WELCOME!

September 19, 2022

Telling your Story:
How Joining
The CDC National ALS
Registry Makes a Difference

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Telling Your Story: How Joining the CDC National ALS Registry Makes A Difference

Patti Stanco, MHS
Assoc. Dir., Mission Engagement

ALS®
ASSOCIATION

- Overview of the Registry
- Why it matters and telling your story
- How to enroll and updates on data
- Summary of the Registry Annual Meeting
- Questions

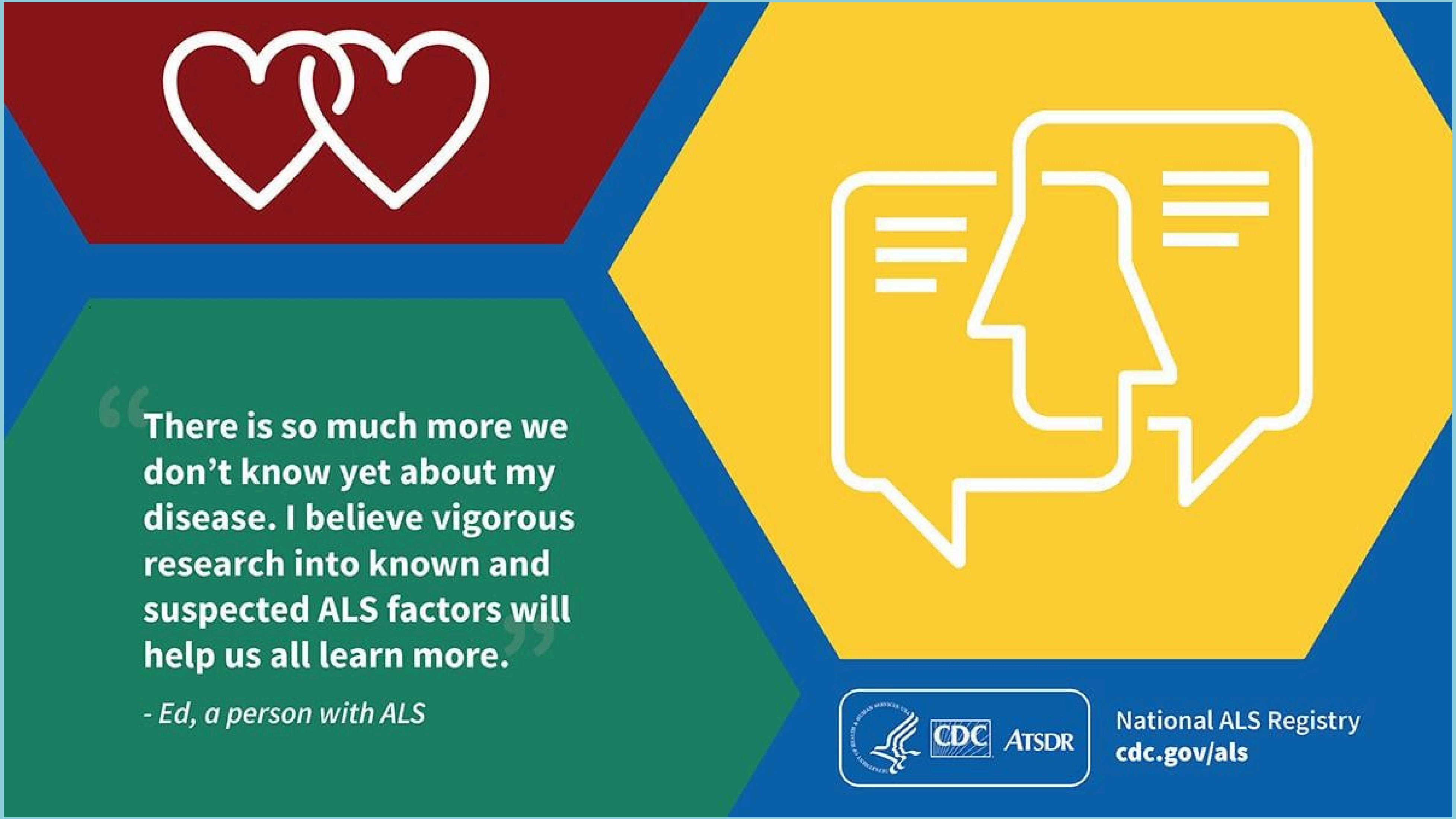
National ALS Registry

- Centers for Disease Control and Prevention/Agency for Toxic Substances and Disease Registry (CDC/ATSDR)
- The only national ALS Registry
- Passed by Congress in 2010; launched in 2012

GOALS OF THE REGISTRY:

- Find out what causes ALS
- Report on the number of ALS cases in the U.S.
- Learn the risk factors of ALS

ALS ASSOCIATION



> There is so much more we don't know yet about my disease. I believe vigorous research into known and suspected ALS factors will help us all learn more.
>
> *- Ed, a person with ALS*

National ALS Registry
cdc.gov/als

After the diagnosis…. now what?

After the diagnosis…. now what?

"Why did this happen to me or my loved one?"

Care Team

Multidisciplinary Clinic

Equipment

Support Group

Transportation

Home Modifications

Stress

Finances

Seeking Hope

Grief

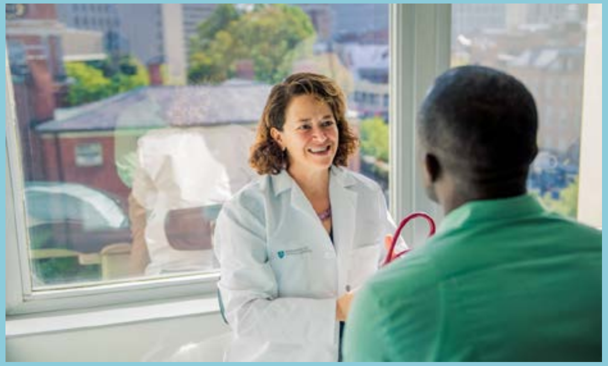
Medications

Learn about Research

Treat symptoms

Where do people learn about the Registry?

ALS Clinic or Neurologist



Conferences

Internet searches & websites

What causes ALS?

Walk to Defeat ALS

New registration packet

Support group

Care Services Staff

ALS ASSOCIATION

ALS Has Many Questions. With Focused Research, We Can Find Answers.

What Is ALS?

Amyotrophic lateral sclerosis (ALS) is a rapidly progressive, fatal neurological disease. It affects nerve cells in the brain and spinal cord, causing nerves in the muscle to die. This affects voluntary muscle movement. These things we know, but there are many unknowns about the disease. Persons living with ALS today, and those who will live with it tomorrow, seek answers to these unknowns. Research is the way forward.

> "There is so much we don't yet know about my disease. I believe vigorous research into known and suspected ALS factors will help us all learn more. Continuing ALS research is the best way to keep hope alive."
> *- Ed, a person living with ALS*

The National ALS Registry Is Leading This Research.

In 2010, the federal Agency for Toxic Substances and Disease Registry (ATSDR) established the National ALS Registry to allow persons living with ALS in the U.S. to voluntarily provide their data for research purposes. Strategic research is one way the Registry is working to better understand what causes ALS. This research may potentially lead to treatments to prevent, halt, or reverse ALS.

This research is filling a significant gap in our understanding of the disease. There is no other voluntary national database that has the capacity, or the specialized data, to carry out these types of investigations. This research could be the turning point for this disease.

> "The ALS Registry gives scientists the opportunity to look at the big picture to better understand what might be causing ALS. This knowledge could be the key we need."
> *- Becky, a person living with ALS*

Collaborating With Leading Researchers.

The Registry identifies significant areas that need investigation. Then, the Registry funds crucial, groundbreaking research in these areas. The Registry funds and collaborates with some of the world's leading research institutions. Since 2010, ATSDR has funded 13 Registry research studies in the U.S. and abroad and will continue to fund more studies. Researchers from all around the world are able to share their findings. This kind of collaboration is new and the key for success.

Examples of the research include:

Environment

- The University of Pittsburgh is examining known occupational and environmental pollution exposures in persons living with ALS.
- Dartmouth College is studying if specific chemicals (such as pesticides, algae blooms in lakes, and chemicals from factories) may be a risk factor for ALS.

Genetic & Medical

- The University of Miami is looking at the relationship between environmental factors and genes in persons living with ALS.
- Stanford University is researching if medical conditions (such as high cholesterol, diabetes, autoimmune diseases, or certain drugs) can affect a person's risk of getting ALS.

> "A better understanding of personal and environmental risk factors for ALS could lead to understanding of its triggers as well as treatments. With the Registry's ALS patient data, we have valuable, focused information that may help us better understand risk factors. We can share our unique findings with other researchers across the world. Sharing improves the base of knowledge and speeds up the discovery of treatment for the disease. The Registry's ALS research will make an important difference, and I know it will ultimately improve outcomes for persons living with ALS."
> *- Dr. Evelyn Talbott, epidemiologist and researcher*

Looking to the Future.

ALS research has changed dramatically over the last seven years. More researchers are studying the disease today, and technology continues to improve. The Registry plays a major role to support combined efforts. It works with researchers from many top institutions, and through the Registry we are able to share key findings that will benefit other research projects.

For more information on ALS Registry funded research, you can go to: cdc.gov/als

ATSDR

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 pathwa

About the Registry

The federal Agency for Toxic Substances and Di
the National ALS Registry in 2010 to collect and
with ALS in the U.S.

Its purpose is to gather data to better understa

- Estimate how many new cases of ALS a
- Estimate how many people are living w
- Better understand who gets ALS;
- Better understand what factors affect t
- Enhance research to find the cause(s) o

The Registry collects and analy
provided by people living with

Researchers use the data to loo
if there are common risk factor
possible to get the most accura
answers to important question

The National ALS Registry also funds research t
the Registry has funded over one dozen studies
the world's leading research institutions, to stu
genetic traits, and cyanobacteria.

