ALL ALS Community Newsletter

September 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 Howard:
About three years ago, Howard noticed weakness in his right hand. After seeing several doctors who, despite their best efforts, could not give him answers, Howard was referred to Henry Ford Hospital in Detroit, MI.

At the time, he believed that he would be provided with an explanation that would allow him to return to his normal, everyday life, including spending time with his wife and two daughters and playing pickleball, a sport he had enjoyed four days a week for several years.

Instead, he received a diagnosis that would permanently alter his life: ALS. Howard was shocked by the diagnosis. Yet, despite all the uncertainties and change that accompanied it, one thing remained consistent and unyielding: his positive outlook on life.

Choosing to Live Happy: Howard's Five Principles:
"I have always been a happy person," Howard shares. "Every day, I wake up happy... and ready to tackle the adventure of life."

He credits five principles for helping him maintain that outlook and live an “honest, happy life”: Irrational Confidence, No Fear, Giving Is Living, Guilt Free Living, and Why Not?

#1 Irrational Confidence: Howard champions the well-loved mantra: “believe in yourself,”, even when the odds may seem uncertain.

He approaches life with an unwavering confidence that things will work out and the conviction that blessings will result from that self-belief. For Howard, this means that he wholeheartedly upholds and reaffirms the belief that “[he] will survive this... [he] will find a way to survive this.”

#2 No Fear: Inspired in part by the Disney movie Luca, Howard believes that there is power and growth to be made by having fears, then facing and, ultimately, conquering them.

“You should always have something that scares you on your calendar... If you can stop being afraid of things, you can open up the possibilities for success and greatness.”

#3 Giving Is Living: For Howard, giving to others is one of the things that makes life feel most meaningful. Whether giving your heart, your mind, your time, or your resources, he believes that the more you give of yourself, the more alive you feel.

#4 Guilt-Free Living: Howard views guilt as a destructive emotion. He asserts that letting go of guilt allows people to live an honest and genuine life- to make decisions based on their true emotions, preferences, and beliefs, instead of in response to internal or external pressure caused by guilt.

#5 Why Not?: When uncertainty or apprehension gets in the way, Howard asks himself a simple question: “Why not?” Whether it means trying a new food, taking up an alternative hobby, or pursuing something new, he believes that life is an opportunity to explore.

These tenets have helped Howard maintain a hopeful perspective while living with ALS, and an important part of putting his five principles into action is participating in research. As a participant in ALL ALS at the University of Michigan, Howard is contributing to research that can help change the future for people living with ALS and lead to new treatments and significant technological advancements.

Howard remains hopeful that researchers will ultimately “crack the code” on ALS, not only for himself, but for everyone living with the disease.

An Unexpected Blessing:
However, Howard’s five principles are not the only thing that have sustained him throughout his journey with ALS, for his diagnosis and all

of the subsequent life changes led to a revelation: he has an extraordinary amount of love and support in his life.

This was Howard's unexpected blessing, as this knowledge broadened his understanding of and deepened his appreciation for the people who had and continued to bolster, encourage, and love him. For this reason, Howard says, "I am blessed to be sick."

To listen to Howard speak on his journey and approach to living with ALS on the "Waking Up to Life" podcast, click the button below.

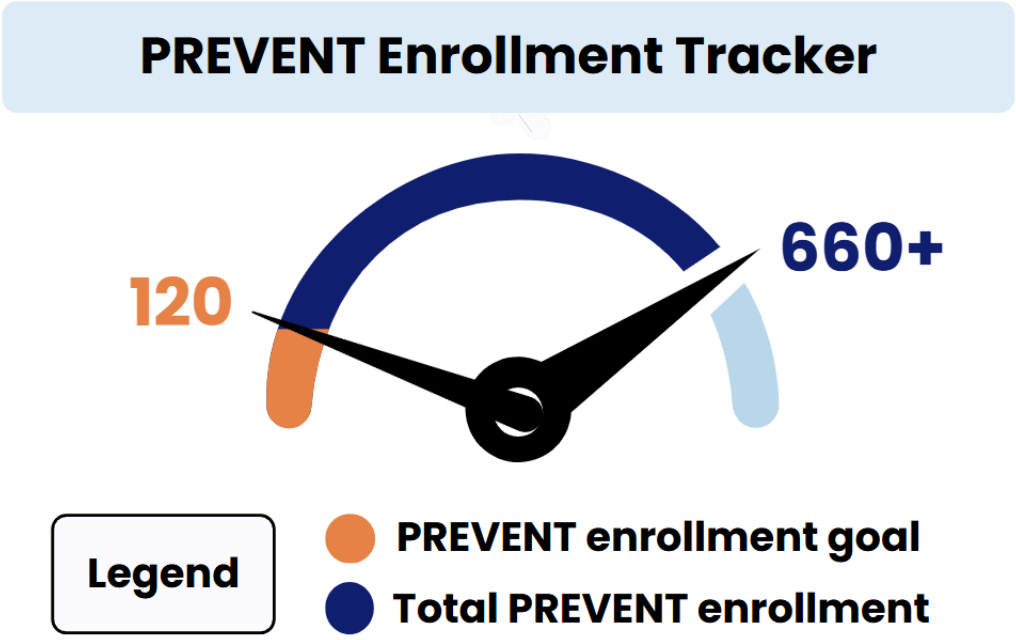
Podcast ft. Howard

Interested in being spotlighted as an ALL ALS participant?
Email us by clicking the button below.

