ALL ALS Community Newsletter

June 2026

Together, We're Making a Difference

Interested in learning more about or participating in ALL ALS? Visit the ALL ALS website or connect with our team by clicking the buttons at the end of this newsletter!

Participant Spotlight

Meet Kathy:
Kathy grew up in a large family, being one of seven sisters. Despite there being no history of ALS in previous generations, three of her sisters, Mary, Patty, and Teri, have developed and passed from ALS, over the course of the last 12 years.

In 2018, following Patty's diagnosis, Kathy pursued genetic testing and discovered that she carried an ALS-related genetic variant in her TARDBP gene.

After her results came back, additional testing was conducted amongst the family, which revealed that her sisters' ALS was familial.

Since then, Kathy's family has dedicated themselves to ALS research that aims to shed light on the genetic causes of the disease and advance treatment options.

"This fight is personal" - Kathy

A Family's Commitment to Research:
Upon Teri's diagnosis, Kathy began exploring potential research opportunities for her sister, including the Silence ALS trial at Columbia University, through which an experimental treatment is designed to target the known genetic variant of each individual participant. Ultimately, Teri chose to participate, and although Teri passed before she was able to receive the drug herself, the experimental treatment that was developed from her genetic material has been used to treat other patients with a similar genetic form of ALS.

Kathy and her daughter have continued their family's commitment to research by participating in ALL ALS. In addition, Kathy and her family have raised more than $50,000 to support people living with ALS.

Sources of Inspiration:
Over the last 12 years, Kathy has prioritized supporting her sisters throughout their ALS journeys: physically, emotionally, and spiritually. She feels fortunate that she was able to assist them through the good and the bad- the daily struggles of living with ALS and the many moments of joy, such as the birth of her niece.

The strength her sisters demonstrated continues to inspire her. Kathy shared that they showed her "how to be strong, how to live life to the fullest, regardless of the challenges of ALS, and [how to] never lose faith... Their grace, faith, grit, and determination to live every day... keeps me fighting for them and for myself and others."

Hope for the Future:
Kathy remains hopeful that a future without ALS is possible with continued research and community engagement.

Currently, Kathy finds joy in spending time with her husband, children, and grandchildren, serving her community through her church ministry, and crafting in her spare time. She will cherish the lessons in courage and resilience her sisters taught her.

As Kathy notes, "every day is a gift. Embrace life and live every day to the fullest."

Study Progress Updates

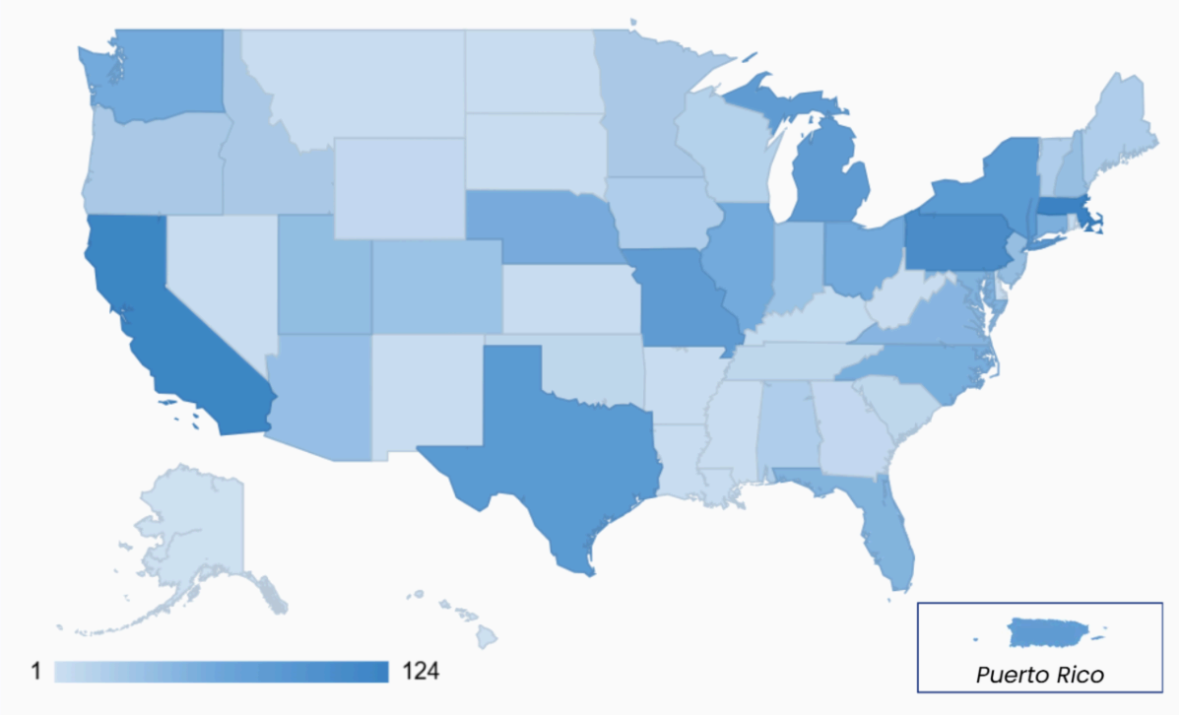
Total Participants Enrolled in ALL ALS:	Participants Enrolled in ASSESS Study:	Participants Enrolled in PREVENT Study:
1,716	**1,192**	**524**

