



Rosenau Family
Research Foundation

December
2024
Newsletter

In This Edition

1

Happy Holidays from RFRF

2

KTRN 2025

3

Ongoing Collaboration with the National Organization for Rare Disorders (NORD)

4

Soundbites

2024 has marked my first full year as Fractional Marketing Director for Rosenau Family Research Foundation (RFRF). I came to this role as a layperson in the field of rare diseases, and throughout this year of both personal learning and organizational growth, I have witnessed the overwhelming amount of compassion, care, and expertise that exists in this community.

I have been humbled by the stories of resilience and love of patients and their families. I have listened in awe as researchers describe their career journeys and the work in which they are immersed. I have experienced the dedication of the RFRF team as we strive to improve the lives of patients impacted by Krabbe disease and Cystic Fibrosis. And it has had a profound effect on my life.

In this holiday season, I speak on behalf of the entire team here at RFRF when I say that we are grateful for everyone in our community. You work tirelessly to change lives for the better, and we are honored to be doing that work alongside you. Sending you our warmest wishes for a festive and peaceful holiday season, and onward to 2025!



Rachel Jackson
Fractional Marketing
Director



KTRN 2025

PRESENTED BY



Rosenau Family
Research Foundation

MARCH 11-13, 2025

MINNEAPOLIS, MN

Registration is now open for KTRN 2025!

The focus of the 2025 meeting is 2030. In addition to highlighting current scientific advances in Krabbe disease, we plan to hold a series of panel discussions to help identify current gaps and needs in Krabbe disease as well as those gaps that should be prioritized and addressed over the next five years. There is a preliminary agenda in place, which you can find [here](#).

Register Now

We have also **created a video** from interviews at KTRN 2024 that highlights the spirit of the meeting and its benefits for the rare disease community. We invite you to share the video with your networks to spread the word about the event, especially anyone you think might be interested in attending.



Sponsorships

There are several sponsorship levels available for KTRN 2025, which you can see by clicking the button below. We are continuing to offer custom options to ensure we are connecting with our partners and providing the most valuable opportunity possible.

Please email ktrn@rosenaufoundation.org with any questions or to inquire about a sponsorship.

**Sponsorship
Opportunities**



Ongoing Collaboration with the National Organization for Rare Disorders (NORD)



This fall, the Rosenau Family Research Foundation (RFRF) continued our collaboration with NORD Students for Rare by tabling at NORD's 2024 Rare Diseases and Orphan Products Breakthrough Summit in Washington DC.

NORD Students for Rare is a nationwide network of student-run chapters at high schools, colleges and medical schools. It is committed to rare disease awareness and education. This fall's meeting included training and presentations on topics such as student-led fundraising campaigns, student research grant opportunities, and ways to work with nonprofit research institutions. Students were also able to attend all Summit sessions. Along with the peer-to-peer presentations and presentations by the network's leaders during the student meeting, RFRF provided an overview of the Foundation's history, mission, and vision and announced our intention to work with NORD to develop and sponsor a summer internship program for students to gain healthcare or research-related exposure and experience in rare diseases. This was enthusiastically received and discussions around the summer internship program have continued with the hope of implementing such a program in the near future.



Soundbites

NOW ACCEPTING

Letters of Intent

FOR OUR FALL GRANT CYCLE

We are now accepting Letters of Intent (LOI) for our fall grant cycle! We were energized by how many of you utilized our first ever spring grant cycle this year and are looking forward to seeing that passion continue into this fall cycle.

Submit Your LOI

RFRF Out & About

Our Executive Director, Gabriel Cohn, had a busy fall season traveling to conferences.

On October 20-21, RFRF had a table at the NORD 2024 Rare Diseases and Orphan Products Breakthrough Summit in Washington, DC (see recap on page 3). We are looking forward to more collaborations with NORD and the Students For Rare program in 2025!



Dr. Cohn also attended the North American Cystic Fibrosis Conference, September 26-28 in Boston.



Dr. Gabriel Cohn at the NORD Summit



RFRF sponsored the Cystic Fibrosis Foundation's 2024 Breath of Life Gala, which took place on November 2nd in Prior Lake, Minnesota.



Chris Lee, PhD and his team at the Biomedical Research Institute of New Jersey have published a preprint of their most recent work, funded in large part by RFRF research grants in 2020 and 2022, on bioRxiv. You can read the preprint [here](#).



Connect With Us!

General Information

www.rosenaufoundation.org

info@rosenaufoundation.org

Grants

www.rosenaufoundation.org/grants-process/

grants@rosenaufoundation.org

 @RosenauFoundation

 @rosenaufoundation

 @rosenaufoundation

 @Rosenau_Fdn

