We are pleased to announce that this past October, at the recommendation of our Scientific Advisory Board, we awarded the Robert F. Schoeni Award for Research to Dr. Sami Barmada and his research team for their proposed work: Development of an anti-body based TDP-43 biomarker for in vivo PET imaging. Dr. Barmada’s team has received a one-year award of $50,000 for 2020-2021.

The overall goal of Dr. Barmada’s proposal is to establish a more accurate means of identifying ALS, using PET (positron emission tomography) imaging to highlight deposits of TDP-43, a protein that accumulates in the great majority of individuals with ALS. PET scans are similar to CT scans, but involve the use of a tracer that is injected just before imaging. PET scanning is used often for other conditions, but this would be the first application of this technology to ALS. However, many PET tracers are unable to cross from the blood (where the tracer is injected) into the brain and spinal cord (where ALS strikes). To address this problem, the team plans to attach its PET tracer (an antibody that recognizes the abnormal TDP43 protein) to another antibody that crosses the blood/brain barrier – in essence, one antibody piggybacks on another to solve the barrier issue. The hope is to use PET imaging to identify abnormal TDP-43 deposits in animal models of ALS, as well as tissue from ALS patients. The successful development of this imaging technique could then be used to accurately diagnose ALS and track its progression.

Sami Barmada team receives 2020-21 Robert F. Schoeni Award for Research

In the final days of 2020, the President signed the ALS Disability Insurance Access Act. This new law eliminates the five-month waiting period for individuals with Amyotrophic Lateral Sclerosis (ALS) before they can receive Social Security Disability benefits.

Help Wanted

Active Against ALS is looking for a part-time Administrator/Bookkeeper to work with our Board. If you are interested, please email us at info.activeagainstals@gmail.com.

Trivia Night

Join us for Trivia Game Night Sunday, March 14 7:00 pm
Cost: $25 per person
Overall winner will receive a $50 Zingerman’s mail order gift card. Winners of each round will receive Active Against ALS swag. Register to play or donate here.

The Barmada research team at U-M includes (from left to right): Dr. Colin Greineder (a specialist in the blood brain barrier and piggybacking methods), Dr. Ryan Pakula (a talented postdoctoral fellow), Dr. Peter Scott (an expert in PET imaging and tracers), and Dr. Peter Tessier (a pioneer in creating antibodies and other tracers).
Meet the Webers

The family’s advocacy efforts with Active Against ALS are personal.

Scott is a software developer at Duo Security and Gail has an interior design business. Daughter Malia, age 13, an 8th grader at Slauson Middle School, is a flutist, artist, dancer, writer, and bookworm. Tim, age 11, is a 5th grader at Lawton Elementary. He loves hanging out with his friends, playing soccer, video games, piano, biking, reading, art and being outdoors.

Scott was born and raised in Ann Arbor, but the couple’s path back here began in Bethlehem, Pa., where Gail is from, and where their love of music brought them together while playing in the Lehigh University orchestra. After college Gail and Scott moved to the Washington, D.C. area for work. Gail’s parents moved to Grand Rapids in 2003, and after several years vacationing in Michigan to visit their families, Scott and Gail happily settled in Ann Arbor in 2006.

The Webers’ favorite Active Against ALS events include the Electric Bolt, Twinkie Run, and Youth Swimathons at Huron Valley Swim Club. Last year they participated in the May ALS Awareness Campaign and the “Get Up and Go for ALS” event, in which they were one of the top fundraising teams!

Sadly, Gail’s family is no stranger to ALS. “I first learned about ALS when my Aunt Joyce was diagnosed in 1992. She died 1994. Then, in 2008 my cousin, Craig, was diagnosed at age 48 and it started to seem like more than a coincidence.” Soon after, Craig’s dad, Gail’s Uncle George, started exhibiting symptoms, and eventually he too was diagnosed with ALS along with FTD (Frontotemporal Dementia). Both Craig and George died in late 2010. Gail’s uncle Gene is living with a slowly progressing form of ALS that was initially misdiagnosed as Multiple Sclerosis.

Between their deaths, Gail’s mom, Julia, noticed a slight issue with her speech, and decided to visit the ALS Center at Mercy Health Saint Mary’s in Grand Rapids to see if they had any insights into what was looking more and more like familial ALS. Despite “passing” initial tests, an EMG showed that Julia was already fighting ALS

Over the next several years Julia’s symptoms progressed. Difficulty with speech, and then swallowing, required a feeding tube for nutrition. Frequent falls necessitated the use of a walker. Julia eventually needed a tracheostomy for help in breathing. Ultimately, mobility issues with her arms and hands diminished her ability to type. Thankfully, Julia had recorded her voice early on, and was able to use it with eye gaze technology until even that became too arduous. Gail’s mom died in December 2019 and her memorial service was held in February 2020, right before the beginning of the COVID pandemic.