ATSDR

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

What if I need help?
Caregivers and others can help you in person or even over the phone

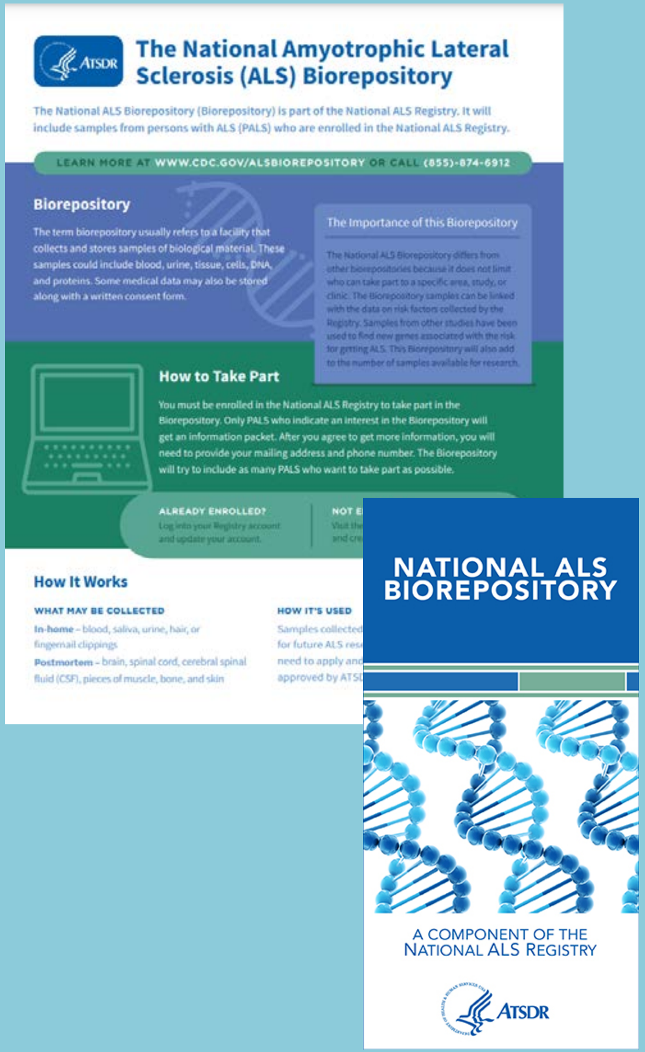
No computer? Don't worry! A family member, caregiver, or friend with a computer can help you. You can also contact your local ALS chapter, office or clinic for registration assistance.

What 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



The National Amyotrophic Lateral Sclerosis (ALS) Biorepository

The National ALS Biorepository (Biorepository) is part of the National ALS Registry. It will include samples from persons with ALS (PALS) who are enrolled in the National ALS Registry.

LEARN MORE AT WWW.CDC.GOV/ALSBIOREPOSITORY OR CALL (855)-874-6912

Biorepository

The term biorepository usually refers to a facility that collects and stores samples of biological material. These samples could include blood, urine, tissue, cells, DNA, and proteins. Some medical data may also be stored along with a written consent form.

The Importance of this Biorepository

The National ALS Biorepository differs from other biorepositories because it does not limit who can take part to a specific area, study, or clinic. The Biorepository samples can be linked with the data on risk factors collected by the Registry. Samples from other studies have been used to find new genes associated with the risk for getting ALS. This Biorepository will also add to the number of samples available for research.

How to Take Part

You must be enrolled in the National ALS Registry to take part in the Biorepository. Only PALS who indicate an interest in the Biorepository will get an information packet. After you agree to get more information, you will need to provide your mailing address and phone number. The Biorepository will try to include as many PALS who want to take part as possible.

ALREADY ENROLLED?
Log into your Registry account and update your account.

NOT E
Visit the
and cre

How It Works

WHAT MAY BE COLLECTED

In-home – blood, saliva, urine, hair, or fingernail clippings

Postmortem – brain, spinal cord, cerebral spinal fluid (CSF), pieces of muscle, bone, and skin

HOW IT'S USED

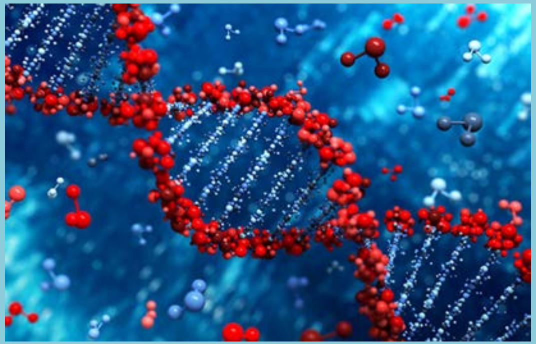
Samples collected
for future ALS rese
need to apply and
approved by ATSD

NATIONAL ALS BIOREPOSITORY

A COMPONENT OF THE NATIONAL ALS REGISTRY

ATSDR

ALS
ASSOCIATION



Answering risk factor surveys is a meaningful way to share your story

I had back surgery and never fully recovered. Instead of getting stronger, I started getting weaker.

When I was growing up, I spent summers on my grandma and grandpa's farm. My grandpa would take me fishing on a lake nearby that used to get full of algae.

Parkinson's seems to run in my family and a cousin has Multiple Sclerosis – I wonder if that means anything.

The ALS Association Strategic Priorities

Ensure Access & Prevention

Ensure people with ALS have access to effective treatments, and cases of ALS are being prevented

Empower & Engage

Empower people with ALS to engage with the world in the way they want

Reduce Burdens

Reduce the physical, emotional, and financial burdens of living with ALS

Ensure Support for ALL

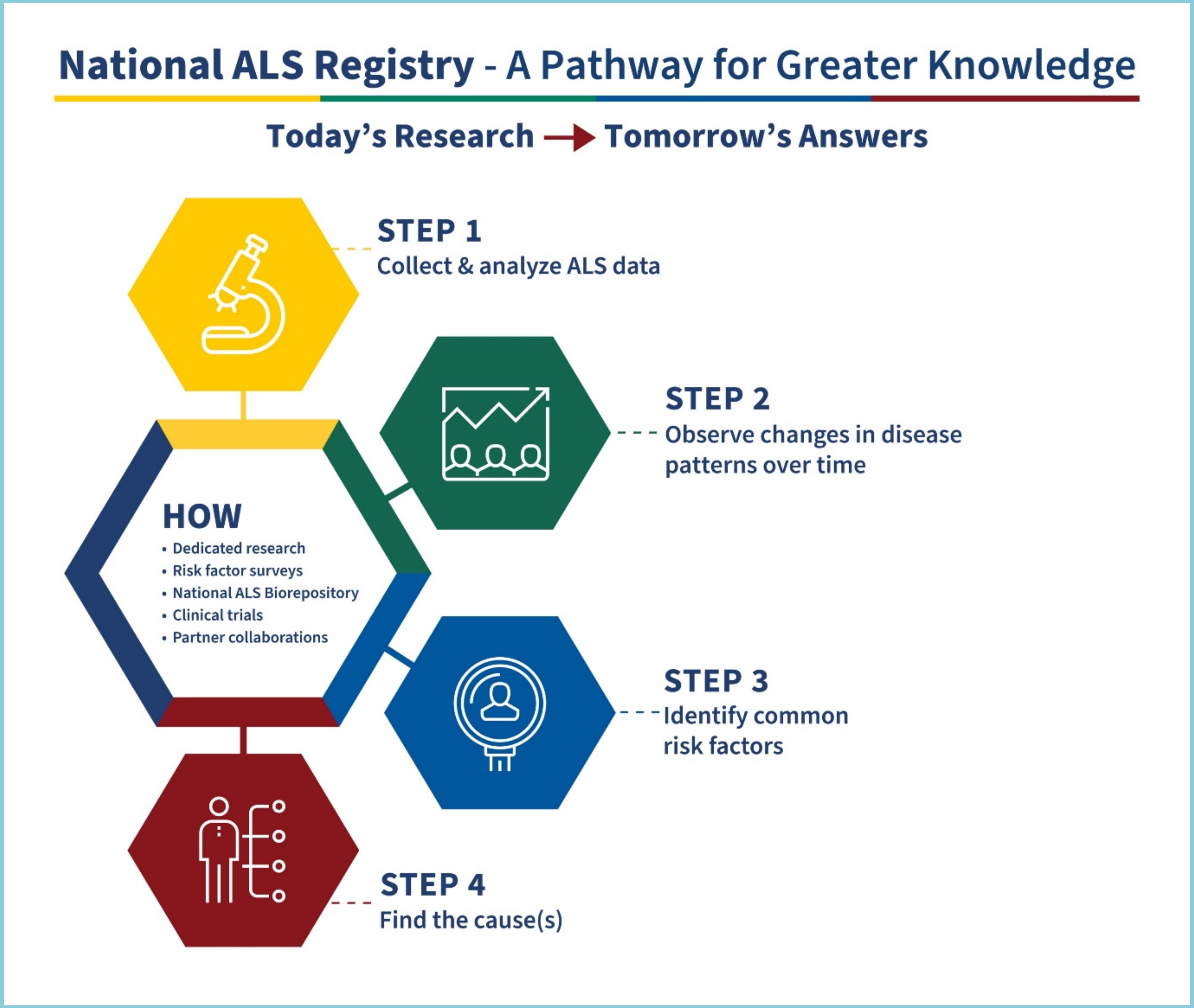
Ensure ALL people with ALS and their caregivers recieve high quality services that benefit them

Create Accountability

Create a culture of accountability to ensure meaningful impacts for people with ALS

OUR MANTRA:

Whatever It Takes



National ALS Registry - A Pathway for Greater Knowledge

Today's Research → Tomorrow's Answers

STEP 1
Collect & analyze ALS data

STEP 2
Observe changes in disease patterns over time

HOW
- Dedicated research
- Risk factor surveys
- National ALS Biorepository
- Clinical trials
- Partner collaborations

STEP 3
Identify common risk factors

STEP 4
Find the cause(s)

Reasons to Consider Joining the Registry

By completing the risk factor surveys people living with ALS can help direct researchers towards a treatment and a cure.

