

Let's Go!

**ACTIVE
AGAINST
ALS**



ANN ARBOR NEWSLETTER
FALL 2013



Welcome, New Board Members!

ANN ARBOR ACTIVE AGAINST ALS IS THRILLED TO WELCOME FOUR NEW BOARD MEMBERS AND EXECUTIVE COMMITTEE

Elizabeth DeRose, whose daughter was coached by Bob Schoeni for years, has been a volunteer with Active Against ALS since our founding in 2008. Elizabeth has worked in communications and advertising, and brings years of fundraising experience and non-profit community building skills. She is co-chair of the Development Committee.

Stacey Johns read an article about the Boxcar Derby in early 2012 and got her hands on a boxcar that same day! Her father, Michael Johns, passed away from ALS in October 2010, and her two children raced in their grandfather's honor. Stacey brings to the board rich design and marketing experience. She is co-chair of the Family Field Day Committee.

Sara Robins has long been committed to community involvement and has volunteered at Active Against ALS for many years. She brings extraordinary energy and organizational skills to the board. Sara has been on the Family Field Day Committee since 2011, and we now welcome her as secretary of the board.

Nick Stamos learned about Family Field Day and signed up to help out. Nick's father, a much beloved gym teacher in Ann Arbor, passed away from ALS in 2004. Nick believes the emphasis on being active and involving children reflects and honors his father's legacy. Nick brings vision and team building expertise to the board. He is co-chair of the Development Committee, and also the liaison with Phi Delta Theta.

Heartfelt thanks to **Jackie Dalton** and **Amanda Mercer** who are stepping down from the board. We are grateful that both will remain closely connected to Active Against ALS. Jackie has been integral to our running events and the Buhr Park Swimathon. Amanda made an invaluable contribution as captain of the Channel For ALS Team, and also organized the Holiday Relays and the Twinkie Run.

A huge thank you to our founding Executive Committee: **Suzanne Ross, Joel Dalton, Kristin McGuire** and **Cathy Shakespeare**. Their nearly five years of dedicated service have been integral in enabling Active Against ALS to grow into a sustainable organization.

New Executive Committee

Susan R. Miller
Chair

Laura Stidham
Vice-Chair

Sara Robins
Secretary

Cathy Shakespeare
Treasurer



From left to right: Sara Robins, Susan Miller, Laura Stidham, and Cathy Shakespeare

Our New Website is Live!

Check out our new website at activeagainstals.org. Many thanks to the James A. and Faith Knight Foundation for their support and encouragement of this project.





Reflections from Bob



In the summer of 2008 Gretchen and I were getting ready to begin new positions within the University of Michigan and our oldest daughter was headed into her last year of elementary school. We were excited about these upcoming challenges and transitions. But then on July 29 – just over 5 years ago – we were told that I had ALS. Our plans and expectations for the future changed dramatically.

Numerous times I have wondered what our lives would have been like without ALS. What would our daughters' interests be? What professional experiences would we have had? Would we have made as many new friendships, or felt as connected to our community?

Living with ALS, or any serious health condition, is challenging. I don't believe I will ever think that my life with ALS is "better" than the life I would have lived without this disease. What I do know is that the list of good things that have happened these last five years is long and getting longer.

Towards the top of that list is the creation of Ann Arbor Active Against ALS and all of its incredible accomplishments. The organization, created four months after my diagnosis, has raised hundreds of thousands of dollars to support cure-based research. Their donations are supporting research toward what I believe to be the most innovative and promising treatments, including the new stem cell trial at the University

of Michigan. Active Against ALS has also been an important resource for individuals with ALS, their families, and their friends. People affected by this disease have been drawn to the group's events as a way to demonstrate their support of patients and to fight for an effective treatment.

Developing medical treatments is expensive, and the financial resources raised by Active Against ALS are critically important. But arguably just as important has been the incredible development of community. A group of individuals, already with commitments to their professional careers and their families, found time to create a nonprofit and grow it into an organization that is the focal point of numerous events every year. The community they have developed in Ann Arbor and beyond has benefited me and many others. I am particularly gratified to see young children and youth heavily involved in Active Against ALS. Their energy and innovation are awe-inspiring!

The last five years have certainly not gone the way that Gretchen and I thought they would on July 28, 2008 – but they also have not gone the way we thought they might on July 29. The list of wonderful experiences continues to grow, thanks in large part to Active Against ALS. Hopefully in five years I will write another piece for the newsletter and the list will be even longer!



Bob and Gretchen with daughters Maddie and Sophie.



Way to go, Channel Swim Team!

