



MULTI-SPORT MOVEMENT TO END LOU GEHRIG'S DISEASE

## So Others May Live

#### **Our Supporters**

Thank you to these great friends and brands for all of your support. Warriors, they're there to support you, too! Think of them for your next event or purchase.



# Holiday Wishes from All of Us at the Blazeman Foundation

Well, the holiday cards and letters have started rolling in. For us, this is a warm reminder of how many friends we've made and how many lives we've touched over the years. As I look back on the last six years, I'm grateful for all we've done together but more important, for the community we've created. We've all come together to support one another in many ways as we battle ALS. And with



every trip to the mailbox around the holidays, I'm reminded of just how lucky we are to have all of you as our friends.

Many of our newsletters have included inspirational stories of personal battles with ALS, and on behalf of someone we love with ALS. I'm delighted to share Brent and Bishop's stories with you this month. And each month, I plan to include more of your inspirational stories in each newsletter, so I'm inviting you to tell yours. If you'd like to share your experience with the rest of the Blazeman Foundation community, please send your story, with a picture or two, to me via email.

Our latest **research projects** are in full swing with all the funds escrowed...thanks to our supporters...we could not do this without you!

September brought us to the Westchester Triathlon where we gave a community support grant to **MAC Angels**, a 501c3 ALS Charity that focuses on the community. Their commitment speaks for itself and the stories we heard at the triathlon speaks volumes for the support they give each and every family.

This year's Kona #179 was **Carrie McCoy** from Ohio who supports us every year in our major fundraiser Cycle for ALS. Carrie literally rolled through the finish line like a bolt of lightening! (**Video**) Carrie spoke to us on the phone before race day and we know she carried Jon's memory along with her on that long road to Havi.... Carrie had lots



Make a donation today!

Join Team Blazeman!

The list of registered
Blazeman Warriors
keeps growing! We are
proud to have you
representing us on the
battlefields!

of company racing in Kona that we knew, including **Bishop Leatherbury**, **Garen Riedel** and **Cherie Gruenfeld**.

Warriors cheering them on included **James and Monica Garris**, **Debbie Alexander** and **April Harstook**. Needless to say we wish we could have been there...and we will return in 2014!

Another event that took place in Kona on race week was

Mike Rouse's annual Birthday Run. Mike ran 61 miles in memory of Jon this year while raising funds for the BMF research projects...Thanks again Mike for your continued support and thank you Kimmie for supporting Mike along the way with drinks and hotdogs!



Kimmie and Mike

The end of October brought us to the City Bikes Ironman 70.3 Miami where we connected with long time supporter **Yair Shalev** and this

year's # 179 April Harstook. As always, Race director Wilber Anderson and crew treated us very well and we also had the chance to reconnect with Leanda Cave!

Leanda signed her 2013 race kit which will be auctioned for the BMF...stay tuned! As I write this letter I see a picture of Blazeman Warrior Dr. Jeffrey Galvin on facebook taken by his wife Liz running the NY Marathon. Running is Jeff's first love...triathlon came later! Check out Dr. Jeff's pictures on FB!



Bob, Leanda, me and Wilber

And just because it is December it doesn't mean we are slowing down. We are busy all month long and in the process of planning for another busy winter including some great Cycle for ALS events in February. We have several planned throughout the country but there's still time to plan one in your city. (It's also a great way to work off those holiday dinners, too!). And there is still time to make a gift to the Foundation to help us continue the fight in 2014.

In the meantime, Bob and I would like to wish you all the best of HOLIDAYS to you and your family. We hope every day of this holiday season and the New Year to come is filled with joy, peace of mind, good health, family, and friends.

'Til next time...

Mary Ann
 Jon's mom

#### Inspirational Stories to Share with You

#### Brent Bieshaar's Xterra Odyssey Across America

Like many of us, Brent saw Jon's story during the Ironman coverage on TV in 2005. That year, he shared Jon's story with some wrestling students he was coaching as a way to teach them about "competing for something bigger than yourself." One their own, his students adopted the mantra 'face your fears and live your dreams.' They emblazoned that on shirts they wore throughout the season.

About a year ago, as Brent planned an odyssey: to compete in an XTERRA triathlon every week of the 2013 season. Twenty four races in twenty one states. Around the same time, Brent learned that a classmate, Don Young, was recently diagnosed with ALS. So, Brent combined the inspiration from the Blazeman and the friendship for Doug and decided to race for something bigger than himself this year.



