From Bob & Gretchen

Like you, it’s been a surreal several months of COVID-coping for us. During this time, Gretchen and the girls quickly transitioned to online teaching/learning – and the four of us negotiated shared Wi-Fi and workspaces to each get our work done. Bob quickly adapted to using Eyegaze to interface with the computer, which has been life changing - incredible technology. Our furry family members Marley and Lola were ‘in heaven’ having family members home all day every day. We’ve grieved the loss of our dear friend Graydon Krapohl. We’ve celebrated Maddie’s college graduation through Zoom. We try to remember it’s the little things that matter! The highlight has been shared meal-making and eating together each evening, which didn’t happen as often as we liked pre-COVID. None of us enjoys the social isolation that comes from trying to keep our family safe from the virus.

So we’ve resorted to walks with friends, zoom calls with family, and lots of email check-ins. Neighbors decorated their yards with well wishes for Maddie’s graduation. We organized a water balloon/fireworks celebration for the 4th of July. Bob hosted a socially distanced musical event to bring neighbors together to listen to a jazz combo on a beautiful summer evening. We visited with extended family on their patios. Maybe you have found other ways to be together, even at a distance! We’d love to learn from you!

What will the fall bring? Maddie will start the second term of her Master’s in Elementary Education at U-M. Sophie will be a junior at Tufts, taking hybrid classes, and missing the normal busy-ness of the fall field hockey season, which has been canceled. Bob and Gretchen will keep hoping for a successful vaccine and hoping to see more of you out and about (socially distanced of course). We hope you and your families stay safe and find ways to be active this fall.

A message from Gayle

Heartfelt thanks for your continued support during this challenging and unprecedented time. We hope you are staying safe.

While we were able to dance with you at Music to Warm the Soul in February, the pandemic prevented us from connecting with you at our annual meeting in March to share news from Dr. Peter Todd and Dr. Paul Valdmanis about their research, and to hear from some of our volunteers about why they volunteer. Our ALS Awareness campaign in May looked different, too, as we were unable to partner with restaurants and other local businesses. The community met the challenge with an incredible ACTIVE effort to spread awareness by displaying ALS FACTS yard signs, “Chalking your Walk,” and sharing ALS stories on social media.

As the inability to be active together caused us to cancel the Twinkie Run, the Electric Bolt and our youth swim-a-thons, we adapted to this changing reality by creating “Get Up and Go For ALS,” our first virtual fundraiser. We hope you were able to join us!

Suffice it to say, we miss seeing you in person and are eager to be active together as soon as we can do so safely. Until then, thank you for being part of our community and working with us to find a cure for ALS.

—Gayle Rosen, Board Chair, Active Against ALS
May ALS Awareness Campaign exceeds expectations!

When we were unable to partner with restaurants and other local businesses that were closed because of COVID-19, an overwhelming number of you volunteered to make or display ALS Fact yard signs. We quickly expanded the effort to include “Chalk Your Walk for ALS.” Signs and artful “chalked walks” popped up in Ann Arbor, Saline and Ypsilanti, and we received lots of photos of folks with their pets walking throughout area neighborhoods to support our efforts. People from as far away as Vermont and Canada also shared their ALS stories with us on social media. Even during this difficult and financially stressful time, our May ALS Awareness campaign donations totaled more than $5K. We are deeply grateful for your heartwarming support!

We asked you to ‘get up and go’ and you did!

The current environment has challenged us to be more innovative and creative with our fundraising efforts. We embraced that challenge and developed our first virtual fundraiser: ‘Get Up and Go for ALS’. During the month of August, participants were encouraged to choose any activity they wanted to complete such as running, swimming, bouncing a basketball, rock climbing, or any other activity, while helping us raise funds for ALS research. At least a dozen teams stepped up to join our efforts and helped us raise more than $5,000, with several days left to go. Many thanks to all who helped us promote this event and to our participants and donors!
‘ZOOMING’ WITH RESEARCHERS

Profound thanks to our board member Kat Walsh and our current research awardees Dr. Paul Valdmanis, and Dr. Peter Todd, for engaging in a 20-minute Zoom interview in June to share about their work toward treatment and a cure for ALS. During the wide-ranging interview, Kat asked the researchers to describe how they became interested in this field; the importance of their research to better understanding hereditary and other forms of ALS; and how their findings inform our understanding of ALS and neurodegenerative disorders in general. Kat asked about their most exciting discovery so far, and how their efforts have been impacted as a result of the coronavirus pandemic. The researchers also shared about the challenges of staying connected to people with ALS and striving to make their research inclusive to minorities, women and other groups often overlooked in clinical trials. They also weighed in on some of the treatments currently in FDA stage 2 trials, and recognized the urgency felt by patients and families to advance those trials as quickly and safely as possible. Both Dr. Valdmanis and Dr. Todd expressed their gratitude numerous times for the support of our organization. You can find a link to the interview on our website and we hope you will find time to give it a listen.

MAY ALS AWARENESS PARTNERS

Elayna Hickson and family (Ypsilanti), Vince Massey family, Ann Wells Steinhauser, Korrine Miller Palmer, Winnie Jalet and Jalet family, Jenny Gordon, Mike and Jennifer Collins, Pat and Greg Sovitch (Saline), Scott and Gail Bauer Weber family, Rosen/Sugerman family Knut Hill family, Stacy Johns and family, Susan Miller and Allen Batteau, Bob Schoeni family, Mike and Laura Stidham family, Community Day Care, Anne Gilbert, Kristin McGuire, Kevin Ross, David Lowenschuss, Elisabeth Weinstein and family, Mark and Cornelia Dunn family, Skip and Jennifer Heise family, Kirk and Susan Lignell family, Alan and Kathleen Matney family, Deb Good (Canada), Rebecca Begin Andrews family (Vermont), All About Ann Arbor (News/Media)...and ALL the “furry friends” who posed with ALS FACTS signs.

‘GET UP AND GO’ TEAMS & SUPPORTERS


The “Tickled Pink” winners of our May ALS Awareness drawing

Right: Elayna Hickson with daughter Avery (Ypsilanti)
Left: Scott Weber Family: Tim, Gail and Malia (Ann Arbor)

RIVALRY RIDE

Sunday, September 13

Please join us as we ride from Spartan Stadium to the Big House on September 13. This year, however, due to COVID-19, we will not be able to transport riders and their bikes to East Lansing, nor provide ride support with a lunch or SAG wagon. We encourage all who can to ride with us from Michigan State, or, if you are not able to do so, to ride 65 miles whenever, wherever you can—while continuing to raise funds to find a cure for ALS. Register here.

Thank You

TO EVERYONE WHO HAS DONATED, VOLUNTEERED, OR SPONSORED AN EVENT OR PLANNED AN EVENT OF YOUR OWN. WE HAVE NOW DONATED $787,000 FOR ALS RESEARCH!
**Active Against ALS**

Raising Funds. Raising Hope.

2232 S. Main Street, #323 • Ann Arbor, MI 48103
734.531.7959 • info.activeagainstals@gmail.com

**www.activeagainstals.org**

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**Rivalry Ride**

Sunday, September 13

Ride starts at Spartan Stadium and finishes in Arbor.

Register here.

**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.

**Save a Tree!**

Opt out of receiving the paper version of our semi-annual newsletter. Email Kathy at kasiler@aol.com to be taken off our hard copy list and added to our email list for the electronic version.

**Getting Social**

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