Welcome to the ALS Association Wisconsin Chapter.

Enclosed you'll find information on ALS and The Wisconsin Chapter. The Chapter's mission is to assist patients, their families and friends to learn about the disease and to offer support. Thank you for registering with our Chapter. You will be notified of all opportunities to be involved in, including fundraising and educational events.

The Chapter sponsors monthly **Support Groups** throughout the State of Wisconsin. Enclosed is a listing of the locations, times and contact information of each group sponsored by the Wisconsin Chapter as well as independent ALS Support groups. You may also find this information on our Chapter website, www.als.org/wisconsin. Groups are open to individuals with ALS, their families, caregivers and friends and all others touched by ALS. Our groups offer a supportive environment that encourages understanding and open dialogue, including asking questions and discussing challenges and new ideas. Some of the best ideas and solutions come from other persons with ALS and their experiences.

The Chapter **Care Services Staff** is available by telephone, email and in-home visits to help answer questions and address concerns. The Care Services Staff can direct you to various resources and assist you in obtaining needed equipment and services. We are also available to simply lend an ear.

The Chapter also maintains a **Library** of information on ALS which is located at our main office. Please contact Kathleen Huevler at 920-288-7092 or kathleen@alsawi.org and she will facilitate getting the information to you.

The Chapter's **Equipment Loan Program** is available to persons with ALS who are registered with the Chapter. There are various types of durable medical equipment such as wheelchairs, commodes, shower chairs and benches; lift chairs, communication devices and more, available for loan at no cost. If you are interested in more information, please contact David Ferrie, Equipment Coordinator at 414-207-3911 or david@alsawi.org

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The Chapter's **Augmentative Communication Program** is available to persons registered with the Wisconsin Chapter. These are various types of communication devices available for loan at no cost. If you are interested in more information please contact, Angie Pereira, Care Services Director at 414-817-1541 or angie@alsawi.org.

The **Brian Trinastic Memorial Grant Program** provides reimbursement type grants to individuals diagnosed with ALS who are registered with the Chapter. This program helps relieve some of the costs involved with equipment, home modifications and transport to appointments. Information is included in this packet and applications are available on the Chapter website: www.als.org/wisconsin.

Please take your time reading the enclosed information. We understand it may be overwhelming therefore if you have any questions or would like to talk further, please call the Chapter office at 414-763-2220 and speak to one of our Care Services team members.

Sincerely,

Angie Pereira
Care Services Director

ALS Office 414. 763.2220
Fax 414. 231.9100
3333 North Mayfair Road, Suite 104
Wauwatosa, WI 53222
Member National Health Council
www.alsawi.org

ALS Support Groups

Support groups are a great resource for people to maintain control over their lives, to give and take the wisdom and experience that comes from living with a devastating illness. Support groups exist entirely for you, the person with ALS, and your family or loved ones. Find a support group near you below.

Central Wisconsin Support Group
Third Monday of every month from 6:00PM to 7:30PM
Via Zoom or in person.
For more information, contact Meg Posorske at posorske@sbcglobal.net.

LaCrosse Support Group
Second Saturday of the month from 10:30 AM to 12:00 PM
For more information, contact Carolyn Herman at 608.486.2973 or gerlyn5558@gmail.com or Roxanne Fox at foxrox54601@gmail.com.

Madison Area Support Group
Second Tuesday of every month from 1:00 PM to 3:00 PM
Via Zoom or in person.
For more information, contact Angie Pereira at angie@alsawi.org or Kristy Sharp at kristy@alsawi.org.

Milwaukee Area Support Group
Second Wednesday of every month from 1:00PM to 3:00PM
Via Zoom or in person.
For more information, contact Mary DeFrain Jones at mary@alsawi.org.

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Phone: 414-763-2220 / info@alsawi.org / www.als.org/wisconsin

Northeast Wisconsin Support Group
Second Wednesday of every month from 5:00 PM to 6:30 PM
Via Zoom or in person.
For more information, contact Angie Pereira at angie@alsawi.org.

Northwest Wisconsin Support Group
Second Thursday of every month from 1:00PM to 2:30PM
Via Zoom or in person.
For more information, contact Diane Fergot at diane@alsawi.org.

