

RAF Newsletter Vol. 6 Fall 2019



10th Annual RAF Golf Tournament @ Webster Golf Club

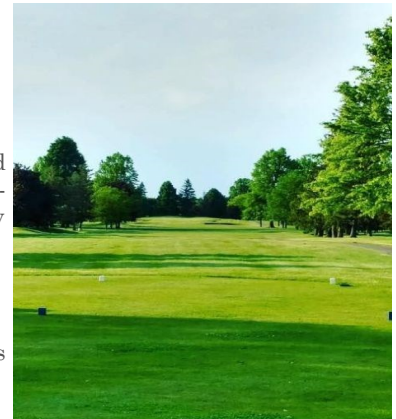
We celebrated our 10th year of raising funds for the RAF at our Annual Golf Tournament! Thanks to everyone who came out to play golf, participated in the raffles, and joined us for dinner. We had 132 golfers who completed 18 holes of golf and 4 golfers who opted for the 9 hole course. It was a beautiful day out on the course. We had several invited speakers for the dinner hour. The message that we received from Dr. Fogel at UCLA was inspiring and we are encouraged to learn of the great work that he and his colleagues are doing in the field of Ataxia research. Dr. Paciorkowski from the University of Rochester Medical Center's Genetic Ataxia clinic addressed the audience and it was good to hear about the work that is being done in the area of caring for patients with Ataxia.

Our keynote speaker was Lindsay Perez who is a physical therapist who does a lot of work with individuals with Parkinson's Disease. Additionally, she has a few clients with Ataxia who are participating in a boxing program that has proven to be beneficial to patients with Parkinson's—Rock Steady Boxing. She works for Genesee Valley Physical Therapy and has a private business—Fighting Chance Boxing. Lindsay along with assistance from Jesse Diehl demonstrated some of the boxing and balance exercises that are used. It was very informative and hopefully offered some encouragement for individuals with Ataxia.

In addition to the doctors and physical therapist who spoke during the

dinner hour, we invited members of our community who are affected by Ataxia to speak about their experience with Ataxia as well as their experience with the RAF. Those statements were read by members of the board and it certainly brought to the forefront why we all are doing what we can in this quest to find a cause and a cure for Ataxia. While the cure may not come in our lifetime, we are hopeful that we can advance the research and a cure can be found for the next generation.

We also wanted to thank Dawgs for a Cause for providing the music during the cocktail hour.



Beautiful day for the RAF 10th Annual Golf Tournament at Webster Golf Club!

UPCOMING FUNDRAISERS

ROC the DAY
December 3, 2019

March Madness
March 21, 2020

March Madness at



The March Madness event at Jeremiah's in March was a great success. Thanks to all who came out and participated in all of the fun, food, drinks, and raffles. We raised over \$2,200 for the RAF!

Jesse Diehl was the lucky winner of the lottery ticket "basket."

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Changes on the RAF BOD



**Dr. Valerie Grapensteter
DNP, RN**

Valerie is the Director of System Clinical Practice at Rochester Regional Health. In this role, she is responsible for the system oversight, direction and implementation of clinical best practice that aligns with the strategic initiatives of Rochester Regional Health. She is a motivated leader within healthcare who drives high quality clinical practice through collective decision making, evidence base practice and strategic planning. Valerie is a Doctoral prepared Clinical Nurse Specialist in the Adult and Geriatric population. She has clinical experience in Medical Surgical and Critical Care nursing and leadership experience in system integration, standardization and optimization.

Valerie has been part of the RAF Mission since the inception by leading the raffles and auctions at our 2 largest fundraising events. She became a board member in January of 2019 and is committed to continuing the RAF's efforts in raising awareness and supporting research in her new role as President of RAF.



Diane Minunni Callan

Diane Minunni Callan is the Senior Vice President, Head of Compliance – Enterprise Corporate Office, Regulatory Change and Academy for TD Bank Group. Diane is a Certified Regulatory Compliance Manager and a Certified Anti-Money Laundering Specialist. Diane lives in Spencerport, NY and has three children.

Diane joined the Board of Directors in January 2017. Diane will be stepping into the role of Vice President of the RAF.

Diane has been an integral member of the board since she joined and brings a vast knowledge of fundraising, charitable organizations, and grants.

RAF has a new website! We are in the midst of recruiting a volunteer to be our webmaster. Our website will be filled with information related to Ataxia research, RAF fundraisers with links to registration, and other articles of interest. Our site is live and an email blast will go out soon with the address.



Amber Goodman

Amber Goodman is the Director of Human Resources for The Pike Company in Rochester, NY. Prior to joining Pike in 2018, she was the HR Director for Walmart Logistics. She was born and raised in Pennsylvania and attended Penn State. Amber, her husband and 2 children moved to Rochester in 2016. She has a passion for helping others and making a difference within her community. Amber joined the board in January 2019 and is committed to the mission of the RAF in raising awareness and supporting the research to find a cause and cure for genetic Ataxia.



Michael Geraci, Esq.

Michael joined the Board in 2014. He became president in 2017 and recently stepped down from that position. Michael is a lawyer at Geraci Law Offices in Rochester with a focus on labor and employment law in addition to criminal defense.

Michael recently ran for a seat on the Rochester City Council—East District.

Please join us in thanking Michael for all of his work as president and we are happy to announce that he will remain on the Board.

To Contact the RAF—please send an email to rochesterataxia@gmail.com or visit our website—www.rochesterataxia.org Or by US Postal Mail to Rochester Ataxia Foundation PO Box 16560 Rochester, NY 14616