Patients can share their thoughts about what factors they think may have contributed to their disease in the Registry. One of the risk factor surveys is an open comment box.

The Registry is the only national ALS research project. Anyone with an ALS diagnosis can participate from the comfort of their home.

There is a biorespository connected to the Registry. When researchers use it for research the samples are connected to the risk factors data.

Components of the Registry

National ALS Registry

1. Risk Factor Surveys

Up to 18 surveys in 5 main subjects. Understanding the risk factors of ALS will drive research towards better treatments, a cure, and even prevention.

2. Biorepository

Currently collecting blood samples. Must enroll in Registry to participate. (Previously collected nail clippings, hair strands, saliva swabs, and post-mortem brain and spinal cord.)

3. Clinical Trial Notification

Patients may opt in to receive notifications about clinical trials for which they may qualify. Personal data is not shared with researchers. Upon receiving the email patients must reach out.

4. Environmental Research

Air pollution
Organic pollutants
Pesticides and algae blooms
Gene-environment interactions
Biomarkers
Environmental risks
Comorbidities

RISK FACTOR SURVEYS

- Demographics and family history
- Disease onset
- Smoking, alcohol, and caffeine use

- Where you lived and worked
- Job history
- Military service

- Physical activity
- Hobbies

- Environmental exposures
- Pesticide use

- Head and neck injuries

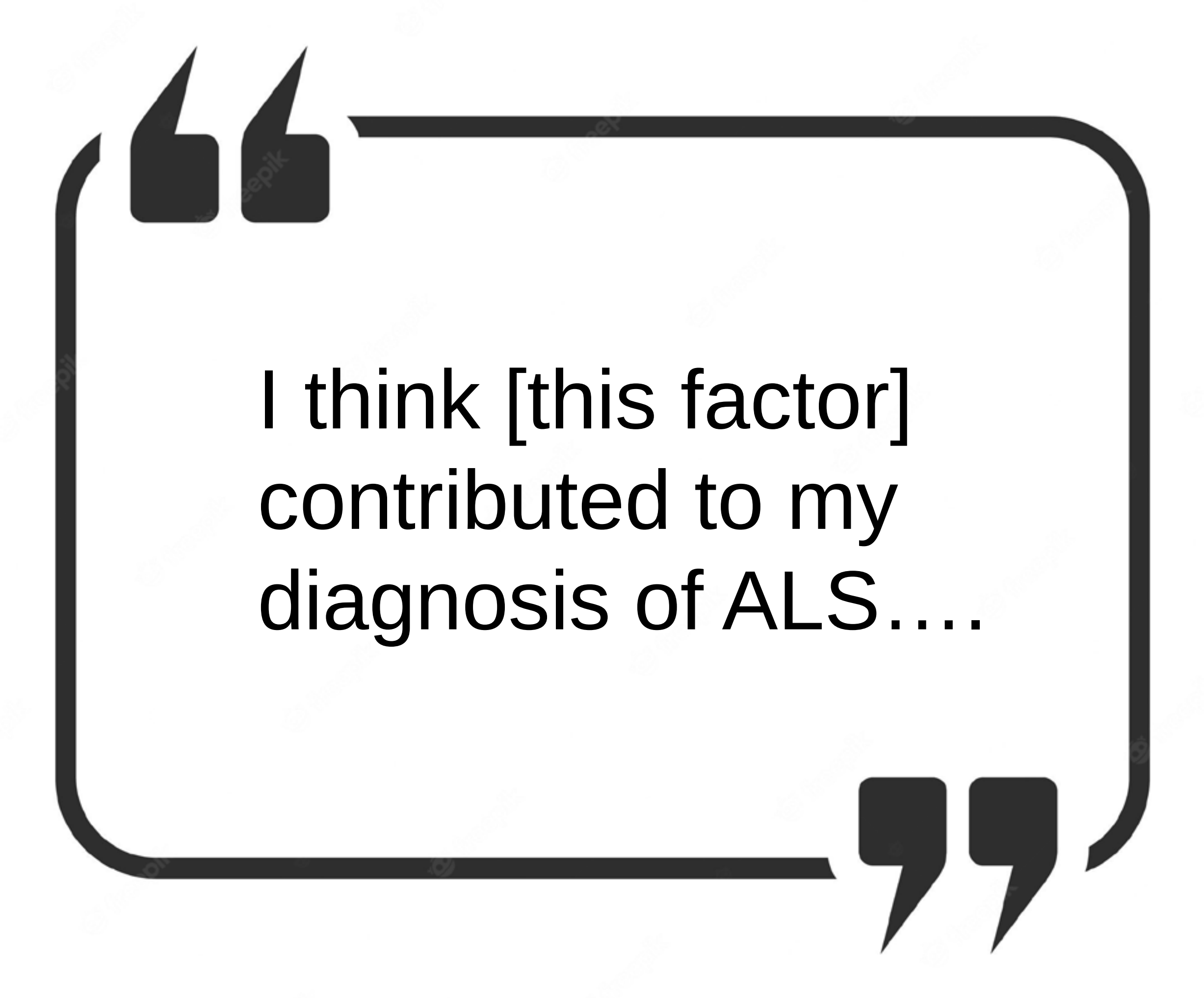
RISK FACTOR SURVEYS

Open-ended question

What are we not asking about?

What are we missing?

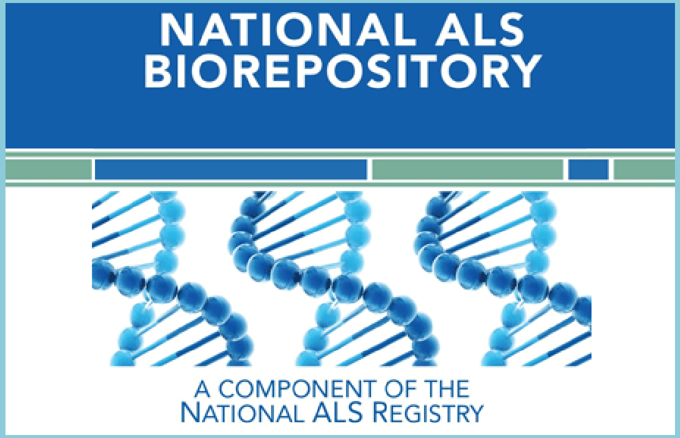
What should we be looking at?



I think [this factor] contributed to my diagnosis of ALS….

BIOREPOSITORY

- Requires enrollment in the Registry
- Step #1 Request a packet of information
- Step #2 Complete informed consent
- Step #3 Schedule in-home blood collection by a licensed phlebotomist
- About post-mortem ….
  - https://cdmrp.army.mil/alsrp/resources/Biorepositories_Postmortemtissues



FEDERAL RESEARCH

- Federal Research on ALS
  - NIH
  - DoD
  - CDC
- The CDC is the only federal agency to focus on etiology and risk factors
- To date, the Registry has funded 21 research projects
- More than half of the CDC’s Registry budget is allocated for research activities
- The ALS Association regularly include funding for the CDC and the Registry in their appropriations requests as part of their advocacy efforts

PASSWORDS & PRIVACY

- Only the last 5 digits of social security number required to enroll
- Choose when or if to change password:
  - Six months
  - Annually
  - Never
- Opt “in” for clinical trial alerts and newsletter

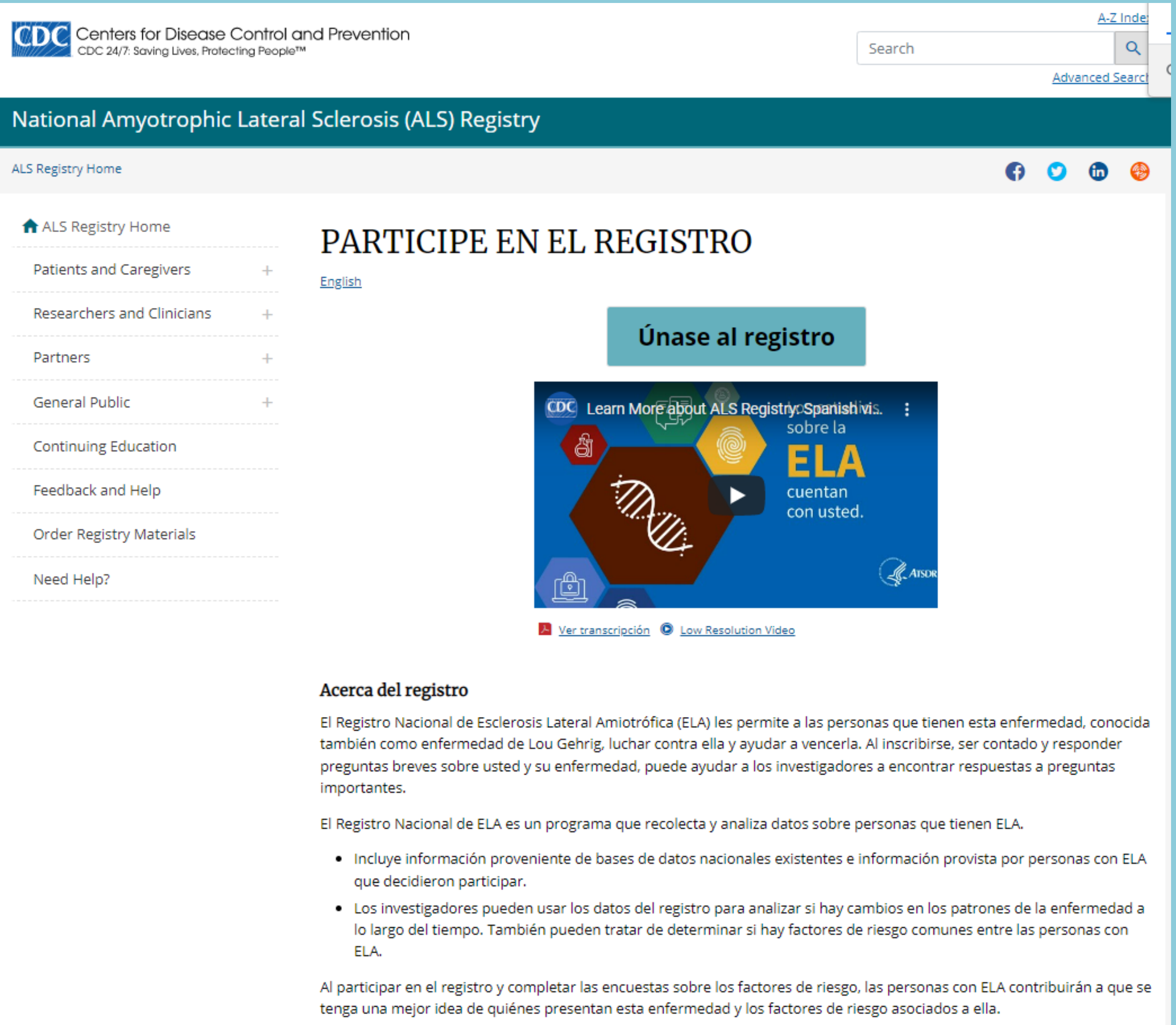
REMINDERS:

