.

• 888-746-9333 newbridge.org

Union County Jewish Family Service of Central NJ Elizabeth

JFS provides free in-home counseling to Union County seniors, age 60+. Income guidelines may apply. Caregiver counseling is also available if the senior is a Union County resident.

• 908-352-8375 655 Westfield Avenue, Elizabeth, NJ 07208 ifscentralnj.org

Resolve Community Counseling **

Scotch Plains

Serves only Union County residents

• 908-322-9180 resolvenj.com

Warren County

Family Guidance Counseling Center

FGCWC offers behavioral health care treatment, rehabilitation, crisis intervention and educational, prevention and support program services through offices located in Washington, Hackettstown, and Phillipsburg. Initial appointment conducted in-person; virtual appointments available.

• 908-689-1000 fgcwc.org

Healing Road **

Hackettstown

• 215-688-5116 healingroadcounseling.com

Jewish Family Service of Somerset, Hunterdon, and Warren Counties

Somerville

JFS offers counseling for individuals of all ages, and support groups for seniors and caregivers.

• 908-725-7799 jewishfamilysvc.org

Omni Healthcare

Phillipsburg

• 908-329-2700 omhsi1.com

COVID-19 and **Neuromuscular Disorders**

American Academy of Neurology COVID-19 Resource Center

 aan.com/tools-and-resources/covid-19-neurologyresource-center/

Muscular Dystrophy Association

 Contact: ResourceCenter@mdausa.org mda.org/covid19

Transportation

Transportation, Disability Parking and Driving Assessments

Transportation is a common concern for many individuals with neurological conditions, whether for medical appointments, social engagements or running errands. There are many different options for transportation in New Jersey including county services, town buses, NJ Transit, and specialized medical transportation companies.

Discuss your transportation needs with your doctor or social worker so they can direct you to resources within your town or county. If a service requires you to prove eligibility, your medical team can provide letters or sign the forms as needed. As you research your options, also consider private companies that provide escorted transportation services.

Bear in mind that most transportation resources require advance notice. As soon as you identify a transport need, such as an upcoming appointment, contact the provider and inquire about how to make reservations and eligibility.

Public Transportation

Access link/NJ Transit - for all counties in New **Jersey**

Access Link is a public transportation service for people with disabilities who are unable to use NJ Transit's fixed bus routes. Access Link provides a shared -ride, curb to curb service that is comparable to bus routes throughout the NJ Transit system. Requires a mandatory transportation assessment, conducted by phone. Registration can take up to 3 weeks. Reservation office is open Monday through Friday 8:30 am to 5:00 pm.

• 800-955-2321 njtransit.com/accessibility/access-link-ada-paratransit

NJ Transit Reduced Fare Program

NJ Transit offers discounted rates for seniors 62+ and those with disabilities. Contact NJ Transit for current eligibility requirements and how to apply for a Reduced Fare ID Card.

• 973-275-5555 njtransit.com

Modivcare (formerly Logisticare) - for individuals with Medicaid

For patients with active Medicaid only, providing car, wheelchair, and stretcher transportation. Reservations are required in advance. You will need to provide your Medicaid policy number when you call to make a reservation.

• 866-527-9933 modivcare.com

Paratransit Systems by County

These programs are available to residents of the respective counties below. They offer curb-to-curb pick-up and drop-off service for medical appointments or errands. Eligibility requirements: residents who are 60+ years old or have a disability (requires a physician's note). The paratransit systems require pre-registration, which may be completed online or by calling the county's Paratransit System office. Members must make transportation reservations at least 48 hours in advance.

ESSEX COUNTY

Essex County Special Transportation System

Travels only within Essex County. No charge for the program.

• 973-618-1280 https://essexcountynj.org/senior-services/

HUNTERDON COUNTY

Hunterdon County LINK Transportation

The Hunterdon County LINK Transportation System provides transportation services to all residents of Hunterdon County, NJ. The Hunterdon County LINK Transportation System is comprised of a variety of services including "scheduled route" services (Flemington Shuffles, Cross County Shuffles), "demand response" services, and customized transportation services and assistance. LINK transportation services include accessible buses, reduced fares for eligible riders with disabilities, and medically necessary out-ofcounty trips.

