

News Of Health

Ed's Story—Everyone With ALS Counts

(NAPS)—Amyotrophic lateral sclerosis (ALS) is a fatal neurological disease that attacks the nerve cells. It first gained national attention as Lou Gehrig's disease, named after the famous baseball player who was diagnosed with ALS in 1939. To date, the cause of ALS is unknown, and there is still no known cure. The disease strikes quickly, usually leading to death within 2–5 years of diagnosis. But every person with ALS has an individual story, and understanding these stories will help researchers ultimately piece together clues about the disease.

Ed Tessaro was diagnosed with ALS in 2009. As he learned to cope with this diagnosis, he reflects, "I've never considered myself a victim of the disease, because I believe in my heart all of us have a wheelchair. In my case, it's quite literal, but with everything that goes on in my life, I realize that every family has had a crisis." One of the things that helps him and others with ALS is reaching out for community support and resources. "The ongoing struggle is to encourage newly diagnosed people to come in and talk about their condition. I want to help people learn about the National ALS Registry, clinical trials, and other resources that can provide support and hope."

The National ALS Registry helps gather information from those who are living with this disease. Researchers from all around the world can access the Registry data to help scientists learn more about what causes this disease. Everyone's story is different, and



Photo credit: Jake Scott-Hodes

Because learning more about ALS is an important step in the battle to defeat it, the National ALS Registry gathers confidential health information from people who are living with the disease to learn more about what causes ALS, possibly leading to better treatments.

everyone's piece of the puzzle is essential. The Registry has found that more than 16,000 people with ALS live in the United States. It is important to include as many people as possible living with the disease to get the most accurate information. When patients join, it helps give researchers more information. This could lead to a better understanding of the causes of ALS, because learning more about the disease is one step further in the battle to defeat it.

If you or someone you care about has ALS, consider learning more about the National ALS Registry by visiting: www.cdc.gov/als.