

2022 Forbes Norris ALS Center NEWS

Fall 2022

Dear Norris ALS Center Family,

We are grateful for your support, which allows us to provide comprehensive care for patients with, as one put it, “this crappy disease.” Few ALS Centers anywhere have the resources and the talented staff to provide holistic and individualized care as we do. Even fewer combine that individualized care with rich opportunities to participate in and benefit from the latest research, clinical trials, and our expanded-access program for those who might benefit from new drugs but don’t qualify for a clinical trial.

Please give as much as you can. Most of our work is not covered by insurance; only with your help will we be able to continue to improve the lives of our patients now and into the future. You can give [online](https://www.cpmc.org/givenow-als) at www.cpmc.org/givenow-als, or use the attached envelope. To explore planned gifts, contact David Lloyd at David.Lloyd@sutterhealth.org, or [415-600-2411](tel:415-600-2411).

Gratefully yours,

Jonathan Katz, M.D.
Liberty Jenkins, M.D.
Robert Miller, M.D.
Dee Holden Norris, R.N.

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**I feel like the care team is
an extension of our family”**

— Megan Merz

Lobbying for state funding for satellite ALS clinics

Only a month after Jeremy Merz and his wife Megan learned they were expecting twins, Jeremy was diagnosed with ALS. And just a few months after his diagnosis, Jeremy, a Sacramento lobbyist, put his advocacy skills to work to secure an additional \$6M in funds for local ALS clinics where ALS patients can get comprehensive care without having to travel to a major metropolitan area, as Jeremy has at the Forbes Norris clinic in Sacramento. Jeremy will receive the Rasmussen Advocate of the Year award from the Golden West Chapter of the ALS Association in January. Life is moving very fast for this family, which now includes 9-week old twins and their 4-year-old sister.

“I feel like the care team is an extension of our family,” says Megan. Adds Jeremy, “They were so disappointed we didn’t bring the babies to our last visit.”

All of our research serves patient care

Directed by Jonathan Katz, M.D. Liberty Jenkins, M.D., clinical trials and other research at the Forbes Norris Center encompasses five interventional treatment trials actively recruiting, and two more opening before the end of 2022:

- Our Healey ALS platform drug trial **brings multiple promising treatments to trial more rapidly than is possible** through standard protocols. It is now testing its fifth medication, with another to start testing soon. Of the four already tested, two have proven not to be helpful, one is under further investigation, and one has yet to report.
- A phase III trial is testing a new formulation of a drug that **enhances the strength of muscle contraction** regardless of the cause of muscle weakness.
- We were part of the phase II and phase III trials that led to authorization of AMX0035 (relyvrio), the third medication now licensed for the treatment of ALS in the US. **Relyvrio slows down disease progression and prolongs survival.**
- Several phase II studies are investigating new drugs **designed to target specific proteins that accumulate in diseased motor neurons** and are thought to be critical to the development of ALS.
- Intrathecal (spinal) gene therapy **may help some patients with a genetic form of ALS.**
- Long-range studies are **using patient clinical data to search for new targets** among the biomarkers and genes that may cause ALS.
- Our robust expanded-access program **makes some of these potentially-effective drugs available to patients** who don't qualify for clinical trials.

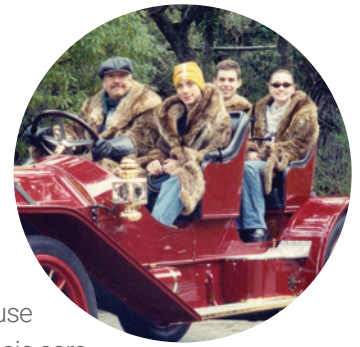
Using technology to stay fully present

Diagnosed with ALS in her forties, when her three children were still in elementary school, Michal was determined to continue to participate as fully as possible in family life, for as long as she could. For example, to keep up her tradition of cuddling and joking while watching movies with her children, Michal used a speech-generating device, controlled by an eye-tracker. She also created family cookbooks for each child, using eye-tracking software to type, edit, and add photos. Using that same technology Michal continued to be a productive team member at work, right up to the end of her life.

“**Michal created a legacy box for each of us, with the cookbooks, letters, and photos — all through her Tobii computer. Creating those gave her a purpose, which helped her endure all her suffering and pain.**” — Michal's husband

A living memorial

When Marshall Mathews was diagnosed with ALS, he decided he didn't want to miss the memorial his fellow car fanatics were likely to have for him, so he planned the first “Plaid Ride” (because Marshall always wore plaid) of classic cars and motorcycles himself. Since Marshall's death in 2003, his wife Nancy has kept the ride going each year, and has turned it into a fundraiser for the Forbes Norris Center. 2022 was the 20th anniversary of the ride, which has grown exponentially since its earliest days, with new friends in their classic cars joining each year. Proceeds go to help improve patients' quality of life, supporting the Center's equipment loaner program, continuing education for staff, and access to other resources to manage symptoms.



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Even though Marshall was so sick, he looked forward to going to the Forbes Norris Center because everybody really cared about what was happening with him, the whole time he was there. Someone is seeing and hearing you; you're not just a patient; you're a whole person.” — Nancy Mathews