• 908-684-8122 ridethelink.com

MIDDLESEX COUNTY

Middlesex County Area Transit (MCAT)

MCAT provides transportation for \$3.00 a trip (one way) fee. to seniors 60+ and disabled residents of Middlesex County. Intermittent transportation is available so that residents may obtain the necessities

of life, with priority given to non-emergency medical services. Registration and reservations are required.

• 800-221-3520 Office Address: 97 Apple Orchard Lane, North Brunswick, NJ 08902 Mailing Address:

PO Box 871, North Brunswick, NJ 0803

MONMOUTH COUNTY

middlesexcountynj.gov

Monmouth County SCAT

The Special Citizens Area Transportation (SCAT) program provides transportation services to elderly residents of Monmouth County to nutrition sites, food shopping medical appointments, and non-competitive employment.

• 732-431-6480 3000 Kozloski Rd, Ground Floor, Freehold, NJ 07728 co.monmouth.nj.us

MORRIS COUNTY

Morris Area Paratransit System (MAPS)

MAPS will provide services outside Morris County to transport patients to Overlook Medical Center. Wheelchair accessible transport available, aides or travel companions may accompany the member. Donations are welcome.

• 973-829-8103 morriscountynj.gov/Departments/Aging-Disabilities-Community-Programming/MAPS

Morris County Dial-a-Ride

These municipal services, available in each town, provide transportation for seniors for a variety of purposes, including medical appointments and personal errands. Check your town's listings for scheduling information and the phone numbers to call to make a reservation.

· morriscountynj.gov/Departments/Aging-Disabilities-Community-Programming/Dial-a-Ride

PASSAIC COUNTY

Passaic County Para Transit

The Passaic County Para Transit Program maintains a fleet of vehicles, which provide transportation for the county's senior citizens and disabled residents in need of non-emergency rides to medical appointments, shopping centers, county run nutrition and adult day care sites, and for the disabled residents to attend group work programs. Special lift vans are available to accommodate non-ambulatory individuals.

• 973-305-5756 passaiccountynj.org

SOMERSET COUNTY

Somerset County

Travel within the county only. Some services also vary by town. Call for more information and registration instructions.

• 908-231-7115 https://ridewise.org/municipal-transportation/

SUSSEX COUNTY

Sussex County Assisted Transportation

Transport available within the county for appointments, errands, and to commute to/from employment.

• 973-579-0480 https://sussex.nj.us/cn/webpage.cfm?tpid=9167

UNION COUNTY Union County Paratransit

The Union County Paratransit System provides specialized transportation services for elderly (60 and over), permanently disabled, and economically disadvantaged residents of Union County. Wheelchair accessible transport available, aides or travel companions are welcome. Services are available only within the county. Cost is \$3 each way, billed monthly to the member's home.

 908-241-8300 ext. 1 ucnj.org/dhs/accessible-transportation/paratransit

WARREN COUNTY

Warren County Demand Response Service

Depending on driver availability and your location, services may be available outside the county. Residents with a disability, senior citizens, veterans, low-income, or who live in certain areas of the county are eligible to participate in the program. Call to determine your eligibility.

908-454-4044 or 866-594-4044 warrencountynj.gov/government/human-services/ transportation-services

Community Resources

Town-Based Services

Check your town website to see if it offers a Senior Citizens and/or disabled persons resource page. It may have town-based transportation program information. (Note: Some towns may consider residents ages 55+ to be a "senior" and eligible for programs.)

Houses of Worship/Faith Communities

Many faith communities have volunteers who offer to transport members to medical appointments. Contact your faith community to see if they offer this service.

First Aid Squad

Some First Aid Squads offer limited medical transportation to residents of the community they serve. Contact your local first aid squad to determine if they offer this service.

Senior Housing Residents

Many Senior Housing residences offer shuttle services, or they may have a services coordinator or social worker onsite to help you plan your transportation.

Private Pay

NJ Find-a-Ride

Online directory of accessible transportation options for seniors and people with disabilities. Search for types of providers throughout the state, including public transportation, paratransit services, shuttles, dial-a-ride services, and private transportation companies.

