

# Let's Go!

**ACTIVE  
AGAINST  
ALS**



ANN ARBOR NEWSLETTER  
SUMMER 2012



## A New Look

As you see in our newsletter, Ann Arbor Active Against ALS has a new look. A committee of board members, volunteers and consultants has been re-evaluating the marketing materials of Ann Arbor Active Against ALS. Thanks to a generous grant of nearly \$20,000 from the **James A. & Faith Knight Foundation**, we have worked with Q Ltd., an Ann Arbor-based marketing and communications company. Soon, we will go online with a newly designed website, and we are finalizing two brochures about the mission, activities and fund raising of Ann Arbor Active Against ALS.

We applied for a grant to support marketing because we believe that we are a unique grassroots, non-profit organization promoting fundraising, compassion, and active living in defiance of ALS. We wanted to ensure that we are communicating our message clearly and powerfully. Our aim in working with Q Ltd. was to improve our communications with members, volunteers and donors. We are hopeful that this work will help us continue to rally community support and raise funds for critical cure-based research.

We are grateful that the Knight Foundation specifically supports the development of local non-profits and that they believed in our marketing goals. This project, identified as a priority by our board a year ago, was made possible because of their generous support.

In the coming months, you will notice changes in our materials. The new website and brochures will be completed soon; we hope to have new t-shirts, water bottles, and other items at upcoming events. In addition, we will be approaching corporate sponsors to increase the support of Ann Arbor Active Against ALS. We welcome your feedback and your thoughts about potential local sponsors.

Ann Arbor  
**ACTIVE  
AGAINST  
ALS**



**WE ARE  
ACTIVE  
AGAINST  
ALS**

**JAMES A. & FAITH KNIGHT FOUNDATION**

**THANKS TO THE KNIGHT FOUNDATION  
FOR SUPPORTING THIS IMPORTANT WORK.**

We welcome your feedback on our new look.





## Donating to ALS Research

As of May 2012, Ann Arbor Active Against ALS has donated over \$110,000 to ALS research. We hope to donate another \$25,000 by the end of the summer. Our board strives to stay informed about ALS research that could lead to a cure or effective treatment as soon as possible. We request regular communications and reports from the labs we support, and we stay in close contact with the directors of these labs to ensure that they spend our dollars wisely. The following is an overview of how your donations have been used by our recipients:

### ALS Therapy Development Institute

Active Against ALS has provided funding to the ALS Therapy Development Institute (ALS-TDI), Cambridge MA, a non-profit biotech company whose sole mission is to find effective treatments for ALS. ALS-TDI tests a wide variety of drugs (both FDA approved and non-approved) which they believe may be effective in treating ALS in a mouse model, ultimately to assess the impact of the drug on disease progression and survival. Our funding has assisted ALS-TDI with the costs of these screenings (approximately \$150,000 for the initial screening of one drug). ALS-TDI currently has two drugs that are past the screening stage and into clinical trials – one in a human clinical trial and another, in collaboration with two major pharmaceutical companies, that they hope will be in human trials soon.

ALS-TDI - [als.net](http://als.net)

### University of Michigan Program for Neurology Research and Discovery

We have provided funding to the University of Michigan Program for Neurology Research and Discovery ([UM]NR&D). In particular, we provided seed money to test a technology to increase the efficiency of screening potential ALS drug treatments. Currently, [UM]NR&D led by Dr. Eva Feldman is working on a very exciting stem cell research program that is fully funded by other sources. We remain in close contact with Dr. Feldman in case opportunities arise to support this research.

([UM]PNRD) - [med.umich.edu/PNRD/index.html](http://med.umich.edu/PNRD/index.html)

### Don Cleveland and John Ravits

Most recently, Active Against ALS has partnered with the Robert Packard Center at Johns Hopkins University to support the research of Drs. Don Cleveland and John Ravits at the University of California, San Diego on a particular gene mutation relevant to ALS. In the fall of 2011, a new gene on chromosome 9 was identified; the gene, known as C9orf72, seems to play a significant role in the development of ALS, as well as in Frontotemporal Dementia, Alzheimers Disease, and possibly other neurological disorders. Active Against ALS helped to fund the one-year Cleveland/Ravits project to analyze the effects of C9orf72 on cell metabolism in order to understand how this gene mutation triggers ALS. Understanding this trigger will potentially lead to effective treatments for ALS.

Robert Packard Center - [www.alscenter.org](http://www.alscenter.org)

Ann Arbor Active Against ALS welcomes your questions, ideas or feedback on our donations to ALS research. Please contact us at [info@a2a3.org](mailto:info@a2a3.org). We thank you for your support!





