



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.

Hello to all Blazeman Warriors and Supporters!

It has been a very busy and exciting time since our last newsletter in July! A simple idea turned into an amazing Ice Bucket Challenge...creating ALS awareness like never before in it's long history! An amazing amount to money was raised for all the various ALS organizations and we are thrilled to have been a beneficiary, enabling us to grow our escrow ALS research account. This also gave us the chance to add to our small community based funding. Thank you all again for your generosity!



Mike Reilly taking it from both sides at IM Mont Tremblant

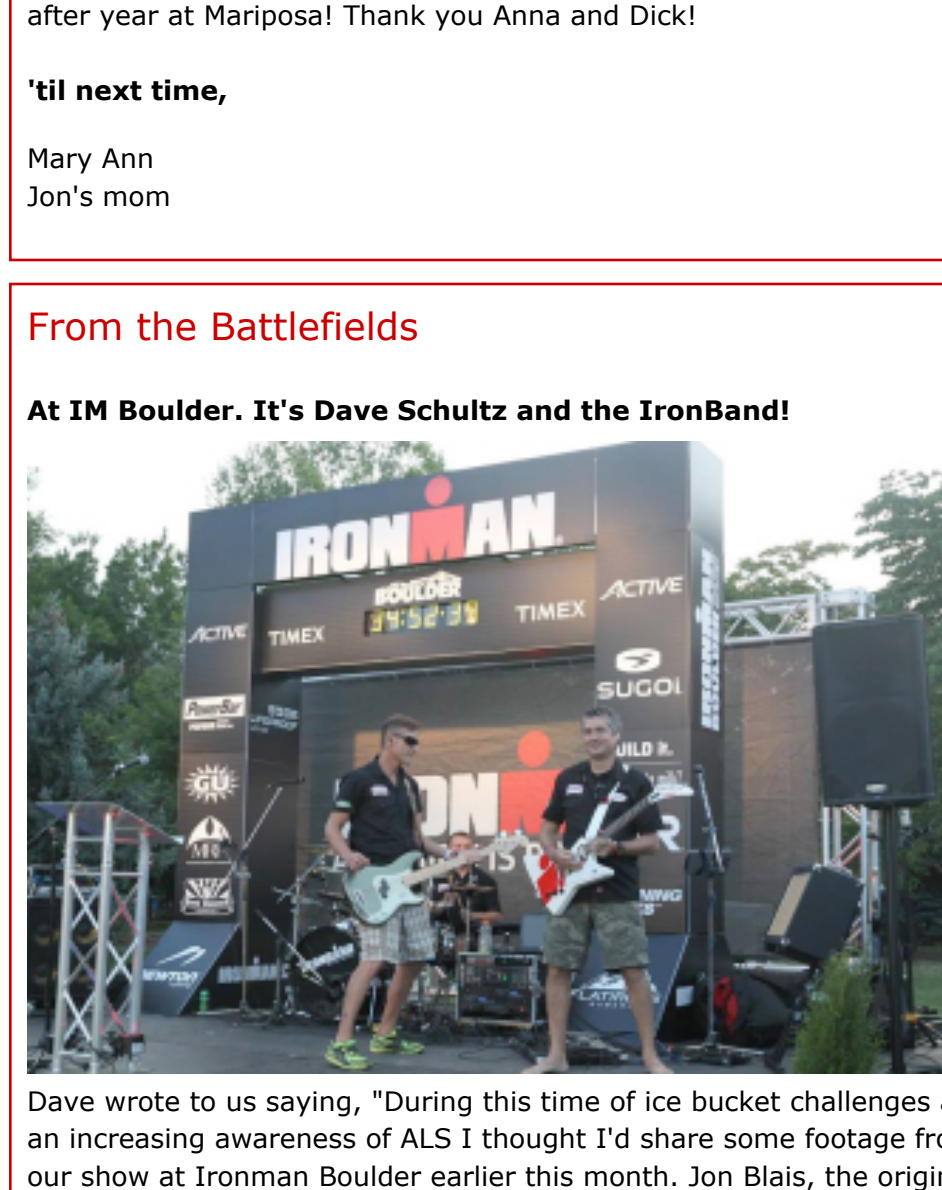
In Mike's own words... "Thinking of the ALS challenge after 19 hours on the finish line!" The vast amount of videos everyone shared is on facebook...so much support...so much gratitude from us! Please check out the Blazeman Foundation for ALS facebook page for some of them!

