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**So Others May Live**

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#### **Greetings Blazeman Warriors and Supporters,**

Well, here we are. Yet another May has arrived. It has been seven years since Jon passed away on the 27th of this month and May is also ALS Awareness Month. This is a time for us to recall the events of seven years ago. I think Jon would be pleased at the accomplishments of his foundation. He did not expect it to last longer than two years...well Jon, a lot of blood, sweat and tears later...it has.



Every time we speak with a friend or family member of a pALS (person with ALS) and they ask what would be the best thing they can do to support that person, the answer to us is simple. Be with them on those tough days right until the end. Being alone is the worse thing for anyone, let alone with ALS...I can't stress that enough.

I like to remember Jon as he was in this picture. It was one of his favorites.

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



Please take a moment on May 27<sup>th</sup> at 8:30PM and give a shout out of **FREEDOM!** And if the spirit moves you...go out for ice cream....Jon's favorite!

We have a few stories to tell this past month...there were three athletes that ran the Boston Marathon 2014...**Mark Searles**, **Ryan Bieshaar** and **Kelly Swan Taylor**. Kelly had unfinished business from last year. More on them below in this newsletter. Another story is **Clay Leonard** and the **Iron Horse Triathlon**...Bob and I am grateful for their terrific support.

Soon we will be traveling to **Eagleman 70.3** where we have several athletes racing under the Blazeman Slots. One of these athletes, **Dr. Michael Meisterling**, #179, whose dad has ALS. We look forward to meeting them all and will include them and the event in our next newsletter. As always, Jon's #179 can be applied for at any race.

Later in June we will be off to the Inaugural **Challenge Atlantic City**...we wish **Rob Vigorito** and **Stephen Del Monte**, the race directors much success in this new endeavor and hope to see some of you there. **Kelly Burns Gallagher** has been awarded #179 and another athlete will be awarded the **Spirit of Blazeman award** at the pre race carbo dinner. That name will not be announced until that evening.

Thank you all again for your support in helping us succeed in funding the best research we can find...and again, longing for the day we hear the words..."**I am an ALS Survivor**"

'till next time,  
Mary Ann  
Jon's mom



## Cycle for ALS 2014!

A HUGE thank you to all the hosts that organized a cycle for the Blazeman foundation for ALS this year!

The events started the beginning of February and ended in April at the **Cycle Studio** in Indiana...the final total is in and we exceeded our goal by 110%! The total raised to this date is **\$77,626.00!** What a tremendous effort by the best team hosts yet! Thank you also to all that participated and contributed this year!



The picture above shows the young chefs for the pancake breakfast prior to the ride at the Cycle Studio in Indiana...what a clever idea!

We broke our record this year thanks to you all and also to the many supporters that came out for the various events. As you know this is our main fundraiser each year and the funds raised goes directly into our research accounts...we have an account set up for each individual research project and what goes in never gets moved around.

Before each project is started we make sure we have the funds to cover it entirely...we never promise funds and then scramble to raise what is needed.

This assures each research institution that we have covered their needs...

Please take a few minutes and visit the [www.waronalds.org](http://www.waronalds.org) and click on the research dropdown.

Thank you all again. We hope you join us again in 2015 for another event and if you know of anyone interested in hosting an event...well, we welcome everyone to help us grow. Please visit [www.cycleforals](http://www.cycleforals) and check out that website.

THANK YOU ALL AGAIN!



**CHALLENGE**  
**ATLANTIC CITY**

**06.29.2014** *we are triathlon!*

**The Blazeman Foundation for ALS and Challenge Atlantic City** are thrilled to be able to award "**The Spirit of Blazeman**" award at this year's inaugural Challenge Atlantic City. Many athletes have watched the video of Jon competing in Kona at the World Championships back in 2005. Jon was approximately 18 months into ALS at that time as he gave everything he had to finish before the 17hr. cutoff. He did finish and rolled across the finish to bring attention to a cruel disease with no treatment or cure...

