

Let's Go!

**ACTIVE
AGAINST
ALS**



ANN ARBOR NEWSLETTER
SPRING 2019



Gala Caps Yearlong Effort

Our 10-year anniversary campaign culminated with the Gala, where we celebrated a decade of inspirational events and accomplishments.

We were thrilled and honored to host 185 guests at our 10-Year Anniversary Gala on November 10, 2018 at Travis Pointe Country Club – the capstone event to our Ten-Year Anniversary Campaign.

The talented Community High School Jazz Combo entertained guests as they enjoyed hors d'oeuvres. Afterward, guests were seated in the dining room for the evening's program. Our emcee and friend, Milan Karol, formerly of The Robert Packard Center for ALS Research at Johns Hopkins, welcomed attendees and led a spirited trivia game designed to bring tablemates together while learning more about our mission. Guests then enjoyed a video highlighting a decade of events and accomplishments.

Following dinner, board chair Michael Meister spoke about his family's personal experiences with ALS and how much the work and support of our caring community of Active Against ALS has meant to him and so many others. He also shared a brief overview of the organization and thanked all who have made our accomplishments possible. He concluded with an exciting announcement that we met our anniversary goal to raise \$125,000! We are thrilled to share that our Gala raised **\$20,303** and with Giving Tuesday and other end-of-year donations, our campaign total has reached **\$195,000!**

A special moment of the evening was honoring Bob Schoeni and Suzanne Ross, our founding board member and first board chair, who passed away in September (see page 2). Bob and the Ross family were presented with plaques designating our two annual research awards: the Robert F. Schoeni Award and the Suzanne Hiyama Ross Award. Guests then viewed a heartwarming video tribute to Suzanne.

(Cont'd)

Looking for new board members

Profound gratitude to our dedicated board members who are stepping down this year: **Joel Dalton, Elizabeth DeRose, Knut Hill, Stacey Johns, Susan Miller and Sara Robins**. Their service and contributions to our organization has been invaluable. They remain committed to supporting our mission or volunteering in various roles. We are appreciative of **Alicia Frenette** for her years of service as our bookkeeper. The loss of our beloved Suzanne Ross created a void in our organization on multiple levels, especially in her role as our first paid administrator. Our current chair, **Michael Meister**, has agreed to step down from the board to accept a temporary appointment as our administrator/bookkeeper, and **Sara Robins** will continue to support the organization by managing our donor database. The board will officially vote in officers at our annual meeting on March 11. As we move forward with renewed commitment and enthusiasm during this time of change and transition we are reaching out to identify individuals who might be interested in serving on our board. If you or someone you know is interested in joining our dynamic leadership team, please don't hesitate to contact **Gayle Rosen**.



Box Car Derby Fans: After a decade of greasing the wheels for ALS research, we are taking a brief hiatus to re-tool the event. While we will not run the derby in 2019, we hope to drop the green flag again in the Spring of 2020! Since 2008, you've helped us raise nearly **\$75,000!** Way to go! Please contact Knut (knuthill@yahoo.com) with questions. Thank you, your Boxcar Derby co-hosts: Active Against ALS and Phi Delta Theta-UM.

Far right: Amy Mayer and Kristin McGuire. Middle: Sandy Kreger and Kevin Ross. Right: Bob Schoeni and Dr. Lu.





Remembering Suzanne Ross

“To put it simply, nothing is the same without her.”



In September, we said a heartbroken goodbye to our beloved friend and long-term Active Against ALS member, Suzanne Ross, who died at home after living valiantly with an advanced cancer diagnosis. Suzanne left this world in the same way that she lived in it;

surrounded by love, and full of passion, humor, a fighting spirit, and an ingrained sense of generosity. She has been at the heart of our grass-roots effort since the very beginning – as a founding board member, our first chair (2008-2013), and most recently, with support from the James A. and Faith Knight Foundation, our first official paid staff person. To put it simply, nothing is the same without her.

Suzanne was a native Michigander. She was born in Royal Oak in January 1963 to Grace and Paula Hiyama. In 1985, she graduated from Kalamazoo College, and then earned her master's degree in Social Work from the University of Michigan in 1987. She and Kevin, her husband of over twenty-two years, settled in Ann Arbor in 1996 where they raised their two children, Katy and Cody. Suzanne was constantly connecting with people around her. She coached youth sports, volunteered at St. Andrew's Episcopal Church, and dedicated endless hours to local organizations in a variety of capacities, including serving for three years as President of the Pioneer Band Association. Katy and Cody like to joke that sometimes the best (or only) food in the house was what she'd prepared for a sick neighbor or a community potluck!