Email Us

PREVENT Enrollment Closure

We are thrilled to share that, thanks to the overwhelming support of the at-risk community, the PREVENT study has successfully reached and exceeded its enrollment goals! **As a result, PREVENT will be closing enrollment on September 30th.**



To our PREVENT participants, we want to express our heartfelt gratitude. We are inspired by your resilience and your generous commitment to advancing science. While enrollment has come to a successful close, the true impact of your contribution is only just beginning. Together, let us continue working toward a future of hope and progress.

Note: Enrollment for the ASSESS ALL ALS study, which enrolls people living with ALS and people living without ALS (and not at genetic risk), will continue to enroll past Sept. 30, 2026.

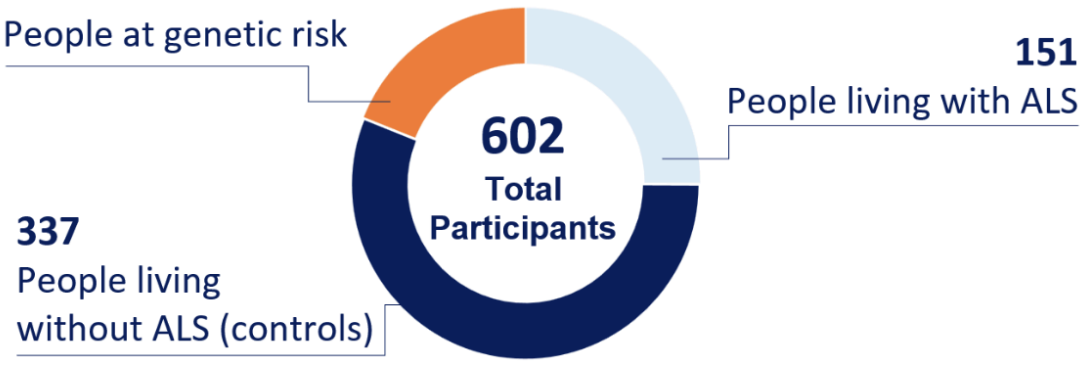
Biomarker Testing Underway

Biomarker testing is a vital component of ALS research because it allows researchers to assess the cells, proteins, and other biological components that may contribute to ALS's development and progression. For this reason, ALL ALS has prioritized evaluating our samples, which are tested in batches (i.e. 100-500 at a time) to maintain sample testing consistency.

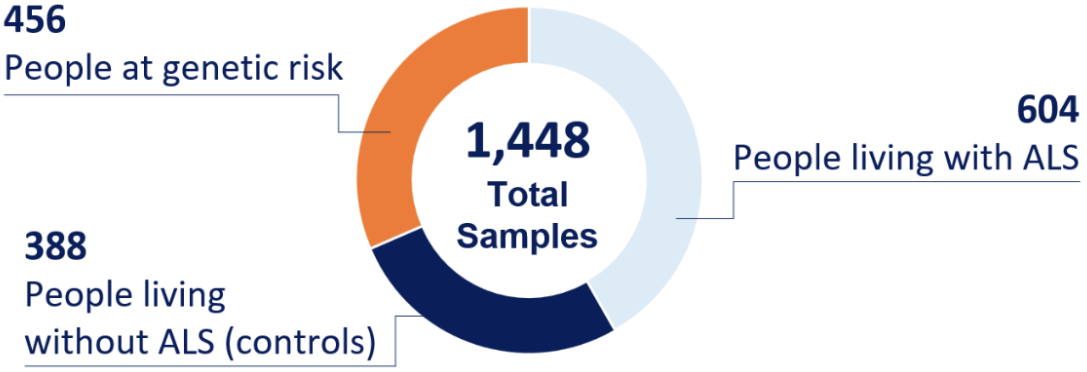
Notably, ALL ALS has officially begun biomarker testing on collected blood samples! These tests will measure the amounts of various proteins in the blood, such as neurofilament light (NfL), that are known or suspected to be significant in ALS and other neurological and inflammation-related disorders.

Review the figures below to learn more about ALL ALS's NfL testing as of August 2026.

How many participants have had their samples tested?



How many total blood samples have been tested?



ALL ALS is hopeful that sharing these test results with researchers will be one of many first steps towards building a better understanding of ALS, developing more effective treatments, and expanding access to future clinical trials.

Study Progress Updates

ALL ALS has enrolled over 2,000 participants!

We were able to achieve this milestone due to the incredible support of our participants and the hard work of our site staff.