There was another important side to Jon...If asked, he would always say..."I am a teacher first" As a special education teacher in San Diego at Aseltine School, Jon had found his true calling there. Jon focused his energy on helping kids who were emotionally challenged and learning-disabled. This is also where he became better known as "The blazeman". Jon did amazing work with the students, bringing his love of sport and the outdoors to these young boys and girls. Through summer recreation programs and outdoor activities, his students learned to overcome obstacles and become stronger through hard work and determination. "The Spirit of Blazeman" award keeps Jon's memory alive by recognizing an individual who inspires others to become a better person; leads by example; and has a passion for the journey of life.

This award will be presented to the winner at the Carbo dinner Friday evening prior to race day!

## Blazeman Warriors Take Back the Finish Line - For Boston. For ALS.

A few short weeks ago, more than 36,000 runners toeing the starting line of the Boston Marathon. Some runners ran to set a new personal record. A few ran to win. But for many, this race had nothing to do with competition. They were there to finish something that was tragically interrupted last year. They were there to "race for something bigger than themselves." A few of these runners were easy to recognize. You saw them emblazoned with the Blazeman Foundation crest, running to honor friends, family and others who've been affected by ALS.

We had a chance recently to interview a couple of them about the race. These are their stories.



Photo of Ryan Bieshaar by Kelly Swan Taylor

### What drew you to the race?

#### **Ryan Bieshaar:**

Boston, I think, is a draw for every marathoner. If you don't aspire to run it, you certainly respect the elite nature of the race. "There is only one Boston."

The Boston Marathon, by its very history, nature, and aura, forces all other marathons into something of a second-rate status. But for me, yes, I had aspired to run Boston. I had a slot so I wanted to race for the Blazeman Foundation...really... how can you let an opportunity to run Boston slip by? Simple answer: you don't.

**Kelly Swan Taylor:** With regard to last year's race, Initially I had spoken several times with Mary Ann and Bob about my race career and they frequently asked if I had run Boston. How could anyone turn down Boston? Even though training was tough in the winter, and I had to run the race with an injury, I was excited to be a Blazeman Warrior and push through the challenge. Unfortunately, a different challenge awaited us at the finish.



## What was the mood like at the Boston Marathon?

### **Ryan Bieshaar:**

Boston was incredible! Both on race day and the days leading up to it. It was such a gorgeous Easter Sunday. I could have stayed out there all day, but we considered it wise to go back and rest in the afternoon. On Monday, there was the nervous anticipation that accompanies any race morning. But that nervousness always evaporates once you cross the start line, and it did that day as well. And then the fanfare! I have never seen anything like it! It seemed that Boston is 26.2 miles of rowdy cheering spectators! And it's impossible not to be drawn in by it... giving little kids high fives, yelling and fist pumping when people cheer for you, dancing ever-so-slightly to "Hangin' Tough" by New Kids on the Block, amongst other songs pumping from sideline speakers. Such an incredible experience.

**Kelly Swan Taylor:** The mood was amazing and electric. I felt more comfortable this year, even with another healing injury bothering me. My husband came to the Expo with me with year, just because I knew he had to experience it with me. We started the day at Old South Church, where I was blessed with a beautiful hand-made scarf. You could barely move at the Expo, with the huge crowds, and the finish line area was an area of anticipation and excitement. I felt that the athletes this year were even more supportive of each other. Right away during the race, because of the heat, I knew that I would not get the time I wanted, so I intended to enjoy every moment as much as possible and just finish strong.

## What were your favorite memories of the race?

### **Ryan Bieshaar:**

There are always posters of support at Marathons, one in particular this year read, "This is our f\*#!-in city". The idea of reclaiming something that was lost, of reclaiming the finish line. I can't say enough about the police that kept the 26.2 miles safe for us all. They deserve so much praise! Overall, it was an incredible experience. I consider myself very fortunate to have been able to experience it.

