



EMPOWERED

**ALS education to Empower
Persons living with ALS
Caregivers, and Practitioners**

2021

LETTER FROM THE DIRECTOR OF CARE SERVICES

Welcome and thank you for being a part of the ALS Association Alabama Chapter's 2021 Empowered Webseries: ALS Education to Empower Persons living with ALS, Caregivers, and Practitioners. Every 90 minutes a person is diagnosed with ALS; every 90 minutes another person passes away due to ALS. At any point in time, an estimated 5,000 people are living with ALS in the United States. Each of those 5,000 individuals is important to, and loved by an entire group of family members, friends, caregivers, social support and healthcare practitioners who will come along side of that person through their healthcare journey as ALS continues to progress and new or increasing barriers arise.

The mission of ALS Association Alabama Chapter is 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. The concept of living life to the fullest includes receiving best-practice, evidence-based care. Persons living with ALS and their family caregivers can be proactive and in the best control of their health and symptom management when they are educated about what to expect and what interventions are available. Social service and health care practitioners best serve Persons living with ALS when proper training is provided and accessible to them. We hope that the current webinar series will be one part of the broader educational picture for people living with ALS, their caregivers, and the entire multidisciplinary care team. The current webinars are programmed to address some of the most common and pressing concerns noted by our stakeholders. Please note that the Chapter, and the Association as a whole, is committed to education and educational resources and encourage you to reach out with any questions or needs you may have. In addition to our webinar series, our Chapter hosts monthly support groups; provides home visits and case management for Persons living with ALS; provides in-service education on request to community healthcare organizations and providers; and has an entire library of print and/or digital informational materials and tools available.

Throughout this e-book, we will be highlighting some of the materials available through the ALS Association and providing links to the downloadable versions. Many of these materials are available in hard copy upon request. Please reach out to any member of our Chapter staff to discuss specific educational materials needs and let us help you get what you need.

Again – on behalf of all of us here at the ALS Association Alabama Chapter, thank you for being a part of our 2021 Empowered Education Series. We look forward to continuing a relationship as part of our commitment to empowering people affected by ALS to live their lives to the fullest as we all do “whatever it takes” to work toward the vision of a world without ALS.

Mission Forward!



Melissa C. Enfinger, MS

Director of Care Services and Public Policy

2021 EMPOWERED WORKSHOPS OVERVIEW & SPEAKERS



Our mission is 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.

2021 Empowered Topics:

Wednesday
JUN
23
2021

SESSION 1



LESLIE RYAN

YOUR ALS TOOLBOX: ESSENTIAL TOOLS AND RESOURCES FOR COMMUNITY HEALTHCARE PROVIDERS SUPPORTING PEOPLE LIVING WITH ALS

This session will feature key information resources and tools available through the Chapter, its partners, and the community to learn best practices for ALS care and symptom management. This webinar will include information on new ALS-specific courses available through our partnership with MedBridge Education and numerous resources available through our National office. We will welcome speaker, Leslie Ryan Director, Education & Professional Development Programs from the National ALS Association to provide us with an overview of available resources and how to access them. [CLICK THE LINK TO REGISTER » https://www.gomeet.com/AccountManager/RegEv.aspx?PIID=E055D68787473F](https://www.gomeet.com/AccountManager/RegEv.aspx?PIID=E055D68787473F)

Wednesday
JUL
21
2021

SESSION 2



DR. PAUL MEHTA

ACCELERATING PROGRESS:

ALS RESEARCH UPDATES FROM THE FIELD

Research is a key mission strategy in our goal to find treatments and a cure for ALS. Join us on July 21 to learn about research going on currently in the state of Alabama – including news from Dr. Peter King, physician and ALS Researcher at The University of Alabama Birmingham and Birmingham VA Medical Director. We will also have an important presentation by Dr. Paul Mehta, Principal Investigator with the CDC ALS Registry and Biorepository on the importance of the National Registry and how every person living with ALS can support research through the registry.

