



ALL ALS Community Newsletter

December 2025

Together, We're Making a Difference

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

Participant Spotlight #1

Meet Michele:

Michele is currently living in Pennsylvania with her husband, Tom. Now that her 3 children have moved out of the house, her extremely energetic and mischievous 9-year-old golden retriever, Chet, gets much more attention (to his delight) and many, many snacks. Michele was diagnosed with ALS in February 2024.



Michele's life with ALS has been "an interesting journey"- one in which she has been tasked with "[dealing] with what ALS throws at [her] every day." In August 2025, she published a memoir that details her experiences of living with ALS. "I wasn't a writer. I had no clue what I was doing. I just started jotting things down." These jots, notes, and thoughts were compiled into her book, *The Art of Living, The Joy of Fighting ALS*. If interested in learning more, click the button below to be directed to the book on Amazon.

Contributing to ALS Research:

Michele was motivated to join ALL ALS because of her commitment to driving meaningful progress in the fight against ALS. At first, her family was slightly taken aback by her interest in research, especially because she opted into ALL ALS's lumbar puncture (spinal tap) option. However, Michele felt that her participation in research was necessary in getting "one step closer to finding a cure, or, at least, a treatment for ALS".

Advocacy and Community Support:

Michele recently joined the legislative team of I AM ALS, a community-led ALS organization. With the legislative team, she has been able to attend and speak at meetings with one of her state's senators, advocate for the ALS community, and rally support for the ACT for ALS. She has found the experience to be quite inspiring, as "everybody has a purpose [for] why they're there. They just want to be involved."

Life, Leisure, and the Future:

Michele is continuously inspired and strengthened by her family, who support her through the big and small moments of her everyday life. In addition, she has been able to cultivate a sense of sustained fortitude and resilience by maintaining her independence: continuing to cook, clean, and complete all the everyday tasks that she can. In her free time, Michele strives to remain busy, researching ALS, lounging in the pool (on hot days), working on her diamond paintings and other artwork, and travelling across the globe. Currently, she is planning a family vacation to Florida for next summer.

Michele's Book

Participant Spotlight #2



Meet Donna:

Donna is the proud mother of 3 sons and 8 grandchildren, 4 grandsons and 4 granddaughters. Her late husband, Gary, and her were high school sweethearts, having shared life and love for 53 years.

Gary was diagnosed with sporadic, limb-onset ALS in September 2024. From then, until his passing in August 2025, Donna was his primary caregiver. As Gary would frequently assert, Donna remained “his rock”, as she continued to be his stalwart friend, partner, and, at times, cheerleader through the daily tribulations of a life with ALS.

Contributing to ALS Research:

Both Donna and Gary ultimately decided to participate in multiple research opportunities, including ALL ALS, because of a desire to contribute to important initiatives that have the potential to help their community, as well as to “find something positive about this horrible disease”. Following Gary’s passing, Donna decided to continue pursuing research “to honor him” and the boundless amount of courage and resilience he revealed throughout his journey with ALS.

“It was a Team Effort”:

Over the past year, Donna and Gary received invaluable support from their family, friends, and community. Their ALS clinic staff, along with the teams from ALS United Mid-Atlantic and the Numotion Loan Closet, provided advice and compassionate care that helped them keep Gary at home, a goal they had shared since his diagnosis. They also found strength and comfort through their faith and ALS support groups. Finally, their main support system consisted of family, including their sons, daughters-in-law, grandchildren, and Gary’s siblings, for whom they will always be grateful.

Moments of Joy:

Donna, Gary, and her family shared many beautiful moments over the last year. Amid the bustle of everyday life, Donna and Gary found time for quiet moments together - reading the newspaper, sitting on the deck listening to the birds, and simply holding hands. They also celebrated important milestones, including Gary’s 70th birthday, which involved plenty of ice cream, and their annual hunting trip. Additionally, Donna, Gary, and her sons were able to have profound conversations, which are

precious moments of connection that they will continue to carry in their hearts and memories.

Donna continues to keep busy, spending her time reading, sewing, gardening, going to the gym, meeting with friends, and committing time to church and Boy Scout activities. Most importantly, she will continue to spend time with her family, as Donna holds the belief that “there’s nothing better than an arm full of kid”!