One more from across the pond...



As a proud Ambassador for Blazeman Foundation for ALS, I willingly accepted the #IceBucketChallenge with **Tom Lewis**. Take up the challenge. Donate. Spread awareness. "So Others May Live" **Chrissie Wellington**

From **Aseltine School** where Jon taught the staff took up the Challenge and remembered Jon...I do know that Jon would have loved to douse Hayden, the headmaster (second from right) personally!



A special shout out to Blazeman Warrior, **Debra Saltz**, who took the challenge for the BMF thirteen times if I counted right! Our constant attorney warrior from Maryland! Debra compiled a **video** of all her challenges on FBI

[Make a donation today!](#)

[Join Team Blazeman!](#)

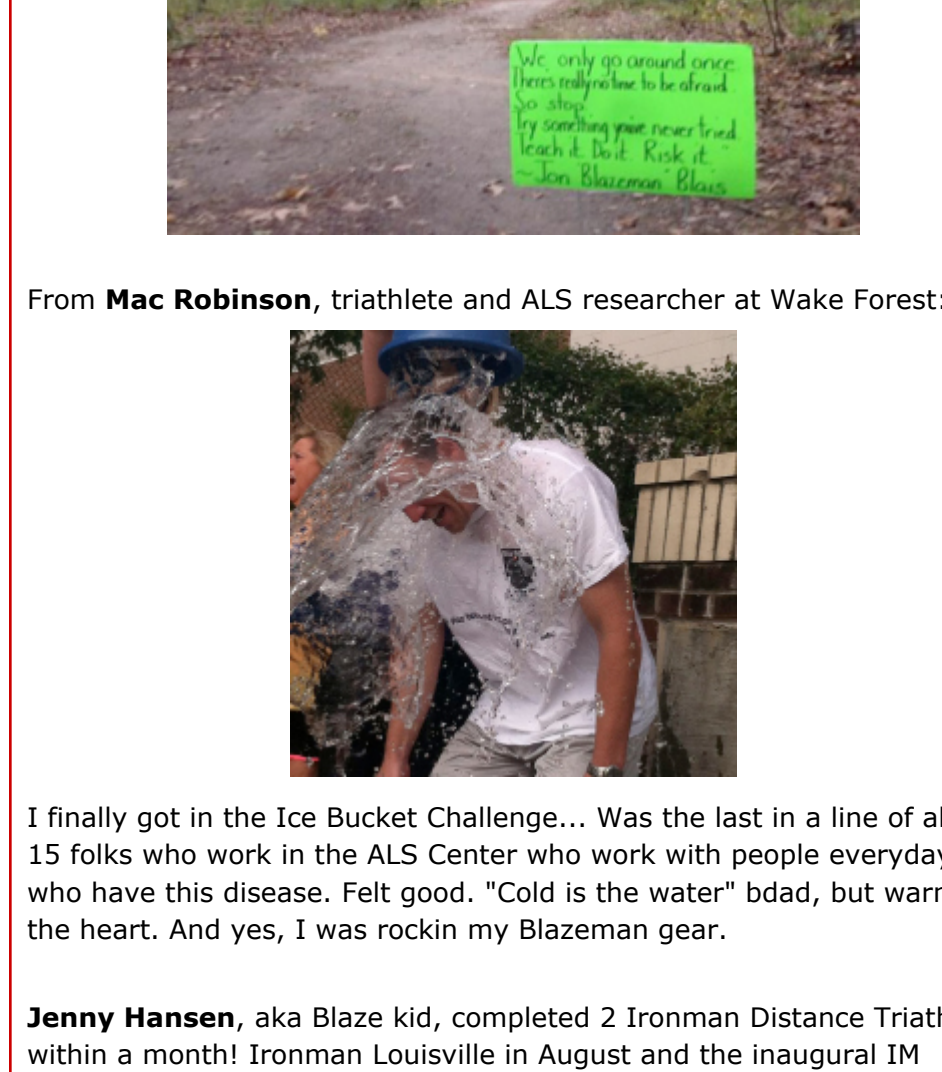
The list of registered Blazeman Warriors keeps growing! We are proud to have you representing us on the battlefields!