# Bon Voyage ALS!



## A BEER AND WINE TASTING IN SUPPORT OF THE CHANNEL FOR ALS SWIM TEAM

**Thursday, July 12, 2012, 6:00 p.m. – 10:00 p.m.**  
**Cobblestone Farm \$75/person \$125/two people**

They head to the pool early in the morning, or late in the evening. They have been swimming up to 15 miles per week, cross-training, and have recently added cold water open lake swims in rain or shine. For two years, these six women have been training to swim a 42-mile relay across the English Channel and back. They hope to set a new world record during this once in a lifetime event, and their preparation has required determination and tenacity.

The Team is ready for temperatures as low as 59°, for all night swimming, jelly-fish and large ships. What they were not prepared for, however, was the challenge of a teammate being diagnosed with breast cancer. Amanda Mercer, Team Captain and A2A3 Board Member, got the bad news in March 2012. Amanda has been training through her chemotherapy treatments, and she is determined to swim with the Team this July. Her diagnosis of breast cancer and the effective treatments available have made her even more resolute about the importance of fundraising for ALS research. Amanda wants those diagnosed with ALS to have the same hope for treatment and a cure that she has.

Please join us to celebrate and cheer on these amazing athletes. We are wishing them luck with a send-off event, Bon Voyage ALS!, the week before they leave for London. Enjoy delicious food, live music, a hope raffle and live auction. This will be a celebratory evening to remember!



*You can be a  
part of the Channel  
for ALS event!*

- Read, see photos and watch a video in an excellent Detroit Free Press article by Michael Rosenberg. <http://www.freep.com/article/20110916/COL22/109160451/Michael-Rosenberg-Six-Michigan-women-plan-swim-English-Channel-raise-120-000-ALS>
- Help us recruit swim and track teams to participate in the virtual crossing 50/50 fundraiser. Sign up at [www.channelforals.org](http://www.channelforals.org)
- Make a donation.
- Help us find corporate sponsors. Email [amanda@a2a3.org](mailto:amanda@a2a3.org) if you can help.
- Host a fundraising party.
- Buy Kento ALS, the English Channel game app, by Five Lakes Studio.



# Supporting the Teams with Their Own Swims

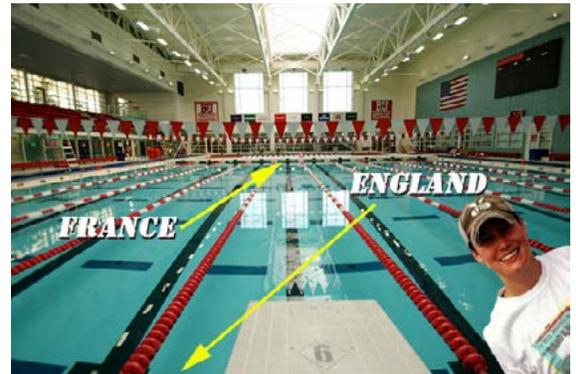
## Susan Rice

Susan Rice, from Jamaica Plain, Massachusetts, is NOT a water person. As a matter of fact, after struggling through a rough swim during her first triathlon, she promised herself she would “never ever swim again.” She was afraid of fish, boats, waves, and water itself. This year, to show solidarity with the Channel for ALS Team, she got over that fear!

Over the course of 8 weeks, Susan swam 21 miles (that is 676 laps of an Olympic-sized pool). Through this virtual crossing of the English Channel, she raised approximately \$2,100 for ALS research. Susan has always been active, and she was determined to put her healthy body to good work.

When Susan came across the Channel for ALS Team’s website, she could not stop thinking about the challenge of the virtual swim. A life-long sports fan, Susan was familiar with Lou Gehrig’s disease. ALS took on new meaning, however, when she met Walter Bentson, a regular at the Milkyway Lounge where Susan works. “Walter Bentson is one of the most amazing people you could ever meet,” Susan says, “and his family has become like a second family to all of us at the Milkyway.” Walter, a former college athlete and an umpire for D-1 college baseball, was diagnosed with ALS in 1990. He is active in his own fundraising efforts for ALS, especially through 100 Innings of Baseball in Boston, and the Kick UR ALS soccer marathon.

Susan swam for Walter and does not regret a second of her time in the water. “I’ve raised money for a great cause that is now close to my heart, and I’ve done so by enjoying the health that I am lucky enough to have.” Susan was thoughtful about the meaning of her swim. “Throughout the crossing, with each mile, I was reminded that not everyone is lucky enough to have a healthy body. We should never take our lives for granted.”



## Hannah Aronow

Hannah Aronow was first on Bob Schoeni’s soccer team in Kindergarten. Seven years later, she is preparing for her Bat Mitzvah, and Ann Arbor Active Against ALS came to mind. Preparing for this milestone includes doing a mitzvah project, a “good deed.” For her mitzvah project, Hannah decided to swim and raise money to help find a cure for ALS.

