



**Rosenau Family**  
Research Foundation

**May**  
**2025**  
**Newsletter**

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# Announcing: 2024 Grant Recipients

Rosenau Family Research Foundation (RFRF) would like to extend its congratulations to its 2024 class of grant recipients!

The mission and vision of RFRF is improving the lives of patients impacted by Krabbe disease and Cystic Fibrosis through research funding and disease advocacy, and helping individuals live life undefined by Krabbe disease and Cystic Fibrosis.

To support this mission and vision, the foundation considers [grant funding](#) for basic science research, translational research, and clinical research that can lead to or enhance treatments and cures for Krabbe disease and Cystic Fibrosis. Programs that promote, through education and awareness, the expansion of newborn screening, Krabbe disease, and Cystic Fibrosis are similarly considered.

"The 2024 funded grants continue a legacy of excellent research being done in the fields of Krabbe disease and Cystic Fibrosis," said RFRF Executive Director, Gabriel M Cohn, MD, MBA. "Our grant recipients also include one new investigator, which is exciting to us as an organization as we work to recruit greater participation in rare disease research."



Daesung Shin, PhD  
*SUNY Buffalo*



Laura Kirkpatrick, MD  
*University of Pittsburgh*



Rachel Wurth  
*Mayo Clinic*



Allison Bradbury, MS, PhD  
*Nationwide Children's Hospital*



Paul Orchard, MD  
*University of Minnesota*

Each full grant application is evaluated by RFRF's Scientific Advisory Committee for alignment with RFRF's goals and objectives, as well as the proposal's scientific merit, significance, robustness, and feasibility (scientific, technical, and financial).

Only grant applications that address specific scientific question(s) or applications that address specific educational/awareness goal(s) and that are aligned with RFRF's mission and vision are funded.

The current RFRF grant cycle began on May 1st with a [Letter of Intent](#) submission period that goes through July 31st.

To learn more about this and past years' grant recipients, visit [rosenaufoundation.org/funded-grants](https://rosenaufoundation.org/funded-grants).





**Renee Muellerleile**  
Executive Director

# Grant Management Platform Development

As Rosenau Family Research Foundation (RFRF) continues to successfully grow and work toward achieving its mission to improve the lives of patients impacted by Krabbe disease and Cystic Fibrosis, we are committed to maintaining efficient, streamlined and cost-effective grant management operations.

Toward this goal, the foundation launched a new online grant management system in November 2023, automating the Letter of Intent (LOI) and grant application submission processes in 2024. This system incorporates enhancements to improve and expand the quality grant information available for objective evaluation of the LOIs and applications, including:

- Planned scientific methodology
- Hypothesis, research plan
- Milestones
- Detailed budget information along with referential data, investigator and organization background information

The online grant management system enables RFRF to administer blinded (scientific merit) reviews and unblinded (feasibility) reviews by our Scientific Advisory Committee at the LOI and application stages in the grant process. This ensures a fair and constructive funding opportunity for all who are interested in applying, and focused support of solid scientific practice and innovation.

With the online grant management system, we were able to quickly configure and manage the LOI and application submission processes for an additional grant cycle launched in May 2024 and recently completed the first full grant cycle, with funding agreements execution in December 2024. We are excited to continue to build out additional features and functionality to increase the efficiency of the overall grant management process and administration of ongoing funded grants. This will include automation of progress and financial reporting submissions and review processes that are easy for our grantees to use, and which will provide RFRF with the necessary information to responsibly oversee the grants. Initially, we will start with reporting from grant recipients that were included in the grant cycles started in the online grant management system and continue with the transition of grantee reporting on grants funded prior to the system implementation.



# KTRN 2025

PRESENTED BY



Rosenau Family  
Research Foundation

MARCH 11-13, 2025

MINNEAPOLIS, MN

KTRN 2025 took place in Minneapolis, MN in March.

The focus of the 2025 meeting was 2030. In addition to highlighting current scientific advances in Krabbe disease, a series of panel discussions were held to help identify current gaps and needs as well as those gaps that should be prioritized and addressed over the next five years.

The panels fostered a spirit of lively conversations and ideas, and reinforced the importance of continuing these discussions outside of the KTRN gathering, finding ways to ensure developments in research and new discoveries are being shared throughout the year among investigators and institutions alike.

Rosenau Family Research Foundation also announced its exciting new Medical Student Internship Program during this year's conference, aimed at drawing in young talent to the field of Krabbe disease research by providing them with the opportunity to work directly in the lab with our investigators. See page 7 for more details and to inquire about sponsoring a student.



**We would once again like to thank this year's sponsors for their generous support. We will see you all next year!**

**GOLD**



**SILVER**



# 2025 Sue Rosenau Legacy Award

Joanne Kurtzberg, MD, was named the recipient of the 2025 Sue Rosenau Legacy Award at the KTRN Meeting in March!

The Sue Rosenau Legacy Award recognizes an inspirational leader who has collectively created lasting change and measurable differences in one or more areas of the Rosenau Family Research Foundation's mission. Dr. Kurtzberg's many contributions and achievements have made her indispensable to the field of Krabbe disease research, and we can think of no one more deserving of this honor.