[CLICK THE LINK TO REGISTER » https://www.gomeet.com/AccountManager/RegEv.aspx?PIID=E055D687884F3D](https://www.gomeet.com/AccountManager/RegEv.aspx?PIID=E055D687884F3D)



DR. PETER KING

2021 EMPOWERED WORKSHOPS OVERVIEW & SPEAKERS

Wednesday

AUG
18
2021

SESSION 3



KATHLEEN SMITH



DR. NAN JIANG



SHERRY KOLODZIECZAK

ALL TOGETHER NOW:

PERSPECTIVES ON ORGANIZING YOUR MEDICAL CARE AND MAXIMIZING YOUR TEAM'S EFFECTIVENESS

The following clinic professionals will be joining us for the panel:

Kathleen Smith MA, CCC-SLP
ALS Clinic Coordinator, Recognized Treatment Center
Alabama Neurology Associates

Nan Jiang, MD, PhD
Co-Director, ALS Care Clinic
The University of Alabama at Birmingham

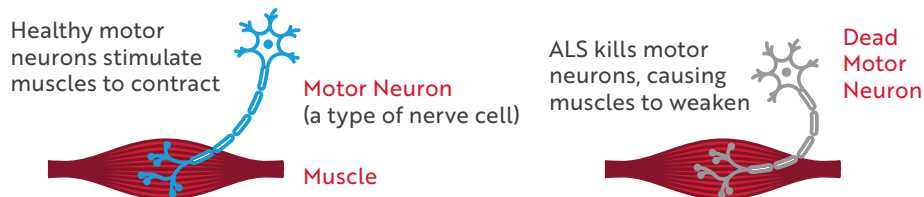
Sherry Kolodzieczak, MS, OTR/L, FEW, PAMC, CNDT
Director of ALS Care Clinic, Certified Treatment Center of
Excellence
Crestwood Medical Center

This session will also feature a panel of people living with ALS, Caregivers, and Clinic Professionals and allow time for Q and A from the audience. Tools such as the Critical Medical Information app and other strategies will be discussed.

CLICK THE LINK TO REGISTER » <https://www.gomeet.com/AccountManager/RegEv.aspx?PIID=E055D687884E30>

What is ALS?

ALS (amyotrophic lateral sclerosis) is a progressive neurodegenerative disease that affects neurons in the brain and the spinal cord that cause people to lose the ability to initiate and control muscle movement, which usually leads to total paralysis and death within five years of diagnosis. There is no cure and no life-prolonging treatments for the disease.



Fighting ALS

Since 1985, The ALS Association has been the only national nonprofit organization fighting ALS on every front – supporting innovative research, enhancing access to clinical care, and promoting better public policies. Our nationwide network of 39 chapters make up one team with a single mission: to discover treatments and a cure for ALS and to empower people with ALS to live their lives to the fullest.



RESEARCH

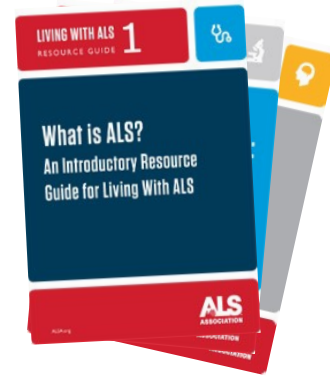


PATIENT CARE



ADVOCACY

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 at [800-664-1242](tel:800-664-1242) or info@alsalabama.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 will help you understand how swallowing is affected by ALS and what you can do to maintain nutrition for energy and strength and to keep your airway open.

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.

All resource guides are available for free download on our website, als.org/navigating-als/resources/living-als-resource-guides. If you would like to order a printed copy of any of the guides, please visit <http://portal.alsa.org/> or contact us csportal@alsa-national.org.

MEDICAL INFORMATION GUIDE

Living with ALS not only impacts a person's daily living, but also factors into the appropriate medical treatment in an emergency situation or hospital stay. When providing care, health professionals and emergency personnel, like paramedics, will have many questions about a person's medical condition. In these stressful situations, it is often helpful to have an organized set of information, which can help inform medical providers about specific issues and considerations.

