ALL ALS Community Newsletter

September 2025

Together, We're Making a Difference

Participant Spotlight

Meet Sheila Greathead:
Sheila Greathead has lived in California her whole life, having been born and raised in the Bay Area, before moving to Sacramento to pursue an MBA. She is the mother of 2 children and has a happy, active 3-year-old grandson. Sheila was diagnosed with sporadic limb-onset ALS in June 2024, after a year and a half of searching for answers.

Since her diagnosis, she has become an active voice in ALS research and advocacy, including her recent participation in the remote cohort of the ASSESS ALL ALS research program. In her story below, Sheila shares how she draws strength from her community, finds purpose through contributing to research, and embraces joy in the meaningful moments she shares with her family.

Contributing to ALS Research:
“As I slowly lose the use of my hands and my ability to talk, a lot of my time is spent trying to understand how to adapt to my changing physical limitations and abilities and trying to stay ahead of the changes. It has been a bit of an emotional rollercoaster as I lose the ability to do the things that I enjoy, which have defined me in the past.
ALS is such a rare disease that I feel it's important for me to do

everything I can to help the researchers find a cure. As I weaken physically and lose the ability to do most of the things I cherish, this is an opportunity for me to offer help that could be valuable to researchers in some way.

Since ALS is rare, researchers have a limited population from which to draw conclusions. Every time we contribute to their knowledge base, we increase the likelihood of finding the cause and ultimately a cure.”

People Who Inspire Me:

“I’ve been particularly inspired by two people. First, Brooke Eby is a remarkable young woman who has been an outspoken advocate for ALS and has posted many informative blogs about her ALS journey. She initiated the ALStogether group on Slack, which has been an amazing resource for support.

Second, Spero Koulouras is a person I 'met' on Slack who was diagnosed in 2019. He worked at the same company I retired from (Hewlett Packard) and shares a common friend from HP. After his diagnosis, he formed a company, Auli.Tech, to 'provide individuals with access to advanced personal assistive technology without the need for prior authorization from insurance gatekeepers.' His team has created an affordable alternative to eye-gaze and hopes to provide them to 1,000 people in 2025. He continues to pursue this despite the progression of the disease.”

Advocacy and Community Support:

“I feel our biggest threat is the loss of research funding, especially on the heels of a breakthrough for the Qualsody1 ALS patients. We don’t know what impact those Qualsody1 results could have on the rest of us. There’s always reason to hope that a cure for one type of ALS might lead to a breakthrough for others. I’ve written to my senators to sign the ALS research funding bill and have recently joined the ALS Association Advocacy group. I wasn’t able to go to the summit in D.C., but did add my name to a blue flag. That picture of all the flags was worth a thousand words.

Each of us will have a unique experience with this disease. At first, I was so stunned by it that I was reluctant to join a support group. I’ve since found comfort in hearing the opinions of others, sharing laughter in an ALS comedy group, and trading thoughts about books in the ALS book club. I generally come away with a helpful suggestion and occasionally get to offer help to a new participant.”

Moments of Joy:

“My family gives me joy every day! My husband has always made it a point to make me laugh every day, and now is no exception. My son gives me huge hugs, takes me on outings with his family, and brings his

2½-year-old to visit as often as possible. My daughter is spending a week each month with me. She provides emotional and physical support and is always on the lookout for adaptive devices. Every day I spend with my family is a blessing.

In November, I finally had to give up golf, but I still play Pinochle once a week with a seniors group. I go to a movie each week with my sister and play bunko with a close-knit group of friends. I also have two friends who come over to help me organize things and dispose of unneeded items."

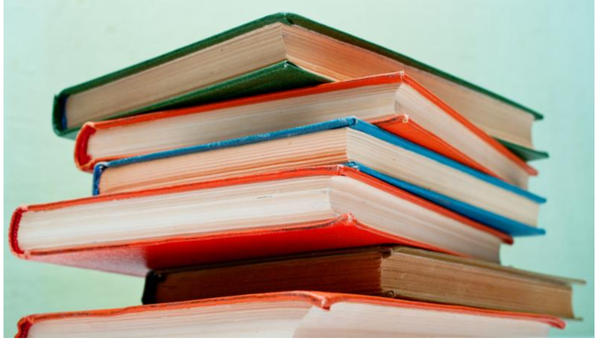
Where is Sheila Now?
Currently, Shelia is overseeing a complicated outdoors home renovation project that seems to just keep expanding! It includes the replacement of an outdoor deck, BBQ, lighting, and landscaping. She is also working on a legacy project for her children.