'til next time,

Mary Ann
Jon's mom

From the Battlefields

At IM Boulder. It's Dave Schultz and the IronBand!



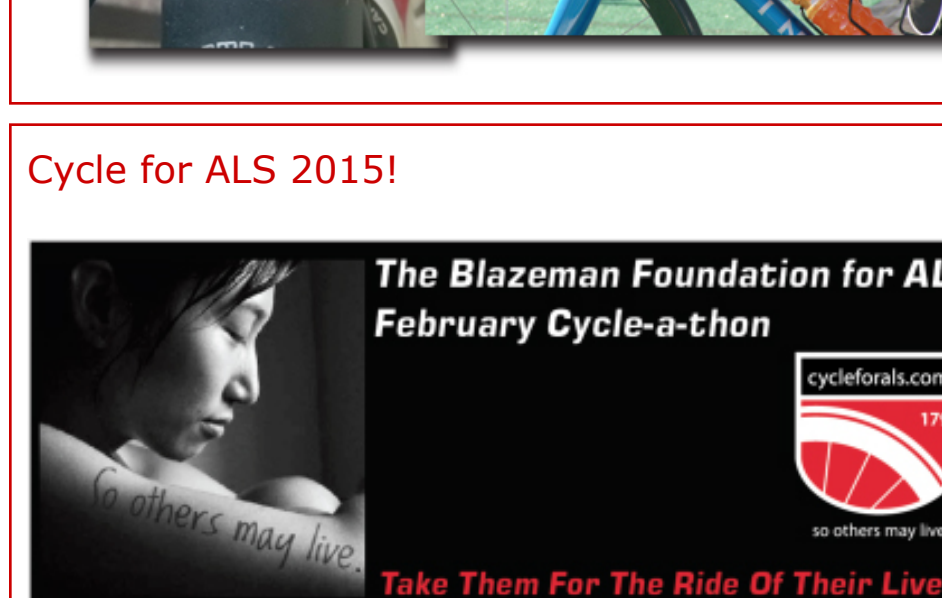
Dave wrote to us saying, "During this time of ice bucket challenges and an increasing awareness of ALS I thought I'd share some footage from our show at Ironman Boulder earlier this month. Jon Blais, the original IRONMAN Warrior Poet....footage from his awe-inspiring finish in Kona in 2005 played on the jumbotron next to us while we played **this song**, one which we wrote while thinking about Jon's struggle."

Thank you, Dave and the IronBand for keeping Jon's memory alive and reminding us all what ALS is...a horrific disease that needs at minimum an effective treatment in the early stage of the disease!

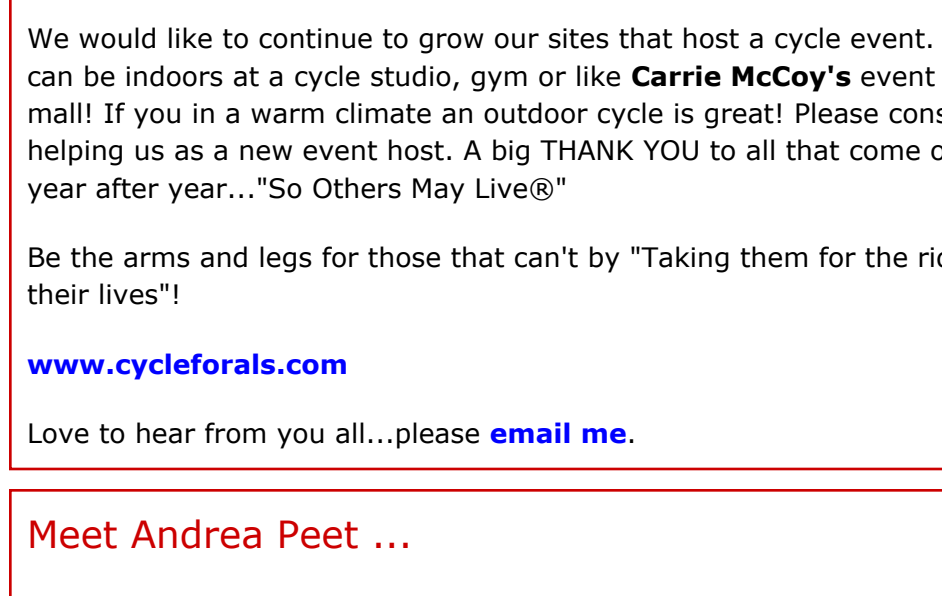
From Blazeman Warrior Don Soranno

Don has been highlighted in **"The Platform Magazine"** Special men's edition, highlighting men who are making a difference. They used Don's story about his race in 2013 at Penticon and spreading of Jon's ashes. Don's entire piece is included in this newsletter! Congrats Don!