Milwaukee Area ALS Caregiver Support Group
Third Wednesday of every month from 2:30PM to 4:30PM
Via Zoom or in person.
For more information, contact Robin Stanczyk at robin@alsawi.org.

Duluth-Superior Area ALS Support Group
TBD
Contact: Anne Supplee at anne@alsmn.org or 612-672-0484, ext 1050.

Statewide Caregiver Support Group
Quarterly. Future dates and times to be determined
Zoom meeting.
For more information, contact Angie Pereira at angie@alsawi.org.

ALS Centers & Clinics

The ALS Association collaborates with some of the best ALS physicians and clinics across the United States to help ensure that people living with ALS have access to specialized care, based on best practices. The ALS Association's Certified Treatment Centers of Excellence and Recognized Treatment Centers provide compassionate care in a supportive, family-oriented atmosphere.

This multidisciplinary care model brings together a team of health care professionals specially trained to address the needs of people living with ALS, allowing them to receive care from each discipline during a single visit. The care team typically includes a neurologist, physical therapist, occupational therapist, respiratory therapist, nurse, dietitian, speech language pathologist, social worker, mental health professional and an ALS Association Chapter liaison.

Certified Treatment Centers of Excellence

Since 1998, The ALS Association's nation-wide network of Certified Treatment Centers of Excellence has provided evidence-based, multi-disciplinary ALS care and services in a supportive atmosphere with an emphasis on hope and quality of life. The ALS Association Certified Treatment Center of Excellence Program designs, implements, and monitors a national standard of best-practice care in the management of amyotrophic lateral sclerosis (ALS). Certifications are based on established requirements of the program, professionals' skill sets, people living with ALS served, active involvement in ALS-related research, relationships with local Chapters, and access to care. Each clinic must meet The ALS Association's clinical care and treatment standards, based on AAN Practice Parameters, participate in ALS-related research and successfully complete an annual comprehensive site review.

Froedtert & The Medical College of Wisconsin
9200 W. Wisconsin Avenue, Milwaukee, WI 53226
414-805-5224
Medical Director: Dominic Fee, M.D. and David Shirilla, M.D.

Milwaukee VA Medical Center ALS Clinic
5000 West National Avenue, Milwaukee, WI 53295
414-384-2000
Medical Director: Dominic Fee, M.D. and David Shirilla, M.D.

The ALS Association Wisconsin Chapter
3333 N. Mayfair Road, Suite 104, Wauwatosa, WI 53222
Phone: 414-763-2220 / info@alsawi.org / www.als.org/wisconsin

Affiliated Clinic

There are ALS clinics located across the country that provide treatment and care based on a multidisciplinary model. These clinics may be affiliated with and/or supported by a private foundation, a university medical system, the Veterans Administration or another non-profit organization. Some clinics may offer opportunities for people living with ALS to participate in research.

Gundersen Health System ALS Clinic
1900 South Avenue, La Crosse, WI 54601
608-775-9000 or 800-362-9567 ext 59000
Medical Director: Michael Leone, M.D.

UW Health University Hospital ALS Clinic
600 Highland Avenue, Madison, WI 53792
608-263-5442
Medical Director: Stephanie Gardon, M.D.

The ALS Association Wisconsin Chapter
3333 N. Mayfair Road, Suite 104, Wauwatosa, WI 53222
Phone: 414-763-2220 / info@alsawi.org / www.als.org/wisconsin

Equipment Loan Program

Empowering individuals with ALS and their families to live fuller lives.

Our Equipment Loan Program is available to any person living with ALS in the Chapter's service area and registered with the Chapter. The Chapter maintains an inventory of gently used medical equipment that has been generously donated to the Chapter at three Wisconsin sites: Milwaukee, Appleton, and Eau Claire.

These items are available at no charge. If your physician, occupational therapist or physical therapist tells you that you would benefit from medical equipment, and your insurance will not cover the expense, we may be able to provide you with these items.

