RAF Newsletter Vol.2
November 2017

ROCHESTER ATAXIA FOUNDATION
RAF
A CAUSE & A CURE

Jesse Diehl, RAF supporter attends the National Ataxia conference

In March, 2017 with support from the Rochester Ataxia Foundation, Jesse Diehl was able to attend the National Ataxia Conference now in its 60th year, which was held in San Antonio, Texas.. Jesse has been diagnosed with Spinocerebellar Ataxia 8 (SCA8) and is interested in learning as much as he can about his condition as well as finding any research opportunities.

While Jesse was there, one of the talks of interest was "Advances in Genetic Diagnosis of the Cerebellar Ataxias, presented by Brent Fogel, PhD. Over the years, the RAF has been supporting the work that Dr. Fogel has been doing. Jesse also learned about the research being done at the University of Florida in Gainesville by Dr. Laura Ranum. Dr. Ranum gave an update on her research.

One of the highlights of attending the conference were the Birds of a Feather sessions. Conference participants attended sessions related to his/her specific Ataxia diagnosis. During these group activities, Jesse was able to connect with others from all over the country who share a similar diagnosis, similar struggles, and similar victories.

In between presentations and group sessions, Jesse learned about several Ataxia research studies. He was able to participate in a research study while at the conference. He was hooked to several electrodes, and answered questions while the clinicians looked at his brain activity. There were several pharmaceutical companies at the conference. Jesse received monetary compensation for donating saliva to a drug company formulating tests to accurately diagnose Ataxia. He used the money towards a plane ticket and accommodations to attend an Ataxia Wellness Day and participate in a research study at Johns Hopkins University in April, 2017.

It was during the conference that Jesse learned of a multi-site drug trial in which the University of Rochester was going to participate.

Thank you to the RAF for this trip!

Jesse Diehl at the National Ataxia Foundation Conference in San Antonio in March, 2017

Ataxia Research at the U of R

The University of Rochester is participating in a multi-site drug trial with Adult Subjects with Spinocerebellar Ataxia (SCA) Dr. Erika Augustine is the principal investigator for the Rochester site. The U of R is receiving compensation from the drug company Biohaven Pharmaceuticals for conducting this research study. The study involves BHV-4157, a drug that is currently approved for patients with another Movement Disorder. This is the first trial with human subjects at the University of Rochester related to Spinocerebellar Ataxia. The purpose of the study is to determine whether the drug, which is thought to block mechanisms causing gait and coordination problems in hereditary SCA, is well tolerated and beneficial for relieving the symptoms of SCA. Enrollment for the trial has ended and results will be available within the next several years.

SAVE THE DATES :

UPCOMING FUNDRAISERS

November 28, 2017 —ROC the DAY

March 24, 2018 March Madness at Jeremiah's Tavern

June 3, 2018 7th Annual Golf Tournament at the Webster Golf Club

---

Inside this issue:

Upcoming Fundraiser

ROC THE·DAY
powered by United Way of Greater Rochester

NOVEMBER 28, 2017

ROC the Day is a 24-hour, online event that gives people in our community an opportunity to support all of the not-for-profit organizations doing great work in the nine-county Greater Rochester area. People will visit ROCtheDay.org, a secure online giving platform, to make a gift. All ROC the Day gifts will help local people and organizations.

The Rochester Ataxia Foundation is participating. Please log-on to the ROC the Day website on November 28 to support the RAF.

RAF Board of Directors

The Rochester Ataxia Foundation Board of Directors is going through some growing pains. As we announced earlier this year, Suzanne Coglitore stepped down as the president but continues to be actively involved “behind the scenes.“ The interim president is Michael Geraci. Michael is a busy, young lawyer who is contributing a great deal of time to the RAF as well as other community organizations.

Michael Geraci

The Board is working on restructuring so that each position is assigned a particular term and successors are in line to take over at the end of the term.

Currently, the Board of Directors Members are:

Michael Geraci, Michael Cullen, Jim Coddington, Patrick Nichols, John Soldi, Ben Muscolino, Tim McDaniel, Pam Tellier, and Alison Diehl. See the RAF website for more details on the board members.

RAF

The RAF wants to Find a Cause, and Find a Cure. We have been very successful in moving forward thanks to our generous supporters raising money to support our organization. We have donated money to the URMC hereditary clinic and Ataxia research going on at UCLA. As you read in Jesse’s article, we assisted in sending him to San Antonio to attend the National Ataxia Conference. If you are interested in volunteering with our organization, or know of a cause that is in keeping with our mission and vision, please contact Alison Diehl at adiehl61@gmail.com. We would love to hear your ideas for projects or individuals who could benefit from sponsorship from the RAF.

Thank you to all of our current and past donors, we truly appreciate your support! Have a wonderful Thanksgiving and Holiday Season!

To Contact the RAF—please send an email to Rochester ataxia@gmail.com or visit our website—www. Rochester ataxia.org