In Rhode Island on a September weekend there was a triathlon that included **Spinworks** members. A number of motivational signs along the ways were spotted! And the **rolls at the finish** speak for themselves! Thank you **Peter!**

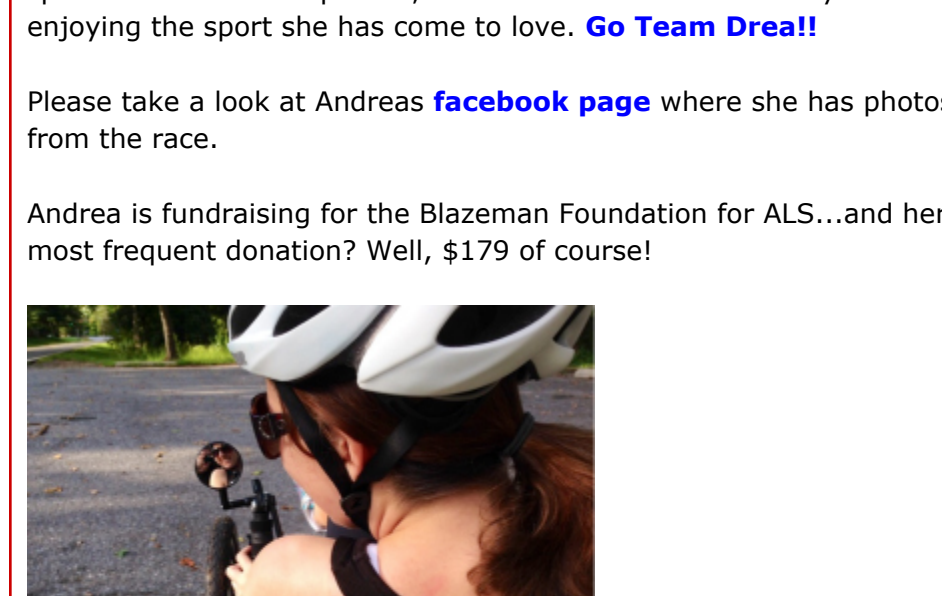


From **Mac Robinson**, triathlete and ALS researcher at Wake Forest:



I finally got in the Ice Bucket Challenge... Was the last in a line of about 15 folks who work in the ALS Center who work with people everyday who have this disease. Felt good. "Cold is the water" bad, but warm is the heart. And yes, I was rockin my Blazeman gear.

Jenny Hansen, aka Blase kid, completed 2 Ironman Distance Triathlons within this month! Ironman Louisville in August and the inaugural IM Maryland in September wearing #179 for both events! Quite a feat as a full time student at Johns Hopkins!