Some examples of items we have are:

- Mobility aids: canes, walkers, manual wheelchairs, power wheelchairs
- Bathroom items: raised toilet seats, commodes, shower chairs, bath benches
- Patient lifts
- Transfer boards and pivot discs
- Over-bed tables
- Threshold ramps, portable ramps

The Process

Your individual abilities need to be evaluated to determine the appropriate equipment for you. Consult your physician, occupational therapist or physical therapist when equipment needs arise.

Questions?

If you have any questions about this program, please contact David Ferrie at 414.207.3911 or david@alsawi.org.

Donations?

Most of the equipment in our program has been donated. Please contact us if you would like to donate equipment to our program. Monetary donations can be designated for this program and will be used to purchase, maintain and deliver equipment. If you wish to contribute to these funds, please contact Kathleen Huevler at 920.288.7095 or kathleen@alsawi.org.

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Communication & Assistive Devices

Empowering individuals with ALS and their families to live fuller lives.

Our Communication & Assistive Device Program is available to any person living with ALS in the Chapter's service area and registered with the Chapter. This program provides assistive and augmentative communication equipment to individuals who have lost their ability to orally communicate.

The Process

An evaluation is completed by a skilled Speech and/or Occupational Therapist. Your therapist will determine which type of equipment would be most helpful and if additional training is required. If your insurance will not cover the expense, we may be able to provide you with these items. Your therapist will contact our Care Services team with their recommendation. The augmentative/alternative communication device or assistive device will be loaned out at no charge. The items need to be returned to our loan pool once you have finished using them, allowing others to have their equipment needs met.

Questions?

If you have any questions about this program, please contact Kathleen Huevler at 920.288.7095 or kathleen@alsawi.org.

Donations?

Many devices purchased via insurance have been donated to our program. If you would like to donate equipment, please contact Kathleen Huevler at 920.288.7095 or kathleen@alsawi.org. Monetary donations can be designated for this program and will be used to purchase, maintain and deliver equipment.

The ALS Association Wisconsin Chapter
3333 N. Mayfair Road, Suite 104, Wauwatosa, WI 53222
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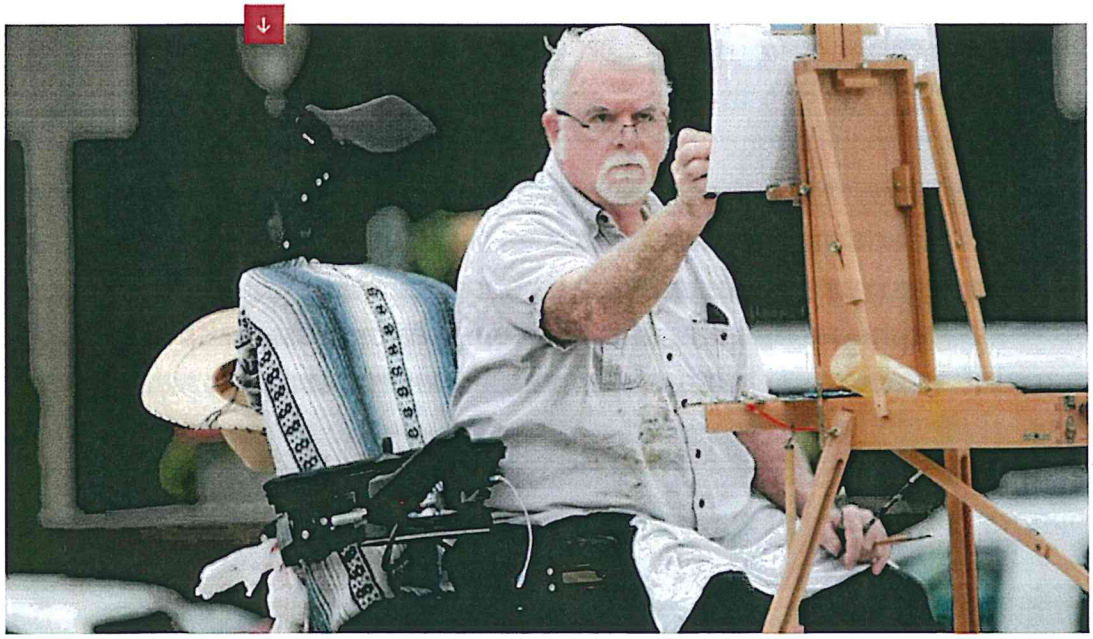
What is ALS?

