

Let's Go!

**ACTIVE
AGAINST
ALS**



ANN ARBOR NEWSLETTER
FALL 2015



Ann Arbor Active Against ALS funds promising research

Over the past year, Ann Arbor Active Against ALS worked closely with our Scientific Advisory Board to determine where our funds should be donated. This year we are pleased to have donated **\$45,000** to each of two different organizations. Through the Robert Packard Center for ALS Research at Johns Hopkins we donated funds, both this year and last, to Dr. Jared Schternekert. This year we also funded promising research by Dr. Sami Barmada, a neurologist and researcher at the University of Michigan.



Dr. Jared Sterneckert,
Dresden University of Technology in Germany

Dr. Sterneckert is screening a library of existing compounds in a C90rf72 stem cell model using pluripotent stem cells. After this process, he will validate any positive findings in order to identify potential compounds that could be evaluated in the clinical setting. We were pleased to fund a portion of this work last year and believe that further funding this year will help in identifying

compounds that will be valuable in the treatment of ALS. Click [here](#) to read more.

Sami Barmada, MD, PhD, University of Michigan

Dr. Barmada is leading exciting work toward options for treatment of ALS by determining why motor neurons are a target of ALS and how the disease spreads from neuron to neuron. We contributed specifically to an effort in Dr. Barmada's lab to evaluate selective inhibitors of nuclear export, and to investigate a protein that has shown promise in preclinical neuronal and animal models of ALS. Dr. Barmada's work incorporates motor-neuron derived stem cells and an innovative tool designed specifically to measure neuronal function in cell plates. Through this work, Dr. Barmada's goal is to develop targeted treatments that prevent the death of motor neurons in ALS, thereby stopping the spread of disease once it has begun. Click [here](#) to read more.



"We are thrilled that with the assistance of our scientific advisory board we have been able to find these really important projects to fund."

— Dr. Caren Goldberg,
A2A3 board member

The Robert Packard Center for ALS Research at Johns Hopkins is the only international scientific organization dedicated solely to curing the disease. They are unique in their approach to ALS by facilitating intense scientific collaboration across institutional and administrative boundaries. The Packard Center aims to fund innovative projects with investigators and scientists from around the world who believe that collaboration is essential in developing treatments.



From Bob



Maddie, Sophie, Bob, and Gretchen

Contemplating my 7-year journey

July 29 marked our seventh anniversary of my diagnosis. What does one do to “celebrate” the anniversary of such an event? I’m not sure. But for some reason I opened up my email and re-read messages sent to Gretchen and me the day we announced our situation to friends and colleagues.

Re-reading those messages brought back some intense emotions: despair, lack of hope, and concern for Gretchen and the girls. It’s probably why I have only read them a few times since 2008.

We are incredibly fortunate that my health has not deteriorated as quickly as we thought it would. My legs and arms are getting weaker, and my voice is not nearly as strong as it was a year ago. Thankfully, I can still function fairly independently, enjoy my family, friends, and community, and continue to work half-time.

When asked, most people say they wish for a speedy death – maybe a heart attack – with no lingering disability or limitations. Seven years ago I probably would have agreed with them. The last several months I have thought quite a bit about this question. I’m struck by the fact that many different religions and life perspectives value struggle.

- I ask not for a lighter burden, but for broader shoulders. – Jewish proverb
- We must embrace pain and burn it as fuel for our journey. – Kenji Miyazawa, devout Buddhist
- The gem cannot be polished without friction nor man without trials. – Confucius
- There is nothing that can cleanse your soul like getting the hell kicked out of you. – Woody Hayes (Okay, Woody Hayes might not qualify as an admirable life teacher, at least not for this Michigan fan, but you get the point!)

While I can’t say I am glad I have ALS, I know my path with this disease has been much easier than others given the slow progression of my condition and the incredible support I have received from so many different people. So it is less clear to me today than seven years ago that the world would be a better place if there were absolutely no disease, sickness, or struggle.

Family Field Day takes a break

After seven fun-filled Family Field Days, we are taking a year off to reassess and re-imagine the day, with the goal of reaching a broader community in the future. FFD, which has been our signature event, was a kick-off to the fall season that met many of our stated mission goals: to raise awareness and funds for ALS while bringing together community members of all ages to have fun and be

active. Although we will miss the gathering this year and deeply thank all those who have been involved with FFD, we are excited about the prospects for a FFD “reboot” that might include new activities, a new location, or connections to other events.



SEND US YOUR IDEAS!

PLEASE feel free to send your thoughts and ideas for a re-imagined Family Field Day or other event. Contact Susan Miller at srmiller@ameritech.net with any suggestions or questions.