As our first board chair, Suzanne helped to shape the core commitments of Active Against ALS: compassion, community, and the belief that working together makes a difference. She led the way in empowering young people to get involved, eager for youth to experience first-hand the good that comes from taking action. As the person who reached out to newcomers and connected with people who had heard of our work, she had a natural way of making everyone feel valued and empowered.

Suzanne approached every endeavor with a can-do attitude and a spirit of joy and inclusiveness. She laughed with her whole body, and hugged with her whole heart. We miss her gift of photography, her voice of encouragement, and her healthy perspective about the important things in life. We are forever grateful that she shared herself and her family with us: Kevin has been our box-car builder guru, and Katy and Cody grew up participating in, helping at, and even organizing their own Active Against ALS events. Her spirit lives on through them.

The world has lost a beautiful person who was dedicated to a life of service. Ever a giver, Suzanne's last act was to donate her corneas to Eversight for sight-recovery surgery. It is our desire to honor Suzanne's legacy, and we are thus determined with more passion than ever to continue raising funds and awareness for ALS, and to continue putting into practice her ideals of community and engagement.



Suzanne with son Cody, daughter Katy, and husband Kevin.



Thank You



TEN-YEAR ANNIVERSARY GALA

Profound thanks to the guests, donors and the cadre of volunteers who made our 10-year anniversary Gala at Travis Pointe Country Club on November 10 a perfect evening. Thank you to our Honorary Committee: Jim Frenza, Mitchell Garner, Judy A. Johns, Hans Maier, Julie & Alex Roberts, Gretchen Spreitzer & Bob Schoeni, Helen & Jeff Starman, Eva Rosenwald & Christopher Taylor. We are grateful to our esteemed emcee Milan Karol and our dynamic guest speaker Ari Weinzwieg. Thanks to the Community High Jazz Combo who provided pre-dinner entertainment. Sincere appreciation to our Gala sponsors: Olympian level: Michael Johns Family; Champion level: [Bank of Ann Arbor](#), [Dr. Lu](#); Fan level: Daniel Halberstam & Ellen Katz, [Shutterbooth](#), Mary F. Sutton, Felecia Garcia, and the Weinstein/Pacernick Family. Thanks also to our In-Kind Donors: Jack's Hardware and [ZingTrain](#). Special thanks to Judy Johns for providing valet parking. We also appreciate our Raffle Prize Donors: Applied Fitness Solutions, Collected Works, Coval Fitness, Kathy Siler, Michigan Theater, Purple Rose Theater, Standard Bistro and Larder and Vie Fitness. Thanks to the individuals and local businesses who purchased advertising for the event program: Arbor Dog Day Care, Hometown Pharmacy, Anne Gilbert of Howard Hanna, The Michael Johns Family, Calder Dairy, Community Day Care, Dr. Lu's Nourishing Life, Team Rehabilitation, The Mix Studio, The Purple Rose, Bank of Ann Arbor, Encore Studio Hebrew Day School, Law Offices of Conlin, McKenney & Philbrick, P.C.; Katz/Halberstam Family, Shuterbooth, Helping Hands Physical Therapy, Shan Dog Training, Morgan & York, Weinstein/Pacernick Family, Felecia Garcia, Monahan's Seafood Market, Stadium Market, Marge Sutton, Final Round. Kudos to the helpful staff at Travis Pointe. A debt of gratitude to our Gala planning committee: Elizabeth Derose, Kristen Freshley, Anne Gilbert, Stacey Johns, Susan R. Miller, Gayle Rosen, Kathy Siler, Katherine Walsh, Elisabeth Weinstein. Special thanks to Stacey Johns who inspired and shepherded our "Reflections and Memories" display. Our deepest gratitude to Knut Hill and Bob Schoeni for producing the incredible videos. Additional thanks to Kristen Freshley who designed the Gala invitations and programs, and volunteered as our official photographer for the memorable occasion.

TO EVERYONE WHO HAS DONATED, VOLUNTEERED, OR SPONSORED AN EVENT OR PLANNED AN EVENT OF YOUR OWN. WE HAVE NOW DONATED MORE THAN **\$555,500** FOR ALS RESEARCH!



