



ALS Research Collaborative (ARC)

YOUR STORY. OUR SCIENCE. BUILDING HOPE IN ALS RESEARCH.

Why ARC Matters for People with ALS

Learning more about ALS is critical to discovering effective treatments, improving how disease progression is measured, and making clinical trials more efficient.

For too long, ALS research has been limited by the lack of a widely accessible, shared source of data from people living with the disease.

The ALS Therapy Development Institute (ALS TDI) is addressing this challenge through the ALS Research Collaborative (ARC) — a program designed to collect and share one of the most comprehensive datasets ever assembled from people with ALS.

How ARC Partners with People with ALS from Around the World

Through the ARC Study, ALS TDI can partner with people with ALS outside the United States to gather data about:

- Lifestyle
- Medical history
- ALSFRS-r scores
- Voice progression

ARC Study data has been collected from individuals since 2014 and continued participation from the ALS community, ARC represents one of the most comprehensive ALS datasets available today — and it continues to grow.



How the ARC Study Will Advance Global ALS Research

ARC data is made accessible to researchers worldwide through the **ARC Data Commons**, an innovative data-sharing platform hosted by the Google Looker platform.

Through the ARC Data Commons, ALS TDI can share these de-identified study data with other researchers, academic institutions, and pharmaceutical companies throughout the ALS space.

This shared information promises to unlock a clearer understanding of the underlying biology of ALS, with the goal of developing new treatments to slow, stop, or reverse ALS.

Why Participate in the ARC Study?

When you enroll in the ARC study, **you are joining a global community of people who are united in sharing their experiences to help end this disease.**

- All data can be submitted easily from home
- Participants choose what data they share and how often
- Participants can view the data they have submitted through a private portal and may share it with their care team
- Participation is voluntary and can be stopped at any time
- All shared data is de-identified to protect privacy

By participating in the ARC Study, your data could lead to the faster development of more effective treatments for ALS. The more data we have, the more we are able to understand what makes each case of ALS unique and develop the targeted therapies to help every single person living with ALS.



Are You Ready to Join the ARC Study?

Join the global community of people with ALS who are participating in the ARC Study.

Enroll in the ARC Study today and begin sharing your data to inform research. To learn more about the ARC Study, and to begin enrollment, visit **www.als.net/arc**, or scan the QR code to the right.



Together, we can end ALS.

