



# ALL ALS Community Newsletter

*March 2026*

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## *Together, We're Making a Difference*

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*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!*

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## Participant Spotlight

### **Meet Ron:**

Ron is a South Carolina resident and a retired United States Air Force Chief Master Sergeant with a total of 27 years of service from 1968 to 1995. He spent 21 years as a military aircrew member before transitioning into the world of finance. In 1990, he accepted a position as an Air Force Base Defense Accounting Officer.



Following his military retirement, he settled into his role as a municipal Finance Director. In the wake of his ALS diagnosis in October 2016, Ron retired and has since dedicated his life to advocacy and ALS community support.

### **Ron's Road to Advocacy:**

Ron's military service has heavily influenced how he's adapted to the adversity that accompanies life with ALS. In the military, he was encouraged to cultivate resilience, maturity, and a strong sense of leadership. He learned how to "start strong, stay strong, and finish even

stronger... Those lessons didn't disappear when... [he] was drafted into a club [he] never asked to join"— "they became [his] anchor."

After the initial shock of the diagnosis faded, "I realized I had a choice. I could... pretend the club didn't exist... or I could step forward and fight to make it a place where people, me included, could actually live, not just survive. I chose the fight."

### **His Commitment Over the Years:**

Over the course of the last nine years, Ron has participated in an experimental drug trial and six observational research studies, including ALL ALS, due to a belief that these studies could hold the answer to faster diagnoses and to successful methods of slowing, halting, or reversing ALS progression.

Ron has also committed himself to many advocacy and community support efforts, including the ALS Association's ALS Focus Committee, I AM ALS's Veteran Committee and annual Blue Flag event management team, ALS Therapy Development Institute, his city's Mayor's Advisory Committee on Disabilities, and the ALS Hope Foundation's Veteran ALS Action Committee.

Although Ron is proud of all the work he (and all the people he has collaborated with over the years) has accomplished, ALS Hope's Veteran ALS Action Committee "holds a special place in [his] heart. It's where [he's] seen, firsthand, how powerful a determined group of people can be when they refuse to accept the status quo".

### **What Ron Has Learned Along the Way:**

Throughout Ron's journey, he has come to cherish the support groups and organizations with which he has chosen to involve himself, as they have each dedicated themselves to cultivating a strong sense of community that emboldens their members to "trade knowledge, share tips, and remind each other that while ALS affects each of us differently, none of us are walking this road alone."

"That's what this journey has become for me: supporting research and each other, learning from each other, caring for each other. It's a space where we take care of ourselves physically, emotionally, and spiritually. A space where we remind ourselves- and each other- of a simple truth: 'I do what I do not for me, but for those behind me.'"

## **Study Progress Updates**

Total Participants  
Enrolled in ALL ALS:  
**1,469**

Participants Enrolled in  
ASSESS Study:  
**1,017**

Participants Enrolled in  
PREVENT Study:  
**452**

Fully Remote Participants

Enrolled:

339

Blood Samples (Vials\*)

Collected:

87,489

CSF Samples (Vials\*)

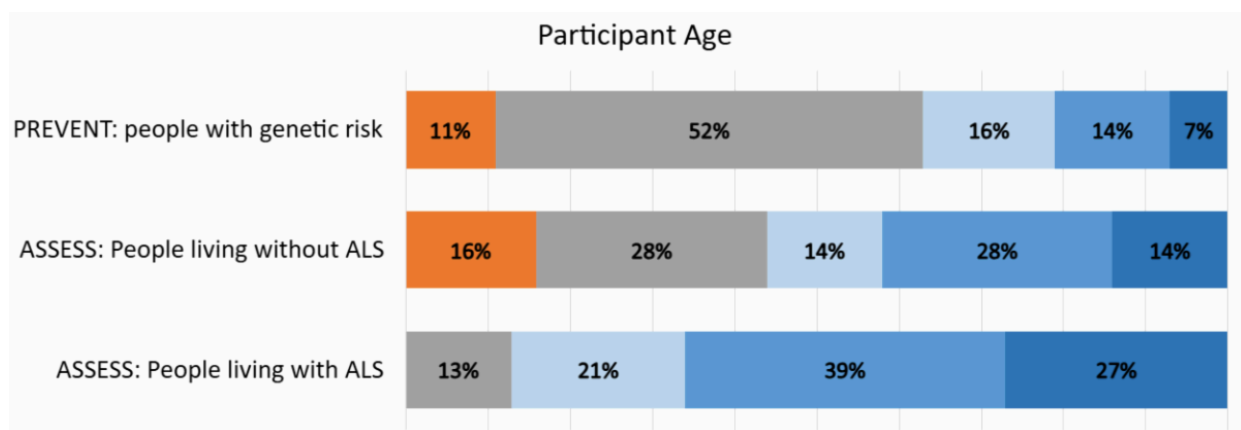
Collected:

10,098

\*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

Since ALL ALS has been enrolling for over a year and half, it is important for the consortium to start analyzing ALL ALS's dataset to better understand our current participant population. By reviewing participants' demographics and clinical health outcomes, ALL ALS can gain insight on whether our current dataset is representative of the entire population of people living with ALS in the U.S. and Puerto Rico. To start, let's examine a breakdown of the age of ALL ALS's participant pool as of February 2026.