Knowing they may carry the ALS (C9orf72) gene mutation and could develop ALS is incredibly stressful for many of Gail’s family members. Gail admits it affects decisions she makes regarding her career, her family, her lifestyle, and any long term plans about the future... “It’s something I think about every day -- I know that if I carry the mutation, the likelihood of ALS onset increases with each passing year.”

Gail believes ALS advocacy is urgently needed. “Advocacy is becoming more important as I realize that enlightening our representatives about the urgency of ALS can have a big effect on funding for research and patient access to experimental treatments.”

The Weber family is incredibly grateful for the fundraising, research, and advocacy efforts of Active Against ALS and other organizations. They are the key to giving people with familial and sporadic ALS, and their families, hope for the future.
Thank You to Board Members Stepping Down

Our deepest appreciation to Bob Durgy, Jenny Jalet, Michael Meister and Kat Walsh who are stepping down from the board. Their passion, commitment, and hard work has tremendously helped direct Active Against ALS. While their official roles are coming to an end, we are confident in their ongoing involvement and support!

Bob Durgy

Bob Durgy has dedicated his efforts to promoting and participating in the Rivalry Ride along with his family. Over the past several years “Team Durgy” has raised more than $20,000. Bob lost his brother Matt to ALS in 2016. A few years ago, Bob shared memories about his brother and his commitment to Active Against ALS. You can watch his heartfelt presentation here.

Jenny Jalet

In 2012, Jenny Jalet was one of the 6 women who completed a double crossing of the English Channel in world record time to increase awareness about ALS and raise funds for a cure. Watch their award nominated documentary: “Swimming Towards A Cure” here. Jenny and her family have enjoyed and supported many of our activities including early Family Field Days, the Twinkie Run, Barn Party for ALS, and our May ALS Awareness month. Team Jalet was one of the top fundraisers for our recent “Get up and Go for ALS” campaign. Jenny helps organize our Youth Swimathons and inspires many young people, including her children Martin and Winnie, to participate in and volunteer for our Huron Valley Swim Club event.

Michael Meister

Michael Meister served as treasurer in 2015 and board chair 2017-2019. Currently, Michael is serving as our part-time Administrator and Bookkeeper. Michael has lost 6 family members to ALS and has supported Active Against ALS since its founding. Along the way he instilled in his sons, Stephen and Matthew, the importance of volunteerism. The trio, along with other family members, has participated in or helped with Family Field Days, Big House Big Heart 5K, Youth Swimathons, Dexter/Ann Arbor Run, Boxcar Derby, Twinkie Run, Barn Party for ALS, ALS Awareness month, and the Rivalry Ride.

Kat Walsh

We have benefitted from the passion, dedication and theatrical creativity of Kat Walsh in ways too numerous to count. Her expertise in development and fundraising has inspired a fresh approach to community building and made us better agents for change. In 2017 Kat assigned a project for her U-M graduate students to design a development and fundraising plan for Active Against ALS, and invited members of the ALS community to hear the students' presentations. In 2020 she recorded a widely shared Zoom interview with two ALS researchers; most recently, Kat choreographed an inspiring virtual board retreat.

Events at a Glance

Virtual Annual Meeting

Wednesday, March 31
6:30 p.m.

Virtual Trivia Night Fundraiser

Sunday, March 14
7 p.m.

Click here for details.

Virtual Twinkie Run

Throughout month of April
Details available soon on social media and our website.

More thank yous

Despite the pandemic, a small but committed group of riders made the 65-mile bike ride from East Lansing to Ann Arbor for the annual Rivalry Ride. The event raised more than $3,300.

Many thanks to York for donating 10% of their sales proceeds from the September 2020 Ann Arbor Velo Club’s Winnewana biking event.

Thank you for all the donations we received from Amazon Smile, Giving Tuesday and our End of Year appeal. We are grateful to ALL of you for your support!
Virtual Annual Meeting
March 31, 6:30 p.m.
Join us as we welcome new board members, enjoy an informative panel discussion and hear from dedicated volunteers. More details available soon on our website.

Save a Tree!
Opt out of receiving the paper version of our newsletter. Email info.activeagainstals@gmail.com to be taken off our hard copy list and added to our email list for the electronic version.

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.

Connect with us
Find us on Facebook, Instagram and Twitter.