- To enroll in the Registry, you must have a diagnosis of ALS. People living with PLS or other related, non-ALS diseases are not eligible to enroll at this time.
- If you need assistance enrolling, it is okay to have a friend, family member, or caregiver help you.
- Sometimes people ask if a family member can enter information for a loved one who has passed away from ALS.

Spanish version

www.cdc.gov/ela

ALS ASSOCIATION



PARTICIPE EN EL REGISTRO

Acerca del registro

El Registro Nacional de Esclerosis Lateral Amiotrófica (ELA) les permite a las personas que tienen esta enfermedad, conocida también como enfermedad de Lou Gehrig, luchar contra ella y ayudar a vencerla. Al inscribirse, ser contado y responder preguntas breves sobre usted y su enfermedad, puede ayudar a los investigadores a encontrar respuestas a preguntas importantes.

El Registro Nacional de ELA es un programa que recolecta y analiza datos sobre personas que tienen ELA.

- Incluye información proveniente de bases de datos nacionales existentes e información provista por personas con ELA que decidieron participar.
- Los investigadores pueden usar los datos del registro para analizar si hay cambios en los patrones de la enfermedad a lo largo del tiempo. También pueden tratar de determinar si hay factores de riesgo comunes entre las personas con ELA.

Al participar en el registro y completar las encuestas sobre los factores de riesgo, las personas con ELA contribuirán a que se tenga una mejor idea de quiénes presentan esta enfermedad y los factores de riesgo asociados a ella.

Hay muchas incógnitas sobre la ELA. Las personas que tienen ELA pueden ayudar a las generaciones futuras.

El Registro Nacional de Esclerosis Lateral Amiotrófica (ELA) permite que las personas que tienen esta enfermedad luchen y contribuyan para vencerla, y ayuden a generaciones futuras.

La investigación de hoy puede llevar a una mejor comprensión y posibles tratamientos del mañana. Las personas que tienen esta enfermedad pueden ayudar a encontrar respuestas al inscribirse en el Registro Nacional de ELA, ser contadas y completar breves encuestas de factores de riesgo.

El Registro Nacional de ELA

Debido a que hay tanto que no sabemos, la investigación dedicada a esta enfermedad es una prioridad. El Registro Nacional de ELA abre un camino hacia más conocimientos.

Acerca del registro

La Agencia para Sustancias Tóxicas y el Registro de Enfermedades (ATSDR), que es una agencia federal, estableció el Registro Nacional de ELA en el 2010 para recolectar y analizar datos sobre personas que tienen esta enfermedad en los Estados Unidos.

Su propósito es reunir datos para comprender mejor la esclerosis lateral amiotrófica.
La información se utiliza para los siguientes fines:

- estimar cuántos casos nuevos de ELA se diagnostican cada año;
- estimar cuántas personas tienen ELA;
- entender mejor quiénes contraen ELA;
- entender mejor qué factores afectan la enfermedad;
- mejorar la investigación para encontrar la o las causas de la ELA.

El registro recolecta y analiza tanto los datos existentes como los nuevos que son provistos por las personas que tienen ELA y deciden participar.

Los investigadores usan los datos para buscar cambios en los patrones de la enfermedad a lo largo del tiempo. Tratan de determinar si hay factores de riesgo comunes y de identificarlos. Es importante incluir a la mayor cantidad posible de personas a fin de obtener la información más precisa. Si elige ser contado, usted puede ayudar a encontrar respuestas a importantes preguntas sobre la ELA.

El Registro Nacional de ELA también financia la investigación para aumentar los esfuerzos por aprender sobre esta enfermedad. Desde el 2010, el registro ha financiado más de una docena de estudios en los Estados Unidos y a nivel internacional. El registro trabaja con algunas de las instituciones que lideran las investigaciones a nivel mundial, para estudiar qué podría causar la ELA, como metales pesados, pesticidas, ciertos rasgos genéticos, y cianobacterias.

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ar.
n que usted puede luchar y no
rsonas con ELA tengan un mejor
puede cumplir un rol en el avance

ermitir que surjan más oportunidades para ayudar. Usted
stados Unidos para inscribirse en el Registro Nacional de ELA.

seguro de si está inscrito? Hay personas que lo pueden ayudar. Le
nbro de su familia, cuidador, amigo, o alguna persona que pertenezca
ficina o centro médico dedicados a la ELA. O puede comunicarse con
00-232-4636, o escribiendo a als@cdc.gov.

ndo las encuestas de factores de riesgo

rsonas con ELA la oportunidad de completar encuestas sobre factores
diferentes, y en ellas se preguntan cosas como su edad, antecedentes
neurológicas, posibles exposiciones ambientales, antecedentes de trabajo,
a oportunidad para que comparta su historia.

encuesta le llevará alrededor de 5 minutos, y usted no necesita
ola vez.

y privados brindan información crucial para el registro. A medida que más
mpleten estas encuestas, más datos tendrá el registro. Cada dato ayuda a
comprender mejor la enfermedad y sus posibles causas.

- Los investigadores de todo el mundo pueden usar estos datos para realizar estudios.

3 Ayude al donar muestras al Banco Nacional de Muestras Biológicas de ELA

Con su consentimiento, usted puede también optar por donar muestras al Banco Nacional de Muestras Biológicas de ELA. Este centro colecta y almacena estas muestras para estudios científicos. La recolección de las muestras, que incluyen sangre y orina, se realiza en su propia casa. Este servicio es gratuito para los pacientes.

Donar estas muestras puede proveerles a los científicos datos clave de ADN y de exposiciones a sustancias químicas, y la muestra puede corresponderse con datos de la encuesta para darles a los investigadores un panorama más completo para estudiar. Ya se ha comprobado que los análisis de estos tipos de especímenes son útiles para el estudio de la ELA y de otras enfermedades.

4 Sepa más sobre los ensayos clínicos y los estudios de investigación, y si puede participar

Usted puede elegir que le envíen mensajes electrónicos para informarle sobre ensayos clínicos y estudios epidemiológicos que podrían interesarle.

Participe en algo de mayor dimensión.

Usted puede formar parte de algo de mayor dimensión al inscribirse en el Registro Nacional de ELA. Obtenga más información en **cdc.gov/ela***.

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

**NOTA: El sitio web no contiene toda la información en español. Usted puede encontrar información adicional en inglés en cdc.gov/ela.*

Enrolling in the Registry

Step 1: Explore & Sign Up cdc.gov/als

- Voluntary
- Have an internet connection on a laptop or device
- Go to the Registry website
- Answer the screening questions
- Complete informed consent
- Create a user ID and password

ALS ASSOCIATION

Enrolling in the Registry

Step 1: Explore & Sign Up cdc.gov/als

- Voluntary
- Read materials and review website information
- Screening Questions
- Informed Consent
- Create a user ID and password

Step 2: Participate

- Ask a tech-savvy family member as project manager
- Tell your story!
- 18 surveys; 5 topics (RISK FACTOR SURVEYS)
- Consider the BIOREPOSITORY & opting in to receive CLINICAL TRIAL ALERTS

