

*RAF Newsletter Vol.5
February 2019*



RAF celebrates March Madness



Come join the Rochester Ataxia Foundation at our Fifth Annual March Madness Fundraiser at Jeremiah's Tavern @ 2200 Buffalo Road in Gates.

March 23, 2019 5-9p.m.

For \$40 enjoy all you can eat appetizers and all you can drink beer, wine, and well drinks. There will be a basket raffle, a 50/50 raffle, and March Madness basketball squares. So bring your family and friends to watch the games and support a great cause. Check our Facebook page for updates—<https://www.facebook.com/rochesterataxiafoundation/>

November 2018 Fundraiser at a Gust of Sun Winery and Griff's Brewery

The RAF held the first Annual Wine and Beer Tasting Event at A Gust of Sun Winery and Griff's Brewery in Spencerport, NY in November. It was a huge success! The goal of the event was to raise money and awareness for Ataxia research and support but with the intent to have fun at the same time.

We were fortunate to have music and entertainment provided by the DAWGS, a local band who donate their time and talent for a good cause. That night we raised over \$1,000 for the RAF and a great time was had by all. Here are some pictures from the event!

**UPCOMING FUNDRAISER—
SAVE THE DATE**

*March 23, 2019
March Madness*

*June 2, 2019
Golf Tournament
Webster Golf Club*



NAF 2019 Annual Ataxia Conference—Las Vegas, NV

Save the Date! March 29-30. The National Ataxia Foundation and Western Region Conference Hosts invite you to attend the largest gathering of those affected by all forms of hereditary and sporadic Ataxia in the world. At this event, attendees will have two days to meet and learn from world-leading Ataxia researchers and clinicians, visit vendor exhibits, and network with others. Sessions at the conference will include topics that help a person with Ataxia manage their symptoms, presentations from some of the top Ataxia researchers and clinicians, small groups that are disease-specific, and updates about the latest in Ataxia research.

Visit the NAF website for further information.

<https://ataxia.org/2019-annual-ataxia-conference/>

RAF donates to Dr. Fogel's research lab @ UCLA

The mission of the Rochester Ataxia Foundation is to find a cause and a cure for hereditary Ataxia. Some very important research is being conducted by UCLA Neurologist Dr. Brent Fogel and his laboratory. One significant step in this process is identifying what type of Ataxia an individual may have.

The last update from the lab was that they had completed the latest round of analysis on several hundred patients with an Ataxia diagnosis, including samples from some undiagnosed Rochester Ataxia Foundation followers. They have some potential candidate genes under evaluation and, if these hold up, they may be contacting families for updates in the coming months.

The RAF continues to support the research being completed by Dr. Fogel. In September of 2018, the RAF sent a check for \$35,000 to Dr. Fogel's lab at UCLA to support the work that he is doing.

This is made possible of course by your generosity. If you would like further information about Dr. Fogel's research, please contact one of the RAF board members. Thank you for your support!



Ataxia Group of Western NY

A newly formed Ataxia Support Group serving Western NY and the surrounding area meets on the 3rd Wednesday of every month. The meeting takes place at the First Congregational Church at 65 Church Street in Spencerport, NY 14559 @ 5:30 PM-7:00PM.

This support group is to remind individuals with Ataxia that they are not alone. Each person may experience Ataxia in a different way but together have many

things in common. This meeting has been a great time for sharing stories, resources, and making connections. Since its inception the group has been averaging about eight people at each meeting. Most have an Ataxia diagnosis, but a few are caregivers, spouses, or friends. Some of the folks are local to the Rochester area, but about half have been driving from the Buffalo area.

Currently there is a support group in New York State for Ataxia, but it is down state. The nearest group in Pennsylvania is over 4 hours away by car.

All are welcome. There is no age limit and one does not have to be diagnosed with Ataxia. Caregivers and family members are welcome! Please contact Jesse Diehl @ jesse.diehl61@gmail.com or 585-315-1578 if you have an agenda item or if you would like further information.

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