**Kelly Swan Taylor:** I tried to high-five as many people as I could, especially the children. I remember one child giving me a high-five and saying "thank you for running today." On Mile 1, I stayed to the left of the course so I could witness the shoe tree memorial that was erected in the honor of one of my high school classmates, in Virginia, who while training for the race in January, tragically was hit and killed by a drunk driver. Her husband was running for her, in her honor, with her bib tucked in his shirt. The sign that meant the most to me was one that said, "Today, you are a hero." The girls at the Wellesley Scream Tunnel were amazing! It went on and on and I again tried to high-five all of them. My run turned into a walk as I wanted to interact with all the girls and told them, "you are making me forget that I am running a marathon, thank you." I saw an older man kiss a younger Wellesley girl, and her face was priceless. Mile 20 gave me a chance to see Lauryl, who helped me last year when I was stranded on the course after the bombing. I am now friends with her and her husband and son. She had a sign made for me and we took a great picture. She handed me a banana that, with her water bottle, gave me the strength to get through the rest of Heartbreak Hill.

## The Finish Line

**Kelly** reflected on the completion of this race. She noted, *The crowds were amazing through the whole course, but the last two turns onto Boylston and the finish gave me goose-bumps. I could barely move my legs anymore, but they pushed me to keep running the whole stretch. As we closed-in on the finish, I saw a group of fundraisers waiting for each other and looking behind us for their other members, so they could finish together. That stuck with me. It was not about a particular race time for them; they were there to finish together. As I crossed the finish, I reached up to the sky and touched my heart, thinking about others who could not finish with me: Jon the "Blazeman", Celeste (my hairdresser, who did cross earlier, with her family), and Meg (my high school classmate).*

The Boston Marathon invited and encouraged runners to "take back the finish line." As **Ryan** said,... *Boston, Massachusetts, the USA, the endurance community and all of its supporters, did reclaim, proving that we are indeed "Boston Strong."* We simply hope that one day there's a finish line for ALS. It's time for us to take back the finish line on that race, too.

## Clay Leonard and the Iron Horse Triathlon Battle in the War on ALS



**Clay Leonard** is an accomplished triathlete and respected race director for events such as the Iron Horse Triathlon in Louisiana. But our respect and compassion for him goes way beyond the race. Clay's father passed away from ALS over 20 years ago but, for him, it seems like it was only yesterday. He lives in a small community in South Louisiana of roughly 5000 people. Unfortunately there have been at least five other people diagnosed in that community. Unfortunately, all except for one has passed away. This is very alarming. Clay joins us in hoping that one day with all of our combined efforts we can find a cure for this horrific disease.

Clay's family and close friends held the First Annual Iron Horse Triathlon in Morgan City, Louisiana on June 23rd 2013. Their mission was to put on a fantastic race for their participants and raise money for the Blazeman Foundation. He is extremely happy to say that we achieved both of our goals. Their race was a tremendous success. We had 180 participants and some very generous sponsors. Clay's son wore Jon's number 179 in the race.

Their race was so successful last year they hope to have 250-300 participants this year. [Click here](#) to learn more about their event. As Clay tells it, "This was one of the most rewarding experiences of our life."



## The Greater Hartford 1/4 Marathon

On April 4th the Blais and Murphy families drove to Hartford for the 8th annual race...the enthusiasm of all the runners, walkers and volunteers made up for the cold and damp weather. The sun did shine briefly and it was captured in the picture below! The Blazeman Foundation for ALS has been the charity beneficiary of this event for the past 7 years.



Race Director, **Kelly Burns Gallagher**, has quite the support for this race year after year. This race is also known for the vast amount of food for the participants. We all volunteered and bdad's voice could be heard cheering on everyone to the finish line! Thanks again Kelly for raising funds for BMF...your constant support has been a blessing to Jon's foundation.

## A Warm Welcome to our newest Warriors!

We are pleased to welcome the following newest warriors to our family. Thank you, and everyone else, for all you do to help our mission.

