

Let's Go!

**ACTIVE
AGAINST
ALS**



ANN ARBOR NEWSLETTER
SPRING 2015



Maintaining the momentum

While the Ice Bucket Challenge (IBC) was wildly successful in raising funds and awareness for ALS, the real challenge now is keeping the excitement going.

Our friend Trickett Wendler posted a story on Facebook some weeks after the height of the Ice Bucket Challenge (IBC): “At the checkout in Target, after friendly chitchat about coupons, the checker asked ‘can I ask if you have ALS?’ I am THRILLED to be asked that question.” The checker told Trickett that a month before she didn’t know what ALS was.

The IBC generated real money; money that is essential for finding a cure for this unforgiving disease. ALSA received \$115 million in donations. ALS TDI received \$3 million, which accelerated some of their drug programs from a 3-year schedule to less than a year. Additionally, the initiative raised awareness to an unprecedented scale. ALSA reported they received donations from over 739,000 new donors. Our own organization received a phenomenal \$20,978 from 239 donors, directly attributable to the IBC. At least 150 of these were first time donors.

ALS is often a solitary experience for people with the disease and their families. The daily challenges leave little energy for bringing the world into their struggle, especially when so few people understand its daily intensity. Milan Karol from the Packard Center for ALS research said that the IBC was an initiative that “helped to bring understanding and recognition to these daily struggles, which many patients and their families found to be a beacon of hope that they weren’t alone after all.”

It is essential that people understand the devastating impact of ALS, and the urgency for pharmaceutical companies and national funding sources to allocate big money toward research. The Ice Bucket Challenge – which brought higher donations than ever to ALS research – was, truly, a drop in the bucket.

ALS in the movie and TV spotlight

“This Oscar belongs to all those around the world battling ALS,” began Eddie Redmayne in his recent Academy Award



acceptance speech for Best Actor, which he won for portraying Stephen Hawking in *The Theory of Everything*. Another 2014 movie, *You're*

Not You, told the story of a classical pianist (played by Hillary Swank) with ALS. A new series on Fox, *Empire*, features a lead character with ALS.

Also, in late January, a long-time news anchor in North Carolina, Larry Stogner, announced his diagnosis on air. Richard Glatzer, the co-writer and director of *Still Alice*, has suffered from ALS since 2011. With the film’s star, Julianne Moore, winning multiple Best Actress awards, Glatzer has talked openly about living with ALS. And NFL player Steve Gleason, also diagnosed in 2011, was recently featured in a 60-second Microsoft ad during the Super Bowl.



The Active Against ALS board takes the Ice Bucket Challenge together last September in Burns Park.



Welcome new board members



Michael Meister is Senior Project Manager for Information Technology Services for the University of Michigan. Having lost six family members to ALS, he knows the devastating effects of this disease and is dedicated to raising awareness. With his sister, Laura Stidham (Vice-Chair), and other family members, Michael has participated in many Active Against ALS events over the years. He is joining the board as Treasurer, and brings years of budgeting, finance, and administrative experience to this role.



Eli Sugerman is a student at the University of Michigan, working towards a degree in psychology and entrepreneurship. He and his family have been involved in all aspects of Active Against ALS since our founding in 2008 – his brother Sam inaugurated the Rivalry Ride on UM-MSU game day, and Eli has already served on a number of organizing committees. He brings great enthusiasm, new ideas, and a willingness to jump in and work.



Katherine (Kat) Walsh is the Director of Student Engagement in the Office of Development at the University of Michigan, where she oversees student philanthropy and Telefund Operations. Kat studied under Bob Schoeni while getting her master's of public policy, and she seemed a perfect fit for the board. She brings extensive administrative experience and much-needed skills in fund development.

Thank You!

Words cannot adequately express our deep appreciations for all that **Cathy Shakespeare** and **Kristin McGuire** have done for our organization as they step down from the board. Cathy, our founding Treasurer, and Kristin, our founding Secretary, did much more than their job titles convey. We are grateful that they will remain closely connected to us and wish them well in their new endeavors.