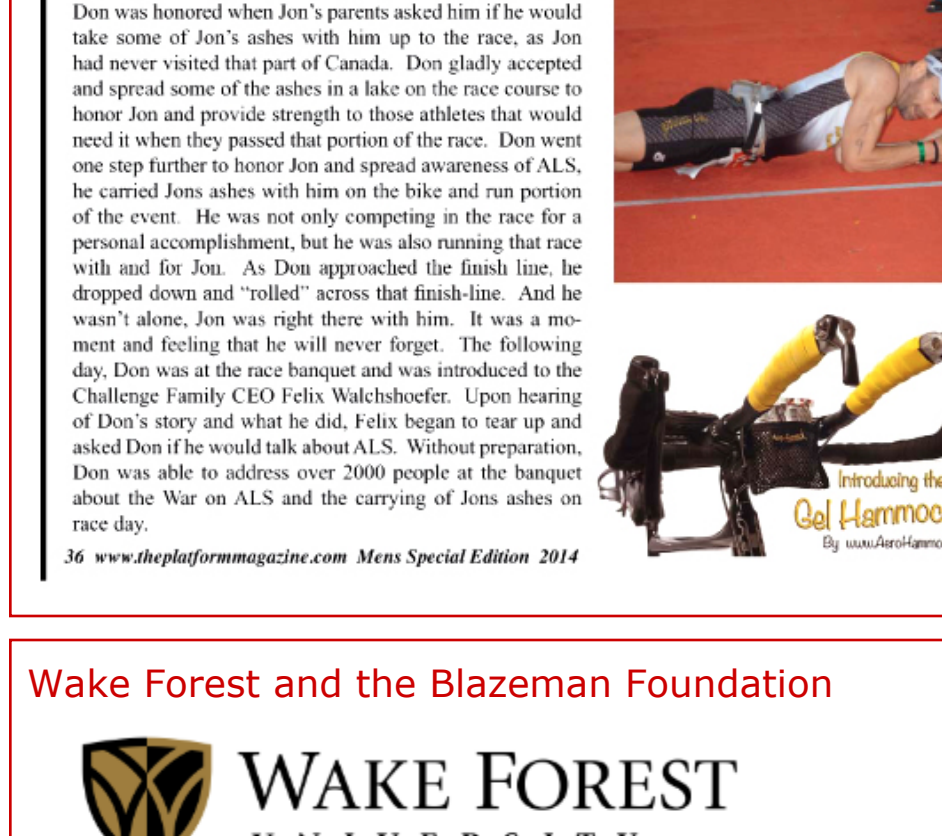
Competitor #179

This past season many athletes across the country have taken the time to apply for Jon's Kona number for their respective race. Getting the chance to tell Jon's story and what the number means to them...we are grateful to know that 9 yrs later Jon's mission to create ALS awareness continues...

In November of 2006 when we took Jon to the 70.3 WC in Clearwater the announcement was made to make 179 horrific...Jon was there that night with us...the following year, in 2007, we spread his ashes in the Gulf with the Ironman Family. Jon had passed away the previous May... Jon had called upon the multisport community.



Cycle for ALS 2015!



In 2006, Jon attended the first Cycle for ALS in Palatine, Illinois...nine years later it continues to be our main research funding event. Thanks to all the wonderful supporters that come out year after year in February we have been able to fund some great research...the first being right in Chicago at Northwestern. Please visit [our research page](#) and see what has been accomplished through our fundraisings! Consider having an event in February for ALS research!!!! We need you!!!!

We would like to continue to grow our sites that host a cycle event. It can be indoors at a cycle studio, gym or like **Carrie McCoys** event in a mall! If you in a warm climate an outdoor cycle is great! Please consider helping us as a new event host. A BIG THANK YOU to all that come out year after year... "So Others May Live!"

Be the arms and legs for those that can't by "Taking them for the ride of their lives!"

[www.cycleforals.com](#)

Love to hear from you all...please [email me](#).

Meet Andrea Peet ...

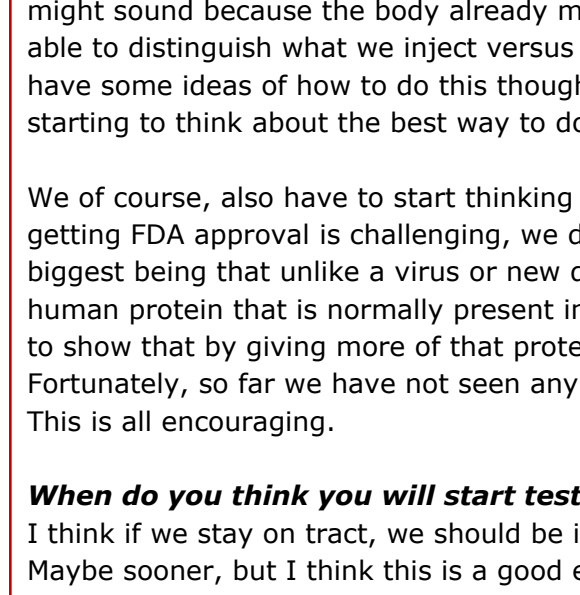
Bob and I received an email the end of August...the kind of email that always makes our heart stop...knowing very quickly what the person will be telling us. **Amanda Peet** was a young triathlete with the world full of promise when the symptoms started after her first Half Ironman in 2013 by April of this yr, seven months later Amanda was using a cane to walk.