• 877-652-1148 nj211.org/transportation-options-new-jersey

Life Ride

A van-based transport company, which can accommodate both ambulatory individuals and those with wheelchairs or assistive devices. Stretcher transport is also available and will require your physician's office to submit a certificate of medical necessity from, which the company can provide. Payment is required before the ride via credit/debit card, check or cash (exact change only).

• 551-225-0080 https://liferide.com

EZ Ride

A membership-based ride program. Members need only a cell phone, not a smart phone, and a credit or debit card. \$15 annual membership. Rides are provided through utilizing transportation services including Uber, Lyft, and other providers. Each ride includes a \$2.50 administrative fee.

• 201-939-4242 https://ezride.org

GoGoGrandparent

GoGoGrandparent turns on-demand transportation companies, like Uber and Lyft, into services that help keep seniors on-the-move. GoGoGrandparent is available nationally and uses a phone-based platform to access transportation for those unfamiliar or uncomfortable with smartphone apps. The system can also text a family member about the rider's status (picked up, en route, dropped off).

• 855-GOGO-USA (855-464-6872) gogograndparent.com

Disability Parking Placards

Many patients ask for the hang tags, or specialized license plates, that they can use in their own cars, or with their caregivers or other drivers, to park in the disability spaces marked in lots and garages with blue lines or signs.

You may be eligible for a Temporary Disability Placard, or a Permanent Placard, depending on your diagnosis, so talk it over with your doctor or social worker. You will need to complete an application and have your doctor sign it to verify your qualifying condition.

Temporary Placard: Bring your completed form to your local police station and they can give you a placard on the spot. The placard is valid for six months from the date you receive it. Call your local police station for more information.

state.nj.us/mvc/pdf/vehicles/SP-68.pdf

Permanent Disability Placard: Send your completed form to the NJ Motor Vehicle Commission in Trenton. The placard will arrive within four to six weeks.

· nj.gov/mvc/pdf/vehicles/SP-41.pdf

NJ Motor Vehicle Commission

• 609-292-6500 nj.gov/mvc/vehicles/disability.htm

Driver Evaluations and Rehabilitation Specialists

Adults who have experienced a physical, neurological, visual, or cognitive change in function may find that their driving performance has changed. For instance, they may get lost more easily, or they find their reflexes have slowed, or they may even feel pain or decreased range of motion that make driving more difficult.

These individuals may benefit from a driving assessment and if appropriate, rehabilitation services to help them retain or return to independent driving, if they are safe to do so

New Jersey Motor Vehicle Commission (MVC): Reporting a Concern

If a doctor, social worker, police officer or family member believes that an individual's driving skills makes them unsafe to be on the road, they may alert the MVC via letter. This also applies to individuals who experienced a seizure within the last 6 months.

- Reporting a Concern: nj.gov/mvc/drivertopics/ reportconcern.htm
- About the Medical Review Unit: nj.gov/mvc/ drivertopics/medreview.htm

Outpatient Assessment and Rehabilitation Facilities

Kessler Institute for Rehabilitation

• 973-731-3900 x2322 kessler-rehab.com/conditions-and-services/outpatientrehabilitation/

Hackensack Meridian Health: JFK Johnson **Rehabilitation Center**

Locations in Edison, Wayne, Brick

• 732-321-7056 ext.1 hackensackmeridianhealth.org/en/Services/ Rehabilitation/Driver-Rehabilitation-Program

Bacharach Institute for Rehabilitation **Pomona**

• 609-748-6866 bacharach.org

Insurance and Financial

Medicare Information from the ALS Association

For individuals hoping to learn more about Medicare and ALS, the ALS Association has created webpages and webinars with recordings, downloadable slides, and FAQs to answer all questions regarding home health benefits, eligibility, and enrollment, and more.

alsa.org/als-care/resources/medicare-information.html

Payment Assistance Options from GBS|CIDP Foundation International

Programs and organizations compiled by GBSICIDP Foundation International that may be able to help making medication and treatment more financially acceptable for struggling patients.

 gbs-cidp.org/support/resources/financial-assistanceresources/

State Health Insurance Program (SHIP) - NJ

SHIP provides free assistance to NJ Medicare beneficiaries who have questions about their health insurance. Volunteer counselors help answer questions about benefits and claims, supplement policies and longterm care insurance.