FOLLOW THE BOUNCING BALL

Lleyton selected Active Against ALS as the recipient of his winnings from a local Charity Ping Pong Tournament, and he won! Congratulations Lleyton and THANK YOU!! Your table tennis skills and generous spirit are inspiring.

RIVALRY RIDE

Nearly 20 riders pedaled to defeat ALS in the 68-mile ride from Spartan Stadium to The Big House on game day. A wild weather day with sun, rain, sleet and snow challenged participants! We appreciate all the cyclists, including a contingent from New Hampshire. Thanks also to Beth Sugerman, our sag wagon driver and Kathy Siler, who live-tweeted sections of the ride in honor or in memory of someone with ALS. Appreciation to Cheryl Sugerman and Shelly Webber who prepared and served the lunch at the park in Stockbridge. Riders and donors raised nearly **\$12,000**. Because so many folks want to attend the game, **this year we are riding on a Michigan bye weekend - September 14**. Join us! If interested, email a2a3rivalryride@gmail.com.

GIVING TUESDAY AND YEAR-END DONATIONS

We are grateful for the generous responses to our Giving Tuesday Appeal on November 27, and our annual End of Year Appeal. These donations totaled over **\$2,475**.



HOCKEY FUNDRAISER

On January 5, the Chelsea Masters Hockey Charity held a fundraising event at the Arctic Coliseum in Chelsea with proceeds designated for the Ann Arbor Rockets and Active Against ALS (in honor and memory of Suzanne Ross). Cody Ross played goalie for one of the games that night. On February 27 Kevin Ross and our board member Sara Robins were on hand at Vets Park to accept a check for **\$2,286 for ALS research**. Huge thanks to Chelsea Masters and Lonnie and Natalie Grantham for honoring Suzanne and our organization with this generous donation.

Events at a Glance

ANNUAL MEETING

Monday, March 11

TWINKIE RUN

Monday, April 1

MAY IS ALS MONTH

NUCLEATE BEER FEST

Saturday, June 1

9TH ANNUAL ELECTRIC BOLT

DATE TBD

Ann Arbor
**ACTIVE
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RAISING FUNDS. RAISING HOPE.

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WWW.ACTIVEAGAINSTALS.ORG

Twinkie Run

Monday, April 1

5 p.m. race number pick-up
6:30 p.m. race start

Custom finisher medals for every participant! Twinkies and other post-race goodies! Click [here](#) for details and registration.

*May is ALS
Awareness Month*

Lend your voice to the fight against ALS to help bring awareness and understanding of this devastating disease.

Nucleate Beer Fest

Saturday, June 1

Veterans Memorial Park.
More details coming soon!

*Seeking New Board
Members*

If interested or curious about joining our dynamic leadership team contact [Gayle Rosen](#) at gaylerosen5@gmail.com.

Ann Arbor
**ACTIVE
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2020 Shadford Road
Ann Arbor, MI 48104

Gala Recap

Cont'd from page 1

Ari Weinzweig, Zingerman's co-owner and founding partner, inspired the gathering with his heartfelt keynote address. He spoke eloquently about hope, the power of our beliefs, and the spirit of generosity. Ari's books echoing those themes were available for sale, and [ZingTrain](#) graciously donated a portion of the proceeds to Active Against ALS.

The evening concluded by announcing raffle prize winners -- drawn from tickets submitted by participants at multiple events throughout our anniversary year.

Words fail to capture the spirit of community and caring that filled the elegant ballroom that evening. We profoundly thank everyone who joined us, as well as our honorary committee, sponsors and advertisers. We are truly grateful for your support and could not have reached our fundraising goal without YOU! We move into the future with renewed resolve to raise awareness and urgently needed research funds to find a cure for ALS.



Keynote speaker Ari Weinzweig and emcee Milan Karol.

Our Heart and History Displayed



A colorful, stained-glass commemorative art piece created by our longtime supporter, Sandy Kreger, graced the

Travis Pointe lobby during the Gala. The work depicts a tranquil landscape with a field, river, leafy trees and a sunrise symbolizing aspects of our organization.



A "Reflections and Memories of Friends and Family" table included photos and

personal stories, and a Dedication Tree adorned with 50 tags of photos, names and remembrances of loved ones affected by or lost to ALS. Guests were invited to add their own stories to the table and tree.



An archival collection: Photos, newsletters, proclamations and memorabilia significant to our history.

Framed, poster-sized photos capturing people and events from our ten-year history edged the elegant ballroom.



Gala Photos