Andrea tells us she started searching the internet after ALS was becoming a probability like Jon did. She found Jon's story and was amazed that they were connected by the number 179. Since Andrea was a young girl in the 7th grade when her parents bought her a French horn, model 179, the number kept coming back at her...it quickly became her lucky number.

We spoke with Andrea and her husband after that email exchange...she told us about her blog where she has been documenting her life as it changes. Please take a few minutes and get to know Andrea and Team Dreal! Andrea and her recumbent bike completed the **Ramblin' Rose** sprint triathlon in Chapel Hill, NC on October 5th with the family and friends, enjoying the sport she has come to love. [Go Team Dreal!](#)

Please take a look at Andrea's [facebook page](#) where she has photos from the race.

Andrea is fundraising for the Blazeman Foundation for ALS...and her most frequent donation? Well, \$179 of course!



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.

Brigitte Paulick	Seth Toback	Sierra Stout
Gary Thomas	Jeff Hosler	Christopher Keller
Erica Heins	Georges Cespedes	

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.

Webster Bank and the Blazeman Foundation

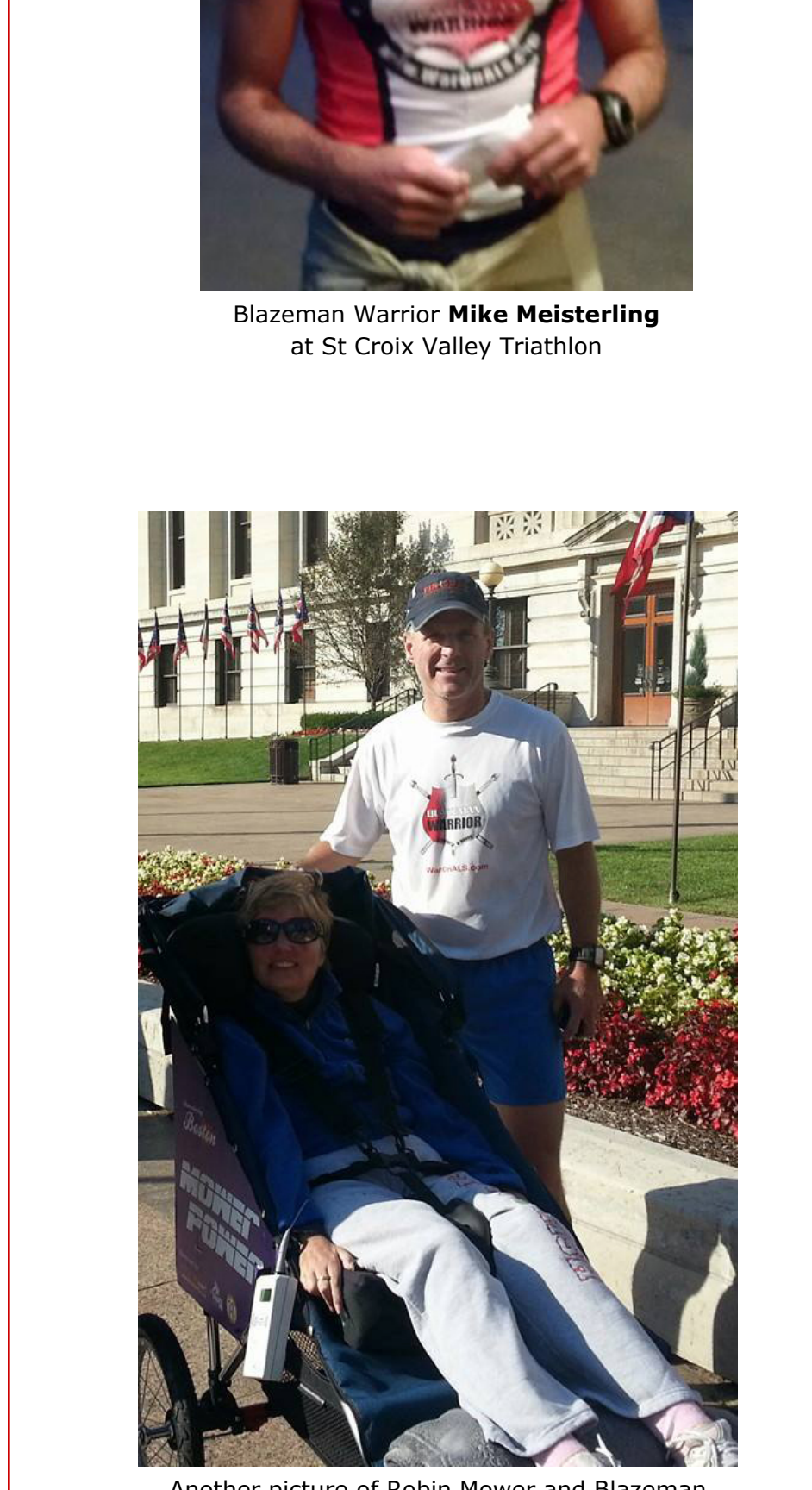


Dave Kent (Branch Manager), Sharon Trask and Bdad at our local Riverside branch!

Webster Bank is the bank of the Blazeman Foundation for ALS and has been since Bob and I became involved with the Foundation after Jon passed away. They were main sponsors of our two local road races and again stepped up with the Ice Bucket Challenge in August when Webster CEO **Jim Smith** took the challenge and rolled the makeshift finish line. Take a moment and check out the [Webster Bank YouTube video!](#)

Warriors in the News!

Blazeman Warrior, Don Soranno, has been highlighted in **"The Platform Magazine"** Men's edition this past month. Don is an example of so many of our Blazeman warriors...always giving of themselves... Congratulations, Don, and thanks for helping raise awareness for our cause!



For more information on how you can help visit: [www.warriors.com](#)



Don continues to support ALS research and awareness through his participation in the Ice Bucket Challenge and his fundraising efforts.

Introducing the new Gal Hammock by... (caption partially obscured)

Wake Forest and the Blazeman Foundation



The following are excerpts from *our interview* and an article written by and about the research done by Carol Milligan, Ph.D. Director of the ALS Center Translational Science Unit, Director at Wake Forest School of Medicine- a program funded by the Blazeman Foundation for ALS and its supporters. Your donations at work!