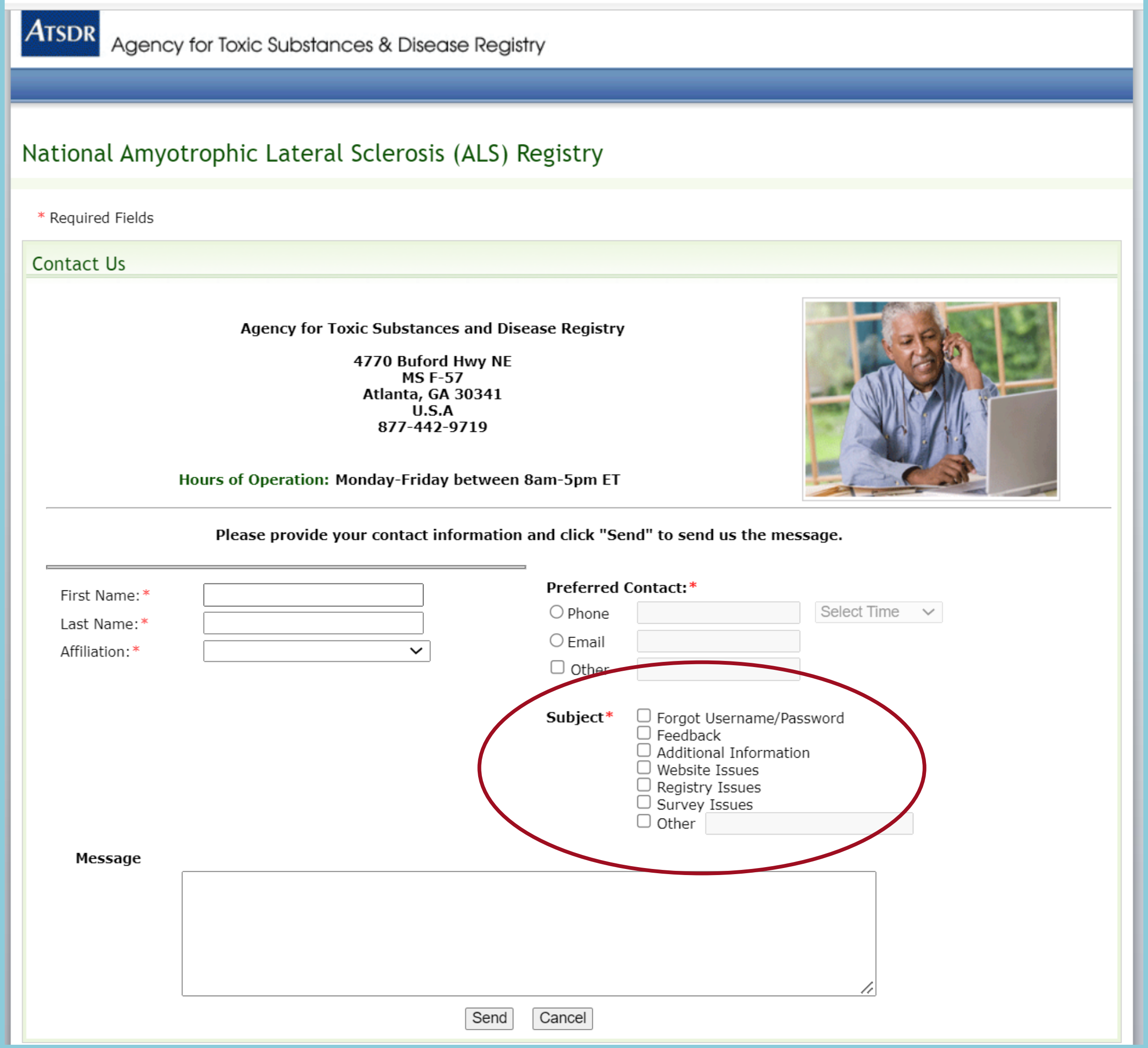
ALS ASSOCIATION

CDC Contact Information for Assistance

If a person living with ALS or caregiver needs to contact the Registry for confirmation of enrollment or technical assistance, please contact:

CDC National ALS Registry
Hours of Operation Monday–Friday 8 AM–5 PM EST

- **Phone 877-442-9719**
- **Email Als@cdc.gov**
- **Web form https://wwwn.cdc.gov/ALS/ContactUS.aspx**



ATSDR Agency for Toxic Substances & Disease Registry

National Amyotrophic Lateral Sclerosis (ALS) Registry

* Required Fields

Contact Us

Agency for Toxic Substances and Disease Registry

4770 Buford Hwy NE
MS F-57
Atlanta, GA 30341
U.S.A
877-442-9719

Hours of Operation: Monday-Friday between 8am-5pm ET

Please provide your contact information and click "Send" to send us the message.

First Name:*
Last Name:*
Affiliation:*

Preferred Contact:*
○ Phone Select Time
○ Email
☐ Other

Subject*
☐ Forgot Username/Password
☐ Feedback
☐ Additional Information
☐ Website Issues
☐ Registry Issues
☐ Survey Issues
☐ Other

Message

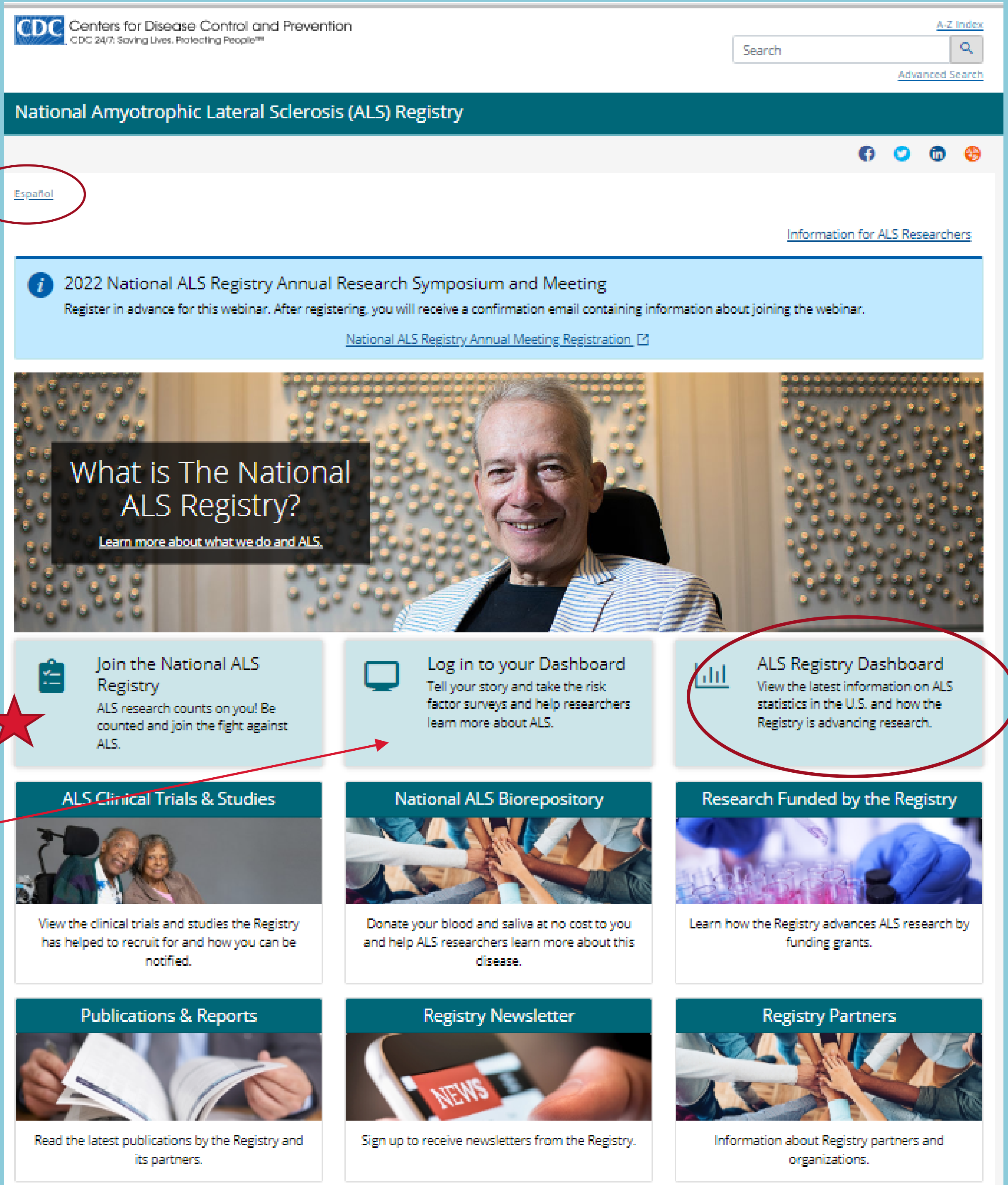
CDC Website

www.cdc.gov/als

Link to Spanish version

Sign up

Log in to complete surveys



CDC Centers for Disease Control and Prevention
CDC 24/7: Saving Lives. Protecting People™

A-Z Index

Search

Advanced Search

National Amyotrophic Lateral Sclerosis (ALS) Registry

Español

Information for ALS Researchers

2022 National ALS Registry Annual Research Symposium and Meeting

Register in advance for this webinar. After registering, you will receive a confirmation email containing information about joining the webinar.

National ALS Registry Annual Meeting Registration

What is The National ALS Registry?

Learn more about what we do and ALS.

Join the National ALS Registry

ALS research counts on you! Be counted and join the fight against ALS.

Log in to your Dashboard

Tell your story and take the risk factor surveys and help researchers learn more about ALS.

ALS Registry Dashboard

View the latest information on ALS statistics in the U.S. and how the Registry is advancing research.

ALS Clinical Trials & Studies

View the clinical trials and studies the Registry has helped to recruit for and how you can be notified.

National ALS Biorepository

Donate your blood and saliva at no cost to you and help ALS researchers learn more about this disease.

Research Funded by the Registry

Learn how the Registry advances ALS research by funding grants.

Publications & Reports

Read the latest publications by the Registry and its partners.

Registry Newsletter

Sign up to receive newsletters from the Registry.

Registry Partners

Information about Registry partners and organizations.

Show Me the Data!

10 YEARS

New Report COMING SOON!

