

SAVE THE DATE

JUNE 17, 2022

ROSS WHITNEY JACOBS FOUNDATION

83-0712698

Raising funds for research in progressive
neurological degenerative diseases



This Year's Outing:
JUNE 18, 2021

Total Proceeds Raised:	\$ 20,289
Total Costs for Event	\$ 8,051
Net Income from Event:	\$ 12,238

Funds to be sent to MICHIGAN MEDICINE \$11,500
SIX YEAR TOTAL RAISED FOR RESEARCH: **\$81,887**

123 golfers 45 sponsors

First Place Men's Team: Bill Henderson, Jeremy Kaleniecki, Larry Schiller, Ryan Markowitz at 13 under par

First Place Women's Team: Marie Baloga, Linda Efrudy, Karen Schickel, Joyce Swilley at 6 over par

First Place Mixed Team: Steven Hartunian, Sara Hartunian, Drew Bykowitz, Scott Strange at 7 under par

Highest Score or those who had the most fun award: The Stick Chicks: Mary Nowak, LeeAnne Hemberg, Sue Kloster, Dianne Stella at 18 over par

Closest to the Pin: Lauren Seng and Ellen Satterlee; Scott Kowalski and Jared Reid

Longest Drive: Sara Hartunian and Suzie Russell (second year in a row for both);
Todd Herzig and Jeremy Kaleniecki

Special thanks to **DAVE AUER** who ran the Dirt Bike Shoot Contest

Drivers with Range Card were won by: Tracy Karamon and Mark Martin

Rescue Clubs were won by: Marie Baloga and Jason Hartunian

We sincerely apologize that there was a mix up with the club providing a box lunch at the turn. We will get it right next year and hope you at least enjoyed the traditional hot dog at the turn.

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GOLF SCHOLARSHIPS PROVIDED BY
THE JUNE & WHITNEY KIMBLE
SCHOLARSHIP FUND

VERY SPECIAL THANKS TO:
Glen Oaks Golf Course,
Farmington Hills, Michigan
Golf Outing Pro <http://www.golfoutingpro.com>
The Development staff at
MICHIGAN MEDICINE:
Kirsten Petriches and Ann Wagar

Volunteers:
Lauren & Mark Seng
Ellen & Kyle Satterlee

THE GOLF COMMITTEE

Larry Jacobs
Bret Beaudoin
Jeremy Schnaidt
Mark Seng

Spencer Jacobs
Mike Wall
Keith O'Donnell
Ryan Gibson





The Jacobs Family's Mission: Answering Ataxia's Many Questions



Ross Jacobs

Nancy and Larry Jacobs' search for answers to their son Ross' increasing physical difficulties led them to the U-M Department of Neurology, where they worked with the experts in the Multidisciplinary Ataxia Clinic. The guidance they received was integral to understanding Ross' neurological condition, but many questions remained. What led to his ataxia and could it have been stopped or delayed?

Ataxia refers to a group of neurological diseases affecting coordination and balance. Symptoms include poor hand and eye coordination, speech problems, swallowing difficulties, and unsteady gait.

The Jacobses were dismayed to learn there was little funding available for clinical research on ataxia, meaning even the most promising ideas might never see the light of day. The large grants needed to advance scientific findings from the laboratory to the clinic are typically reserved for established projects, so new research is much harder to get off the ground. Government entities and foundations require significant amounts of pilot data before research can be considered for that level of funding, yet compiling data is expensive. The lack of new knowledge on ataxia frustrated Nancy. "We were very likely looking at something that could not even be accurately diagnosed until after death and surely, this was going to lead to his death."

It took three years to diagnose Ross, during which time his physical symptoms worsened due to his brain's steady deterioration. The type of ataxia he had, the sporadic fatal insomnia form of Creutzfeldt-Jakob disease, was not inherited and is extremely rare. Ross died in 2015 at the age of 31. In a final act of bravery, he donated his brain to the University of Michigan Brain Bank so it could be used to help researchers develop a better understanding of ataxia.

The Ross Jacobs Research Fund in Neurology

Devastated by Ross' illness and death, Nancy, Larry, and Spencer (Ross' brother) wanted to spare other families that kind of grief. "Ross was a light and a force that cannot be replaced. We want to help so, at the very least, maybe someone gets to keep their loved one longer and that someone's quality of life is improved. We learned a lot through those terrible years, but also saw firsthand how Michigan Medicine doctors and staff were willing to search, ask questions, and collaborate, while providing optimal palliative care. We believe that working with U-M's Ataxia Clinic is the best way to accomplish that goal and give hope to others."

The family's faith in U-M's Ataxia Clinic is well-founded. Now in its sixth year, the clinic provides patients with cutting-edge medical care, including access to physical therapy, speech therapy,

and social work specialists. It also leads the nation in studying the disturbances in cerebellar circuitry underlying ataxia. In 2016, to help answer ataxia's most pressing questions, the Jacobs family established the Ross Jacobs Research Fund in Neurology, grounded in the belief that solutions can be found. Ataxia research of any kind has the potential to impact numerous brain disorders, such as amyotrophic lateral sclerosis (ALS), Alzheimer's disease, and Creutzfeldt-Jakob disease and other forms of ataxia.

"What motivates us to raise funding for research? We watched our beautiful son, Ross Jacobs, deteriorate over a three-year period; the cause of which was unknowable. We searched for a reason; if we knew the reason, surely there would be a way to stop it." — Nancy Jacobs

Advancing Research from Every Angle

In the Department of Neurology, we are committed to addressing ataxia research from every angle. Uncovering the underlying mechanisms of ataxia will help us find better ways to diagnose, treat, and eventually cure these disorders.

Hank Paulson, M.D., Ph.D., the Lucile Groff Endowed Chair in Neurology for Alzheimer's Disease and Related Disorders, leads biomarker development in inherited ataxias. Peter Todd, M.D., Ph.D., the Bucky and Patti Harris Career Development Professor of Neurology, leads in research related to a newly discovered biochemical phenomenon in hereditary degenerative diseases. We are pursuing clinical exome sequencing and are actively engaged in identifying novel ataxia-causing genes, which might provide new pathways for therapeutic intervention. By publishing our findings on the successful use of such sequencing, we are guiding our patients and informing the field. For instance, we know now that clinical features alone cannot diagnose specific genetic forms of ataxia because there are more than 300 genetic causes that can have similar symptoms and signs.

Our goal is to secure funding for clinical trial research studying the efficacy of an identified drug combination in inherited ataxia. We hope to identify symptomatic and gene suppression strategies — and others — and move them from laboratory models to clinical trials. We are also working on identifying new genetic and biochemical pathways that might provide key insights as we develop therapeutic strategies for ataxias.

Supporting ataxia research is critical to expanding knowledge so we can advance better treatments while finding a cure. Gifts to the Ross Jacobs Research Fund in Neurology support these efforts while providing hope for families like the Jacobses.

If you are interested in supporting this fund or others in the Department of Neurology, please contact:

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