

ALS/Lou Gehrig's Disease

Lorri Carey

ALS is a very difficult disease to diagnose. To date, there is no one test or procedure to ultimately establish the diagnosis of ALS.

At the time of Gehrig's death, there was no cure for ALS. Sadly, that remains the case today.

— ALS Association

It may be called Lou Gehrig's Disease, but in February 2004 it became Lorri Carey's. Strikingly beautiful and poised, Lorri remembers the life-changing moment her doctor told her that what she thought were leg cramps from exercise and arthritis in her hands were actually the telltale symptoms of ALS, a fatal neurodegenerative disease that erodes one's ability to move. As the disease progresses, its victims become trapped in a body they no longer can control, unable to walk, talk, breathe, or even blink an eye. The cause of ALS is unknown and its treatment is limited to one FDA-approved drug, which only extends life in some patients by about three months. "We thought about pulling the boys out of school and taking a year to just travel and enjoy our time," says her husband Paul, facing the sobering fact that people with ALS typically live between two and five years after diagnosis. However the family chose another course—a very selfless path to help others. Their teenage sons, Paul Jr. and Christian, started Kids4Cure, engaging their West Chester, Ohio, community in walks to raise funds for research and patient services. To date, the boys have raised \$330,000. As a family, they began attending the ALS Association's annual Capitol Hill Day. Navigating the halls of Congress, the Careys frequently appeal to their Congressman, Speaker John Boehner, on policy issues impacting ALS patients.

After her initial diagnosis Lorri continued working full-time for a consumer products company, but the long hours and travel eventually weighed on her health and psyche. "I thought to myself, 'there has to be more to my life than selling ravioli to local grocery stores,'" she says with a smile.

If asked about her own health, Lorri imparts that she, like many people with ALS, takes the only FDA-approved ALS drug. She looks down at her hands now crippled from ALS, and yet she is thankful that her ALS progression has been unusually slow. With that unquantifiable gift of time, she has chosen to help others. She redirects the conversation to focus on her hometown friend, Joe Toerner. Their common diagnosis brought them together in the last year of Joe's life, when Lorri volunteered to become a caregiver for him one day a week. She helped him get a speech device and got him onto Facebook, which became "his saving grace," she proudly recalls. She was at his bedside when he passed away.

Lorri vowed that Joe's speech device would not go unused. That promise led her to help Sabrina, a young single mother whose ALS progressed to the point that she was on a ventilator and residing in a nursing home. Her parents would travel from Georgia to Ohio to bring Sabrina's six-year-old daughter to visit. "Sabrina really wanted to live for her daughter, but she was tired," Lorri explains. She had frequent infections from her feeding tube. When she made peace with the consequences, Sabrina asked to be taken off the ventilator. Once again, Lorri, the ALS patient-turned-caregiver, was there at Sabrina's bedside in her final hours.

While the Carey men are both protective and proud of Lorri, they are nevertheless focused on doing everything in their power to propel research toward finding the root cause of ALS and effective treatments to slow the progression of ALS and perhaps cure it. They hope the same creative tenacity is being applied in the scientific and policy arenas to open every door and explore every avenue for ALS patients.