18-30 yrs 31-50 yrs 51-60 yrs 61-70 yrs 71+ yrs

Note: There is one ASSESS participant living with ALS within the 18-30 yr age group that is not represented in the chart above.

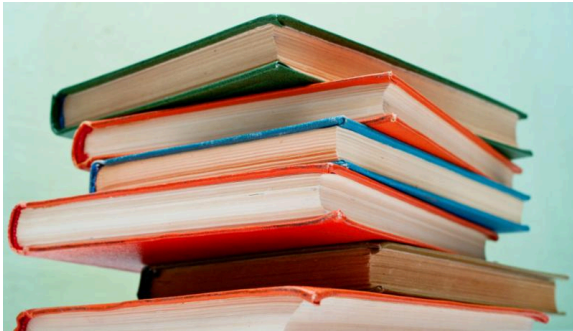
On average, our participants living with ALS are older than our participants living without ALS and at genetic risk (see table to the right). One possible explanation for the variation in average age between cohorts could be that the onset of ALS symptoms and diagnosis tends to occur at an older age (Longinetti & Fang, 2019).

ALL ALS STUDY	AVERAGE PARTICIPANT AGE (YRS)
PREVENT: People living at genetic risk	46
ASSESS: People living without ALS	51
ASSESS: people living with ALS	63

Another important note is that ALL ALS has currently enrolled people living without ALS (controls) across a wide age range. This means that the ALL ALS dataset will have control data that can be compared to the data of people living with ALS and at genetic risk. This is beneficial because comparison data is a necessity in research!

Reference: Longinetti, E., & Fang, F. (2019). *Epidemiology of amyotrophic lateral sclerosis: an update of recent literature [Review of Epidemiology of amyotrophic lateral sclerosis: an update of recent literature]*. *Current Opinion in Neurology*, 32(5), 771–776. <https://doi.org/10.1097/WCO.0000000000000730>

## Book Club & Movie Night



### ALL ALS Book Club:

*Weather Woman* by Cai Emmons

*Weather Woman* is a fiction novel, written by Cai Emmons, a woman diagnosed with bulbar-onset ALS in 2021. The novel follows Bronwyn Artair, a meteorologist, as she struggles with the reality of her newfound ability: she can affect and change the weather. As these powers develop, Bronwyn must restructure her relationship with herself, science, and the natural world. Read *Weather Woman* by purchasing the physical book, ebook, or audiobook on Amazon.

Additionally, Cai Emmons maintained a blog from 2020 to 2023, in which she shared her thoughts, opinions, and

### ALL ALS Movie Night:

*Breadth of Hope*

*Breadth of Hope* is a documentary that follows 3 people living with ALS in the small town of Victoria, Texas in 2010. Watch Craig Fox, Bill Hassel, and Carolyn Shimek onscreen and learn about their personal stories, including how each found meaning, hope, and joy in the midst of this devastating disease. You can view the documentary for free on YouTube or Culture Unplugged's website. Click the relevant button below to be redirected to *Breadth of Hope*.

experiences on life, writing, and living with ALS. If interested, click the button below to be directed to her blog.

[Visit Blog](#)



[YouTube](#)

[Culture Unplugged](#)

## Site Staff Spotlight:

*Hospital for Special Care*



### **Dr. Sabine Lebel-Hardenack:**

In January 2024, Sabine Lebel-Hardenack, PhD joined Hospital for Special Care (HFSC) in New Britain, Connecticut, as a clinical research coordinator, driven by a deep commitment to support individuals living with ALS and their families.

She had previously been the primary caregiver for her late husband throughout his battle with ALS, an experience that profoundly shaped her life. Her own family's journey with the disease continues to inspire her and fortifies her professional and personal dedication to connecting patients to clinical research opportunities.

Sabine's academic background is in molecular biology and plant genetics. She obtained her Master's Degree and PhD from the University of Cologne, Germany, while conducting research at the nearby Max Planck Institute for Plant Breeding. Currently, she serves as the lead coordinator for the ALL ALS Consortium at HFSC, which involves managing and performing the many operational, regulatory, and patient-facing aspects of ALL ALS.