Over the course of the past few months with the craze about the "Ice Bucket Challenge" the question of why we should be able to make the research as opposed to diseases that affect a larger number of people. The answer is simple- because we have nothing to offer ALS patients. While it is true that the quality of care has improved significantly since the time of Lou Gehrig, the fact is that the average lifespan from time of diagnosis to death has not changed. The only way to begin to understand the disease and ultimately develop an effective therapeutic will be through roll-up your sleeves and work hard basic science research. This is not easy, it take time, effort and yes, money.

Tell us about the project that the Blazeman Foundation is currently funding?
Our research project on Heat Shock Protein 70 or Hsp70 is a perfect example of "bench to bedside" research. It is also a good example of the time involved in this type of project. In 1981, a colleague in our department, Dr. Mike Tytell published a paper that demonstrated that supporting cells that surround the squid giant axon made proteins and then transferred those proteins to the axon. One of the proteins was heat shock protein 70.

What is heat shock protein 70?
The protein is called "heat shock protein" because it is one of a series of proteins that cells make more of at times of stress, such as "heat shock." Hsp70 is a "chaperone" protein. It helps to transport other proteins between the different parts of the cells. It is also important because it protects proteins during time of stress when they can be damaged.

Can you move toward a clinical trial?
Recently, our project was "dead in the water." I say this because we simply could not move forward. We had been purchasing the recombinant protein for our studies. For the 2007 study the company that made Hsp70, Stressgen gave us an 85% discount so we could purchase enough for the study. Stressgen was sold to a company that was then sold to another company and for the 2012 study we were getting a 15-20% discount. We simply could not afford to purchase enough protein to move forward. We also found that the quality of the protein started to vary between batches making it hard to interpret results of our studies. If we could not do this to conduct a few experiments, obtaining the protein in sufficient quantity and purity for a clinical trial was out of the question.

But couldn't you get funding to help move the study along?
That was the problem. Nobody wanted to pay for us to make a protein. This is understandable. Funding agencies want you to provide answers not a product. But, if we could not make the protein, we could not do additional studies for get answers. This was very frustrating and we were accepting that the project would just stop.