**Jeff Johnson**  
**Lucy Woolsey**  
**Mac Robinson**

**Michael Kane**  
**Mike Meisterling**  
**Gerardo Ordonez**

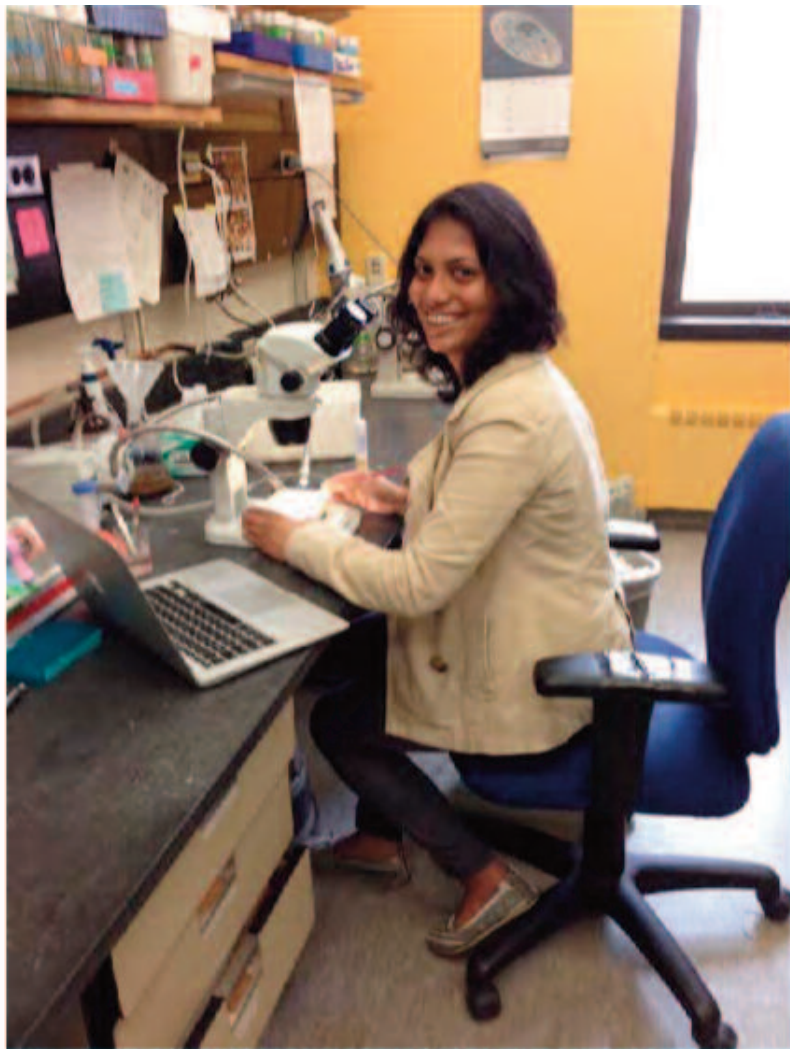
**Allysin Bridges**

**A big welcome to you and we hope to see you at a race this year...please visit our [ning](#) website and start communicating with other warriors and supporters.**

## Research Update: Your Donations in Action

### Sorting Neuronal Survival Signals

For many years, it has been known that growth factors secreted by muscles control neuron--muscle connections and the survival of neurons. Dr. Mugdha Deshpande, the Blazeman Foundation Postdoctoral Fellow for ALS Research in Avital Rodal's lab at **Brandeis University**, has been working to understand how these processes may go awry in ALS. Using fruit flies as a model system, she is focusing on how these survival signals are transported along a travel itinerary within the neuron and how gene mutations causing ALS alter this process. In parallel, Dr. Deshpande is working with Dr. Suzanne Paradis at Brandeis to develop a system to study these signals in mammalian neurons that are affected by human ALS genes, to test if defects are similar to those she saw in the fly model. She has found that growth of these neurons is severely compromised when they carry ALS genes, and is now testing to see how this relates to problems with specific growth signals. By understanding how growth and survival signals are being diverted from their normal travel itinerary in diseased neurons, it will be possible to develop new therapies to return these signals to the appropriate destination, providing a new avenue for future treatment of ALS.



**Dr. Mugdha Deshpande, the Blazeman Foundation Postdoctoral Fellow for ALS Research at Brandeis University.**



## From the Battlefields

### Mark Searles shares his thoughts on this year's Boston Marathon.

Such an inspirational day at Boston. So much emotion and positive energy. Battled some dehydration and needed a few bags of IV's post race but so worth it to support the Blazeman foundation!



