

Let's Go!

**ACTIVE
AGAINST
ALS**



ANN ARBOR NEWSLETTER
SPRING 2018



From a kitchen table to \$500K+ raised

Celebrating 10 years of building community and surpassing expectations

It's bittersweet to mark the 10th anniversary of Active Against ALS. The real celebration will come when fundraising for a treatment and a cure is no longer necessary. And yet here we are, profoundly grateful for our accomplishments and the compassionate community we have forged in the past ten years.

When we sat around a kitchen table in the summer of 2008—a group of friends and colleagues who had just learned of Bob's devastating diagnosis, desperate to do something—we never imagined what would be possible. Since then, together with YOU, we have raised over half a million dollars for cutting-edge ALS research. Also together, we have been ACTIVE in the fight against ALS, whether walking, run-

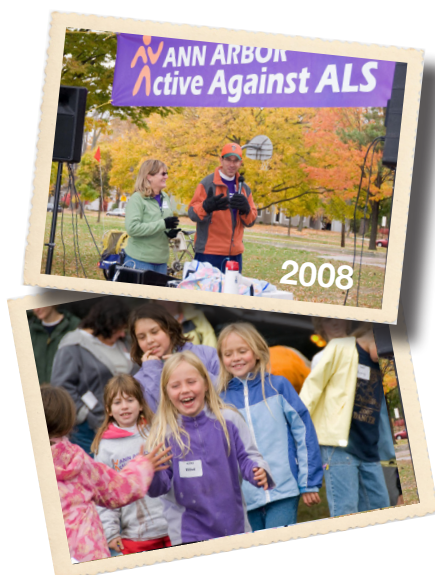
ning, swimming, cycling, dancing, racing box cars, selling lemonade, or cheering.

We are grateful that our grassroots efforts have grown into a non-profit organization that prioritizes two fundamental ideas: the crucial role of compassion and the importance of engaging young people. By building a passionate community and encouraging youth of all ages to experience their power to make a difference, Active Against ALS has a ripple effect. Children who were very young when we began this journey, some not even in school, are now volunteering on their own at events and raising awareness in classrooms and on their college campuses. They understand the power of coming together to find joy in the face of profound challenges, and to insist on doing what can be done.

Ten years later, we are also grateful that Bob's health has not deteriorated

as quickly as it may have. Both his and Gretchen's inspiring, positive spirit helps fuel the energy of our efforts. At the same time, we have encountered many wonderful people who were battling ALS and are no longer with us. We hope, through our ongoing efforts, to honor their lives and their families. We will persevere for as long as it takes to discover a medical response, and to this end, through our 10-year anniversary campaign, we seek to continue laying the groundwork for sustainability. We know that a solid infrastructure is crucial for continuing this important work.

We are grateful for you, our stalwart supporters and volunteers, and we believe that the good times we share and the critical funds we raise are the best way to defy this terrible disease. Thank you for being our partners!



Come to our 10-Year Anniversary Gala!

You are cordially invited to join us on November 10 at the Travis Pointe Country Club for our 10-Year Anniversary Gala event as we reflect on a decade of memories and accomplishments and renew our commitment to moving forward with continued resolve into the future. More details coming soon!

FUNDING RESEARCH. BUILDING COMMUNITY

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2008 - 2018

10



Supporter Spotlight



Jerri Champlin (standing, in pink, second from the right) poses with colleagues at the Electric Bolt in 2016.

‘Electric’ Supporter Jerri Champlin

We are thrilled to shine the spotlight on one of our longtime supporters. Jerri Champlin, who hails from Montana, has traveled to Ann Arbor since 2009 as part of the Electrical Training Alliance (ETA) of the National Electrical Contractors Association (NECA) to participate in their annual National Training Institute (NTI) conference held at the U-M. NTI participants have generously chosen to support Active Against ALS’ Electric Bolt 5K/8K Run when they’re in Ann Arbor each summer.

“I was inspired to get involved in the Electric Bolt after a childhood friend who had ALS passed away. A year later, my NECA chapter president’s sister-in-law was diagnosed with ALS and sadly lost her battle as well. I am devoted to raising funds in both their memories,” Jerri said.

Last summer, she visited Dr. Sami Barmada’s U-M laboratory, and was impressed by the amazing research he and his team are doing.

Electric Bolt organizer Joel Dalton said, “Because of her enthusiasm, ‘Team Jerri’ has raised thousands of dollars each year, easily out-raising all other electrician groups and usually surpassing all other race donors combined.”

Jerri grew up in Salinas, Calif. She earned a B.S. in Business Administration (Industrial Relations) from California State University Fresno in 1981. Jerri and husband Rich, a retired high school agriculture teacher, reside in Dillon, Montana.

Jerri has been with NECA for 30 years, and as the current Executive Manager of the Monterey Bay chapter represents electrical contractors in labor relations issues related to their partners in the electrical construction industry. She is also involved in the electrical apprenticeship program and serves on the NTI Advisory Committee for the ETA. Jerri is an inspiring example of how one person can make a difference in our Active Against ALS community. We profoundly appreciate her support and generosity!

Donor Update: Identifying Research Awards

On the recommendation of our Scientific Advisory Board (SAB), Active Against ALS initiated a new process for identifying promising ALS research we can support. In December, we issued a Request for Applications (RFA) to scientists who are early in their careers, have a primary interest in ALS research, and are motivated to find potential paths for treatments. Within a short time frame, we were thrilled to receive several promising proposals. After carefully reviewing them, the SAB forwarded

their recommendations for funding to our board for final approval. We are pleased to announce funding to two promising researchers: Sami Barmada M.D. and Asim Beg Ph.D. We will fund each researcher \$50,000/year for up to two years. Award recipients will be asked to submit a progress report after the first year to determine funding for year two. Thank you to the distinguished scientists on our SAB for their guidance: Robert H. Brown, JR., M.D., DPhil; Brian C. Callaghan, M.D.; Gerald D. Fischbach, M.D.; Aaron Gitler, Ph.D.; and John K. Kim, Ph.D. Their work ensures that the contributions we raise support the most promising ALS research.