**Heather Techmeier**  
*Finance Director*

# Investment Management Firm Request for Proposal

Rosenau Family Research Foundation (RFRF) is dedicated to enhancing the lives of individuals affected by Krabbe disease and Cystic Fibrosis through research funding and advocacy efforts. Acknowledging the importance of prudent asset management, RFRF entrusts the foundation's assets to a reputable investment management firm. To ensure due diligence, RFRF's Board of Directors (BOD) relies on the expertise of their Investment Committee (IC).

Recently, upon recommendation by the IC, RFRF executed a request for proposal (RFP) process for investment management services. The primary objective of this RFP process was to solicit comprehensive and comparable proposals from qualified investment managers and evaluate these proposals in an impartial and methodical manner.

Hundreds of investment managers were assessed, resulting in the selection of five candidates who provided detailed responses via a formal questionnaire. This information enabled the IC to thoroughly review and assess the candidates. Subsequently, three finalists were identified and subjected to further specific inquiries and a final presentation to the IC. After careful deliberation, the BOD selected [Foster Group](#) as the new investment manager.

Foster Group is a privately held, independent, fee-only financial management and investment management firm. Their fee-only compensation model mitigates potential conflicts of interest, ensuring that advice given is always aligned with the client's best interests. For additional details regarding our investment manager, please visit [www.fostergrp.com](http://www.fostergrp.com).



# Investment Committee Recruitment

RFRF is looking for individuals for our Investment Committee who are:

- Committed to RFRF's mission
- Thoughtful in their approach to working with others and challenging the foundation
- Interactive and engaged
- Inquisitive & personable
- Experienced in relevant fields such as investment, accounting, banking, financial planning, corporate finance, or non-profit financial sector

Click below to get in touch about joining the Investment Committee, or email [info@rosenaufoundation.org](mailto:info@rosenaufoundation.org).

Investment  
Committee Interest

## Medical Student Internship Program

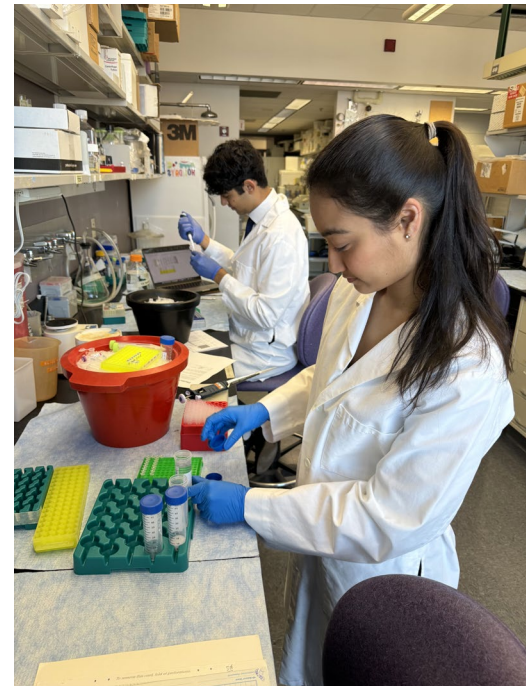
Rosenau Family Research Foundation is invested in engaging with young, talented minds who are interested in rare disease research and advocacy, and recruiting them to focus their studies on the field of Krabbe disease.

About our [Medical Student Internship Program](#):

- Five awards of \$5,000 each are available annually
- Sponsors can nominate a medical student (at any level) for a 6-12 week internship
- One award is given per sponsor

If you are a sponsor interested in discussing a student internship with us, click the button below.

Inquire About  
Student Internship



# 2024 Annual Report is Out Now!



The [2024 Rosenau Family Research Foundation Annual Report](#) is out now! Summarizing another year of hard work, dedication and growth, it showcases our progress as both an organization and a collective field of research. Click the button below to take a look.

[Read the 2024 Annual Report](#)

## iECURE Reports Complete Clinical Response in First Infant Dosed with its In Vivo Gene Editing Candidate

[Important, promising research being conducted by iECURE](#), whose Chief Medical Officer is our Executive Director, Gabriel Cohn, MD, was announced in January. Gene editing has the potential to be a more durable treatment for childhood diseases than traditional gene addition because in gene insertion, the functional gene is inserted directly into the chromosomes as opposed to having the functional genes sit alongside them as occurs in gene addition. Unless a gene is inserted into a chromosome, it will not replicate. The direct insertion of the functional gene therefore allows them to replicate and be distributed along with the quickly dividing cells of a young patient instead of becoming diluted as they grow. If this treatment approach proves to be successful, it could reduce the need for organ transplants and further therapeutics down the line. We applaud this remarkable work and what it could mean for research in the fields of Krabbe disease and Cystic Fibrosis.



[Learn More Here](#)



# Connect With Us!

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## General Information

[www.rosenaufoundation.org](http://www.rosenaufoundation.org)

[info@rosenaufoundation.org](mailto:info@rosenaufoundation.org)

## Grants

[rosenaufoundation.org/grants-process/](http://rosenaufoundation.org/grants-process/)

[grants@rosenaufoundation.org](mailto:grants@rosenaufoundation.org)



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