ALS, or amyotrophic lateral sclerosis, is a progressive neurodegenerative disease that affects nerve cells in the brain and the spinal cord. A-myo-trophic comes from the Greek language. "A" means no. "Myo" refers to muscle, and "Trophic" means nourishment – "No muscle nourishment." When a muscle has no nourishment, it "atrophies" or wastes away. "Lateral" identifies the areas in a person's spinal cord where portions of the nerve cells that signal and control the muscles are located. As this area degenerates, it leads to scarring or hardening ("sclerosis") in the region.



Motor neurons reach from the brain to the spinal cord and from the spinal cord to the muscles throughout the body. The progressive degeneration of the motor neurons in ALS eventually leads to their demise. When the motor neurons die, the ability of the brain to initiate and control muscle movement is lost. With voluntary muscle action progressively affected, people may lose the ability to speak, eat, move and breathe. The motor nerves that are affected when you have ALS are the motor neurons that provide voluntary movements and muscle control. Examples of voluntary movements are making the effort to reach for a smart phone or step off a curb. These actions are controlled by the muscles in the arms and legs.

There are two different types of ALS, sporadic and familial. Sporadic, which is the most common form of the disease in the U.S., accounts for 90 to 95 percent of all cases. It may affect anyone, anywhere. Familial ALS (FALS) accounts for 5 to 10 percent of all cases in the U.S. Familial ALS means the disease is inherited. In those families, there is a 50% chance each offspring will inherit the gene mutation and may develop the disease. French neurologist Jean-Martin Charcot discovered the disease in 1869.

Recent years have brought a wealth of new scientific understanding regarding the physiology of this disease. There are currently four drugs approved by the U.S. FDA to treat ALS (Riluzole, Nuedexta, Radicava, and Tiglutik). Studies all over the world, many funded by The Association, are ongoing to develop more treatments and a cure for ALS. Scientists have made significant progress in learning more about this disease. In addition, people with ALS may experience a better quality of life in living with the disease by participating in support groups and attending an ALS Association Certified Treatment Center of Excellence or a Recognized Treatment Center. Such Centers provide a national standard of best-practice multidisciplinary care to help manage the symptoms of the disease and assist people living with ALS to maintain as much independence as possible for as long as possible. According to the American Academy of Neurology's Practice Paramater Update, studies have shown that participation in a multidisciplinary ALS clinic may prolong survival and improve quality of life.

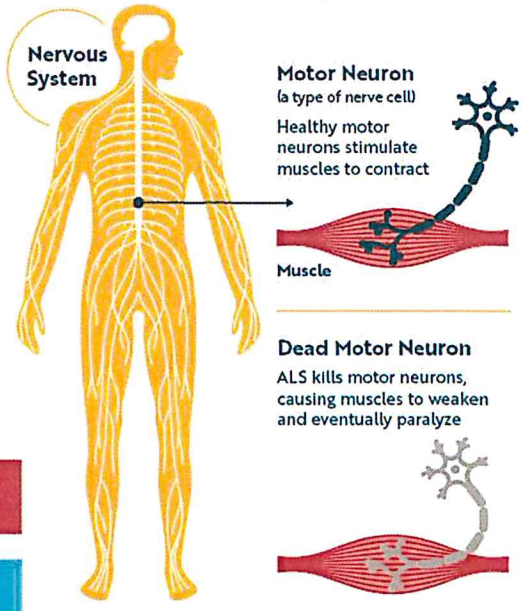
ALS ASSOCIATION What is ALS?

A myotrophic
L ateral
S clerosis

ALS is an always fatal neurodegenerative disease in which a person's brain loses connection with the muscles. People with ALS lose their ability to walk, talk, eat, and eventually breathe.

ALS usually strikes people between the ages of 40 and 70, but it can strike anyone at any time. In the past year, over 20,000 people living with ALS were served through our chapter network.

Although there is not yet a cure or treatment that halts ALS, scientists have made significant progress in understanding what causes ALS. But their work is not done. Together, we work toward a cure.