CLICK THE PHOTO BELOW FOR FULL INFORMATION

<https://www.als.org/navigating-als/resources/medical-information-materials>

<p>ALS Association</p> <p>My Name is:</p> <p>I have ALS (Amyotrophic Lateral Sclerosis), also known as Lou Gehrig's Disease</p> <p><input type="radio"/> I have Advance Directives in place</p>	<table border="1"> <tr> <td>A</td><td>B</td><td>C</td><td>D</td><td>E</td><td>F</td><td>G</td> </tr> <tr> <td>H</td><td>I</td><td>J</td><td>K</td><td>L</td><td>M</td><td>N</td> </tr> <tr> <td>O</td><td>P</td><td>Q</td><td>R</td><td>S</td><td>T</td><td>U</td> </tr> <tr> <td>V</td><td>W</td><td>X</td><td>Y</td><td>Z</td><td>Space</td><td></td> </tr> <tr> <td>Period</td><td>Yes</td><td>No</td><td>Maybe</td><td></td><td></td><td></td> </tr> </table> <p>Emergency Contact Person:</p> <p>Telephone Number:</p> <p>Physician Name:</p> <p>Physician Phone Number:</p>	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	P	Q	R	S	T	U	V	W	X	Y	Z	Space		Period	Yes	No	Maybe				<p>ALS Association</p> <p>Intended for informational purposes only</p> <p><small>© 2020 The ALS Association. All rights reserved.</small></p>
A	B	C	D	E	F	G																															
H	I	J	K	L	M	N																															
O	P	Q	R	S	T	U																															
V	W	X	Y	Z	Space																																
Period	Yes	No	Maybe																																		
<p>I may slur my words or not be able to speak at all, but I UNDERSTAND what you are saying.</p> <p>Speak to me in a normal voice and ALLOW ME TIME to communicate.</p> <p>My caregiver(s) and I are extremely knowledgeable about my condition, treatment needs, and equipment. Please work with us.</p>	<p>IF I am short of breath and/or have low SpO₂, DO NOT give me oxygen unless I have another respiratory condition that requires it. I may need noninvasive positive pressure ventilation to expel CO₂.</p> <p>OXYGEN MAY NOT HELP and may mask respiratory failure. My lungs are healthy; my muscles, including diaphragm, are weak. IF I am using BPAP at home, the settings should be the same as those. IF NOT, a BPAP with a pressure of 12/6, backup rate of 10 with titration as needed may help.</p>	<p>LAYING me on my back may be difficult for me because of the possibility of CO₂ retention due to diaphragmatic weakness, and aspiration due to poor ability to protect my airway. I may be able if using a BPAP or non-invasive mechanical ventilation.</p> <p>AVOID paralytic or general anesthetics, narcotics or muscle relaxants unless absolutely necessary. If used, the ability to rapidly assist ventilation non-invasively or invasively should be available.</p> <p>IF I have a gastrostomy tube, please use that for administration of "oral" medications.</p>																																			

HOSPITAL COMMUNICATION

CLICK THE PHOTO BELOW FOR FULL INFORMATION

<https://www.als.org/navigating-als/resources/medical-information-materials>



PLEASE READ I HAVE ALS

**Do not give me oxygen.
I cannot breathe when I lie
flat. I use _____
to help me breathe.**

I eat & take medications:

- ☐ Via mouth
- ☐ A thickened texture diet
- ☐ Via feeding tube

**I understand what
you are saying. I
communicate using:
_____.**

**I have weakness or
immobility in my:**

- ☐ Neck ☐ Legs
- ☐ Arms ☐ Trunk

Ask Me or Call my Caregiver for More Information

NAME: _____ NUMBER: _____



SPONSORS

THANK YOU FOR YOUR SUPPORT



**BlueCross BlueShield
of Alabama**

Education Sponsor:

Care  **Patrol**
Safer Senior Living. *Your Goal, Our Mission.*

Thanks to our sponsors for helping to drive our mission forward and supporting the EMPOWERED education series - Check out our web site for more information

<https://www.als.org/alabama/local-care-services/empowered>

You drive our mission forward!



Saturday, October 23rd, 2021
STATEWIDE WALK WHERE YOU ARE

**Register a team, as an individual,
SPONSOR OR DONATE TODAY!**

To learn more, visit

www.alsalabama.org

or contact

Victoria Rutledge at victoria@alsalabama.org

ALABAMA CHAPTER STATE ADVOCACY



OUR MISSION

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.

- Currently, ALS is 100% fatal. There is no cure and no life extending treatments. Most people diagnosed with the disease will die within 3 to 5 years.
- We need your voice and your support to help us change the outcomes for people living with ALS and their families and ensure that they have the opportunity to make every moment matter.

What matters in Alabama (State level priorities):

- 1 ALS Awareness:** ALS is a debilitating disease that acts as a “death sentence” for the over 400 Alabamians living with ALS at any given time – and devastates entire families.
- 2 Access to Care:** People living with ALS (pALS) need access to care statewide such as that provided in multidisciplinary clinics. South Alabama is essentially an ALS “Health Desert”.
- 3 Support Telehealth and Access to Technology:** Telemedicine is one way that current clinics can extend their reach to underserved areas and support people throughout the course of the disease when travel becomes too burdensome or impossible. We must permanently extend access to telehealth for People Living with ALS and ensure that Broadband Access and appropriate technology are available for them to receive the care they need in their homes and local communities.
- 4 Research & Cure:** Encourage research funding to ensure scientists have the resources they need to advance potential treatments.