Brent earlier this season

Brent modestly says that this odyssey is probably something that many endurance athletes could handle, but we think the logistics of that many races in so many places is worthy of adding a "fourth leg" to the triathlon! Brent told me that, "as a solo sport, Xterra triathlons have long moments of solitude in the wilderness. Plenty of time to think, reflect and talk to yourself." Or, as Brent said, "I also talked to my friends Jon and Doug. They got me through this odyssey."

That odyssey came to a successful end a few weeks ago. A journey of twenty-four races culminated with the World Championships in Hawaii on October 27<sup>th</sup>

In keeping with the theme of this month's newsletter, Brent recently said, "the best part of XTERRA Across America has been all of the people we have met along the way. We have attempted to tell their stories in such a way that their impact on us can be understood. Unfortunately, words are not enough to convey how this journey and these people have blessed us."



While in Hawaii, Brent had an opportunity to honor Bob and Mary Ann by taking Jon back to the big island again. They held a ceremony at dusk on the edge of a majestic cliff, overlooking the ocean. Clifford Nae'ole, a Hawaiian Cultural Advisor began by speaking of the Hawaiian traditions and how our loved ones remain with us in spirit. Brent continued with a testimony of the work of God in Jon's life, and concluded with some of Jon's familiar words. Take a moment to see his video of that ceremony.

Brent isn't taking the winter off, either. He's working on a spin fundraiser in a few weeks. We'll share updates on that. In the meantime, you can read Brent's race update online. Way to go, Brent! You're an inspiration to us all.

## Bishop Leatherbury: From the Boston Marathon to Kona

While Brent was busy racing across the country, another Blazeman Warrior was traveling on his own odyssey. One that had a few scary moments along the way.

Meet Bishop Leatherbury. His 2013 season was largely based on a training schedule for the Ironman World Championship in Kona. He had countless number of workouts and races to help prepare him for his return to Kona with a goal of shaving an hour off his last time. But nothing could have prepared him for what happened during an early season marathon...in Boston.



Bishop before the 2013 Boston Marathon

Bishop's first Boston Marathon began by soaking in the energy from the crowds that were larger and more enthusiastic than he had ever seen. But with less than three-quarters of a mile left, he heard and felt the

explosions. The idea that it could have come from the finish line crossed his mind but was quickly dismissed that as too improbable to even consider. He and many others continued to the finish line, oblivious to the tragic situation ahead but were stopped short-in sight of the finish line.

The entire scene really was surreal: the deserted area after the finish line which would have packed with finishers; the constant wailing of sirens and law enforcement and emergency vehicles speeding through the streets and runners walking around wrapped in their race blankets on the Boston Commons.

Bishop is truly thankful to be safe and unharmed - he was on pace to cross the finish line around 2:54 in the afternoon and the explosion occurred at 2:50. Wow, talk about good fortune. Those infamous hills in the last half of the race slowed down his pace!

Bishop feels terrible for the people who were injured and killed in the blasts, many of them with horrible injuries, and their families. They were out there supporting and celebrating the accomplishments of their loved ones and to have such a horrific thing happen is unfathomable. He asks that we "keep the dead and injured and their families and loved ones in your thoughts and prayers. And thank you for all of your expressions of concern and support-it has really been overwhelming."



With time to shake off that tragedy, Bishop continued with his BHAG ("Big Hairy Audacious Goal") of beating his prior finish time at Kona by over an hour. When he ran Kona two years ago, he sprinted up Ali'i Drive and through the finish line chutes. By doing that, he hit his goal on the nose but missed much of the crowds and excitement of the finish line. This time he was determined to savor and enjoy the finish line experience. The finish line at the IronMan World Championship is like none other. This is the only race where the crowds for the last runner are bigger and more enthusiastic than the winners (which finish almost nine hours before the last finisher).

As soon as you take the right hand turn onto Ali'I Drive, the

crowds are wall to wall and the closer you get to the finish line (a little under a half mile) the denser and more enthusiastic the crowds are. He slowed down, He went from side to side high fiving fans, and took it all in and finished the race doing the Blazeman Roll.

We're happy to report that his finish time was 13:25:20, a 35 minute improvement over his prior Kona time. He's very pleased with the result, especially considering some difficult conditions on the bike.



On the run at Kona

Like the theme of this newsletter, Bishop attributes this success to the importance and power of friends and relationships. Lots of people along the way helped me through long training rides, long runs and that was every bit as rewarding and important a part of the journey as the race itself. And he recently told me that, "there were a lot of people looking out for me this year."