Facts About ALS

5,000+
people are diagnosed per year

2-5 years
is the average life expectancy

10 percent
of cases are inherited through a mutated gene

90 percent
of cases occur without family history

$2 billion
is the estimated cost to develop a drug to slow or stop the progression of ALS

$250,000
is the estimated out-of-pocket cost for caring for a person with ALS

Every **90 minutes** someone is diagnosed and someone passes away from ALS

There is NO CURE for ALS

SYMPTOMS

Progressive loss of muscle control

ALS gradually prohibits the ability to:

- Speak
- Swallow
- Walk
- Grasp objects
- Move
- Breathe

DIAGNOSIS

Difficult to diagnose

ALS is often diagnosed by ruling out other diseases, which may take months or years

MILITARY

Veterans are more likely to get ALS

ALS impacts veterans regardless of the branch of service served in and affects those who served in both peacetime and war

The ALS Association Core Values: COMPASSION. INTEGRITY. URGENCY.

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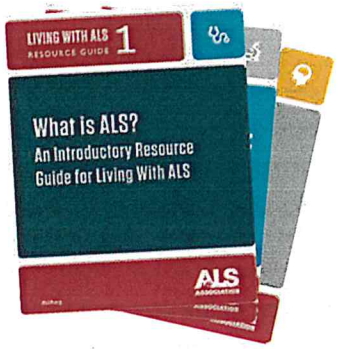
Image

Living with ALS Resource Guides



The ALS Association's Living with ALS Resource Guides were created because of the rapidly expanding information & research in the clinical management of ALS. These educational materials were designed to inform & educate people about ALS in a comprehensive & easily understood format. They address many of the common concerns & issues that face people living with ALS.

Reading all 12 resource guides at one time can be overwhelming to persons with ALS and their families. We highly recommend that you only access the information that pertains to your present circumstances.

Once you have reviewed one or more of The ALS Association's Living with ALS Resource Guides, you may have questions and you may want to know where to go for even more information. Feel free to contact The ALS Association Wisconsin Chapter at kathleen@alsawi.org and we will gladly help you.

Resource Guide 1: What is ALS? An Introductory Resource Guide for Living with ALS

This resource guide provides an overview of ALS, what it is, and how it affects your body. It provides information on what kind of resources are available to help you deal with ALS more effectively.

Resource Guide 2: After the ALS Diagnosis: Coping with the "New Normal"

This resource guide addresses the psychological, emotional, and social issues that you must face when your life is affected by ALS. It provides information on how to cope with the many lifestyle changes and adjustments that occur when you live with ALS.

Resource Guide 3: Changes in Thinking and Behavior in ALS

This resource guide addresses how thinking and behavior may be affected by ALS and how these changes can impact disease course, symptom management, and decision making.

Resource Guide 4: Living with ALS: Planning and Making Decisions

This resource guide reviews areas where careful planning and decision making will be required and will provide you with resources to help you and your family plan for the future.

Resource Guide 5: Understanding Insurance and Benefits when You Have ALS

This resource guide provides strategies and helpful hints to better navigate health insurance and benefits. While understanding insurance and benefits may feel overwhelming, the guidelines outlined here should help simplify the process for you.

Resource Guide 6: Managing Symptoms of ALS

This resource guide discusses a variety of symptoms that may affect you when you have ALS. As the disease progresses, various functions may become affected and it is helpful to understand potential changes so that you know what to expect and how to manage these new changes and symptoms.

Resource Guide 7: Functioning When Mobility is affected by ALS

This resource guide covers the range of mobility issues that occur with ALS. It discusses exercises to maximize your mobility, as well as how to adapt your home and activities of daily living to help you function more effectively.

Resource Guide 8: Adjusting to Swallowing Changes and Nutritional Management in ALS

This resource guide covers the range of mobility issues that occur with ALS. It discusses exercises to maximize your mobility, as well as how to adapt your home and activities of daily living to help you function more effectively.

Resource Guide 9: Changes in Speech and Communication Solutions

This resource guide covers how speech can be affected by ALS and explores a variety of techniques, technologies, and devices available for improving communication. By maintaining communication with others, you continue to make a significant difference in their lives, while retaining control of your own.

