

ALS Has Many Questions. With Focused Research, We Can Find Answers.



What Is ALS?

Amyotrophic lateral sclerosis (ALS) is a rapidly progressive, fatal neurological disease. It affects nerve cells in the brain and spinal cord, causing nerves in the muscle to die. This affects voluntary muscle movement. These things we know, but there are many unknowns about the disease. Persons living with ALS today, and those who will live with it tomorrow, seek answers to these unknowns. Research is the way forward.



“There is so much we don’t yet know about my disease. I believe vigorous research into known and suspected ALS factors will help us all learn more. Continuing ALS research is the best way to keep hope alive.”

- Ed, a person living with ALS

The National ALS Registry Is Leading This Research.

In 2010, the federal Agency for Toxic Substances and Disease Registry (ATSDR) established the National ALS Registry to allow persons living with ALS in the U.S. to voluntarily provide their data for research purposes. Strategic research is one way the Registry is working to better understand what causes ALS. This research may potentially lead to treatments to prevent, halt, or reverse ALS.

This research is filling a significant gap in our understanding of the disease. There is no other voluntary national database that has the capacity, or the specialized data, to carry out these types of investigations. This research could be the turning point for this disease.



“The ALS Registry gives scientists the opportunity to look at the big picture to better understand what might be causing ALS. This knowledge could be the key we need.”

- Becky, a person living with ALS

Collaborating With Leading Researchers.

The Registry identifies significant areas that need investigation. Then, the Registry funds crucial, ground-breaking research in these areas. The Registry funds and collaborates with some of the world's leading research institutions. Since 2010, ATSDR has funded 13 Registry research studies in the U.S. and abroad and will continue to fund more studies. Researchers from all around the world are able to share their findings. This kind of collaboration is new and the key for success.



Examples of the research include:

Environment

- The University of Pittsburgh is examining known occupational and environmental pollution exposures in persons living with ALS.
- Dartmouth College is studying if specific chemicals (such as pesticides, algae blooms in lakes, and chemicals from factories) may be a risk factor for ALS.

Genetic & Medical

- The University of Miami is looking at the relationship between environmental factors and genes in persons living with ALS.
- Stanford University is researching if medical conditions (such as high cholesterol, diabetes, autoimmune diseases, or certain drugs) can affect a person's risk of getting ALS.

“A better understanding of personal and environmental risk factors for ALS could lead to understanding of its triggers as well as treatments. With the Registry's ALS patient data, we have valuable, focused information that may help us better understand risk factors. We can share our unique findings with other researchers across the world. Sharing improves the base of knowledge and speeds up the discovery of treatment for the disease. The Registry's ALS research will make an important difference, and I know it will ultimately improve outcomes for persons living with ALS.”

- Dr. Evelyn Talbott, epidemiologist and researcher

Looking to the Future.

ALS research has changed dramatically over the last seven years. More researchers are studying the disease today, and technology continues to improve. The Registry plays a major role to support combined efforts. It works with researchers from many top institutions, and through the Registry we are able to share key findings that will benefit other research projects.

