

Let's Go!

**ACTIVE
AGAINST
ALS**



ANN ARBOR NEWSLETTER
FALL 2016



Meet SAB member John Kim

Our Scientific Advisory Board (SAB) provides us with valuable insight and council on the most promising ALS research. In this issue we are delighted to shine the spotlight on SAB member John Kim, whose involvement we greatly appreciate.



Dr. John K. Kim grew up in South Korea and moved to the U.S. with his parents and three siblings when he was seven. He graduated from Yale, and earned his Ph.D. at UC-Davis before completing his postdoctoral training at Harvard Medical School.

Early on, John considered careers in music (as a classical violinist) as well as medicine, but research eventually won out. "My undergraduate research made me realize I wanted

to be a scientist," he explains. "I could discover things and be creative about solving problems. I also felt a deep connection with past scientists whose pioneering discoveries helped shaped what we know about our natural world today."

John and his wife Laurel moved to Ann Arbor in 2006 when he was offered a faculty position at the University of Michigan Life Sciences Institute. They soon discovered they had incredible neighbors. "When our neighbor Bob Schoeni was diagnosed with ALS and our neighbors banded together and founded Ann Arbor Active Against ALS, I marvelled at their resolve and spirit. I feel so lucky to have met them," he says.

While his family participated in many of our events, John eventually realized he could contribute in other meaningful ways since his research was tangentially related to some recent ALS research. With encouragement from his friend Dave Lowenschuss, John volunteered to serve on our Scientific Advisory Board in 2014.

Last summer, John accepted a faculty position at Johns Hopkins University where he continues his research in genetics, studying how small molecules called non-coding RNAs coordinate the expression of virtually every gene in our bodies.

"Supporting some of the great local scientists' work dovetails effectively with national ALS efforts," says John. "Some challenges in the immediate future are to better understand the mechanisms that lead to ALS, including the genetic causes and the underlying pathology. These efforts must go hand-in-hand with new drug screens and targeted therapies. Basic research is critical and the advent of next-generation research tools makes this a truly exciting and hopeful time to take on ALS."

Yeehaw!

A NEW Event!

We are excited to announce a fun new event!

The 2016 Barn Party for ALS

will be held on **Friday,**

November 18 from 6:00

– 10:00 p.m. at the

Washtenaw Farm Council

Grounds. There will be

square dancing and a DJ,

kids' raffle, silent auction,

photo booth, and food

and drinks. Tickets – in

advance/at door: Adults

\$25/\$30, includes one beer

or wine ticket; children

\$15/\$20. Register [here](#).



*Hope to see
y'all there!*



Reflections from Bob

Hello, Active Against ALS supporters!

Gretchen and I hope you had a fantastic summer. It's been a period of transitions for our family. In July we helped move Gretchen's parents from Bowling Green to Avon, Ohio. Leaving the home they designed and built over 40 years ago was certainly challenging, but there are lots of terrific memories for Gretchen's family. We found many treasures sifting through the boxes, including Elmer's 1955 army uniform in mint condition, a W2 of \$1200 he earned while in the military, and memorabilia from Gretchen and her sister Libby's childhood. Fortunately, Elaine and Elmer have found a wonderful new community very near to Libby and her sons, Max and Michael; helping this important life transition go much more smoothly than we ever imagined.



In August we took our oldest daughter, Maddie, to college in Maine for her freshman year. She is excited about the new adventure. Gretchen, Sophie, and I will miss her smiling face and cheery disposition, but we are happy she has found a school that we all think will be a good fit for her. Maddie has many wonderful experiences ahead. I feel very fortunate to experience this important transition with my family. July 29 marked the eighth anniversary of my diagnosis. Back in 2008 I certainly didn't think I would be here to share in this event. I am thankful for each and every day. Whatever transition your family is experiencing, we wish you all the best!



News from Johns Hopkins' 16th Annual ALS Symposium

In March, Susan Miller and Suzanne Ross accepted the **Robert Packard Center for ALS Research at Johns Hopkins University's** Partners in Collaboration Award. The award was presented during the center's **16th Annual ALS Research Symposium**, an annual event that brings together 180 scientists from more than 50 institutions to share their latest findings.

While there, Susan and Suzanne learned about a new initiative called **Answer ALS**. Described as the "single largest coordinated and collaborative effort to end ALS in the history of the disease," this effort brings together nearly two dozen research entities and 1,000 patients.

Sadly, just last month, one of the Packard Center's other award recipients, former Traveler's Insurance CEO **Jay Fishman**, succumbed to ALS. "Susan and I met Jay and his wife while in Baltimore," said Suzanne. "We were so saddened to hear of his passing."