A huge thank you and congratulations to Amanda Mercer (capt.), Bethany Williston, Jenny Sutton Jalet, Susan Butcher, Melissa Karjala, and Emily Kreger for achieving their **\$120,000** fundraising goal just before the one-year anniversary of their record-breaking swim! Initiatives to raise funds and educate about ALS included: The Kento Puzzle App, Individual and Team Virtual Crossings that brought many local high schools into the action, a Bon Voyage ALS! send-off party, dedicating legs of the swim to individuals with ALS and tweeting those names during the swim, and a screening of the MSU Today-produced documentary, *Swimming Towards A Cure*.



Thank You



BOX CAR DERBY MARCH 2013

The 5th Annual Boxcar Derby was cold, fast and fun! An upstart team of 5-year olds upset the field and won both the nine and under age group and the

open division. One team member exclaimed for all to hear, "This was the best day ever!" Many thanks to the Keith Weidmayer family for donating over 100 straw bales to help ensure the safety of the course and drivers.



LEAH WEBBER RUNS FOUR MARATHONS!

Who could imagine running a marathon on a treadmill? How about four! For her Bat Mitzvah community project, Leah ran 104.8 miles over the course of four months. Thank you, Leah, for raising thousands of dollars and increasing awareness about ALS. You are an inspiration!



TWINKIE RUN APRIL 2013

Over 250 runners and walkers braved the cold and wind on April 1 to participate in the 4th Annual Twinkie Run. Twinkies (well, fake Twinkies this year!) kept people smiling. Many thanks to our long-time sponsors and volunteers. We hope to see you next year when the real Twinkies are back!



BURNS PARK RUN MAY 2013

Thank you to the organizers of the Burns Park Run and to the hundreds of runners who came out to fill the neighborhood streets in early May! It was a wonderful morning of runners and walkers of all ages. Almost \$1,000 was raised for ALS research. Thank you to all of you generous donors!



ISR RUNS FOR BOB AT DEXTER-A2 RUN

Twenty colleagues of Bob Schoeni from the Institute for Social Research (ISR) ran in the 40th Annual Dexter-Ann Arbor Run in June and raised over \$850. ISR colleagues have participated in six runs to honor Bob and have raised thousands of dollars for ALS research.

THE ELECTRIC BOLT

Nearly 300 runners and walkers helped raise almost \$30,000 at The Electric Bolt in July. Tremendous race sponsorship came from the National Joint Apprenticeship and Training Committee (who donated nearly \$15,000), American Technical Publishers, Underwriters Laboratories, International Brotherhood of Electrical Workers Local Unions 124, 606, 42 and 307, Ann Arbor Track Club, and Physical Therapy in Motion. Amazing individual and fundraising efforts included Team Schoeni, Team NJATC, Suzie Cantin, Jamie McDermott, and Keleigh Lee. For results, pictures or video: www.activeagainstals.org.



TEAM SCHOENI RUNS FOR COACH BOB

Team Schoeni, comprised of seven girls who were coached by Bob Schoeni, were determined to make a difference by raising money for ALS research. "Coach Bob is an amazing, wonderful person and we would love to help him," they wrote. They trained hard, ran fast, and raised over \$4,500!

BUHR PARK SWIMATHON

On July 10, sixty-one swimmers from the Buhr Park Sharks team swam a collective 94.7 miles to raise almost \$3,500 for ALS research. It was a fun morning, energized with sideline music and dancing. Thanks to the swimmers and their families, supporters and coaches!



*Join us at the
6th Annual
Family Field Day!*

**SUNDAY, SEPT. 29
1-5 PM
AT BURNS PARK**

RELAY RACES

SPORTS CLINICS (NEW)

THIS YEAR: GOLF!!

WORLD DANCE

YOGA

BOLLYFIT

FUN RAFFLE ITEMS

ANN ARBOR'S BEST
ROOT BEER FLOATS!

Bring a friend!

Ann Arbor
**ACTIVE
AGAINST
ALS**

RAISING FUNDS. RAISING HOPE.

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WWW.ACTIVEAGAINSTALS.ORG

*Active Against ALS
wins Bezonki Award!*

Active Against ALS was honored to receive a Bezonki Award, given out annually by the *Ann Arbor Chronicle*. The award recognizes individuals and organizations that positively impact the local community.

One Step Ahead

This amazing documentary about Bob and Gretchen's journey, Active Against ALS and the Channel Swim premiered in May 2013 on Detroit Public Television. We thank Palindrome Productions for donating hundreds of hours to make this extraordinary film. Watch it at: vimeo.com/palindromevideo/onestepahead

Family Field Day

Sunday, September 29 1-5 p.m.

Help us make this the best Family Field Day ever! Join us for a fun afternoon at Burns Park, and bring a friend. Games, music, raffle, free chair massages. There is something for everyone!

*Create Your Own
Fundraiser*

If you have an idea to raise funds for ALS research, we'd love to help you get your effort going. We have had bikers, runners, swimmers, and lemonade makers! Check out the great initiatives at <http://www.activeagainstals.org/events/create-your-own/>

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