On February 23 more than 150 folks of all ages gathered at the Circ Bar in Ann Arbor for a fun evening of music and dancing. Active Against ALS created **Music to Warm the Soul** to celebrate life, and in particular the life of Suzanne Ross, whom we lost to cancer in 2018. She was a founding board member, first board chair and then our first administrator; Suzanne was truly the soul of Active Against ALS. With passion, smarts and a good bit of infectious laughter, she guided the organization through our first five years, building, with other committed board members, the foundations that have enabled us to grow and succeed in the years since.

Inspired by Suzanne’s love of music, Music to Warm the Soul was an event we know she would have loved: bringing community together for a memorable evening of music and dancing while raising awareness of and much-needed funds for ALS research. Attendees listened and danced to the music of local bands, including the Pioneer High School Jazz Band, Salmagundi, and Naked Ace. Others visited in the lounge while enjoying the quieter music of the cutler/fessler duo and J. Donahy. Ann Arbor mayor Christopher Taylor and his wife Eva Rosenwald emceed the evening, sharing remembrances about Suzanne, her connection to Active Against ALS and the broader community, especially her involvement with the Pioneer Band Association and other youth groups.

In losing Suzanne, we lost a dear friend and leader; however, our memories and commitment remain strong as we continue the multiple efforts she spearheaded. Through us her spirit and music will play on…
Why I Swim

By Nathan Adox in memory of Uncle Dave Adox

For the last four years, I have been raising money in memory of my Uncle Dave to help others who suffer from ALS. I swim as far as I can at the Active Against ALS Swim and Dive-athon held annually at our Huron Valley Swim Club. My Uncle Dave was always a lot of fun to be with; he loved to play and explore and laugh. We loved visiting him in New Jersey, meeting at our cottage in Canada, and having him visit us in Ann Arbor. Six years ago he was diagnosed with ALS. He was only 42 years old and super healthy – until ALS. The only thing I knew about ALS before Uncle Dave got it was that Lou Gehrig died from it. I thought only old people got it, and not anyone in my family. The next two years dramatically changed for our family. All of our trips and vacations were to visit Uncle Dave in New Jersey. We had parties, painted murals, made t-shirts, planted trees and made gardens celebrating life with Uncle Dave. He adopted a new mantra: “Until Further Notice, Celebrate Everything!” that we all live by now.

Our family had everything it needed, but once Uncle Dave got ALS, we needed SO MUCH HELP. That’s why I don’t stop swimming until my arms practically fall off to raise money for ALS research. I set huge goals that my parents thought were great, but very challenging. I started with 100 laps when I seven years old and last summer, when I was 10, I swam 300 laps (that’s a little over 4 miles). I swam them all for Uncle Dave. I have raised a total of approximately $8,300 for Active Against ALS. My friends and family in Ann Arbor donate, and so do Uncle Dave’s friends from all over the US and Canada. I can’t wait for the weather to warm up so I can get back into the pool this summer to raise more money in memory of Uncle Dave. “Until Further Notice, Celebrate Everything!” To learn more about ALS and how my Uncle Dave embraced ALS and fought to be able to donate his organs, please click here and here.

Swimathons: Making a Splash for ALS Research

Since 2010, local Ann Arbor youth swim teams have been raising money for Active Against ALS during annual swimathons. Over the years, youth swimathons have taken place by the Buhr Park Sharks, Huron Valley Swim Club, Liberty Athletic Club, and the Racquet Club of Ann Arbor.

In July 2012, six women from Ann Arbor inspired the world with a double crossing swim of the English Channel, in world-record time, to raise awareness of ALS and money for a cure. The determination and passion of Emily Kreger, Melissa Karjala, Susan Butcher, Bethany Williston, Jenny Jalet, and Amanda Mercer further inspired local youth swimmers. Channel swimmers Amanda Mercer and Jenny Jalet regularly dedicate their time to the swimathons. “It’s so inspiring to watch young athletes push themselves athletically and philanthropically,” said Amanda.

“Watching a tired swimmer’s face smile just after they have attained a goal they once thought unattainable is amazing,” added Jenny.

To date the swimathons have netted nearly $110K for ALS research! This summer, please consider sponsoring one of our energetic and determined youth swimmers – or swimming your own lengths in support of their efforts! Thank you!
TO EVERYONE WHO HAS DONATED, VOLUNTEERED, OR SPONSORED AN EVENT OR PLANNED AN EVENT OF YOUR OWN, WE HAVE NOW DONATED $486,731 FOR ALS RESEARCH!

MUSIC TO WARM THE SOUL

Heartfelt gratitude to everyone who attended or supported “Music to Warm the Soul” at The Circ Bar on February 23 to celebrate the life of Suzanne Ross and raise funds for ALS research. Though we don’t have the final numbers just yet, it looks like our fundraising efforts for this event will net around $7,000! We were honored to have Ann Arbor mayor Christopher Taylor and his wife Eva Rosenwald as emcees for the evening. Thanks to all our fabulous performers who donated their time: Naked Ace, Pioneer Jazz Band, Salmagundi, cutler-fessler duo and J Donahay.

Thanks also to our generous sponsors: Allen Batteau & Susan Miller, Jim & Jean Wedemeyer, Karen Hiyama, Bob Schoeni & Gretchen Spreitzer, Elaine Spreitzer & Elizabeth “Libby” Showalter, Ross Family, Shutterbooth, and the many individuals and businesses who purchased advertising for our program. A shout-out to our event program designer Julia Kartush.

HAPPY ANNIVERSARY, BOB & GRETCHEN!

December 30 was a day of celebration for the Schoeni family as Bob and Gretchen celebrated their 30th Wedding Anniversary. Thank you to members of our board and others in our community who celebrated the couple’s momentous occasion by donating to our organization in their honor.

LUCKY’S MARKET

We were saddened by the closing of Lucky’s Market in Ann Arbor. They partnered with us to raise awareness of ALS and over the years we were the designated beneficiaries of their “Bags for Change” community project to raise research funds. Thank you to Lucky’s for the many ways they supported the Ann Arbor community and Active Against ALS. They will be missed.

It’s official, thanks to you!

Thanks to more than a decade of your generous support we have outgrown our hometown roots of “Ann Arbor” Active Against ALS. We now fund researchers nationally, our board includes members beyond the Ann Arbor community, and our events attract interstate participation.

As we embrace the future, “Active Against ALS” reflects the more global approach to our mission and purpose. We believe every individual can have a global impact through his or her local community and we vow to continue our work to foster compassionate communities here in Ann Arbor. We encourage other communities, nationally, to follow our lead and join us under the umbrella of Active Against ALS.
Save a Tree!
Opt out of receiving the paper version of our semi-annual newsletter. Email kasiler@aol.com to be taken off our hard copy list and added to our email list for the electronic version.

Twinkie Run
Saturday, April 4 (note date!)  
7:45-8:59 a.m. race number pickup/9:00 a.m. RACE START  
Custom finisher medals for every participant! Twinkies and other post-race goodies! Click here for details and registration.

Shop to Fight ALS!
Show your support for Active Against ALS!! Visit our online store through Red Bubble to purchase a variety of items such as hoodies, tees, mugs, bags and more! All proceeds fund ALS research.

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

Active Against ALS
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