Take Action: How can you help support people affected by ALS?



Join the ALS Association Alabama Chapter to urge your state legislators to take action and make ALS a top priority in Alabama.



Targeted communications between policy makers and self-advocates



Statewide action alerts via email and social media

The ALS Association Alabama Chapter

300 CAHABA PARK CIRCLE | SUITE 209 | BIRMINGHAM, AL 35242

advocacy@alslabama.org • 800-664-1242 • www.als.org/alabama/advocacy



HOW TO BECOME AN ADVOCATE

OUR MISSION

The ALS Association is leading the fight 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.

ALS ADVOCATES

Our goals are ambitious, and ALS Advocates help us achieve them. Advocates are empowered with the information and tools to make a difference in the lives of those living with ALS. Our Advocates:

- Share their passion and stories with elected officials and their staff to advance the Association's legislative priorities
- Step out of their comfort zone to effect real change
- Amplify our voice on Capitol Hill and in state capitols across the country

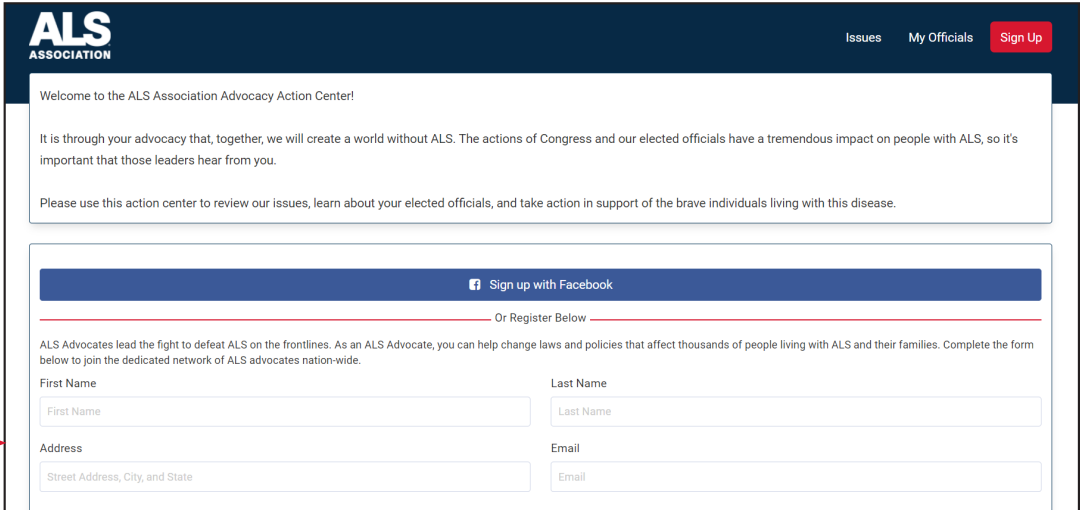
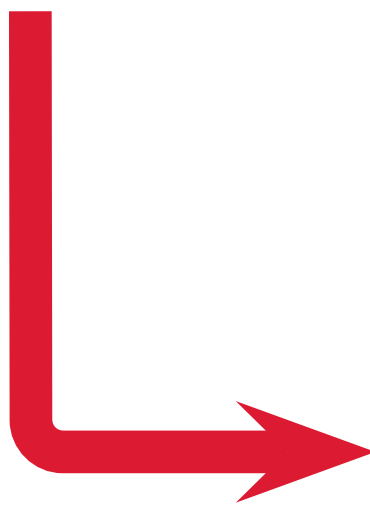
JOIN US

We need your help. As an ALS Advocate you will:

- Educate decision-makers on the latest research and needs of people with ALS
- Develop relationships and educate your members of Congress
- Participate in legislative action alerts via email, among other advocacy-related activities

SIGN UP

- Becoming an ALS Advocate is easy! Simply visit www.als.org/advocacy and click on "Action Center" to complete the ALS Advocate sign up illustrated below:



The screenshot shows the ALS Association Advocacy Action Center sign-up page. At the top, there's a dark blue header with the ALS Association logo on the left and links for "Issues", "My Officials", and a red "Sign Up" button on the right. Below the header, a white box contains a welcome message and a brief explanation of the advocacy center's purpose. The main section of the form is titled "Sign up with Facebook" and "Or Register Below". It includes a paragraph explaining the role of an ALS Advocate. The registration form consists of four input fields: "First Name", "Last Name", "Address" (with a placeholder "Street Address, City, and State"), and "Email".