Fully Remote Participants Enrolled:	Blood Samples (Vials*) Collected:	CSF Samples (Vials*) Collected:
385	**119,980**	**13,022**

**The number of vials collected per visit and sample volumes are dependent on sample type and can vary between visits. Not all participants are providing CSF samples.*

ALL ALS Data Spotlight

As ALL ALS continues to enroll, it is important for the program to understand who is participating, as the characteristics of our participant pool have direct implications on how our dataset relates to the broader ALS population. In turn, this impacts how the data can be used for research down the road. Today, let's explore where our participants are located across the U.S. and Puerto Rico as of May 2026.



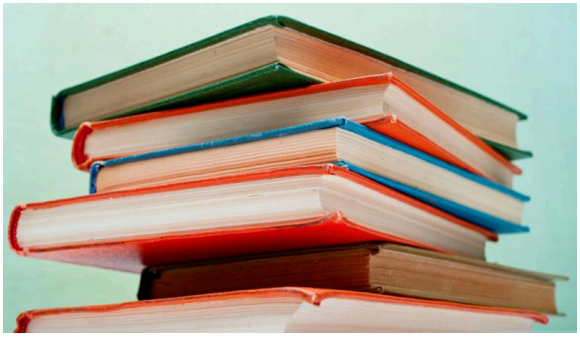
Note: The darker the blue, the more participants that self-reported living in that state or territory. The states with the greatest number of participants are Massachusetts (124), California (119), and Pennsylvania (104), while the states with the lowest number of participants are Alaska (1) and Hawaii (1).

A number of factors affect the geographic distribution of our participants, including proximity to an ALL ALS site and access to a multidisciplinary ALS clinic or an active research center.

With this knowledge, ALL ALS can develop outreach strategies aimed at reaching ALS populations within the lower enrolling states and regions. If this outreach successfully results in increased interest and enrollment,

our dataset will be more reflective of the general ALS population, which is an important objective of ALL ALS.

Book Club & Movie Night



ALL ALS Book Club:

Soft Foods for Easier Eating Cookbook by Sandra Woodruff, MS, RD, LD/N & Leah Gilbert-Henderson, PhD

In this cookbook, Sandra, a Registered Dietitian and Nutritionist, and Leah, a Nutrition Scientist, share over 150 adaptable soft food recipes that account for the reality of living with swallowing difficulties, otherwise known as dysphagia.

If you are interested in practical, delicious, and nutritionally balanced recipes for smoothies, soups, entrees, and desserts, as well as in-depth tips on meal planning, recipe modifications, and cookware, consider purchasing the cookbook on Amazon or an online bookstore. (*Please Note: This cookbook should not replace direct advice from a clinician.)*

ALL ALS Movie Night:

Indestructible

Indestructible documents Ben Byer's life in the three years following his ALS diagnosis in 2002. Watch the film to see Ben travel around the world in search of treatments and community and witness his desire to embrace hope, humor, and creative expression amidst a life with ALS.

Click the button below to be directed to the Indestructible website, where you can view the film for free.

Website

New ALL ALS Sites Activated!