Resource Guide 10: Adapting to Changes in Breathing When You Have ALS

This resource guide explains how breathing is affected by ALS. Specifically, it will teach you the basics of how the lungs function, the changes that will occur, and how to prepare for the decisions that will need to be made when the lungs need maximal assistance.

Resource Guide 11: Approaching End of Life in ALS

This resource guide examines thoughts and feelings about dying and end of life. Approaching end of life is difficult and support is critical to help sort out feelings, expectations, and plans. By talking to friends, family, professionals, and planning and communicating your wishes, you can help prepare for the best possible end-of-life phase.

Families and ALS: A Guide for Talking with and Supporting Children and Youths

This resource guide is the result of many years of clinical social work practice and research with families, children, and youths affected by neurological illness. While much attention is paid to the person with ALS and their adult family member/caregivers, children and youths are often voiceless, despite experiencing much of the same shock, sadness, caregiving, and grief as their adult counterparts.

These manuals along with a variety of other educational resources may be viewed and downloaded from The ALS Association website directly at no cost via this link: http://portal.alsa.org/
Hard copies of the manuals are available to persons living with ALS. You can order your complimentary hard copy online at http://portal.alsa.org or contact The National ALS Association via their toll-free number at (800)782-4747 or email csportal@alsa-national.org.
The Care Services Staff with The ALS Association Wisconsin Chapter is always here to assist you. Please contact us at kathleen@alsawi.org for more information or questions.

CLINICAL TRIALS FOR ALS

Clinical trials have proven to be the most reliable way — and ultimately the fastest way — to discover treatments that really work. The goal of clinical trials is to answer specific scientific questions to find better ways to prevent, detect, or treat ALS, or to improve care for people with ALS.

People with ALS, along with family members and caregivers, are essential partners in this research. There are many ways you can search for a clinical trial, whether you want to participate in a trial or simply to get more information.

NEALS: www.neals.org/als-trials/search-for-a-trial

With support from The ALS Association, The NEALS consortium — the largest international consortium of clinical trials and sites — provides up-to-date information for finding both interventional and observational trials.

- **Highlight:** In addition to the website search function, people with ALS and their caregivers can speak directly with Carly Allen, the ALS Trial Liaison and Communications Manager at NEALS at (855) 437-4823 or alstrials@neals.org. The links to individual trials also provide information on the Principal Investigator, the study's purpose/summary, eligibility criteria, and trial contact information.

ALS Signal: iamals.org/get-help/als-signal-clinical-research-dashboard

IAMALS has developed a search tool for clinical trials called ALS Signal, which also provides up-to-date information for finding both interventional and observational trials.

- **Highlight:** The Signal provides graphics of the various stages of clinical trials across the world. The links to individual trials link back to www.clinicaltrials.gov. The PaCTD ratings are provided for each trial meeting a criteria of patient-centric trial design including access to experimental therapies, scientific progress, and being patient-friendly.

ClinWiki: www.clinwiki.org

ClinWiki has developed an ALS-specific search tool which also provides information for finding both interventional and observational trials.

- **Highlight:** Trials can be searched through various categories such as ALS onset, breathing ability, remote monitoring, etc.

ClinicalTrials.gov: www.clinicaltrials.gov

Clinicaltrials.gov is a Web-based resource maintained by the National Institutes of Health (NIH) and provides information on finding interventional and observational trials.

- **Highlight:** Information is provided and updated by the trial sponsor or principal investigator of the clinical study. It is the largest database of privately and publicly funded clinical studies conducted around the world.

For More Information on Clinical Trials, visit www.als.org/research/clinical-trials-for-patients

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06/02/21

ALS FOCUS

BRINGING THE PERSPECTIVES OF PEOPLE WITH ALS AND THEIR CAREGIVERS TO THE FOREFRONT OF RESEARCH, CARE, AND ADVOCACY.

WHAT IS ALS FOCUS?

ALS Focus is a patient and caregiver-led survey program that asks people impacted by ALS about their needs and burdens. The goal is to learn about individual experiences throughout the disease journey so that the entire ALS community can benefit.

