



Rosenau Family
Research Foundation

December
2025
Newsletter

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Happy Holidays

from



Rosenau Family
Research Foundation

Wishing you a season wrapped in peace, comfort, and joyful moments with the people who mean the most.

As another year comes to an end, I look back on the work that this community has done, and I am proud to be a part of it. From the vital research being carried out by our grant recipients to the collaborations and partnerships between rare disease organizations and institutions, we are moving the needle forward on our mission to improve the lives of patients impacted by Krabbe disease and Cystic Fibrosis through research funding and disease advocacy, and to help individuals live life undefined by Krabbe disease and Cystic Fibrosis. Thank you to each and every one of you in Rosenau Family Research Foundation's network for being a continued source of inspiration and hope.



Rachel Jackson
Fractional Marketing Director

Here's to a bright 2026!

Grant Recipient Highlight: Paul Orchard, MD



Paul Orchard, MD, has been awarded a \$360,000 grant from the Rosenau Family Research Foundation to establish a registry for Krabbe disease. This project aims to gather critical data to improve the understanding, diagnosis and treatment of Krabbe disease.

With patient consent, the registry will collect clinical information, genetic data and patient outcomes to support families and researchers. The project is unique because it brings a community-driven approach by collaborating with advocacy groups and families to obtain information, which includes patient progress, challenges and needs. This will help expand knowledge on the variability of the disease process and the anticipated outcomes of the patients affected with Krabbe.

Dr. Orchard is the Medical Director of the Inherited Metabolic and Storage Disease Program and a Professor in the Department of Pediatrics, Division of Blood and Marrow Transplant & Cellular Therapy. Dr. Orchard's focus is in the use of hematopoietic stem cell transplantation and other cell therapies for inherited metabolic disorders, with a special interest in the inherited leukodystrophies, the mucopolysaccharidoses and osteopetrosis. His clinical research is in evolving new and combination therapies to decrease toxicity and improve outcomes, with a particular interest in the use of gene therapy approaches.

Click below to watch our introductory interview with Dr. Orchard, and follow along with his grant journey at rosenaufoundation.org/orchard-2024.

A video thumbnail with a teal border. On the left, there is a pink and white abstract graphic. The text in the center reads: "AN INTERVIEW WITH Paul Orchard, MD" in blue and pink. Below this is a red play button icon. To the right of the play button, the text says "Grant Recipient" and "University of Minnesota Medical School". At the bottom, there is the Rosenau Family Research Foundation logo, which consists of a pink heart shape with a white outline and the text "Rosenau Family Research Foundation" in blue and pink.





SAVE THE DATE

KTRN 2026 will take place March 18-20 at the
Hilton Minneapolis/Bloomington!

Registration will open on Monday, January 12th.

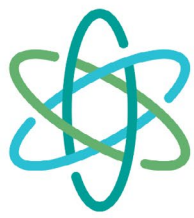
SPONSORSHIP LEVELS

We have several sponsorship levels available, which you can find on the next page.

We are continuing to offer custom options, to make sure we are connecting with our partners and giving you the most valuable opportunity possible.

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





KTRN2026

PRESENTED BY



Rosenau Family
Research Foundation

MARCH 18-20, 2026

MINNEAPOLIS, MN

GOLD SPONSOR // \$5,000

- 5 complimentary registrations
- 1 platform presentation
- Inclusion of logo on event registration page
- Recognition as a Gold Sponsor on the RFRF website and in all social media posts
- Opportunity to add a promo or educational item to the attendee bag

SILVER SPONSOR // \$3,000

- 3 complimentary registrations
- Recognition as a Silver Sponsor on the RFRF website and in all social media posts
- Opportunity to add a promo or educational item to the attendee bag

BRONZE SPONSOR // \$1,500

- 2 complimentary registrations
- Recognition as a Bronze Sponsor on the RFRF website and in all social media posts
- Opportunity to add a promo or educational item to the attendee bag

NON PROFIT SPONSOR // \$1,000

- 2 complimentary registrations
- 1 platform presentation
- Recognition as a Non-Profit Sponsor on the RFRF website and in all social media posts
- Opportunity to add a promo/educational item to the attendee bag

Custom Opportunities Available



Connect With Us!

General Information

www.rosenaufoundation.org

info@rosenaufoundation.org

Grants

rosenaufoundation.org/grant-process/

grants@rosenaufoundation.org



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