Study Progress Updates

Participants Enrolled in
ASSESS:
806

Participants Enrolled in
PREVENT:
380

Fully Remote Participants
Enrolled:
277

Blood Samples (Vials*)
Collected:
61,184

CSF Samples (Vials*)
Collected:
7,579

Speech Assessments
Completed:
3,286

**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.*

DIGITIZE ALL ALS Study



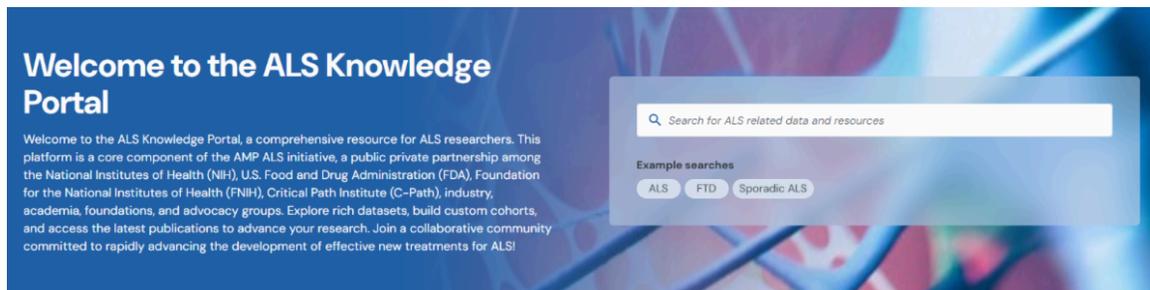
The ALL ALS Consortium has launched a new study component, called the DIGITIZE assessments, at 14 of the ALL ALS sites. The DIGITIZE assessments use digital ankle and wrist monitors to track and collect participant movement and activity measurements over time.

This data collection is incredibly valuable, since movement measurements can contextualize and supplement other clinical data to provide better understandings of disease progression.

Following a 2 week period of continuous monitor use at the beginning of DIGITIZE, each participant will wear the monitors for the first week of every month for up to 12 months. Additionally, participants will meet with their ALL ALS site team remotely or in-person every 3 months to complete a series of physical exercises and surveys. To participate in DIGITIZE, individuals must be participating in ASSESS or PREVENT at one of the ALL ALS sites that are currently carrying out the study and be able to take a few steps with or without the aid of an assistive device. If

you are interested in completing the DIGITIZE assessments, reach out to your site team for more information.

ALS Knowledge Portal



AMP ALS has officially launched their ALS Knowledge Portal as of September 2025. The Accelerating Medicines Partnership for ALS (AMP ALS) is a critical component of a public-private partnership that was born out of the 2021 Accelerating Access to Critical Therapies for ALS (ACT for ALS). AMP ALS has managed to build a network of government, industry, academia, and non-profit organizations, including the NIH, FNIH, and FDA, that collaborate to push forward principles of open science and natural history research. One of its most important initiatives was to construct the Knowledge Portal, which is a centralized digital repository that stores important datasets from many different research programs, including ALL ALS.

The ALS Knowledge Portal allows researchers from across the globe to review, analyze, and request clinical data from a wide selection of available datasets and collaborative research programs. As a resource, it is a meaningful step forward for the ALS research community, as it streamlines much of the data storage and sharing process, breaking down research silos and facilitating easier access to critical research information. Ultimately, with the launch of the ALS Knowledge Portal, ALL ALS's data can begin being shared and analyzed to conduct pivotal research that may lead to the development of better ALS drugs and treatments. Click the button below to be directed to the ALS Knowledge Portal's website.

[ALS Knowledge Portal](#)

Site Staff Spotlight:

University of Washington



Dr. Michael Weiss:

Michael Weiss, MD is one of the site principal investigators (PIs) of ALL ALS and the founding Director of the Division of Neuromuscular Diseases and a Professor of Neurology at the University of Washington (UW) Medical Center. As the co-Director of the UW ALS Association Center of Excellence, he attends clinic weekly.

He completed his neurology residency training at Georgetown University, his fellowship training in neuromuscular disorders at the University of Maryland, and his fellowship in neurochemistry and neuroimmunology at the National Institutes of Health (NIH). He joined the UW faculty in 2001.