Outside of work, Sabine enjoys spending time outdoors—walking her dog, hiking, and gardening—as well as traveling and, most of all, getting together with her children.

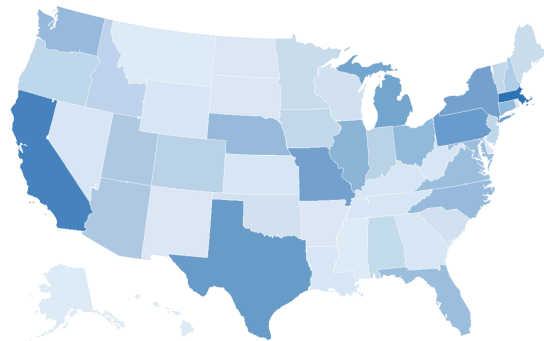
# New ALL ALS Sites Activated!

In the first three months of 2026, two new ALL ALS sites officially activated and began enrolling participants in the ASSESS ALL ALS study: the **University of Pennsylvania** in Philadelphia, PA and **Vanderbilt University** in Nashville, TN.

Activation of a new sites expands participation opportunities for ALS community members and broadens ALL ALS's impact. Let us celebrate this achievement together: thank you, University of Pennsylvania and Vanderbilt University staff, for coming on board and helping advance ALS research through ALL ALS!

## ALL ALS is in ALL 50 States & Puerto Rico

As of February 2026, ALL ALS has officially enrolled participants from all 50 US states and Puerto Rico. This is a remarkable accomplishment that showcases the importance of providing accessible research to the ALS community.



As ALL ALS continues to grow, this milestone will act as a reminder of the hard work of our ALL ALS consortium and site staff, the collaborative efforts of ALL ALS's community partners, and the steadfast dedication of the ALS community to advancing ALS research.

## Connecting with the ALS Community

## ARC & ALL ALS Webinar: January 21st, 2026

The NEALS Consortium hosted a collaborative webinar between the ALL ALS Consortium and the ALS Research Collaborative (ARC) to present information on how these two research studies are working together in pursuit of a shared goal.

ARC and ALL ALS:  
Two Research  
Studies, One  
Shared Goal



NEALS Webinar  
January 21, 2026



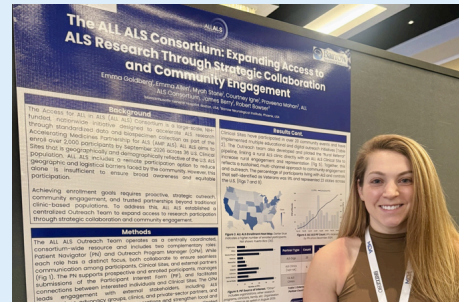
[Learn More](#)



## 16th Annual ALS Network Research Summit: January 22nd-24th, 2026

The ALL ALS Outreach Team, as well as several other ALL ALS staff members, including UCSD site staff, attended the Annual ALS Network Research Summit in Pasadena, CA.

[Learn More](#)



## MDA Clinical & Scientific Conference: March 8th-11th, 2026

In March, Emma Goldberg, PhD, ALL ALS' Outreach Program Manager, attended the MDA Clinical & Scientific Conference in Orlando, FL.

[Learn More](#)

# A Historic Moment for ALS Research

Historic federal investment is actively evolving and advancing of the ALS research landscape. In 2026, ALS community members, advocates, and organizations helped secure \$313 million in federal funding for ALS research- the largest annual investment in the history of the disease. Since 2019, federal funding for ALS research has grown to more than \$1.6 billion, after remaining widely unchanged for decades.

A major component of the recent federal investment was the Accelerating Access to Critical Therapies for ALS Act (ACT for ALS), which was approved in 2021. To continue reading about the ACT for ALS, click the button below.

[Learn More](#)

This section was developed in collaboration with I AM ALS. To learn more about I AM ALS, visit their website: [www.iamals.org](http://www.iamals.org)

## ALL ALS Community Webinar



On January 7th, 2026, ALL ALS hosted a quarterly Community Webinar, in which Dr. James Berry shared ALL ALS study and data updates and Dr. Katherine Burke highlighted the launch of the DIGITIZE assessments. A recorded video of the webinar is available on the ALL ALS website.

The next Community Webinar, which will include a focus on AMP ALS and the ACT for ALS, as well as guest speakers from the NIH and I AM ALS, is scheduled for April 15th, 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](#)

## Join ALL ALS on Facebook!

**We're excited to share that ALL ALS is now on Facebook!** Whether you're a participant, caregiver, or supporter, you can follow along to stay informed on ALL ALS.

Click the Facebook button at the bottom of this newsletter to visit our page.

### CONTACT ALL ALS:

Website: [all-als.org](http://all-als.org)

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