Study Progress Updates

Total Participants Enrolled in ASSESS:	Total Participants Enrolled in PREVENT:	Total Fully Remote Participants Enrolled:
624	**302**	**203**
Blood Samples (Vials*) Collected:	CSF Samples (Vials*) Collected:	Speech Assessments Completed:
~40,000	**~5,000**	**~1,700**

**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.*

Book Club & Movie Night



ALL ALS Book Club:

Liberation of Being: Allowing

ALL ALS Movie Night:

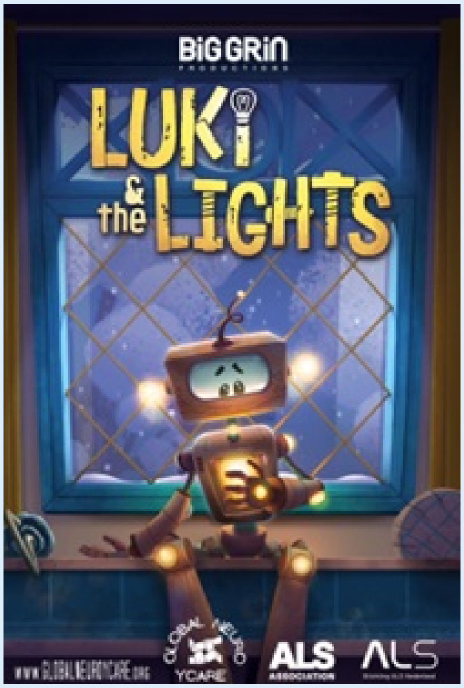
LUKi & the Lights

Terminal Illness to Teach Us How to Live by Dylan Shanahan

Following his ALS diagnosis, Dylan Shanahan, an athlete and scholar, used eye-gaze technology to write this powerful memoir that details his journey and philosophy on living with this life-altering illness. Pulling from his understandings of naturopathic medicine, Aikido, and the intrinsic value of human life, Dylan confronts the lifestyle changes and limitations accompanying ALS with profound resilience, strength, and hope.

His memoir shares his perspective on finding purpose in confronting the challenges of ALS and argues that other people living with ALS can similarly find meaning and personal autonomy by reframing their attitude and embracing an evolving relationship with change. Experience Dylan's story by purchasing his physical book on Amazon, his ebook on Kindle, or watch his Author interview on YouTube.

LUKi & the Lights is a children's silent short film released in 2023, following a robot being diagnosed with ALS. After LUKi receives the news, he struggles to reconcile his new reality, while finding strength in the unwavering support and optimism of his community of friends. Watch the full film on the Global Neuro YCare (GNYC) website, learn more about the film and the filmmakers on their Instagram or Facebook pages, or download their Coloring and Activity book for a fun, educational activity.



Research Staff Spotlight

Dr. James D. Berry:

James D. Berry, M.D., MPH is one of the many principal investigators (PIs) of ALL ALS and the primary PI for the East Coordinating Center at Massachusetts

General Hospital (MGH).

As a PI, he works with his colleagues and the leadership team of ALL ALS to oversee the conduct and manage the entire ALL ALS program. This includes tasks like protocol development and amendments, study adherence, performance monitoring, and research collaborations.

Dr. Berry is a neurologist who specializes in ALS care and research. His work is focused on identifying ALS biomarkers, particularly those related to abnormal inflammation, improving ALS understanding, and accelerating therapy development. He is the Winthrop Family Scholar in ALS Sciences, Director of the MGH Neurological Clinical Research Institute, Chief of the Division of Motor Neuron Diseases, and contributor to ALS resource groups, panels, and subcommittees.

Outside of work, Dr. Berry enjoys spending time with his family and has become an interested gardener, amazed at the resilience and growth he sees in his garden.

Dr. Robert Bowser:

Robert Bowser, PhD, is one of the many principal investigators (PIs) of ALL ALS and the primary PI for the West Coordinating Center at Barrow Neurological Institute (BNI). As a PI, he works with his colleagues and the leadership team of ALL ALS to oversee the conduct and management of the entire ALL ALS program.

This includes protocol development and amendments, interactions with NIH leadership, presentations to AMP ALS committees and external organizations and patient facing groups on ALL ALS progress and updates, overall study adherence, performance, monitoring, and achieving milestones.

Dr. Bowser pioneers research for ALS and other neurodegenerative diseases with a focus on discovering and validating biomarkers and defining mechanisms of neurodegeneration, incorporating biomarkers into clinical trials, and using human postmortem tissues to examine gene and protein expression. At BNI, his roles include the Chair of the Department of Translational Neuroscience, Chief Scientific Officer of BNI, and the John P. and Betty Van Denburgh Chair for Neuromuscular Disease. He also extends his leadership activities to co-direct the NEALS Biorespository, Target ALS postmortem tissue core, and the

Target ALS Natural History Study.

In his free time, Dr. Bowser, enjoys hiking and biking in Arizona and beyond.

Site Staff Spotlight:

University of Alabama

Dr. Nan Jiang:

Nan Jiang, MD, PhD is one of the site principal investigators (PIs) of ALL ALS.

She is an Associate Professor in the Division of Neuromuscular Disease, Department of Neurology at the University of Alabama at Birmingham (UAB). She completed her neurology residency training at the University of Florida in Gainesville and her fellowship training in Neuromuscular Disease at Duke University. She joined the UAB Neurology Department in 2017.