In the last 3 months, ALL ALS has activated their 36th and 37th research sites: the **University of California in Los Angeles, CA** (UCLA) and **Synapticure**, a national, virtual neurology clinic. Through the activation of these two new sites, the program has expanded participation and accessibility options for both people living with ALS and living without ALS.

UCLA and Synapticure are both set to enroll within the ASSESS ALL ALS study. UCLA plans to enroll participants living with ALS into the in-person and remote ASSESS cohorts, as well as participants living without ALS (controls). Due to the virtual nature of their service, Synapticure has prepared to remotely enroll participants living with ALS. If you are interested in contacting either site, feel free to review their site contact information on the ALL ALS website or email the general ALL ALS inbox for more information.

Let's collectively send UCLA staff a heartfelt welcome and sincere thank you for their dedication to ALS research!

Site Staff Spotlight:

University of Puerto Rico Medical Sciences Campus

Frances M. Aponte Caraballo:

Frances M. Aponte Caraballo, MS, is a Public Health Professional and Clinical Research Coordinator who is currently pursuing a Doctorate in Public Health with a specialty in Environmental Health at the University of Puerto Rico Medical Sciences Campus Graduate School of Public Health.

In her current role, she primarily focuses on analyzing data, including clinical and population-level data, to learn about the impact a disease has on broader populations, identify disease risk factors, and address health disparities.

Much of her current work centers on ALS. Day-to-day, Frances coordinates clinical research operations, oversees community engagement efforts, and contributes to research through study design, statistical analyses, and the distribution of critical scientific information.

Her contributions helped lead to the development of the first ALS Registry in Puerto Rico, which strengthened clinical and research infrastructure in the region.

Outside of work, Frances enjoys baking, chocolate making, and traveling. She especially appreciates quiet moments with a good cup of coffee, which she considers her favorite part of the day.

Participant Support Feature Launched!

A critical component of ALL ALS is digital surveys that collect a variety of important information, such as environmental and military history.

In order to optimize participant experience, ALL ALS has launched support hours that allow participants to meet with experts that can assist them with routine technical questions, such as password resets and survey settings management. If you are interested in receiving personalized survey support or have questions, feel free to contact your ALL ALS site team for more information.

Connecting with the ALS Community

Stronger Together NEALS Webinar:
June 8th, 2026

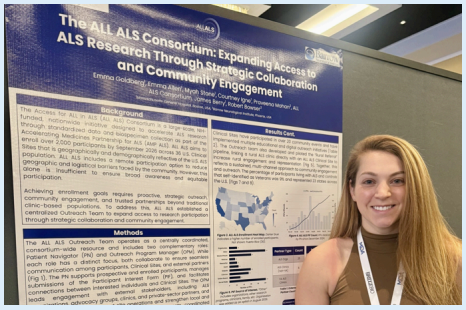
The NEALS Consortium hosted a collaborative webinar between the ALL ALS Consortium, the CDC National ALS Registry, Target ALS, and the FDA ALS Natural History Consortium to present on how these studies are working together to broaden research access, generate critical data, and drive treatment development.

Watch Webinar

2026 AAN Conference :
April 18th-22nd, 2026

Several members of the ALL ALS Outreach Team attended the 2026 American Academy of Neurology (AAN) Annual Meeting in Chicago, IL.

Learn More



Spring ALS Community Events:

Throughout the spring, many ALL ALS staff attended and participated in ALS community events across the U.S, including walks, health fairs, and Lou Gehrig's Day baseball games.

Learn More

ALL ALS Community Webinar

On April 15th, 2026, ALL ALS hosted a Quarterly Community Webinar, in which Dr. Robert Bowser shared ALL ALS study developments and data and Dr. Amelie Gubitz highlighted the important work of the Accelerating Medicines Partnership for ALS (AMP® ALS).

A recorded video of the webinar is available on the ALL ALS website.

The next Community Webinar, which will feature a discussion on biosample management, is scheduled for June 24th, 2026 at 2:00 PM PDT/ 5:00 PM EDT. Click the relevant button below to view the "Webinars" page of the website or to join the webinar email registry.

Webinars Page

Join Registry

AMP® ALS Newsletter

The Accelerating Medicines Partnership for ALS (AMP® ALS) is a public-private partnership and ALL ALS collaborator driving progress in ALS biomarker research and identifying new promising treatment targets. Interested in learning more about their ongoing work?

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