There are many **unknowns** about ALS.

People living with ALS can help future generations.



The National Amyotrophic Lateral Sclerosis (ALS) Registry allows persons with ALS to fight back, help defeat ALS, and help future generations.

Research today may lead to better understanding and potential treatments tomorrow. By signing up for the National ALS Registry, being counted, and taking brief risk factor surveys, people living with ALS can help find answers.

The National ALS Registry

Because there is so much that we don't know, dedicated research is a priority. The National ALS Registry provides a pathway for greater knowledge.

About the Registry

The federal Agency for Toxic Substances and Disease Registry (ATSDR) established the National ALS Registry in 2010 to collect and analyze data about people living with ALS in the U.S.

Its purpose is to gather data to better understand ALS. The information is used to:

- ▶ Estimate how many new cases of ALS are diagnosed each year;
- ▶ Estimate how many people are living with ALS;
- ▶ Better understand who gets ALS;
- ▶ Better understand what factors affect the disease;
- ▶ Enhance research to find the cause(s) of ALS.



The Registry collects and analyzes existing data, as well as new data provided by people living with ALS who choose to participate.

Researchers use the data to look for changes in disease patterns over time. They try to determine if there are common risk factors and identify them. It's important to include as many people as possible to get the most accurate information. If you choose to be counted, you can help find answers to important questions about ALS.

The National ALS Registry also funds research to increase the efforts of learning about this disease. Since 2010, the Registry has funded over one dozen studies in the U.S. and internationally. The Registry works with some of the world's leading research institutions, to study what may cause ALS such as heavy metals, pesticides, certain genetic traits, and cyanobacteria.

How You Can Help.

Joining the Registry is one way you can fight back and help create a better future for people with ALS. There are several ways you can play a role in advancing research.



1

Join the Registry

This is the first step in unlocking more opportunities to help.

Have questions? Not sure if you have enrolled? There are people who can help. You can ask a family member, caregiver, friend, or your local ALS chapter, office, or clinic. Or you can contact the Registry at (800) 232-4636 or email als@cdc.gov.

2

Support the fight by taking the risk factor surveys

The Registry offers the opportunity for people living with ALS to complete risk factor surveys. There are 17 different surveys, and they ask about things such as your age, family history of neurological diseases, possible environmental exposures, your work history, and physical activity. This is a chance for you to share your story.

On average, a survey will take about 5 minutes to complete, and you do not need to complete all the surveys at one time.

Why it's important:

- ▶ Your personal, private data provides crucial information for the Registry. As more people with ALS complete these surveys, the Registry has more data. Every piece of data helps researchers better understand the disease and its possible causes.
- ▶ Researchers across the world can use these data for studies.

3

Help by donating specimens to the National ALS Biorepository

With your consent, you can also choose to donate biological specimens to the National ALS Biorepository. This facility collects and stores these samples for scientific study. Collection of the specimens is done in your own home, including blood and urine. This service is free to patients.

Donating these specimens can provide scientists with key DNA and chemical exposure data, and the specimen can be matched with survey data to give researchers a more complete picture to study. Analysis of these types of specimens has already proven useful in studying ALS and other diseases.

4

Learn more about clinical trials and research studies, and if you can participate

You can choose to receive emails informing you about clinical trials and epidemiological studies that may interest you.

Be Part of Something Bigger.

You can be a part of something bigger by joining the National ALS Registry. Learn more at cdc.gov/als.



U.S. Department of
Health and Human Services
Centers for Disease
Control and Prevention
Agency for Toxic Substances
and Disease Registry



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 preferences. 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 ✓ Drug payment and reimbursement
 - ✓ Clinical trial design ✓ Clinical care
 - ✓ Regulatory review ✓ 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. The Summer 2021 Telehealth survey is for people with ALS and current 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.

SUMMER 2021 TOPIC:
TELEHEALTH:
People with ALS and current caregivers, please share your experiences with us.

JOIN US — YOUR RESPONSES MAKE 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.



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, 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





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**

**Thank you for being a part of our
2021 Empowered Workshop Series.**

**For more information about the
ALS Association Alabama Chapter,
please visit our website at alsalabama.org
or call us at 800-664-1242**