As Director of the ALS Association Certified Treatment Center of Excellence at UAB, she takes care of patients with ALS, as well as a wide range of other neuromuscular disorders. She is also actively involved in clinical research as a site PI and co-PI on multiple ALS and myasthenia gravis clinical studies. She is deeply passionate about the clinical and research work she is involved in for ALS, finding it incredibly meaningful and rewarding.

Outside of work, she enjoys spending time with her family, cooking food to share with friends and colleagues, and playing tennis.

Melanie Benge:

Melanie Benge, RN is the Clinical Research Nurse Coordinator for the Neuromuscular Disease Department at the University of Alabama at Birmingham.

She primarily works with ALS patients. She received her Registered Nurse degree from

Indiana University. She has been a nurse for 35 years, with the last 22 years being a Clinical Research Nurse Coordinator.

Her favorite aspect of clinical research is being able to offer patients medications and/or devices that they would not be able to obtain outside of research. Over the course of her career, she has been moved by the grace shown to her by her patients, especially her ALS patients.

Outside of work, Ms. Benge enjoys spending time with her family and 2 precious grandchildren. Traveling is also one of her passions.

Survey: *Healthcare professionals comment on how meaningful and affirming patient support is in their everyday life.* ***Show appreciation for an ALL ALS research staff member or site by sharing a positive message or memory about them. Access the survey by scanning or clicking the QR code to the right!***

Connecting with the ALS Community

End the Legacy Genetic & FTD Community Summit:
June 6th-8th 2025

Emma Allen, an ALL ALS Patient Navigator, attended the End the Legacy Summit in Philadelphia, which brought together individuals at risk for ALS and FTD, as well as clinicians, researchers, and advocates.

Learn More

Phoenix Bite Night:
June 7th 2025:

ALL ALS participated in ALS Arizona's annual Bite Nite fundraiser by hosting an educational table at the impactful culinary event.The fundraiser raised $550,000 and featured moving stories, community programs, and groundbreaking updates in ALS research and care.

Learn More

ALL ALS Community Webinar

On July 9th, 2025, the ALL ALS research program hosted their quarterly Community Webinar featuring an overview of ALL ALS and important study updates. During this webinar, Emma Allen, ALL ALS Patient Navigator, explained how participants and interested individuals can get in touch with the program. Caroline Piecuch, ALL ALS Study Coordinator at the University of Michigan, detailed what happens once participants are connected with a research coordinator and discussed the next steps for enrollment.

A recorded video of the webinar is available in the “Webinars” section of the “News & Events” tab on the ALL ALS website, as well as registration links for the next three Community Webinars. The next Community Webinar is scheduled for October 1st, 2025, from 5:00 to 5:30 Eastern Standard Time.

Webinar
Link

Tips for Lumbar Puncture (LP) Preparation

Reducing Procedure Anxiety

Although lumbar punctures (LPs) are routine and typically low-pain procedures, it's completely normal to feel a bit anxious. Pravin Pant, a Nurse Practitioner at Massachusetts General Hospital (MGH), offers some helpful tips to make your experience more comfortable:

- Stay Hydrated:
    - Drink plenty of (non-alcoholic) fluids before and after your LP. Being well-hydrated can:
        - Make it easier to collect cerebrospinal fluid (CSF).
        - Help replenish your CSF faster (usually within about 30 minutes).
        - Reduce anxiety and help you feel more relaxed overall.

- Set Communication Preferences:
    - Everyone experiences medical procedures differently. Some people like to know exactly what's happening step-by-step, while others prefer not to hear the details. Let your clinician know what works best for you. It's okay to say, *“Please talk me through it,”* or *“I’d rather not hear too much.”*

- Focus on Breathing:
    - Deep, steady breathing helps you stay calm. Try this simple technique during your LP:
        - Inhale slowly for 3 seconds.
        - Exhale gently for 3 seconds.
    - Relaxed breathing reduces muscle tension, which can help

the procedure go more smoothly.

- Stay Ahead of Pain:
    - Most discomfort from a LP comes from the initial Lidocaine (or other numbing agent) injection to numb the area:
        - If you feel any pain during the procedure, speak up- your clinician can give more Lidocaine.
        - If you feel a shooting sensation down a leg, let the clinician know- it's always helpful for clinicians to know how you're feeling.
        - If approved by your clinician, using a Lidocaine patch before the procedure can ease the initial sting.

- Set the Vibe:
    - Think about what might make you feel more comfortable:
        - Listening to relaxing music.
        - Listening to a podcast or a favorite movie.
        - Chatting with the staff or telling stories.
    - Distraction can be a powerful pool for easing anxiety.

Remember: this is your experience. Don't hesitate to speak up about your needs and preferences. You are an important part of the research team and your well-being is a priority. Your comfort matters.

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