

About the Scott Stafne ALS Research Fund

- Amyotrophic Lateral Sclerosis (ALS) is a fatal neurological disorder that causes paralysis through the progressive death of motor neurons.
- Thirty thousand Americans have ALS, and 250,000 Americans alive today will eventually die from the disease. ALS can strike at any age and most patients die within 4 years of diagnosis. There is no known treatment or cure.



When Scott was diagnosed with ALS in August 2004, at age 32, our entire family was devastated, as are all families faced with this diagnosis. Over the past four years, we've reached out to our entire family network: friends, relatives, neighbors, church community, and colleagues. It's never easy to ask for support from others, yet **we have been amazed and uplifted** by the responses we've received.

We've learned that people very much want to help, but feel helpless, and welcome the opportunity to show how much they care. We also are learning that **ALS is an illness a family cannot fight by itself**. We are just one of a growing community of ALS patients and families who have joined the fight to find a cure for ALS in the short term. We believe the best use of our financial resources today continues to be with the ALS Therapy Development Institute (ALS TDI).

To support ALS TDI, we established the **Scott Stafne ALS Research Fund** in late 2004. In 2007, the Muscular Dystrophy Association partnered with ALS TDI and committed \$18 Million to fund ALS TDI research in the short term. This further backs our passionate commitment to this research organization—and continues to validate the **over \$94,000 in generous donations** we have received to date.

The ALS Therapy Development Institute is a nonprofit biotechnology company discovering **treatments for patients alive today**. Their research focuses on finding a short-term solution to stopping the progression of ALS and finding a cure. This organization runs the largest centralized ALS drug discovery program in the world. We personally visited the ALS TDI labs in Boston, connected with the staff and researchers, spoke with other patients and families, and believe funding ALS TDI research is vital to the discovery of a treatment and cure for ALS.

Our goal is to reach a total of **\$100,000** raised for ALS research. We are so close! Your help will make this happen. We continue to encourage you to donate to ALS TDI today—as a gift for friends, together as a family, or in conjunction with your church or workplace.

Thank you for considering supporting the Scott Stafne ALS Research Fund at ALS TDI. We hope that your experience is as positive as ours and that you feel buoyed, as we do, by being part of an enterprise that is fueled by love, courage, and hope. We continue to teach our daughters these same values each and every day we have left to spend together as a family.

Thank you for giving us the hope to live our lives to the fullest, in spite of this devastating illness.

Sincerely,
Scott and Kirsten Stafne