Welcome to our newly created Science Advisory Board

We are very pleased to announce the creation of our own Scientific Advisory Board (SAB). The SAB is made up of established researchers from around the country who have kindly agreed to provide consultation to our board on how best to allocate the funds we raise. We are deeply appreciative of their time and guidance. The new SAB members include:

Robert H. Brown, M.D., Ph.D., Chair and Professor, University of Massachusetts Medical School

Brian C. Callaghan, M.D., Assistant Professor, U-M Medical School; Associate Director of Research, U-M Comprehensive ALS Clinic

Gerald D. Fischbach, M.D., Chief Scientist and Fellow, Simons Foundation

John K. Kim, Ph.D., Associate Professor, U-M Life Sciences Institute; Research Associate Professor, U-M Medical School

Tribute to Dr. Roger Martinez



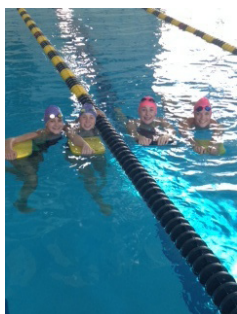
Active Against ALS was saddened to learn of the death of Dr. Roger Martinez in November. Dr. Martinez, an internist in Nashville, Tenn. for 25 years, was diagnosed with ALS only 13 months before his death.

We came to know about Dr. Martinez through his son, Joe, a U-M anesthesiologist. Joe learned about Active Against ALS when he read about the Twinkie Run last spring, and contacted us, interested in connecting with others touched by the disease, and spreading awareness about its impact. Since then, Joe has helped with many of our events, including serving on the planning committee of our 2014 7th Annual Family Field Day, and organizing an awesome Ice Bucket Challenge with a large group of his colleagues. When his father passed, Joe asked if we could set up a special tribute page on our website in his father's honor. We are appreciative of all who have paid tribute to Dr. Roger Martinez's life as well as to Joe's dedication to his father's memory and efforts to cure ALS.



Thank You

MT. LEBANON AQUA CLUB SWIM-A-THON



Our hats go off to high schoolers Emma Buerger and Hannah Bumgarner for organizing a swim-a-thon on September 20 to raise money for ALS research. Hannah, who had Bob Schoeni as a soccer, softball, field hockey, and

basketball coach when she lived in Ann Arbor, wanted to be active to support Coach Bob. Over 50 swimmers participated and, with "tons of supporters," they raised over \$8,000, surpassing their \$5,000 goal. Thank you, Emma and Hannah, and congratulations to all of the swimmers!



FAMILY FIELD DAY

Thank you to everyone who came out for the 7th Annual Family Field Day on September 28. We appreciate the many local businesses that donate to this event, and our wonderful volunteers. We love all the kids who are active against ALS during this high-energy afternoon in the park.



RIVALRY RIDE

The Rivalry Ride, which started as one 13-year-old's bar mitzvah project, has become an annual fall ritual for the Sugerman/Rosen family and friends. It has grown every year, and even the weather is starting to cooperate. On October 25, a sunny, blue-skied Saturday, over 20 riders pedaled from the Big House to the Spartan Stadium for the 3rd annual Ride.

Thanks to all the riders and to Sam Sugerman for his inspiration and energy!

Events at a Glance

**7TH ANNUAL
BOX CAR DERBY**
Saturday, March 28

**APRIL FOOL'S
TWINKIE RUN**
Wednesday, April 1

**WATER TABLE AT
THE DEXTER-A² RUN**
Sunday, May 31

**4TH ANNUAL
ELECTRIC BOLT**
Sunday, July 26

WHOLE FOODS DAY - SEPTEMBER 18

Thank you to Whole Foods - Washtenaw Ave. for making Ann Arbor Active Against ALS the recipient of a 5% Community Support Day on September 18.

We appreciate our board members who spent the day talking with people about Active Against ALS, and a big thank you to all the shoppers that day!



2ND ANNUAL BEER FEST



In response to popular demand, the Beer Fest is now an annual event at Burns Park. We had a great night drinking (very!) local beers and testing the chilies — no

one minded the chilly temperature. Thanks to Jackie and Joel Dalton for organizing this great evening, and to the beer makers and volunteers.

Ann Arbor
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RAISING FUNDS. RAISING HOPE.

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Box Car Derby

Saturday, March 28

The 7th Annual Box Car Derby is coming SOON! Come zoom down the hill on Saturday, March 28, with the Phi Delta Theta brothers.

April Fool's

Twinkie Run

Wednesday, April 1

No foolin'! Join the wacky, fun 6th Annual Twinkie Run. Starts at 6:00 p.m. Wed., April 1 at Gallup Park in Ann Arbor.

Water Table at the

D&A Run

Sunday, May 31

Put on your Active Against ALS t-shirt and help us at the water table/aid station at the 2015 Dexter-Ann Arbor Run!

Electric Bolt

Sunday, July 26

Run a cool race on a shady course in July. Sign up for the 4th Annual Electric Bolt on Sunday, July 26. It's a great 5k and 8k along the Huron River in Ann Arbor.

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