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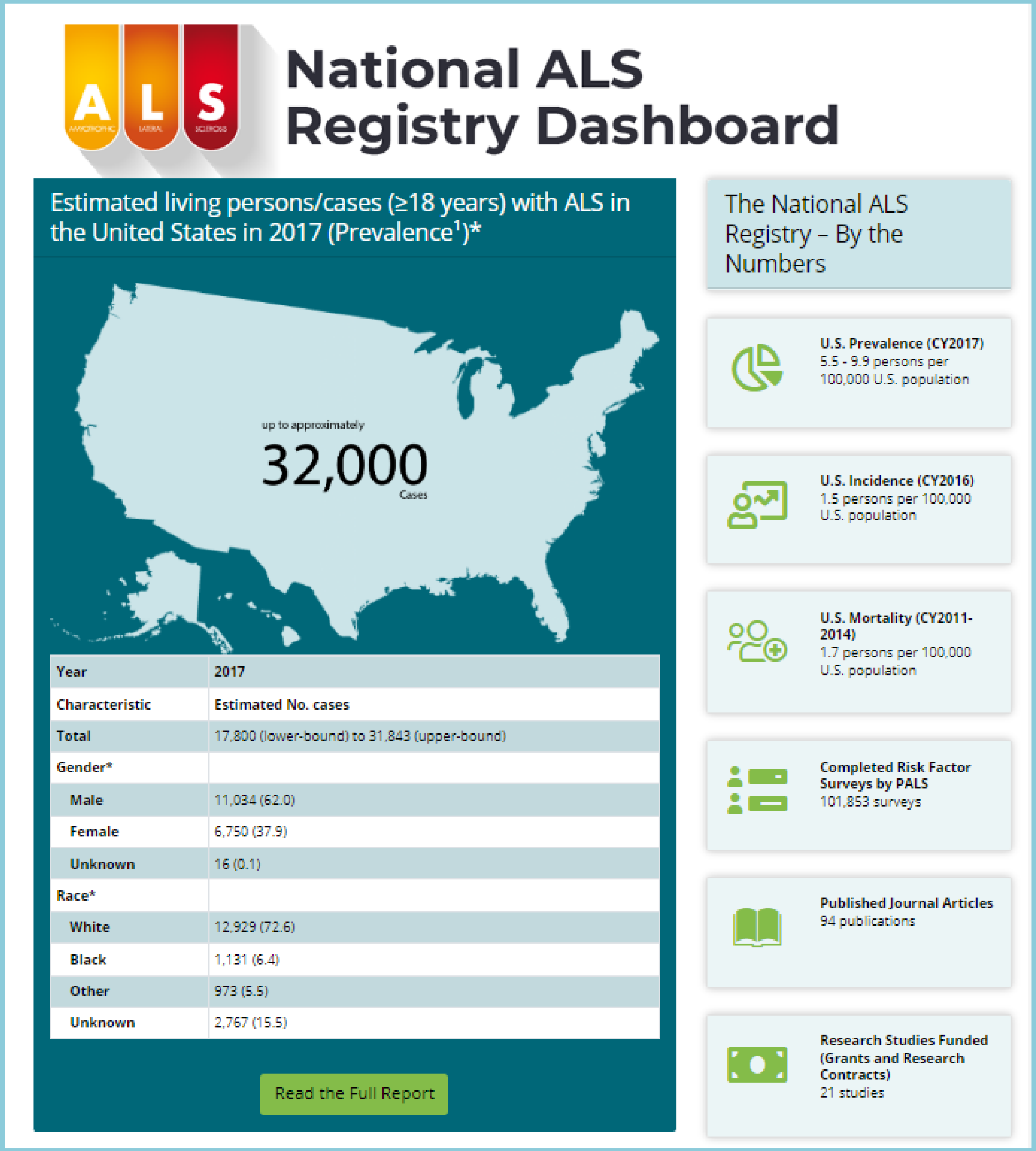


National ALS Registry Dashboard

Estimated living persons/cases (≥18 years) with ALS in the United States in 2017 (Prevalence[1])*

up to approximately 32,000 Cases

Year	2017
Characteristic	**Estimated No. cases**
Total	17,800 (lower-bound) to 31,843 (upper-bound)
Gender*	
Male	11,034 (62.0)
Female	6,750 (37.9)
Unknown	16 (0.1)
Race*	
White	12,929 (72.6)
Black	1,131 (6.4)
Other	973 (5.5)
Unknown	2,767 (15.5)

Read the Full Report

The National ALS Registry – By the Numbers

U.S. Prevalence (CY2017)
5.5 - 9.9 persons per 100,000 U.S. population

U.S. Incidence (CY2016)
1.5 persons per 100,000 U.S. population

U.S. Mortality (CY2011-2014)
1.7 persons per 100,000 U.S. population

Completed Risk Factor Surveys by PALS
101,853 surveys

Published Journal Articles
94 publications

Research Studies Funded (Grants and Research Contracts)
21 studies

Estimated new persons/cases (≥18 years) with ALS in the United States during 2014-2016 (Incidence[2])

4,861-6,045 new cases

Year	2014	2015	2016
Characteristic	**Estimated No. (%) cases**	**Estimated No. (%) cases**	**Estimated No. (%) cases**
Total	5,695	6,045	4,861
Gender			
Male	3,088 (54.2)	3,174 (52.5)	3,119 (64.2)
Female	2,178 (38.2)	2,708 (44.8)	1,740 (35.8)
Unknown	429 (7.5)	163 (2.7)	2 (0.0)
Race			
White	4,727 (83.0)	4,962 (82.1)	3,733 (76.8)
Black	333 (5.8)	365 (6.0)	335 (6.9)
Other	254 (4.5)	325 (5.4)	224 (4.6)
Unknown	381 (6.7)	393 (6.5)	569 (11.7)

Read the Full Report

Research Studies Using Registry Biospecimens
22 studies[3]

Research Studies Using Registry Datasets
5 studies

Biorepository Premortem Participants
>1,400

Biorepository + Johns Hopkins Postmortem Autopsies
>180

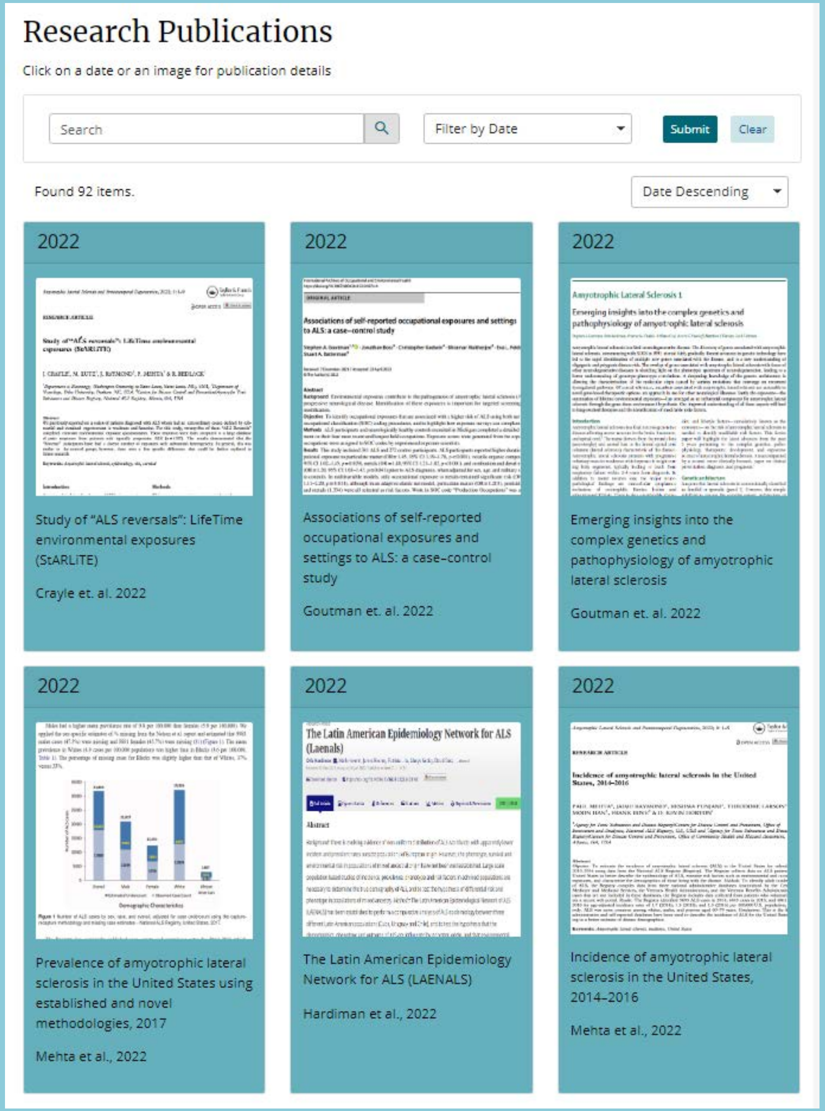
Research Study Recruitment (Clinical Trials and Epidemiological Studies)

Active Studies Currently Recruiting
24 studies

Closed Studies where Recruitment Already Occurred
43 studies

Highlights from the latest report:

- Cases collected from other databases = 12,477
- Estimate of missing cases = 14,043
- Self-enrolled = 5,323 (Thank you!)
- Total = 31,843



Research Publications

Click on a date or an image for publication details

Found 92 items.