• 800-792-8820 state.nj.us

Healthcare.gov

Provides information about health insurance and available plans through the ACA exchange.

· healthcare.gov

NJ Save

NJ Save is an online application to help low-income seniors and individuals with disabilities save

money on Medicare premiums, prescription costs, and other living expenses.

· nj.gov

PA COMPASS

COMPASS is a website that allows individuals and community-based organizations access to screen for, apply for and renew a broad range of social programs.

· compass.state.pa.us

Good Days

Good Days is a national non-profit advocacy organization that provides patient assistance, financial resources, and emotional support and guidance for patients with chronic disease, cancer, or other lifealtering conditions.

• 877-968-7233 2611 Internet Blvd., Suite 105, Frisco, TX 75034 mygooddays.org

Patient Advocate Foundation

Patient Advocate Foundation provides direct services to patients with chronic, life threatening and debilitating diseases to help access care and treatment recommended by their doctor.

• 800-532-5274 421 Butler Farm Road, Hampton, VA 23666 patientadvocate.org

Medicine Assistance Tool

PhRMA's Medicine Assistance Tool helps patients, caregivers and health care providers find information about financial assistance and other resources.

• 571-350-8643 medicineassistancetool.org

National Organization of Social Security Claimants (NOSSCR)

The National Organization of Social Security Claimants' Representatives (NOSSCR) is a specialized bar association for attorneys and advocates who represent Social Security Disability Insurance and Supplemental Security Income claimants throughout the adjudicative process.

• 845-682-1880 1300 I Street, NW, Suite 825, Washington, DC 20005 nosscr.org

Needy Meds

NeedyMeds has free information on medication and healthcare costs savings programs including prescription assistance programs and medical and dental. NeedyMeds offers a free drug discount card that may help patients obtain lower prices on medications.

• 800 503-6897 50 Whittemore St., Gloucester, MA 01930 needymeds.org

HealthWell Foundation

HealthWell Foundation provides assistance with copays, premiums, deductibles and out-of-pocket expenses for supplies, supplements, surgeries, and more. HealthWell Foundation offers financial assistance through a number of Disease Funds, with new funds opening every year.

• 800-675-8416 healthwellfoundation.org

MedMonk

Medmonk's co-pay, voucher, and patient assistance programs improve patient access to medications. Delivered electronically and traditionally, these programs allow patients to stay on therapy and prevent disruptions to care regardless of the site of administration.

 info@medmonk.com medmonk.com

RxAssist

RxAssist is a resource center with information about patient assistance programs, Medicare Part D, programs for low-cost medications and any other issues related to pharmaceutical access. RxAssist offers a comprehensive database of these patient assistance programs, as well as practical tools, news, and articles so that health care professionals and patients can find the information they need.

rxassist.org

Financial And Legal Planning

National Academy of Elder Law Attorneys

Elder law attorneys can assist in legal and financial long-term planning. They can assist patients create documents such as advance directives, wills, power of attorney, and assist with Medicaid planning.

 1577 Spring Hill Rd, Suite 310, Vienna, VA 22182 703-942-5711 naela.org

PSI ACCESS Program

Pro-Bono Attorneys to help you navigate insurance issues and medication denials.

• 877-851-9065 to speak with a pro-bono attorney

End of Life Services and Bereavement Support

Throughout the course of treatment, medical teams work with patients and families to sustain quality of life - placing the focus on the patient's physical comfort, as well as supporting the emotional and spiritual well-being of both patients and their loved ones. There may come a time that curative treatment is no longer appropriate or desired, but for the medical teams, the emphasis on quality of life remains both during the patient's final days and for the patient's loved ones, as they face loss and experience feelings of grief.

The following resources place the focus on end-of-life: helping patients define, share, and enact their end-oflife wishes and providing support to patients and their loved ones with information, appropriate treatment, and bereavement services.

Advance Care Planning

Preparation is the key for every event in life and your health is no exception. Atlantic Health System supports patients in defining their health care goals and wishes in times of serious illness or injury. These vital decisions, made in advance, empower patients to guide their medical team in providing treatment that respects the patients' unique values and preferences.

Ask your doctor or your social worker to walk you through the process of advance care planning and help you shape your own goals of care. Following are websites that can also provide information and education.

