

RAF Newsletter Vol.4 October 2018

RAF Fundraising Updates



SAVE THE DATE

November 9th! Come join the Rochester Ataxia Foundation and friends at the First Annual Wine & Beer Tasting Event. We are partnering with A Gust of Sun Winery and Griff's Brewery located

at 5324 West Ridge Road in Spencerport, NY for an evening of fun that includes samplings of locally produced wine, beer, and music. Come out between the hours of 6 & 9 p.m. to support the RAF! For your listening pleasure, The Distribution Dawgs will be donating their time and talent for a great cause. You may purchase tickets from any board member, at the door, or advance sale tickets available here:

<https://www.eventbrite.com/e/wine-beer-tasting-tickets-51476206720>

UPCOMING FUNDRAISERS—SAVE THE DATES

Wine & Beer Tasting Nov. 9, 2018

ROC TheNov. 27, 2018

March Madness Day March 23, 2019

NAF conference March 29-30, 2019

Updates on past Fundraising Events

Hornell Irish Festival



Our friends and supporters in the southern tier always remember to invite the RAF to the annual Irish Festival in Hornell, NY. Thanks to the generous support from festival goers, the RAF raised \$300. Pictured here are Tim McDaniel, his daughter Meredith, and son James.

March Madness 2018

Our most successful March Madness event ever at Jeremiahs Tavern! We had record attendance and with tickets sold, raffles, and auction items, we raised over \$5,200 for the RAF.



2018 Golf Tournament

After a very dry Spring, the skies opened up on our golf tournament. The golfers were deluged with torrential rain. This did not prevent us from having a great time and raising money for the RAF. Fundraising was down a little over previous years and we finished up with ~\$15,000 raised for the RAF.

Ataxia research update from Dr. Fogel @ UCLA

Dr. Brent Fogel at UCLA is one of the incredible clinician scientists whom we have been supporting since 2012. He and his laboratory have performed whole exome sequencing on hundreds of ataxia patients, including many of the undiagnosed patients from our community. Dr. Fogel's team was among the first to study the value of genomic sequencing in patients with sporadic adult-onset ataxia, discovering that more than one-fifth harbored a genetic cause, helping to define the standard of care for genetic testing in ataxia patients. The Fogel Laboratory has been continually searching for new ataxia genes, as well as novel or extremely rare variations in known disease genes, causing disease in previously undiagnosed patients. Dr. Fogel's group recently reported the discovery of a new disease gene, Spinocerebellar Ataxia, Type 41 (SCA41), and has published the first reports of the US prevalence of other recently discovered rare ataxias such as SCA36 and SCA42. Donations from the Rochester Ataxia Foundation enable the Fogel Laboratory to conduct pioneering investigations that otherwise would not be funded.

Dr. Fogel's lab thanks the RAF for providing crucial support to identify the genetic causes of ataxia, so that they can develop new treatments and potentially cures.

Western NY Ataxia Support Group

Jesse Diehl, an RAF supporter and an individual diagnosed with SCA8 saw the need for an Ataxia support group close to home. The nearest groups were downstate and in Pennsylvania. So, with guidance from the National Ataxia Foundation (NAF) he formed a new group that meets once a month at the First Congregational Church in Spencerport, NY. The first meeting was in September and the next one is coming up on October 17 @ 5:30p.m. This group is for individuals with any form of Ataxia, their families, their caregivers and anyone who is interested. The goals of this group are to share information, discuss research opportunities, health and wellness, coping strategies and whatever else is on the minds of the participants. Nine people attended the first meeting, some of them traveling from the Buffalo area. We would like to continue to get the word out about this group which offers support, increase Ataxia awareness and hopes for a cure. The RAF was represented at the meeting and will partner with this group—working towards finding a cause and a cure!

Wanted: a few good men and women

RAF is in the process of recruiting new members for our Board of Directors. We have had some changes on the board recently. Valerie Grapensteter has joined us and Tim McDaniel and Patrick Nichols have left the board. We are thrilled to have Valerie on board. One of the tasks she has assumed is project leader for the RAF's new website as well as providing invaluable support during the golf tournament and fundraising events. We thank Tim and Patrick for their service and wish them well as they embark upon new opportunities. Please let any of our board members know if you are interesting in joining or contact us using the contact information listed below.

Thank you, thank you, thank you! As always, thank you for supporting and attending our fundraising events! With your help, we are working towards finding the cause and a cure for Ataxia! You may contact us at:

Rochester Ataxia Foundation P.O. Box 16560, Rochester, NY 14616

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