The survey data we collect is:

- Open and free to the entire ALS community
- Protected – All data and findings are de-identified using a unique code called a global unique identifier (GUID)
- Combined with other ALS research studies that use a GUID, such as the National ALS Registry and clinical trials, to broaden the impact of your participation
- **Actionable!** Data will be used to inform decisions and strengthen programs and policies around:
  - ✓ Drug development
  - ✓ Clinical trial design
  - ✓ Regulatory review
  - ✓ Drug payment and reimbursement
  - ✓ Clinical care
  - ✓ Home health, and more

Every step of the survey development process is informed and reviewed by a committee of people with ALS and caregivers.

WHO CAN PARTICIPATE?

- People living with ALS
- Current or past caregivers of people with ALS. Spring 2021 survey is for current and past caregivers only.

**Participants must be at least 18 years old and reside in the United States. Survey instructions and questions are presented in English.*

HOW LONG WILL IT TAKE?

Registering for Focus and completing the surveys will take approximately 15-25 minutes.

WHERE?

Access the survey at als.org/als-focus or use the QR code on this page.

SPRING 2021 TOPIC: CAREGIVER NEEDS:

Past and current caregivers, please share your experiences with us.

JOIN US — YOUR VOICE MAKES AN IMPACT

The ALS Association is recruiting people with ALS and their caregivers for the ALS Focus survey program to capture their needs, preferences, and experiences as they meet the challenges of ALS.

Participate in research in addition to clinical trials. Know how your experiences and opinions compare to the rest of the ALS community.

ALS ASSOCIATION

For more information, please contact ALSFocus@alsa-national.org

01/25/21

ALS FOCUS FREQUENTLY ASKED QUESTIONS

BRINGING THE PERSPECTIVES OF PEOPLE WITH ALS AND THEIR CAREGIVERS TO THE FOREFRONT OF RESEARCH, CARE AND ADVOCACY.

WHAT IS ALS FOCUS?

- ALS Focus is a unique survey platform led by people with ALS. The goal is to understand the needs, preferences, and experiences of a broad and diverse population of people living with ALS and their caregivers. ALS Focus includes a survey portal that generates new surveys periodically throughout the year to inform and influence decisions that affect our community.
- ALS Focus is a cross-sector collaboration to place the preferences of people with ALS and their caregivers at the center of treatment and policy development, through survey-based research.
- Findings from ALS Focus surveys are open and freely available to the entire ALS community and inform clinical trials design, impact policies and regulatory decision making, payment and reimbursement decisions, patient and caregiver care, and more. Participant identities will not be shared.

HOW CAN FOCUS HELP ACCELERATE DRUG DEVELOPMENT AND IMPROVE CARE FOR PEOPLE WITH ALS?

ALS Focus surveys collect data and deliver critical information to research, regulatory, and insurance authorities, providing new insights into the experiences, views, and preferences of those living with ALS and their caregivers. ALS Focus surveys a broad range of people with ALS and current and past caregivers across disease progression and around the U.S., improving ALS drug development, clinical trial design, regulatory decisions, payment and reimbursement models, clinical care, home health services, and more.

WHAT KIND OF INFORMATION IS COLLECTED?

After the registration process, ALS Focus collects demographic information such as age and gender. A section on health is also included for participants to periodically update their health status. The subsequent surveys collect feedback and insights into the experiences, opinions, preferences, and health outcomes from those living with ALS and their caregivers.

WHAT ARE THE GOALS OF THE ALS FOCUS PROGRAM?

Scientific data are highly useful when justifying how to build policies and programs. In ALS Focus, we collect data to:

- Determine, in a scientifically sound manner, what is most important to people with ALS and caregivers across the spectrum of disease and disease progression.
- Develop and validate tool(s) to measure what is most important to people with ALS.
- Inform policy and regulatory decision making.
- Inform a benefit/risk study and additional preference studies.
- Inform payment and reimbursement decisions.

HOW WILL SURVEY DATA BE USED?

