In the fall of 2006, as the Duffy family finished watching The 2005 Hawaii Ironman Triathlon World Championships, they all found themselves overwhelmed at what they had just seen. Jon Blais, a 34-year-old special education teacher, had finished this Ironman competition, and though Jon was a life-long runner who had participated in over 200 races, this had been his first Ironman and would also be his last. Six months before, Jon had been diagnosed with Amyotrophic Lateral Sclerosis (ALS). Touched by Jon’s story, his courage, and his determination to get the better of this disease, 13-year-old Brian commented, “I want to help him.” At the time, Brian’s parents Karen and Mike, thought it was just a passing comment, but Brian continued to talk about Jon Blais and ALS and told Karen and Mike, “I really mean it when I say that I want to help Jon, and I want to get in touch with him, talk to him and let him know that I want to raise money for him and ALS.” The Duffys contacted Jon and his family and communicated with them on a consistent basis as Brian’s commitment to help became deeper, and he and Jon grew closer. As Brian’s interest in ALS continued to grow, he went to the Walk to Defeat ALS in Centennial Park and met Dr. Jonathan Glass,
the Director of the Emory ALS Center that has been providing care for ALS patients and their families since 1997. Dr. Glass invited Brian to take a tour of the research laboratory, and it was during the tour that Brian decided that he would raise money for ALS and contribute what he had raised to the Emory ALS Center. He began researching different venues and possible ways to raise money, decided on a 5K race, and this was how the ALS Run for Life 5K began. The inaugural ALS Run for Life 5K was held on April 14, 2007 with 180 participants and raised $10,000. Over the next three ALS Run for Life 5Ks, the participation and money raised continued to increase and, in 2010, over 1,000 people participated and $23,000 was raised. In four years, Brian has donated over $50,000 of proceeds raised through the ALS Run for Life 5K to the Emory ALS Center. Preparations are under way for the 5th annual ALS Run for Life 5K, which is expected to have well over a thousand participants, many of whom run in honor of friends and family who have had or are currently suffering from ALS. At every race, there is what started out for the first race as a poster board and has evolved to a banner, with the names of ALS patients that participants are honoring. The names on the banner have continued to increase along with those who take part in the ALS Run for Life 5K—a race that was started because 13-year-old Brian Duffy’s heart was touched by those who suffer from a very complicated, deadly disease that too little is known about and for which a cure is not yet known.

Amyotrophic Lateral Sclerosis, also known as Lou Gehrig’s disease, is a neurodegenerative disease that attacks the motor neurons of both the upper and lower body causing degeneration in the spinal cord and the brain. As the disease progresses, the neurons in nerve cells gradually waste away and eventually die off, and the ability for the neurons to send messages to muscles continually decreases. The physical effect of this decreasing muscle-messaging decline causes muscle weakening, twitching, the inability to move arms, legs and ultimately the entire body. As the condition worsens, and when the muscles in the chest area stop working, the ability to breath becomes more difficult. It is known that approximately 10% of ALS cases are caused by a genetic defect; the cause of the other 90% is unknown. Statistically there are more men than women with ALS, and the average age is between 40 and 60. The life expectancy is within two to five years following diagnosis.

One of the reasons that Brian chose to have a 5K was because he has been a runner since he was 7-years-old and began competing in triathlons for kids. He has continued to run and swim, competing in various events and triathlons throughout the year, and he is on the swim team and cross country team at Lambert. Brian was selected by 21st Century Leaders as one of 20 teenagers in Atlanta to be in the "20 Under 20" Class of 2009. At the awards dinner, each of the honored teenagers were asked to give an impromptu speech, and Brian spoke of his experience founding and putting on the ALS Run for Life 5K and about ALS. He has also spoken to local organizations and written numerous essays about this experience, the disease, and why this motivates him. Brian has participated in local missions with groups from Johns Creek Methodist Church and, in 2009, he participated in a mission trip to Dulac, Louisiana to rebuild homes for Hurricane Katrina victims. He was the recipient of the Golden Panther Award, presented to 8th graders at Riverwatch Middle School for acts of kindness to others. Mike Duffy is proud of all that Brian has accomplished at such a young age and says,

"Having the ALS Run for Life 5K each year means the world to me. Seeing the money go to help patients with ALS and to find a cure for this dreadful disease really motivates me to just keep raising more money. When I meet people with ALS, and I tell them what I’m doing, their faces light up and they look as if they completely forget that they have this horrible disease.”

Brian Duffy
“Brian is an incredible young man; his unwavering commitment to raise awareness to ALS is truly inspiring—very rare in the youth of today. It was Brian’s vision to start the ALS Run for Life 5K and his family just acted on it. We are very proud of him!”

The day after the ALS Run for Life 5K has been run, Brian and his family—Karen and Mike and brother, Kevin, who help Brian with the planning throughout the year and the day of the event—start the preparations for next year’s race. “It means a lot to me to have this race and raise a lot of money for ALS,” said Kevin. “I don’t want to see any more people suffer like Jon did.” The first two races were held at South Forsyth High School and then moved to The Avenue Forsyth. From obtaining sponsors for the race to securing the finish line timing for the 3.1 mile course, the efforts and planning for every race go on all year to be ready for an event that takes a few hours on one day. But for Brian, raising money to cure ALS is a mission that he gladly lives with every day; it is a part of who he is and as he says, “Having the ALS Run for Life 5K each year means the world to me. Seeing the money go to a help patients with ALS and to find a cure for this dreadful disease really motivates me to just keep raising more money. When I meet people with ALS, and I tell them what I’m doing, their faces light up and they look as if they completely forget that they have this horrible disease.” The Emory ALS Center—the recipient of all the proceeds from each race—is so appreciative and Director Dr. Jonathan Glass says, “Brian is an extraordinary young man. After seeing the story on Jon Blais, he became passionate about supporting ALS research, and he has followed through with his actions. His enthusiasm infected the rest of his family, and the Duffs are now important partners in our efforts to raise consciousness and support for the Emory ALS Center.”

Jon Blais died on May 27th, 2007, a month after the first ALS Run for Life 5K. It was Jon’s courage that inspired Brian to start an event to raise money for the horrible disease that took Jon’s life at such a young age. “I was heart broken for a long time,” said Brian. “I knew this day would come eventually, but I didn’t expect to be so depressed for such a long time, and I didn’t think I would ever come out of it. But then I had a dream one night about Jon. We were walking down Ali’i Drive in Kona, Hawaii (the site of the finish line at the Ironman World Championships) and we were just talking. But then he stopped me and said, ‘Brian, don’t you dare stop fighting because I didn’t. Fight for a cause that’s bigger than you….and don’t worry, we will see each other again.’ He then gave me a big hug and I found myself waking up in tears. I knew then that I could not let him down and promised to never give up the fight against ALS.” And that is exactly what Brian Duffy is doing as he continues to run for life.