We thank Bishop for the tremendous fundraising he did for the BMF in honor and memory of his dear friend **Karen Kelly...**her memory lives on in all of us.

Bishop also has a Cycle for ALS event coming up in February, along with another shot at finishing Boston. We'll help you look for him in the months ahead with updates in this newsletter. Godspeed, Bishop. You're also an inspiration to us all.

### Cycle for ALS - Coming Soon!



## Cycle for ALS - Coming Soon!



Confirmations and dates are starting to come in for the February 2014 cycle event! What better ways to start moving in the dead of winter; and at the same time fundraise for a cause bigger than yourself! This event is our main fundraiser and your support is needed for all PALS, current and future. ALS is one of the most underfunded diseases and at the same time the most devastating! We need your help!! Please contact me via email if you would like to get involved.

A warm welcome this year to Al Lamothe, James Garris, Sean Luitjens and The Energy Lab! We are happy to have the return of our all our hosts from last year. Please check out the website...www.cycleforals.com

This years event is dedicated to our friend and past president **Karen Kelly**...yet another alswarriorpoet that has found her freedom. Karen's story is below with her picture.



#### From the Battlefields

From **Danielle Liubicich** wearing #179 at Lake Tahoe:

I feel incredibly lucky to have been able to race this year. I was reading an article on the Ironman page that was titled: "You know you're an ironman when..." and they had readers complete the sentence. My favorite answer was one of the last ones printed: "when you race for the ones that can't." I



always thought that if I had the opportunity to race an ironman, that I would do it to support others as well. This quote was something I took to heart when I read it, and it helped inspire my little crowd rise campaign to fundraise / raise awareness for several special causes.

#### A new look to the Blazeman estore.

The fleece vest or pullover is a great item for fall/winter!!

Bob and I recently received a note from Blazeman Warrior **Sameh Mikhail**, telling us he had a son this past April...**George Blaze Mikhail**! We are thrilled to hear that yet another Blaze has been born! George makes number three that we know of!

Blazeman Warrior, **Darin Nellis**, has been busy with his new documentary "JFK, A President Betrayed" that aired in November. You can check it out online **here**.

Congratulations Darin!

From **Carrie McCoy**'s friend **Amy Kurtenbach**...sharing her thoughts to Carrie post Kona:

"I know you are probably getting overloaded with messages from people, but I wanted to give you my two cents as to why your day was so special to me (because it is all about me you know)!;) I don't think you ever knew that Jon Blais is one of my hero's. To me he is Ironman. I always thought the pros and age groupers were awesome but to be honest they have never really made a connection to me on a personal level. But that changed after I watched the Kona IM in 2005. Jon's story touched my heart. At the time I was working on a neuro inpatient rehab unit in Columbus. I am a PT and I know what ALS is and what it does to a person. To see him complete an Ironman and knowing how

physically challenging it had to have been for him changed my view of the Ironman. It was no longer an event that only the elite could complete and he instantly became my first Ironman hero. I didn't initially start thinking I could go out and do an Ironman but it did make me question my own capabilities and why I was scared to try anything longer than a 5k distance, and after that I started taking (baby) steps towards endurance events in general. Wasn't until 2009 that I completed my first IM. And I thought about Jon when I was out there that day. My hero and I was finally there, competing an event that I never thought would be possible because he gave me a glimmer of something that I could do more. I even had a plan that I was going to roll across that line...but I got so caught up in the excitement of finishing that I actually forgot until I had already crossed the line. So, to have you wear his #179 at Kona...awesome!!! I cried twice last night, once when the screen when blank and I couldn't see you finish. The second time was when I finally got to see you roll across that line. So fitting that one who inspires so many got to wear the number of a person so inspiring to me!! Congrats on your day, I couldn't be happier for you!"

# From The Blazeman Foundation for ALS Charity Slots for EagleMan 2014



The proceeds from the Blazeman for ALS slots are earmarked for the University of Maryland's Brain and Tissue Bank, a program for ALS patients to donate their tissue postmortem for research. This is a much-needed area that

most ALS patients and their families are not aware of. Jon donated his organs,

UNIVERSITY of MARYLAND SCHOOL OF MEDICINE

realizing how important and underfunded this area is. Of note, **Robert Vigorito**, past TriColumbia President and Race Director harvested Jon's organs; they had met in 2005 competing at the Ironman World Championship together. Please visit our website to learn more about Jon and his foundation's contributions to cutting edge research. A big thank you to the CTA for continuing to support us as a charity!