Dr. Weiss is board certified with the American Board of Psychiatry and Neurology, with added qualifications in Neuromuscular Medicine, and the American Board of Electrodiagnostic Medicine. In addition, he is a fellow of the American Academy of Neurology. Dr. Weiss's research has mainly focused on clinical treatment trials and natural history and biomarker studies for ALS, including investigator-initiated trials. Dr. Weiss's investigator-initiated trials are evaluating the neurotherapeutic properties of mexiletine, an oral medication used to treat irregular heartbeats, chronic pain, and muscle stiffness, and its potential to modify disease and reduce muscle cramps. He has been inspired by the ALS patients in his clinic to try to help find better treatments that can improve their lives and arrest or slow their disease.

Outside of work, Dr. Weiss enjoys spending his free time with his family, hiking, traveling, and watching classic movies.

Lila Brisk:

Lila Brisk is the lead clinical research coordinator for the ALL ALS research program at the University of Washington (UW). She works alongside the UW Neuromuscular Trials team, which conducts research for patients with ALS, chronic inflammatory demyelinating polyneuropathy (CIDP), myasthenia gravis, and other myopathies.

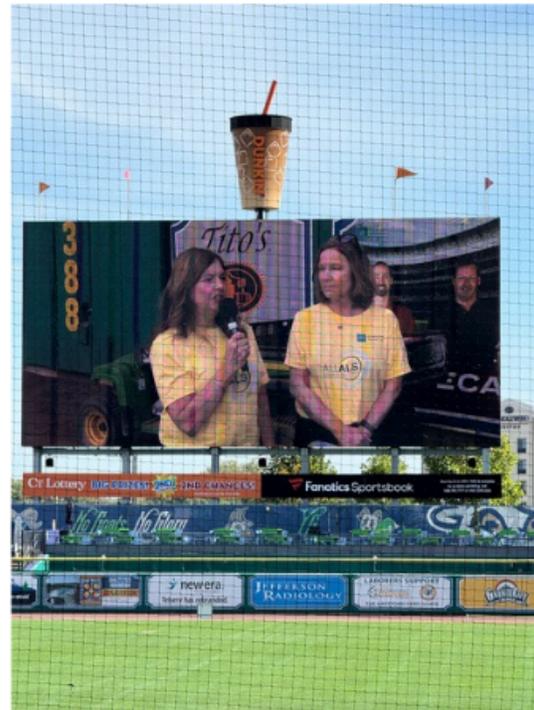


She primarily works with people living with ALS and finds this research to be incredibly meaningful.

In 2023, Lila graduated with a bachelor's degree in biology from UW and commenced work as a research scientist, where she studied the use of gene therapy for neuromuscular disorders. She began working in clinical research a little over a year and a half ago. In her current role, she enjoys having the opportunity to combine her passion for science with her love for patient interaction. Lila is particularly interested in ongoing genetic biomarker research and is hopeful for new ALS treatment development.

Outside of work, she enjoys being with friends and family, baking sourdough bread, playing with her two cats (Finn and Mitzy), and rock climbing.

Connecting with the ALS Community



ALS Community Events: September-November 2025

Throughout the fall months, staff members from across the 33 active ALL ALS sites attended many local ALS walks, symposiums, and tournaments. At these events, ALL ALS staff were given the opportunity to engage with many ALS community members, as well as collaborate with organizations on raising awareness for ALS.

[Learn More](#)



ALL ALS Community Webinar

On October 1st, 2025, the ALL ALS research program hosted their 3rd quarterly Community Webinar.



A recorded video of the webinar is available on the “Webinars” page of the “News & Events” tab on the ALL ALS website, as well as the webinar email registry sign-up. Our next Community Webinar is scheduled for January 7th, 2026 from 2-2:30 PST/5-5:30 EST.

Click the button below to be redirected to the ALL ALS website's webinar page.

[Webinar Page](#)

ALL ALS Instagram

ALL ALS is now on Instagram!

We're excited to share that the ALL ALS community is growing online. Follow [@all_als_](#) to connect with our community, view event photos, and stay up to date on ALL ALS news and milestones.

On Instagram, ALL ALS will be highlighting why participants are ALL IN for ALL ALS. If you or a loved one is currently participating and would like to share your story, please reach out to our team at info@all-als.org. We'd be honored to showcase your experience!



CONTACT ALL ALS:

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