The surveys inform decisions and strengthen policies and programs around:

- Clinical trial design
- Care services
- Home health practices
- Clinical endpoints and scales
- Regulatory actions and decision-making
- Value-based reimbursement models for ALS therapies

All findings and de-identified data will be shared openly with the entire ALS community for free.

HOW WILL PARTICIPANT PRIVACY BE PROTECTED?

Participants must first register for an account on the portal by providing their email address and setting a password. Participants (people with ALS and current and past caregivers) will be asked to provide their name, date of birth, and place of birth to generate a Neurological Global Unique Identifier (NeuroGUID). This study refers to a NeuroSTAmP™, which is a NeuroGUID substitute, and serves to de-identify participant responses to all Focus surveys. The personal information that participants enter when generating their NeuroGUID is NOT stored.

HOW DOES ALS FOCUS DIFFER FROM THE CDC'S NATIONAL ALS REGISTRY?

Data from the National ALS Registry looks for disease pattern changes and seeks to identify whether there are common risk factors among individuals with ALS. Information from the Registry is used to estimate the number of new cases of ALS diagnosed each year and to better understand who gets ALS and what environmental factors affect the disease. In contrast, ALS Focus is a platform for people with ALS and caregivers to communicate their needs, preferences, and experiences as they meet the challenges of ALS throughout the disease journey. Data collected will be used to inform change and strengthen ALS programs and policies.

The CDC is a partner of ALS Focus. People who were assigned a Neurological Global Unique Identifier (NeuroGUID) when they filled out the Registry are eligible to have their Registry data linked to their ALS Focus data on a de-identified basis. Any researchers who want to use the linked data must have permission from the CDC and the ALS Association.

WHO CAN PARTICIPATE?

Anyone with ALS, and anyone who is a current or past caregiver of a person with ALS is invited to participate. A proxy is allowed to take the survey on a patient's behalf. The survey program is in English.

HOW LONG DOES THE SURVEY TAKE TO COMPLETE?

Once registered on the Focus platform, each secure online survey can be completed in approximately 5-15 minutes.

WHO IS RESPONSIBLE FOR THE ADMINISTRATION OF THE ALS FOCUS SURVEY PROGRAM?

ALS Focus is administered by The ALS Association with support, guidance and oversight from the ALS Focus Steering Committee, which includes co-chairs of the Patient and Caregiver Advisory Committee (PCAC), the Food and Drug Administration (FDA), industry sponsors Apellis, Biogen, Genentech, Ionis Pharmaceuticals, Cytokinetics, and Biohaven Pharmaceuticals, academic experts, and our partners at Neurological Clinical Research Institute at Massachusetts General Hospital (that houses the Focus survey). The director of the ALS Focus survey program is Sarah Parvanta, Ph.D.

FOR MORE INFORMATION ON ALS FOCUS, VISIT WWW.ALS.ORG/ALS-FOCUS

TO SIGN UP, VISIT WWW.ALSFOCUS.ORG

FOR A QUICK START GUIDE ON HOW TO REGISTER, CLICK HERE

FOR QUESTIONS, PLEASE CONTACT ALSFOCUS@ALSA-NATIONAL.ORG

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01/25/21

The National ALS Registry: Get The Facts

The National Amyotrophic Lateral Sclerosis (ALS) Registry enables persons with ALS to fight back and help defeat ALS (Lou Gehrig's Disease). By signing up, being counted, and answering brief questions about your disease, you can help researchers find answers to critical questions.

Learn more at www.cdc.gov/als or (800) 232-4636

Who can sign-up?

Anyone with ALS

What do I need?

- A computer with an internet connection
- An email address

No computer? Don't worry! A family member, caregiver, or friend with a computer can help you. You can also contact your local ALS chapter, office or clinic for registration assistance.

What if I need help?

Caregivers and others can help you in person or even over the phone

What kind of information is collected?

- Basic demographics (e.g., age, sex, height, weight)
- Military history
- Physical activity
- Family history

Will my information be private?

- YES! Only approved registry scientists can see it, NOT employers or insurers
- You CANNOT be looked up in the registry by name

Do I need to update my information?

YES! Every six months – you'll get an email reminder

YOU JOINING =

- More information for research
- A better understanding of ALS
- The chance to help create a better future for persons with ALS