Thank you for your dedication to research!

Total Participants Enrolled in ALL ALS:	Blood Samples (Vials*) Collected:	CSF Samples (Vials*) Collected:
2,046	**152,407**	**15,686**

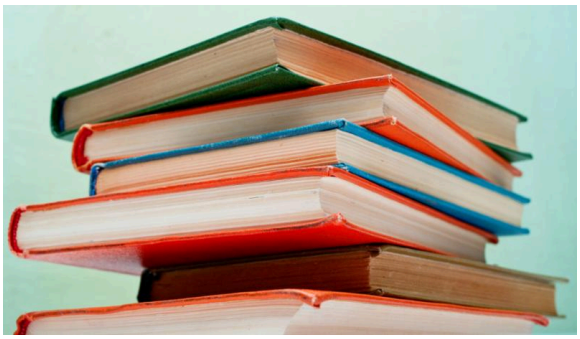
**The number of vials collected per visit and sample volumes are dependent on sample type and can vary between visits. Not all participants are providing CSF samples.*

Express Your Appreciation

ALL ALS's staff work hard to support you throughout your time in the program. **Click the button to express your appreciation to your research team by sharing a positive message.**

Staff Appreciation Survey

Book Club & Movie Night





ALL ALS Book Club:

Clinical Trial: An ALS Memoir of Science, Hope, and Love by Robert K. "Bert" Ranum

Clinical Trial shares the story of Bert Ranum, who was diagnosed with C9orf72-associated ALS after the disease had already touched multiple generations of his family. As Bert navigates life with ALS and participation in a clinical trial, his story uniquely intersects with that of his wife, Laura, a neurogenetics researcher studying neurological disease.

Blending family, science, and personal experience, the memoir offers a compassionate perspective on research participation and the hope it can represent for families affected by ALS. Read *Clinical Trials* by purchasing the physical book or ebook on

ALL ALS Movie Night:

New Life

Looking for an ALS-related movie with a Halloween twist?

New Life is a 2023 post-apocalyptic horror-thriller that follows two women, one of whom, Elsa, is living with ALS. As we follow Elsa's thrilling attempts to pursue a woman on the run, Elsa's changing physical abilities, caregiving plans, and living accommodations are thoughtfully woven throughout the story.



Disclaimer: *New Life is a horror film and contains graphic*

Amazon or another online bookstore.

violence, disturbing imagery, and other mature themes.

New Control Opportunity

ALL ALS is introducing an *optional* Super Control Group for eligible ASSESS control participants (people living without ALS and are not a increased genetic risk). Control participants who choose to join will complete additional in-person visits and assessments, including blood collections approximately every four months and a neurological exam at the final visit.

These additional activities will help researchers better compare the data collected from our controls and participants living with ALS, which will strengthen future biomarker research and improve clinical understandings of how ALS changes over time.

Interested? Connect with your ALL ALS study team to learn whether participation may be an option for you.

Site Staff Spotlight:

Vanderbilt ALS Research Center



Nicola Rutherford:
Nicola “Nic” Rutherford, PhD, is the BioCoRe Branch Leader and an ALL ALS site coordinator at the Vanderbilt ALS Research Center (VARC) at Vanderbilt Health. In these roles, she supports day-to-day study activities, including study visit and data management. She also coordinates the VARC biorepository to ensure that participant samples are carefully collected, tracked, and made available for meaningful research that supports treatment development.

Nic earned her doctorate in Medical Sciences with a concentration in Neuroscience from the University of Florida. However, her connection to ALS research began before graduate school while working in Dr. Rosa Rademakers’ laboratory at Mayo Clinic, where she was part of the team involved in the 2011 discovery of the C9orf72 mutation, a landmark discovery in ALS and FTD research. After several years in other areas of

science, including biotechnology, she was excited to return to ALS research in 2024 and dedicate herself to building direct connections with patients and families while contributing to scientific discovery.

Outside of work, Nic enjoys reading, baking, cross-stitching, and quilting, though these hobbies often compete with the joyful chaos of life with two young children. Originally from England, she also enjoys catching up on British television with *Taskmaster* being a personal favorite.

DIGITIZE ALL ALS

If you are an ASSESS participant living with ALS, we invite you to take part in an exciting *optional* study assessment: DIGITIZE.

To learn more, click the button below.

Learn More

ALL ALS Community Webinar



On September 2nd, ALL ALS hosted a Quarterly Webinar, in which Dr. Robert Bowser shared ALL ALS study developments and Dr. Emma Goldberg discussed recent ALL ALS data, which highlighted enrollment in rural and urban areas across the U.S.

Guest speaker, Dr. Robert Allaway, also provided an overview of the ALS Knowledge Portal, including how ALL ALS data is stored and accessed by researchers.

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

The next Community Webinar is scheduled for November 18th, 2026 at 2:00 PM PST/ 5:00 PM EST. Click the relevant button below to view the “Webinars” page of the website or to join the webinar email registry.

Webinars Page

Join Registry

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