2022

Study of "ALS reversals": LifeTime environmental exposures (StARLITE)

Crayle et. al. 2022

2022

Associations of self-reported occupational exposures and settings to ALS: a case-control study

Goutman et. al. 2022

2022

Emerging insights into the complex genetics and pathophysiology of amyotrophic lateral sclerosis

Goutman et. al. 2022

2022

Prevalence of amyotrophic lateral sclerosis in the United States using established and novel methodologies, 2017

Mehta et al., 2022

2022

The Latin American Epidemiology Network for ALS (LAENALS)

Hardiman et al., 2022

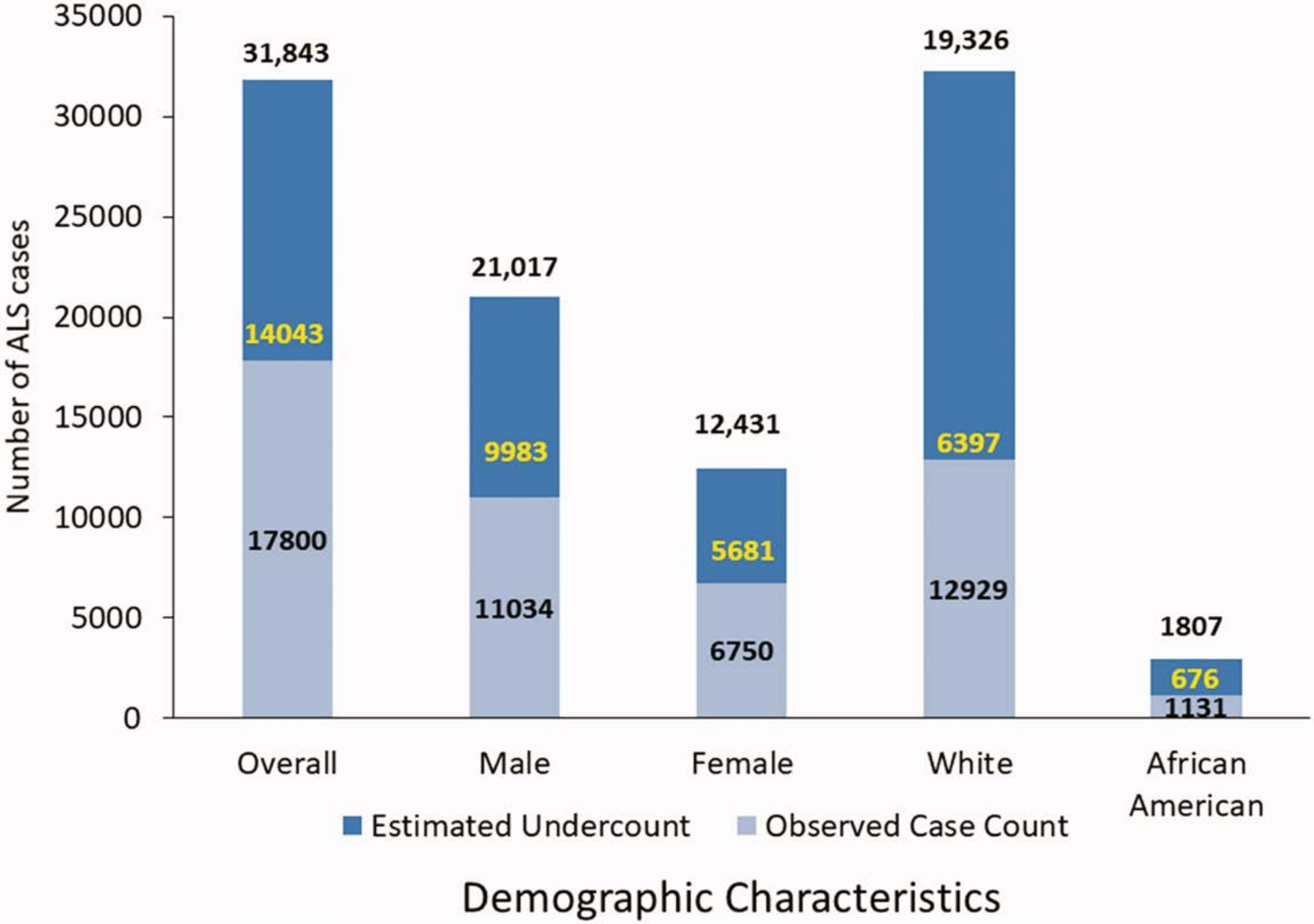
2022

Incidence of amyotrophic lateral sclerosis in the United States, 2014–2016

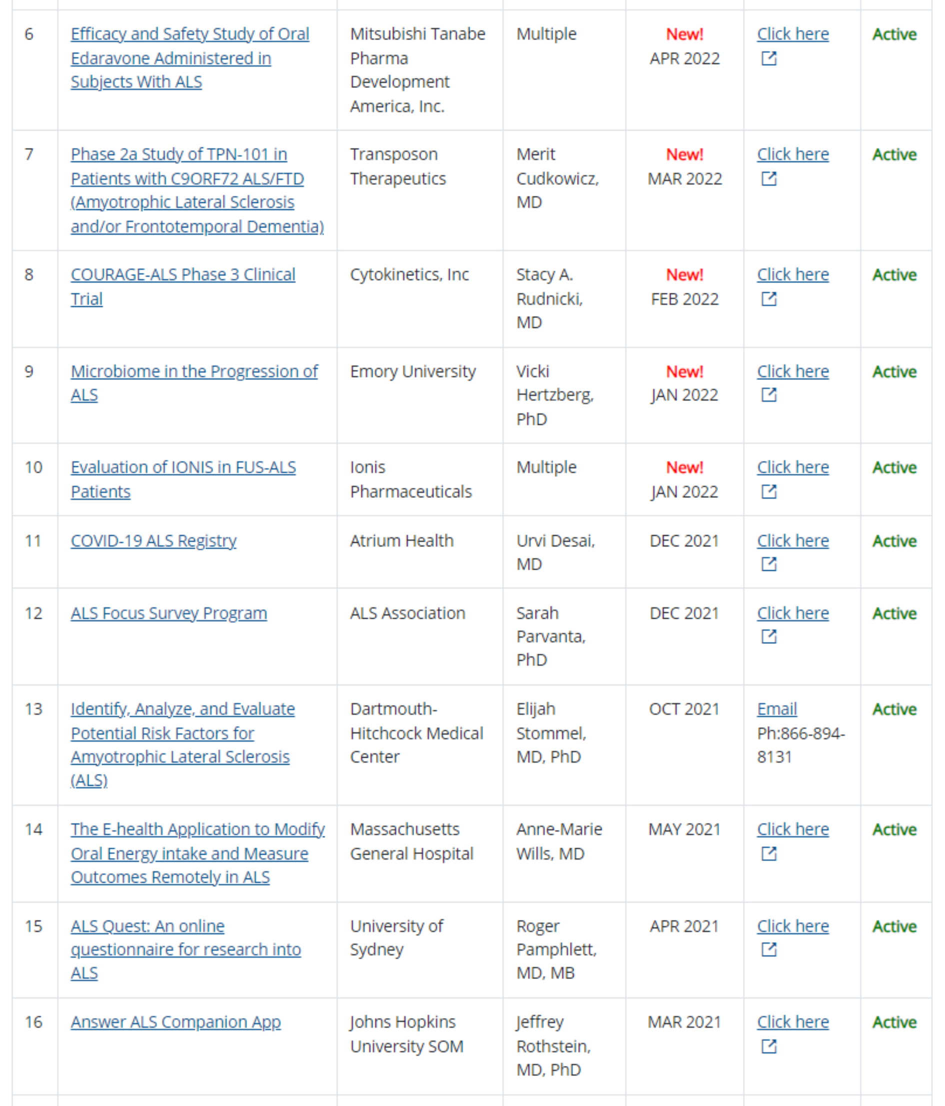
Mehta et al., 2022

Prevalence of amyotrophic lateral sclerosis in the United States using established and novel methodologies, 2017 Paul Mehta, Jaime Raymond, Reshma Punjani, Moon Han, Theodore Larson, Wendy Kaye, Lorene M. Nelson, Barbara Topol, Oleg Muravov, Corina Genson & D. Kevin Horton

https://doi.org/10.1080/21678421.2022.2059380



Clinical Trial Notifications



ACTIVE – ALS Research Notification for Clinical Trials and Studies

The following are approved ALS studies and clinical trials that have used the National ALS Registry for patient recruitment purposes. Email notifications have already been sent out to PALS meeting the specific study criteria.

Active: currently recruiting for the specified clinical trial or study
To view list of closed (recruiting has ended) clinical trials and studies click here .

To receive automatic notifications about the latest clinical trials and studies, please join the Registry, click here.

This list will be updated as new research proposals are approved by ATSDR.

No	Study Name	Institution	Investigator	Research Notification Date*	Information Link	Status
1	Radicava®/(Edaravone) Findings in Biomarkers From ALS	Mitsubishi Tanabe Pharma	James Berry, MD	New! JUL 2022	Click here	Active
2	Feasibility of the BrainGate2 Neural Interface System in Persons with Tetraplegia	Massachusetts General Hospital	Leigh R. Hochberg, M.D. Ph.D	New! JUN 2022	Email	Active
3	Home-based Remote Digital Monitoring to Assess ALS progression	Emory University	Jonathan Glass, MD	New! JUN 2022	Click here	Active
4	Healey ALS Platform Trial	Massachusetts General Hospital	Merit Cudkowicz, MD	New! MAY 2022	Click here	Active
5	Rasch-built Outcome Measures to Improve ALS Clinical Trials	Emory University	Christina Fournier, MD	New! APR 2022	Click here	Active
6	Efficacy and Safety Study of Oral Edaravone Administered in Subjects With ALS	Mitsubishi Tanabe Pharma Development America, Inc.	Multiple	New! APR 2022	Click here	Active
7	Phase 2a Study of TPN-101 in Patients with C9ORF72 ALS/FTD (Amyotrophic Lateral Sclerosis and/or Frontotemporal Dementia)	Transposon Therapeutics	Merit Cudkowicz, MD	New! MAR 2022	Click here	Active
8	COURAGE-ALS Phase 3 Clinical Trial	Cytokinetics, Inc	Stacy A. Rudnicki, MD	New! FEB 2022	Click here	Active
9	Microbiome in the Progression of ALS	Emory University	Vicki Hertzberg, PhD	New! JAN 2022	Click here	Active
10	Evaluation of IONIS in FUS-ALS Patients	Ionis Pharmaceuticals	Multiple	New! JAN 2022	Click here	Active
11	COVID-19 ALS Registry	Atrium Health	Urvi Desai, MD	DEC 2021	Click here	Active
12	ALS Focus Survey Program	ALS Association	Sarah Parvanta, PhD	DEC 2021	Click here	Active
13	Identify, Analyze, and Evaluate Potential Risk Factors for Amyotrophic Lateral Sclerosis (ALS)	Dartmouth-Hitchcock Medical Center	Elijah Stommel, MD, PhD	OCT 2021	Email Ph:866-894-8131	Active
14	The E-health Application to Modify Oral Energy intake and Measure Outcomes Remotely in ALS	Massachusetts General Hospital	Anne-Marie Wills, MD	MAY 2021	Click here	Active
15	ALS Quest: An online questionnaire for research into ALS	University of Sydney	Roger Pamphlett, MD, MB	APR 2021	Click here	Active
16	Answer ALS Companion App	Johns Hopkins University SOM	Jeffrey Rothstein, MD, PhD	MAR 2021	Click here	Active