Inspired by the six women crossing the Channel, Hannah decided to join them in their effort. She realized she couldn’t actually make it to the Channel with them, but she set her mind to doing the virtual crossing. She has set her mind to swimming the full 21 miles as a show of her commitment to “Tikkun Olam” (repairing the world). She hopes to raise \$2,100, and also to mark a beginning of her work for charitable causes. Visit her fundraising page online - <http://www.a2a3.org/hannah-aronows-bat-mitzvah-swim-for-als/>



# Thank You

Thank you to everyone who has donated, volunteered, come to an event, or planned an event of your own! We have now donated over \$110,000 to ALS research!!! What started out as an effort to support one person and family has grown into a community of people who are ACTIVELY doing something together to defy ALS in the name of the many who have been impacted by this debilitating disease.



## BURNS PARK RUN 2012

It was another great Burns Park Run this year! Thanks to all the runners who donated and raised funds for ALS research, totaling almost \$1,000. We appreciate you!

## GARAGE SALE

Thank you to Ellen Katz and Jackie Dalton and their many helpers for a terrific garage sale! Some were happy to clean out basements, others were thrilled to find great buys - and we raised almost \$1,000 for ALS research.



## TWINKIE RUN

Eat your Twinkies and run! Over 250 runners and walkers participated in the 3rd Annual Twinkie Run on April 1st at Gallup Park. Many thanks to our generous sponsors, volunteers and participants! See you on April 1st next year, and don't forget the fun home-made Twinkie contest! To find results or to see photos and video, go to [www.a2a3.org](http://www.a2a3.org).



## PIZZA HOUSE and PHI DELTA THETA

Thank you to Pizza House and Phi Delta Theta for their spring fund-raiser. We appreciate the on-going support of Pizza House, a true community-based business!



## 4th ANNUAL BOX CAR DERBY

The 4th Annual Box Car Derby on March 24th featured new ramps, a new starting mechanism and newly-designed box cars. Kids of all ages had fun zooming down the hill, cheered on by Phi Delta Theta students! A big thank you to **AutoTrader** for their generous sponsorship this year. And thank you to the great fraternity brothers at Phi Delta Theta who make this race possible!

## VIRTUAL CROSSING PARTICIPANTS

Thank you to our Virtual Swimmers of the English Channel. Congratulations to Michael Winkleman, Tracy Janevic, and Susan Rice who each swam 21 miles! And best of luck to the other swimmers who are getting in their laps (1,478 of them!).



## TAPPAN MIDDLE SCHOOL ENOUGH! CLUB

Many thanks to the inspiring students of Tappan Middle School's Enough! Club. They set a goal of raising \$2,000 for ALS research this year - and they surpassed that goal! Through awareness and fundraising activities (including a Vow of Silence Day, a Water Week and a car wash/bake sale), they raised \$2,500. Congratulations to a group of students who understand that they can make a difference in the world.

## GOLDFISH SWIM SCHOOL

Swimmers of all ages came to the Goldfish Swim School on a Friday evening in May to raise money in honor of the English Channel Team. Thanks to the Swim School and to all of the great swimmers who came.

## Events at a Glance

**BUHR PARK SHARKS SWIMATHON**  
TUES., JULY 10

**BON VOYAGE ALS!**  
THURS., JULY 12

**ENGLISH CHANNEL SWIM**  
JULY 25 - 31

**2ND ANNUAL ELECTRIC BOLT 5K**  
SUN., JULY 29

**5TH ANNUAL FAMILY FIELD DAY**  
SUN., SEPTEMBER 30

## Don't Miss Out!

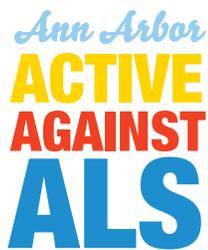
Subscribe to our events calendar to get notifications of A2A3 events for your google or apple calendar. To sign up, visit

[www.a2a3.org](http://www.a2a3.org)

*Ann Arbor*  
**ACTIVE  
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RAISING FUNDS. RAISING HOPE.

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info@a2a3.org



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Ann Arbor, MI 48104

*5th Annual  
Family Field Day*

Mark your calendars! The 5th annual Family Field Day is Sunday, September 30th from 1:00 – 5:00. We are planning for a great afternoon for kids and adults. Registration coming soon.

*English Channel  
Swim*

You are invited to Bon Voyage ALS!, a send-off event to support our English Channel Swimmers. Thursday, July 12, Cobblestone Farm. Register, donate or sponsor online, [a2a3.wufoo.com/forms/bon-voyage-als](http://a2a3.wufoo.com/forms/bon-voyage-als)

*Buhr Park Sharks  
Swimathon*

Thanks to the amazing swimmers of the Buhr Park Sharks Swim Team. On Tuesday July 10th they will swim hundreds of laps to support ALS research.

*2nd Annual  
Electric Bolt 5K*

Join us for a 5K through Gallup Park! Great prizes, great people, great cause. Register online now, [a2a3.wufoo.com/forms/r7x1p5](http://a2a3.wufoo.com/forms/r7x1p5)

WWW.A2A3.ORG