What changed?
The Blazeman Foundation! I had had a conversation with Bob and Mary Ann about the different projects we had going on in the lab. Around the same time, a fellow from our "Innovations" group learned about our results with Hsp70 and thought they might be able to help move it forward toward clinical trial. With the conversations between Bob and Mary Ann and Innovations, the Department of Neurology and our board. Another key piece of this was that Mac Robinson, a former student in my lab was completing his postdoc. Mac had done the initial work on Hsp70 on the chick muscle neurons. He also began to make the recombinant protein. It is a tricky protein to make because it is rather big, but Mac has a good protocol started. That was about the time he finished his PhD work. He went onto to do work in our Genomics Group and got his Masters in Public Health Science. But he realized that of all the disorders to devote his efforts to, ALS was the one most in need. So with the momentum generated by the Blazeman Foundation, Mac joined our department as a junior faculty member in our ALS group.

And how is the project going?
I think we are making progress and pretty much are on schedule. We started with Mac's original protein and purification protocol. The big problem was being able to make enough of the protein and to be able to get it purified. Mac has achieved that. He is getting very good yields of protein. By our analysis, it looks to be fairly pure. We have just begun testing it in animals.

So you are well on your way?
Well, we are on the right track. We are at a crossroads right now that is both very exciting and a bit scary. We have to decide if we should continue to improve the purification process or do we move toward having the protein be made in a GMP facility. GMP means "good manufacturing process" and this is the standard for all clinical agents. We have begun discussions about this, and the folks at one GMP facility think we have it to a point where they can take over. This will be an expensive endeavor- with an estimate of about \$200K to make enough protein for an initial phase 1 safety trial. As a scientist I do not want to hand this over until we get the results from our animal studies confirming that the protein is working as we expect. I think we are looking at least another six-to ten months before we know this for sure. We also need to complete a dose response study that will give us a better idea of the appropriate starting dose. Our initial studies used only one dose- simply because we could not afford to do more. But if we are seriously thinking of going into patients, then we need to do this right and get a dose response. I think if we get confirmation that we can repeat our original results with our protein, we could have a GMP facility start production while we work out the dose response, and I have a colleague who is interested in doing this.

And, with discussions of going into patients- we have more questions to answer as well. For example, we need to demonstrate that we can detect the protein we inject into patients, and that it is getting to the area we expect it to be - to the muscle. We are working with our ALS clinicians to figure out the best way to do this. This is not as easy as it might sound because the body already makes Hsp70, so we need to be able to distinguish what we inject versus what the patient makes. We have some ideas of how to do this though. But, the clinicians are starting to think about the best way to do the first safety trial.

We of course, also have to start thinking about going to the FDA. While getting FDA approval is challenging, we do have a few advantages, the biggest being that unlike a virus or new drug, we are treating with a human protein that is normally present in the body. Our first step will be to show that by giving more of that protein, we do not harm the patient. Fortunately, so far we have not seen any adverse effects in our mice. This is all encouraging.

When do you think you will start testing in patients?
I think if we stay on track, we should be in a Phase 1 trial in 3-5 years. Maybe sooner, but I think this is a good estimate. If course, that is only phase 1 and will only test safety. It will be the Phase 2 and 3 trials that will look for effect.

So bench to bedside?
Yes, we started in the early 2000's with cells in a dish. Actually, in 1981 if you trace back to Mike's original study. And, after all this, there is still no guarantee that it will work. This is really the hard part. When I start to think about how much we have done, and how much we have to still do- and how much it is going to cost- it is unerving. No one else is doing this. But it's time like this when I go look at the Blazeman Website, "Decision must be instant. Commitment must be total."

Photo Gallery

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

Jeff Galvin pushing Robin on a leg of the Toledo to Columbus run!

Chuck Nardod at NJ State Tri 2014

Blazeman Warrior **Jenny Hansen** on the run at IM Maryland. She PR'd during her second Ironman in a month!

Blazeman Warrior **Mike Meisterfing** at St Croix Valley Triathlon

Another picture of Robin Mowler and Blazeman Warrior Jeff Galvin at the Toledo to Columbus Run for ALS Awareness

Bill Almond #179 at Goddard Park Triathlon 2014