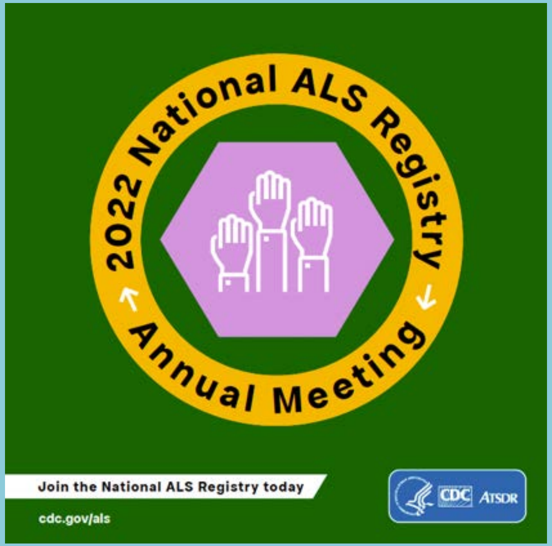
ALS Registry Annual Meeting (Aug. 29-30, 2022)

- **NEED FOR BIOSAMPLES:** In a sample survey of ALS researchers, 71% of respondents anticipate needing biosamples in the next 6-12 months

- **CURRENT RESEARCH:** Several presentations on studies looking at potential risk factors (overlap of EPA supersites and incidence of neurodegenerative disease)

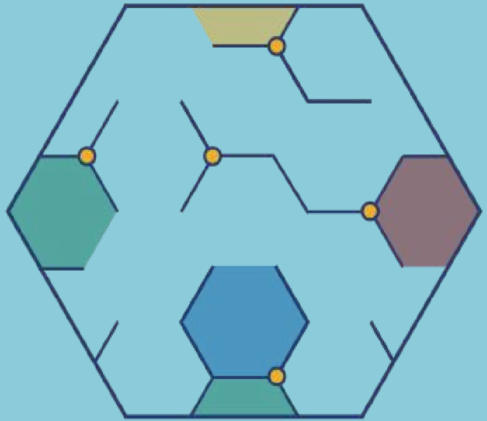
- **OPEN COMMENT QUESTION IN SURVEYS:**
  - Comorbidities (example: autoimmune disease)
  - Medications (example: statins)
  - Immunizations
  - Military-specific exposures
  - Exercise and physical labor
  - Emotional trauma and stress

- **FEEDBACK: Suggestions from people living with ALS:**
  - Minimize the delay of collecting data
  - Work on improving diversity in the data collected



More ALS Data Helps Complete the Puzzle of ALS

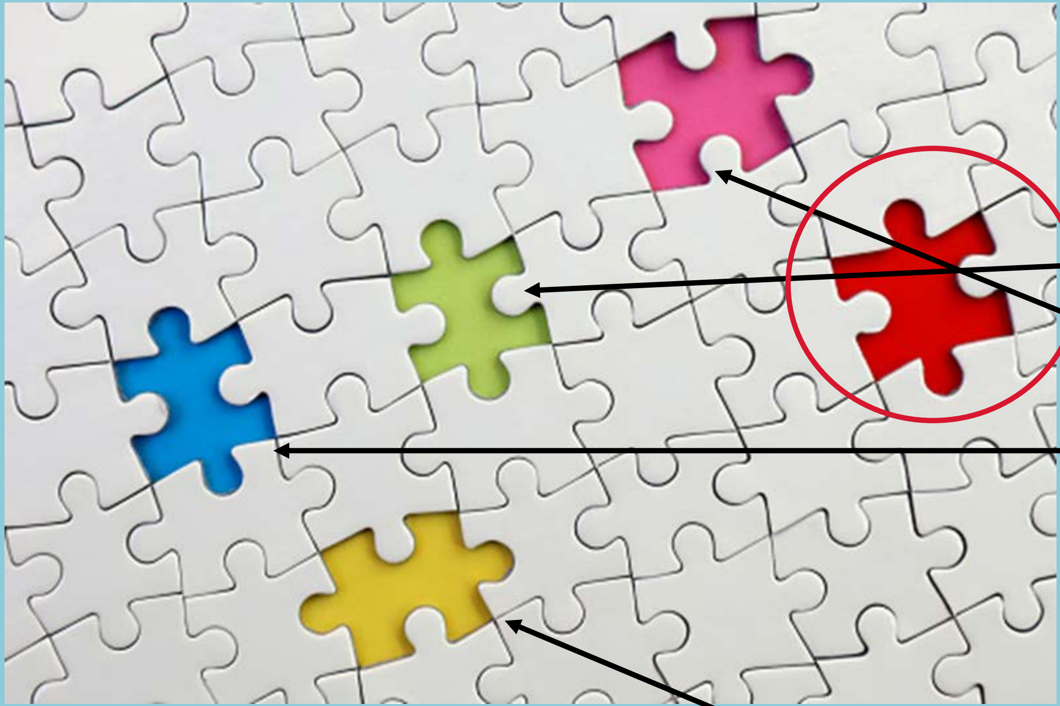
5 data points vs 5000 data points



More ALS Data Helps Complete the Puzzle of ALS

More ALS Data Helps Complete the Puzzle of ALS

Answering risk factor surveys is
a meaningful way to share your story



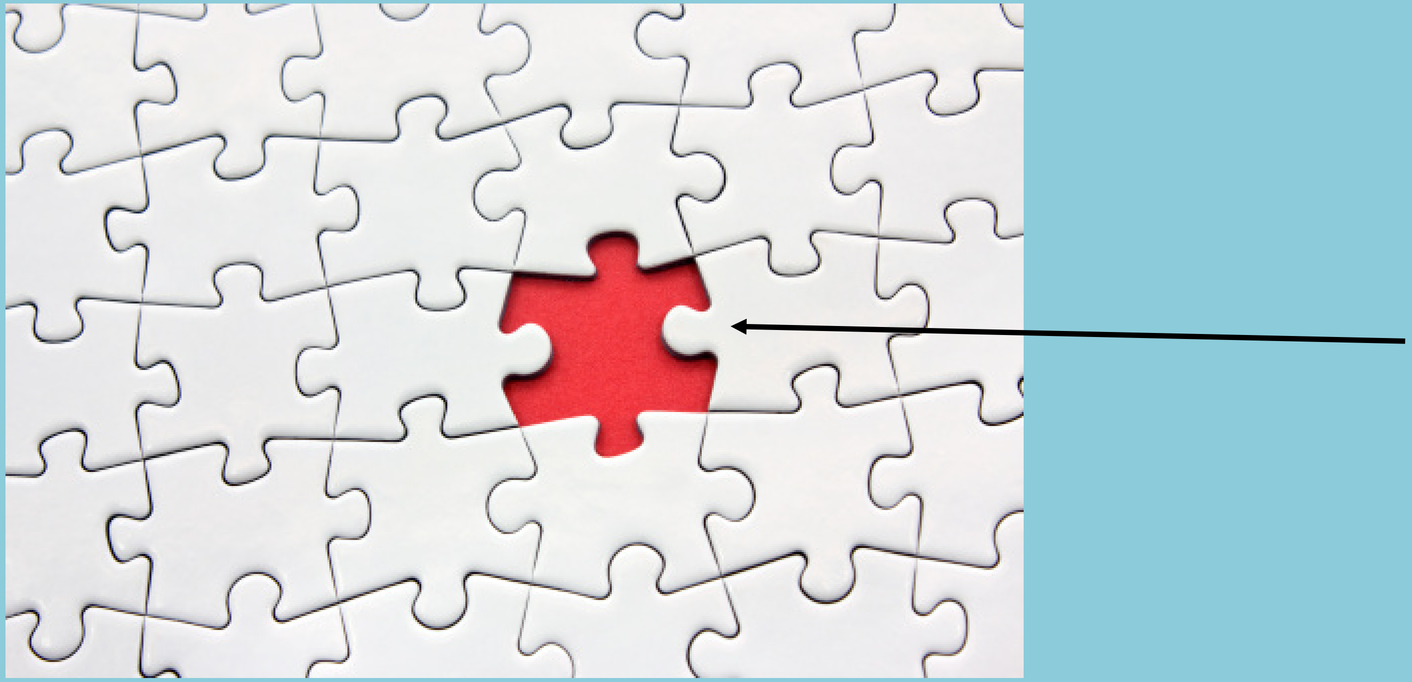
I had back surgery and never fully recovered. Instead of getting stronger, I started getting weaker.

When I was growing up, I spent summers on my grandma and grandpa's farm. My grandpa would take me fishing on a lake nearby that used to get full of algae.

Parkinson's seems to run in my family and a cousin has Multiple Sclerosis – I wonder if that means anything.

New enrollee

More ALS Data Helps Complete the Puzzle of ALS



What is YOUR story?

Hear from ALS patients and why they’re joining the National ALS Registry to fight for their future and future generations. Your ALS experience could help change theirs.

The National ALS Registry

Be counted.
Fight back.
Make a difference.
#ALS
#BeCounted


[illegible] learn about ALS risk factors.

Join the National ALS Registry today!

ALS
ASSOCIATION

Visit
www.cdc.gov/als

Questions?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Your ALS Experience Could Change Theirs.

Learn More

Join the National ALS Registry now.

Contact:
Patti Stanco
patricia.stanco@als.org
(202) 464-8045


Join the National ALS Registry.

With your help, we can advance research.

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Learn More


Turn ALS Research Into ALS Progress.

Become part of the National ALS Registry.

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Join Now