Thank You



BARN PARTY FOR ALS

Over 160 adults, children and honored guests attended our Barn Party for ALS and helped kick-off our 10th anniversary year! Everyone enjoyed great food, beverages, and dancing in the spirit of being Active against ALS. We raised more than \$7,500 to donate to research labs aggressively seeking a cure or effective treatment for ALS. We acknowledge and thank our generous sponsors: **Shutterbooth** (Silver), **Chela's** (Bronze), **Old National Bank** (Copper), **University Lending Group** (Copper), Brooks Painting (Copper), **Barb Young - State Farm** (Copper). Additional, wonderful donors included: Calder Dairy, North Peak Brewing Company, Meijer, Dexter Cider Mill, Emma & Patricia Silverman, Morgan & York, Busch's-Main St., Hometown Pharmacy and Stadium Market Thanks also to our generous in-kind silent auction and raffle donors: Barb Young-State Farm, Crystal Mountain, Motawi Tileworks, POP! Designs & Creations, Sandy Kreger Glassworks, Sea Glass Fine Art, Silk Thumb Florist, Bebe's Nails & Spa, Applied Fitness Solutions, Body Conscious Massage, Goldfish Swim School, Hannah Rose, Kin Movement, Miles of Golf, Fit To Go With Molly, Relax Station, AA Civic Theater, Argus Farm Stop, Barry Bagels, Brecon Grille, Cardamom, Carlyle Grill, Quality 16, Cherry Republic, Common Grill, Purple Rose, Cottage Inn, Croswell Theater, Emagine Movie Theater, Fraser's Pub, Great Harvest, University Musical Society, Lucky's Market, Mac's Acadian Seafood Shack, Michigan Theater, Susan Meister Quilts, Nicola's Books, Pacific Rim by Kana, Paesano Restaurant, Salt Springs Brewery, Smokehouse 52 BBQ, Spencer's, Trader Joe's, Wines for Humanity, Wolverine Tap Room, Zingerman's Roadhouse, Zola Bistro, Pacernick Pops, Learning Express and Target. A shout out to all our dedicated volunteers who helped make the Barn Party for ALS such a fun and successful event. See photos of the Barn Party [here](#).

TO EVERYONE WHO HAS DONATED, VOLUNTEERED, OR SPONSORED AN EVENT OR PLANNED AN EVENT OF YOUR OWN. WE HAVE NOW RAISED MORE THAN **\$500,000** FOR ALS RESEARCH!



RIVALRY RIDE

Nearly 40 riders pedaled to defeat ALS in the 68-mile ride from Spartan Stadium to The Big House on game day. A rainy start gave way to beautiful, breezy weather. We are thrilled so many new riders joined us including virtual riders and those who bicycled the week before! Thanks to all the riders and donors we raised nearly \$20,000! A shout out to Stacey Johns for designing our new logo. Thanks to Beth Sugerman, our sag wagon driver, and Ben Stidham and Stephen Meister, our Twitter-car drivers, who supported our ability to live-tweet sections of the ride in honor or in memory of someone with ALS. Kudos to the Knut Hill family and Denise and Ryan Murphy who set up lunch at the park in Stockbridge, and the Stockbridge Subway for accommodating us. Appreciation to the Dalton family for hosting the post-ride tailgate potluck. Kudos to Pioneer Students Active Against ALS and Michigan Students Active Against ALS for helping to publicize the ride. Please contact us at a2a3rivalryride@gmail.com if you are interested in riding with us to Spartan Stadium on October 20, 2018. See photos from the ride [here](#).



GIVING TUESDAY AND YEAR-END DONATIONS

We are grateful for the generous responses to our second Giving Tuesday Appeal on November 28, and our annual End of Year Appeal. These donations total over \$4,345 that will go directly towards ALS research.

Events at a Glance

10TH ANNUAL BOXCAR DERBY

Saturday, April 8
1:00-4:00 p.m.

TWINKIE RUN

Saturday, April 22

ALS DAY IN A2

Thursday, May 10

8TH ANNUAL ELECTRIC BOLT

Sunday, July 29

SAVE THE DATE! 10-Year Anniversary Gala

Saturday, November 10

Ann Arbor ACTIVE AGAINST ALS

RAISING FUNDS. RAISING HOPE.

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Box Car Derby

Sunday, April 8/1-4 p.m.

Race with Phi Delta Theta Brothers near The Big House (Keech Ave). Ages 5 and up. Classic Boxcars for kids; Big Boxcars for high school, college, and adults. Information [here](#). Register [here](#).

Twinkie Run

Saturday, April 22

6:30-7:59 a.m. race number pick-up, 8 a.m. race start. **Note date change due to the Easter holiday.** Custom finisher medals for every participant! Twinkies and other post-race goodies! Click [here](#) for details and registration.

May is ALS Awareness Month

Ann Arbor Mayor Christopher Taylor has proclaimed **May 10th** ALS Awareness Day. Lend your voice to the fight against ALS to help bring awareness and understanding of this devastating disease.

8th Annual Electric Bolt

Sunday, July 29

Run along the beautiful Huron River and finish in the heart of Kerrytown. More info/register [here](#).

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