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## BLAZEMAN FOUNDATION FOR ALS

Dear ALS Clinical Medical Director,

In May of 2005, at age 33, our son Jonathan was formally diagnosed with ALS after approximately one year of some subtle symptoms which were masked by the affects of training for the endurance sport he loved so much. A veteran triathlete, Jon's lifelong dream was to compete at the World Championship Ironman in Kona, Hawaii. He wanted to swim, bike and run all 140.6 miles of the big island. Well, he was given that chance five months after his diagnosis and finished the race under his own power, putting a brave face on ALS. Jon saw the opportunity to turn that publicity into a powerful weapon in his war on ALS. And at the personal level, he committed to donating his spinal cord, brain and other organs to the NICHD Brain and Tissue Bank for research before he passed away on May 27<sup>th</sup> 2007. Jon was 35 yrs old.

Following Jon's example, we are continuing his battle with ALS. The Blazeman Foundation has grown steadily ever since as we grow supporters, fans and followers every year. We raised money to support four University research projects in addition of establishing two Post Doctoral positions. We have also partnered with the NICHD Brain and Tissue Bank at the University of Maryland to increase the availability of ALS tissue so that researchers have ALS tissue available for study.

What is critical is to inform ALS patients and their families of the vital role that donation of post mortem tissue can make to finding the cause and cure for ALS. Although this is a difficult topic, from our experience there is a significant number of ALS patients and their families who would welcome the opportunity to donate post-mortem tissue.

We are working closely with the NICHD Brain and Tissue Bank who will make all arrangements for tissue recovery. The Bank has experience in collecting tissue from a wide array of disorders in every state of the US and Canada. Over 3,500 cases, including ALS, have been donated to the Bank since 1991. Nearly 1000 researchers in 23 countries have used tissue from the Bank for their research.

Clinicians, who enhance ALS tissue collection by discussing this topic with the patient's family, have free access to the donated tissue in the future.

We have enclosed brochures describing the need for tissue donation. If you have questions regarding the tissue donating process, please call or e-mail the NICHD Brain and Tissue Bank. We will provide additional brochures as needed.

Thank you for considering our request to continue Jon's fight in the war on ALS.

Mary Ann and Robert Blais

Blazeman Foundation for ALS

*"Remember the -blazeman... Ironman's Braveheart"*

*"Pick a Stronger Word than Help...Cure."*