

# STUDIO CITY

MAY 2024

*Life*



*Meet The Longos*

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Cover Photo by Craig X Sotres



# Help for People Living with ALS

by Sheri Strahl, MPH, MBA,  
President & CEO, ALS Network

“The friend I never wanted and never knew I needed.” It’s a phrase I’ve come to hear all too often over the last few years to describe the ALS Network, a nonprofit and the largest local provider of ALS care services, dedicated to changing the course of a devastating and complex disease.

Amyotrophic lateral sclerosis (ALS), also known as Lou Gherig’s Disease, is a progressive neurodegenerative disorder that affects nerve cells in the brain and the spinal cord. With more than 31,000 Americans battling ALS at any given time, there are no cures and only limited treatments.

Every 90 minutes someone is diagnosed, and someone passes away from ALS, with the average life expectancy at just two to five years. During the course of the disease, people lose the ability to move, speak, swallow, and, eventually, to breathe - all while their minds and senses continue to function.

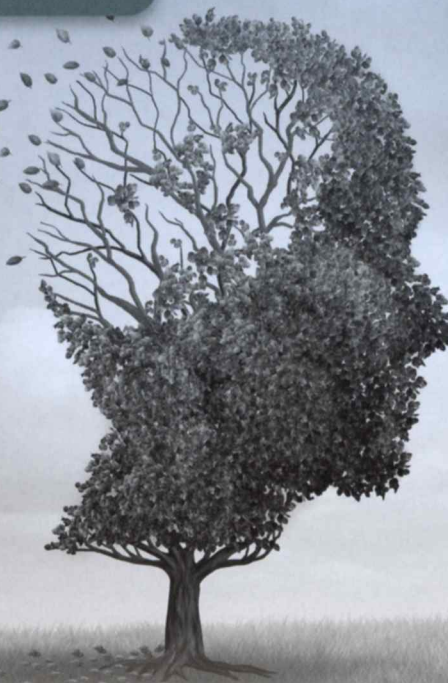
With philanthropic support, the ALS Network strives to provide a haven of guidance and support throughout an individual’s entire ALS journey, while aggressively searching for treatments and cures through our state-of-the-art research program.

Bolstered by decades of knowledge and unparalleled expertise, the ALS Network understands the ALS communities in California and Hawaii like no one else - connecting need with support; questions with answers; thought leaders with new ideas; research to funding; and advocates to challenge the status quo.

Why do we foster such a comprehensive approach to helping those in need? The answer is simple, to end ALS, together. If you or a loved one needs support or information about ALS, visit [alsnetwork.org](http://alsnetwork.org) for details.

The ALS Network provides free expert advice and assistance for people living with ALS, their caregivers, and loved ones right here in Southern California - offering more than 30 diversified support groups each month, robust equipment loan programs, help navigating complex benefits systems, and so much more.

We coordinate comprehensive care, partnering with ALS medical clinics; we build key partnerships with government, businesses, and community organizations to raise funds and awareness, and move forward legislative priorities. All the while, we partner with clinicians, researchers, and biotechs to aggressively pursue new treatments and cures.



# Moonshot to End ALS

with Dr. Richard Smith

A trailblazer in the field of ALS research and therapy development, Richard Smith, MD, director of the Center for Neurologic Study, and a member of the ALS Network’s scientific review committee, is advocating a change in the way drugs are developed for ALS and similar diseases. To accelerate the discovery process, he’s advocating for funding moonshot ideas that are approved within months if not weeks. To advance this concept, the Center for Neurologic Study is contributing \$1.5M to the ALS Network’s therapeutic discovery efforts.

Smith’s most recent research, published in the *European Journal of Neurology*, is as novel as his success in developing drugs for ALS. Smith, along with Amprion Pharmaceuticals and colleagues worldwide, discovered a subgroup of ALS patients in which self-replicating toxic proteins are detectable and likely contribute to disease origination and progression.

Next, in collaboration with the ALS Network, Smith plans to implement a natural history study to discern if the course of ALS is different in those in which the self-replicating protein is detected. The ALS Network is uniquely positioned to help facilitate studies like Smith proposes. Relationships with each of the specialized ALS clinics across California and Hawaii, where people receive multidisciplinary care, will help reach the largest ALS patient population in the nation.

To inquire about a study visit [alsnetwork.org](http://alsnetwork.org) for details.