For more information on racing at the Ironman 70.3 EagleMan Triathlon "for a cause bigger than yourself" please contact me at <a href="mailto:blazemanmom@comcast.net">blazemanmom@comcast.net</a> The slots are \$500 each and 100% of the proceeds are earmarked for the tissue acquisition program.

Bob and I look forward to seeing you all at EagleMan in June!

### Challenge Atlantic City Coming in 2014!



**Rob Vigorito** may have retired from the Columbia Triathlon Association last year but not from being a race director! Vigo and his partner **Steve Del Monte** have taken on a new challenge...Challenge USA!

Located in Atlantic City this ironman distance event is sure to please with relay teams also for those that like being part of a team. The Challenge Family welcomes athletes to experience the inaugural USA event. The Blazeman Foundation is excited to be a part of this new event. Jon will be a special part of the Challenge and his number 179 will be given to the athlete that embodies the tenants Jon followed. Athletes may apply via email.

For more information on Jon and the event please visit the Challenge website.

#### Remembering Karen Kelly...

Karen came into our lives while we were caring for Jon after his diagnosis in 2005...I remember her sending Jon an email telling him how she had been touched by ALS, losing her grandfather and mother to the disease. Karen knew she had the SOD1 gene and was at an increased risk of also following the same path.

Karen later became president of Jon's foundation and also qualified for Kona and wore Jon's number

179...the first to so at the World Championships. Fast forward to 2012 she moved to Kona, living her dream...

That dream was short lived as she felt her body telling her ALS was with her too...her diagnosis was confirmed in the summer of 2012 and she passed away on Friday September 13th...just a



little over a year after her diagnosis...

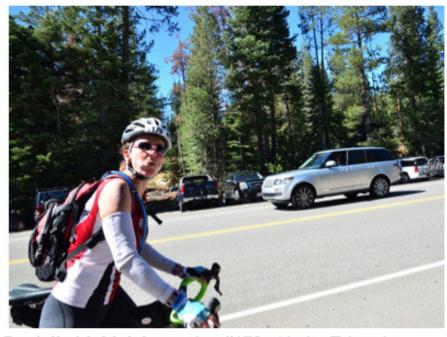
Speaking with Karen during that time she never complained and stated she had accepted what was given her. Below is an excerpt from her obituary...Karen was 62 yrs old at the time of her passing...

Karen always had a passion for athletics, and began competing in various triathlons in support of ALS research and in memory of her mother, maternal Grandfather, and her dear friend, elite athlete Jon Blais. All were victims of the disease. As a founding member of the Blazeman Foundation for ALS, Karen was the first Team Blazeman athlete to have the honor to wear #179 in remembrance of Jon Blais in the 2007 Ironman World Championship in Kona, Hawaii. Karen was passionate about raising ALS awareness and fundraising, and following her ALS diagnosis in August 2012, continued to inspire others to carry on the war against ALS. She continued to enjoy life to the fullest until her recent passing in her home in Salt Lake City, Utah. A private Celebration Of Life event was held at her Salt Lake City home, hosted by her partner Mr. Gary Hewlett, on Sunday, September 29 followed by a spreading of her ashes on October 14, 2013 at the bay in Kailua-Kona, Hawaii to coincide with the 2013 Ironman World Championship.

## Photo Gallery



Meeting some athletes from Brazil at the Miami expo booth...Junior, Alexis, Maiko and Yanes



Danielle Liubicich wearing #179 at Lake Tahoe in September



Matty Reed at Miami...can I get any shorter!





Matt Russell rolling at Kona this year. Looking good!



**Gary Hewlett** (Karen's soul mate) relaxing on a post-Kona ride.



On May 2, 2005, twenty-year Multi-Sport veteran Jon Blais a.k.a. "Blazeman" at age 33 was diagnosed with the fatal motor neuron disease ALS (Amyotrophic Lateral Sclerosis). Blazeman dubbed himself the "ALS Warrior Poet" and brought his battle to the big island of Hawaii on October 15th that year, where he became the first person with ALS to complete the Ironman World Championships. It was his last race. In 2006, a number of athletes, inspired by Jon's 2005 efforts, rolled across the finish line in Hawaii in honor of Jon and his battle against ALS. In 2007, the Blazeman Foundation for ALS expanded Team Blazeman, comprised of "Blazeman Warriors" who have committed to raising awareness and funding a search for a cure for ALS..."So Others May Live."

Forward email