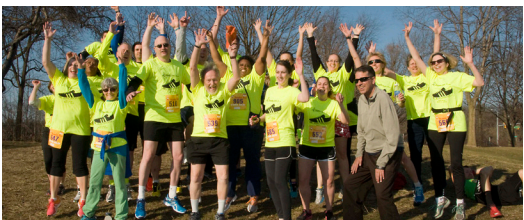


Thank You



BOX CAR DERBY

March 28 was a brisk, sunny, and beautiful day for the 7th Annual Box Car Derby with Phi Delta Theta Fraternity. Over 50 racers, aged 4 to 22, participated in the annual race down South University. Congratulations to Team Daschunds for winning the overall award for the third year in a row! Congratulations also go to Teams Box Your Sox Off and B.C. Riders for raising the most money to fight ALS. Hungry racers and cheering fans alike were treated to the delicious grilled food of [Antonio's Italian Market](#), courtesy of the [PDT Michigan Alumni](#). Thanks to the media coverage by CTN TV, who posted a story [here](#) (starting at 3:07) and to [MLive](#) who took pictures and video. We appreciate the tremendous support of our 2015 sponsors: [Foley & Lardner LLP](#), [MB Financial](#), [Pagoda Fine Carpentry](#), [Beal Properties](#), [Meadowlark](#), [Cross Fit Tree Town](#), [Buffalo Wild Wings](#), [Phi Delta Theta Michigan Alumni Association](#), [Blue Leprechaun](#), [The M Den](#), [Biggby Coffee](#), and [Cherry Republic](#). Look for a new car design for high school and college-aged young adults in 2016!



TWINKIE RUN

April 1 was a gorgeous day for the 6th Annual April Fool's Day Twinkie Run! Nearly 600 participants, including two large teams, ran the wacky and fun race at beautiful Gallup Park. To see photos of the ISR Runs for Bob team, the Relay for Life team, and all Twinkie lovers, click [here](#) and [here](#). We're also getting more famous! SHAPE Magazine recently included the Twinkie Run in their list of "10 Food Fueled Races Around the Country," and we're in "The Runner's Bucket List," by Denise Malan. Continued thanks to our generous sponsors: [JyTech Polymers](#), [Dakotech](#), [Transition Rack](#), [Ajax Spring](#), and [Meijer](#) (Ann Arbor-Saline Road)! We could not continue to thrive without your support and the incredible energy of our amazing volunteers.

TO EVERYONE WHO HAS DONATED, VOLUNTEERED, OR SPONSORED AN EVENT OR PLANNED AN EVENT OF YOUR OWN. WE HAVE NOW RAISED MORE THAN **\$355,000** FOR ALS RESEARCH!



ELECTRIC BOLT

Almost 500 people participated in the 5th Annual Electric Bolt on July 26. The beautiful course passed through three scenic city parks and ended in a new place this year - the heart of Kerrytown! Kudos to Team NTI (National Training Alliance), Team Bob, and Team Schoeni, who raised over \$12,000 between individual donations and a special tool bag sale by Team NTI. Adding race proceeds and sponsorships, the race has netted more than \$16,000 for ALS research. A heartfelt thanks to our primary sponsors, the [Electrical Training Alliance](#) and the [American Technical Publishers](#), who make this picturesque race possible. A special thank you to the [Ann Arbor Track Club](#), [Zingerman's Bakehouse](#), [Zingerman's Coffee](#), and [Physical Therapy in Motion](#). And many thanks to [Ann Arbor Running Company](#) for hosting packet pick up and helping promote the race. Click [here](#) photos and [here](#) for race results.



HURON VALLEY SWIM CLUB SWIMATHON

Thank you to the Huron Valley Swim Club for choosing us as the recipient of their donations for their annual swimathon on July 8. The 117 swimmers raised over \$9,000 for ALS research! Many thanks to the generous sponsors, [Sun & Snow](#), [Jersey Mike's](#), and [Quality 16](#).



BUHR PARK SHARKS SWIMATHON

On July 7, these hardy swimmers swam almost two miles each, in the rain, to raise funds for ALS research during their 6th Annual Swimathon. Thanks to all the great coaches, supportive families, and smiling volunteers.

Events at a Glance

BEERFEST

Saturday, October 3

4TH ANNUAL RIVALRY RIDE

Saturday, October 17

8TH ANNUAL BOX CAR DERBY

Sunday, April 10

Ann Arbor ACTIVE AGAINST ALS

RAISING FUNDS. RAISING HOPE.

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WWW.ACTIVEAGAINSTALS.ORG

Come be a part of our

3RD ANNUAL BEERFEST!

Saturday, October 3 • 4:30-10:00 p.m.

This year's Burns Park Brewers Beerfest will feature LIVE music, 20 different homebrews from skilled local brewers, non-alcoholic homebrew root beer, a chili cook-off, brats, pretzels, and more. Beer will be sold by the glass for \$5, with logo glasses available for purchase to use for the evening. Kids are welcome! Click [here](#) to register and for more information. Click [here](#) to become a sponsor.

BEER SPONSORS ARE NEEDED!

Sponsorship costs range from \$25 to \$140:

Sponsor benefits include:

- The opportunity to taste, name, and design a label for the beer
- Sponsor acknowledgement on signage at the event
- Exclusive access to special reserve beer at the event, including Swaney bourbon barrel-aged offerings



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