Atlantic Health System Advance Care Planning Tools

Atlantic Health System offers an online guide, with videos, documents, and links, to help you explore and decide what matters most to you and then encourages you to discuss these ideas with people who are important in your life.

 atlantichealth.org/patients-visitors/education-support/ support-resources/advance-care-planning

The Goals of Care Coalition of New Jersey

This organization comprises medical professionals throughout the region who believe human interests and personal values must be at the core of medical decisionmaking. The organization provides professional training to healthcare practitioners, and community education to individuals, to ensure all patients with serious illness get the care they need and no less, and the care they want and no more.

goalsofcare.org

The Conversation Project

The Conversation Project® is a public engagement initiative of the Institute for Healthcare Improvement (IHI). Our goal that is both simple and transformative: to help everyone talk about their wishes for care through the end of life, so those wishes can be understood and respected. Prepare for Your Care PREPARE is a stepby-step program with video stories to help you have a voice in your medical care, talk with your doctors, and complete an advance directive form to put your wishes in writina.

prepareforyourcare.org/en/welcome

Capturing Legacy

Memories Live

The mission of Memories Live is to help people with life-limiting illnesses preserve their images, stories, and wisdom by creating personalized movies to pass on to their loved ones. The directorial team conducts interviews either in person (in NJ/NY metro area) or virtually (anywhere) with the individual either on camera, or via audio recording. The questions and conversation starters are sent to the individual in advance. There is no cost for this service.

• 646-245-1698 memorieslive.org

Palliative Care

Palliative care is a multidisciplinary medical service designed to enhance the quality of life for patients who suffer from serious or chronic illnesses. This is accomplished by not only relieving symptoms, but by also ensuring that all treatments are aligned with individual preferences and values. The professional palliative care team is made up of physicians, advanced practice nurses, registered nurses, chaplains, consulting psychiatrists, dieticians, and social workers. They maintain close contact with the patient's primary care doctor and specialists to ensure a seamless continuum of care.

Palliative care is appropriate for people of any age or stage of illness, whether it is curable, chronic, or life-threatening. Some patients may even make a full recovery. The medical team provides patients and their families with a wide range of palliative care services, including:

- · Expert pain and symptom management
- Social, psychological, and spiritual support
- Education on medical treatment options and disease
- Assistance with health care decision-making and

identifying goals of care

- Planning transitions to the home or other care settings
- · Bereavement support and services, including those offered by Atlantic Home Care and Hospice

Patients may also receive supportive care at home. which can include physical therapy, occupational therapy, and the services of a home health aide, all of whom can visit 1 to 2 times a week. They can help patients retain strength and mobility as well as assist with bathing and dressing. In-person and telehealth appointments are available.

Contact your doctor's office to request a referral to Palliative Care or for at-home supportive care services.

atlantichealth.org/conditions-treatments/palliative-care

Hospice Care

Those who have a life expectancy of six months or less and wish to forgo curative treatments may benefit more from hospice care.

Hospice care helps individuals facing terminal illnesses live as fully as possible with comfort and dignity and manages their care when they can no longer benefit from curative treatment. It also helps prepare individuals and family members for a peaceful death. Hospice physicians, nurses, social workers, chaplains and trained volunteers and bereavement professionals, partner to address the patient's needs and desires and those of the family.

Hospice services are typically provided at the patient's home, with team members making visits during weekdays. Most of the care for patients receiving services at home is provided by family. A nurse remains on call 24/7.

Some individuals seek inpatient hospice options, either at in-patient hospice facilities or skilled nursing facilities.

At-home hospice and insurance coverage:

- Hospices services are traditionally covered by private insurance, Medicare Part A and Medicaid.
- If a family wishes to hire additional care for the patient beyond what hospice providers provide, those costs would be paid out-of-pocket. Please see the "Help at Home" section for the names of private care agencies who can provide supplemental care.
- Inpatient hospice and insurance coverage:
- Insurance will cover the cost of hospice services provided at an inpatient facility.
- An inpatient stay for hospice typically requires an outof-pocket payment for room and board.

 Insurance would cover room and board if the patient's symptoms were deemed too difficult to manage at home, which the hospice provider can determine.

A physician or nurse practitioner must provide a referral for hospice services.