Youth Philanthropy at Work



In May, two Board members attended the 2016 Fifth Grade Mini-Grant Reception sponsored by the Ann Arbor Area Community Foundation Youth Council to receive the year-long fundraising efforts of **Hebrew Day School's (HDS)** 5th grade Student Council. In the fall of 2015, HDS students applied for and received a \$100 mini-grant from the Youth Council to use as seed money to raise funds for a local nonprofit. Over the year, they learned about ALS and our organization, participated in our events and annual meeting, and visited Dr. Barmada's lab. They used their \$100 to hold food/water sales at HDS events and raised additional funds through an appeal to family and friends. We were truly astonished when they presented us with a check for **\$3,019.15!** "It was rewarding," said one student, "to see that the work we did went to help stop a disease." A BIG THANK YOU to the students for all their work and to their teacher, Carol Gannon, for guiding them in this amazing effort.



Thank You

TO EVERYONE WHO HAS DONATED, VOLUNTEERED, OR SPONSORED AN EVENT OR PLANNED AN EVENT OF YOUR OWN. WE HAVE NOW DONATED MORE THAN **\$400,000** TO ALS RESEARCH!



TWINKIE RUN

Nearly 500 participants, including teams [ISR](#) Runs for Bob and [U-M Relay For Life - College of Pharmacy](#), ran this unique race at Gallup Park. To see photos, click [here](#). Thank you to our generous Silver sponsors, [Bank of Ann Arbor](#) and [Blue Care Network of Michigan](#). Special thanks also to [The Local Bike Shop A2](#) and [Tortoise and Hare](#). We could not do it without your support as well as the support of our volunteers!

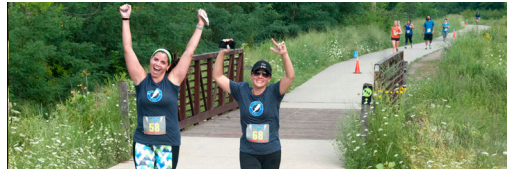


BOX CAR DERBY

Over 200 people came out to race and cheer for more than 45 teams. Thank you to the [Phi Delta Theta](#) Brothers, participants and volunteers. This was our most successful Box Car Derby yet! Thank you to our generous Gold sponsors, [Foley & Lardner](#), [Suburban of Ann Arbor](#), our wonderful Silver sponsors, [Hotels Unlimited](#), [Michigan Alpha Alumni Association](#), our awesome Bronze sponsor, [Michigan Lighting Systems](#), and our In-Kind sponsors, Biggby Coffee and AB Heller. Click [here](#) to see photos and [here](#) to see a highlights video!

DEXTER-A² RUN

Thank you to the Stidhams, Meisters, Lowenschusses, and Daltons for hydrating and cheering on runners!



ELECTRIC BOLT

Nearly 300 people ran in town and (new this year) 11 people ran remotely across 17 states and one other country. Overall, the race netted more than \$10,000. Thanks to our primary sponsors, the [Electrical Training Alliance](#) and the [American Technical Publishers](#), who make this picturesque race possible. Thanks also to: [Ann Arbor Track Club](#); [IBEW Local 639 San Luis Obispo](#); [National Electrical Contractors Association Monterey Bay](#); [Black Diesel Coffee](#); [Physical Therapy in Motion](#); and [Zingerman's](#). Many thanks to [Ann Arbor Running Company](#) for hosting packet pick up and helping promote the race. You can check out photos from the run [here](#) and the Argo Dam and Finish Line [here](#). For race results, click [here](#).



YOUTH SWIMATHONS

Over two weeks in mid-July, four incredible youth swimathons took place at local swim clubs. Thank you to the swimmers, divers, coaches, volunteers, and donors from [Buhr Park Sharks](#), [Huron Valley Swim Club](#), [Liberty Athletic Club](#), and [Racquet Club of Ann Arbor](#)! We had over 245 participants swim over 260 miles, and raised more than \$20,000 for ALS research!!! Hooray to such amazing, inspiring and ACTIVE young people!

Events at a Glance

LUCKY'S BAGS FOR CHANGE

Now thru November 5

5TH ANNUAL RIVALRY RIDE

Saturday, October 29

4TH ANNUAL BEERFEST

Saturday, October 29
(Tentative date)

BARN PARTY

Friday, November 18

Ann Arbor
**ACTIVE
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RAISING FUNDS. RAISING HOPE.

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WWW.ACTIVEAGAINSTALS.ORG

*Lucky's Bags for
Change* Now thru Nov. 5

Shop at Lucky's Market with your reusable bags and receive a wooden dime for each one used. Place the "dimes" in the Active Against ALS bin and we'll receive double your donation at the end of the quarter!

Beerfest

Tentative date: Sat., Oct. 29

Join us for the 4th Annual Beerfest! Come out for a FUN evening and raise your pints of local ales to support ALS research! Watch our website and Facebook page for more details.

Rivalry Ride
Saturday, October 29

Join our 5th annual Rivalry Ride on U-M vs MSU game day! This year the ride will be from the Big House to Spartan Stadium. Register [here](#).

Barn Party
Friday, November 18

Please join us at the Washenaw Farm Council Grounds for a fun night of square dancing, live DJ, kids' raffle, silent auction, and more! Register [here](#).

Ann Arbor
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