**Congratulations, Mark(L)!**

### From the world of Xterra Across America...TEAM BAD!



So, one may be wondering who is TEAM BAD? Bad as in "Good"...

The men of TEAM BAD are **Brent Bieshaar, Kevin Adams and Ben Dillon (BAD)**...racing in support of the Blazeman Foundation. The team name comes from the first letter of their last names. Wishing them a successful and healthy season!

### From Blazeman Warrior Debra Saltz...

May is ALS awareness month. It is also the month I start doing triathlons after an 18 month hiatus. Looking forward to rolling across the finish-line twice this month in memory of Jon Blais and all that have succumbed to this horrific disease.



On Saturday, May 3<sup>rd</sup> the Rye Tri Club with **Phil Gormley** put together a biking event of hill repeats on Claire's Climb in Greenwich, Connecticut to remember Phil's sister, Claire Gormley Collier. Claire passed away on May 4<sup>th</sup> 2009. Bob and I attended this event benefitting **MAC ANGELS**, the non profit whose mission is supporting pALS and their families in the community.



### Research Update from Wake...

Please take a moment and read what your funding is supporting at [WakeForest University](http://WakeForestUniversity.edu)!

### **Blazeman Gear...**

Time to purchase some gear to spread the words of the Blazeman...we have some nice t-shirts, bike and teck shirts to wear and start the dialog about ALS! Also, our War on ALS® Greepers below!

Please check out our [estore](#)!!





From deep in the ALS battlefields...**Frank Wray**, our friend and pALS, from Florida.



## Photo Gallery

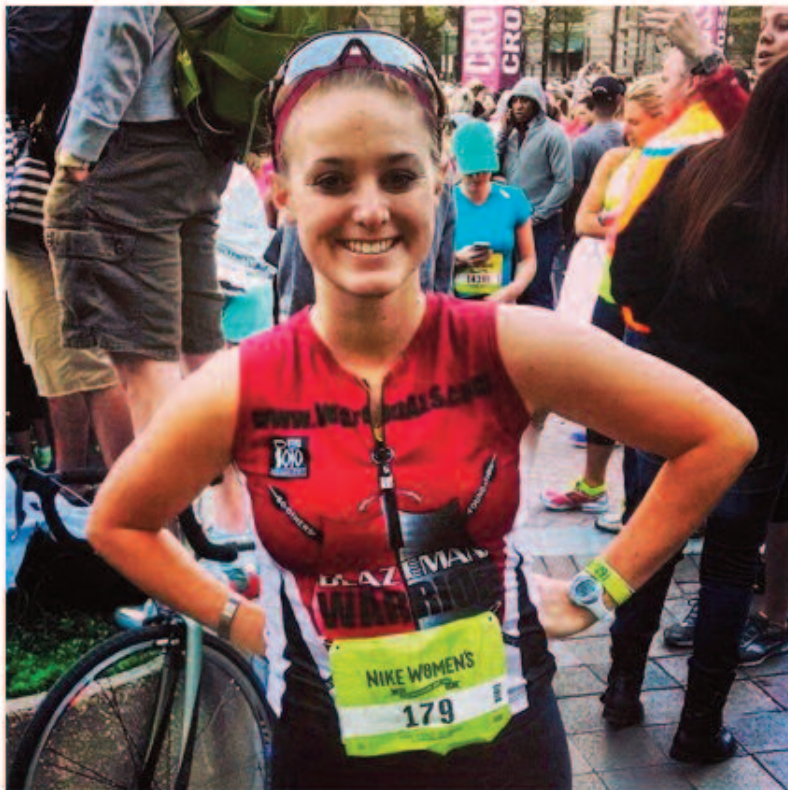
Thank you so much for sharing your highlights and favorite moments from the 2014 Cycle and other events! But don't stop now! Please keep sending your photos of the many events coming up!



**Don and Mindy Soranno at a local race recently**



Jake Lamothe wearing his new Blazeman kit



Jenny Hansen Nike Woman's run





**Rodney Ward at his first full marathon in Madrid!**



**Ryan Bieshaar Boston Marathon 2014**

# ABOUT TEAM BLAZEMAN



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."

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