Home Care and Hospice at Atlantic Health System

Atlantic Visiting Nurse – Hospice has been providing end-of-life care for over 35 years in Essex. Morris, and Somerset counties in patients' homes, assisted living facilities and skilled nursing facilities.

• 973-379-8440 atlantichealth.org/conditions-treatments/visiting-nurse/

Hospice service providers are available throughout New Jersey. Your doctor or social worker can provide a list of additional at-home hospice providers based on geographic location or preference.

Inpatient Hospice Services **Center for Hope Hospice and Palliative Care**

Center for Hope offers a sliding scale for payment based on the patient's financial circumstances.

• 908-889-7780 111 Dehart Pl. Elizabeth 1900 Raritan Rd. Scotch Plains cfhh.org/home.html

Karen Ann Quinlan

• 973-383-0115 99 Sparta Avenue, Newton karenannquinlanhospice.org

Villa Marie Claire

The hospice facility is located in Saddle River, though the facility is currently closed for renovation. Inpatient hospices are currently provided at Holy Name Medical Center in Teaneck, which owns the hospice.

• 551-248-4800 Current location: Holy Name Medical Center, 718 Teaneck Road, Teaneck villamarieclaire.org

Vitas Healthcare

Wayne, NJ

 855-443-1436 220 Hamburg Tpke, Wayne vitas.com/care-services/inpatient-hospice-care

New Jersey Medical-Aid-in-Dying for the Terminally III Act (MAiD)

New Jersey's MAiD law allows terminally ill patients to request a doctor's prescription for medication that will end their suffering peacefully. To learn more, visit the NJ Department of Health website for information. Atlantic Health System encourages you to speak with your physician if you have questions

 nj.gov/health/advancedirective/maid newjerseydeathwithdignity.org acamaid.org

Bereavement Support

Reaching out to others is often difficult when we are struggling with grief, but experience teaches us that the more support and understanding we have around us, the better we will cope. Below are some resources to help with finding ways to heal after the loss of a loved one.

Atlantic Health System - The Thomas Glasser Caregivers Center at Overlook Medical Center

The Caregiver Center offers an array of resources for individuals seeking services and support after the loss of a loved one: a comprehensive resource guide, support groups, individual counseling, and in-person and virtual seminars held throughout the year.

Support Groups

Atlantic Visiting Nurse Home Health and Hospice – Hospice Bereavement Groups

Atlantic Home Care and Hospice offers several types of bereavement groups to the community, including those for spouses and adult children who have lost a parent.

 973-379-8472 or 973-379-8400 atlantichealth.org

Chilton Medical Center – Bereavement Support Group

Professionally run support group for those age 50+ grieving the loss of a loved one. Pre-registration is not required

- Meets fourth Tuesday of the month
- 973-831-5367 atlantichealth.org

Joseph T. Quinlan Bereavement Center

Newton and Hackettstown, NJ & Milford, PA

The center provides emotional support and education about the grief process for hospice families and the community. Services include Individual Support, Ongoing Support Groups, Grief Lecture Series, Annual Memorial Services, Classroom Support Services and Community Education and Workshops.

 800-882-1117 or 973-940-0413 karenannquinlanhospice.org

AARP

Offers access to an array of resources and information on loss, grief, and end-of-life issues, including financial and legal issues, claiming benefits, funeral arrangements, bereavement publications, widowed persons, traumatic loss, advance directives, and estate planning.

• 800-424-3410 aarp.org/families

The Compassionate Friends

Offers supportive services to bereaved parents, grandparents, and siblings after the death of a child of any age. Also manages an online support community.

• 877-969-0010 or 630-990-0010 compassionatefriends.org

DOROT Telephone Bereavement Support Group

DOROT offers a weekly telephone-based bereavement support group. Professionally run, this group provides a safe, caring environment for former caregivers who have suffered the loss of a loved one and are seeking a supportive place to grieve and heal. Registration required.

• 877-819-9147 dorotusa.org

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atlantichealth.org/neuroscience



Atlantic Health System does not endorse or recommend any service listed in this directory and resources are referenced for informational purposes only. The information in this directory was most current available at the time of publication, however, some programs/services/contact information may change or become outdated. Please check with individual organizations to verify accuracy and availability of programs and services.