

Hope for Vision

2021 ANNUAL IMPACT REPORT



pediatric
retinal
research
foundation



A Message from Our President

Dear PRRF Community,

It is my honor to present you with The Pediatric Retinal Research Foundation (PRRF) 2021 Annual Impact Report. In 2021, 85% of the PRRF's total operating expenses were used for research and programs to benefit children with blinding, retinal diseases and their families. We are committed to fiscal responsibility, efficiency, and low overhead in all we do.

The PRRF began 2021 by welcoming Stephanie Saville as Foundation Manager and Luisa Recchia as Community Outreach Coordinator. Stephanie has fortified our infrastructure in many ways - social media presence, IT infrastructure, contact database, development initiatives and much more. Luisa has nurtured our connection to the PRRF community, most notably our Family Advisory Committee and January's inaugural Family Connection Conference. They have helped further our dual mission to support our community and further the quest for a cure.

On the research front, there has been significant progress along the pathway of bringing Noregen™ from a potential therapy developed in the lab to phase 1 clinical trial to becoming an FDA-approved therapy (from "bench to bedside") for familial exudative vitreoretinopathy (FEVR) and other diseases.

It is remarkable to consider how far we have come as a Foundation in the last year, despite how challenging things seemed due to limitations borne of the global pandemic. We adapted and expanded to continue to further our dual mission to support our community and pursue the quest for a cure. Thanks to the generosity of supporters like you, we achieved tremendous results for 2021. Springtime is about growth and optimism, and we look forward to the challenges and achievements that await us in 2022.

On behalf of the children and their families, whom we serve,

Antonio Capone, Jr. MD

President

The Pediatric Retinal Research Foundation

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PRRF Mission

To support the community of families impacted by blinding pediatric retinal diseases and champion the quest for a cure.

Highlights and Accomplishments

In 2021, the Foundation invested in the expansion of our community outreach programs, we continued to formalize our organizational structure with key staff roles filled, and analyzed the needs of the Pediatric Retinal Research Lab to ensure longevity and support of research initiatives. A brief summary of our accomplishments is highlighted below.



The inaugural **Family Advisory Committee (FAC)** was created to give a voice to the families supported through PRRF. The FAC will ensure the patient and family voice is represented in the Foundation's initiatives.

In an effort to provide valuable resources and connections to families, the Family Advisory Committee launched a **private Facebook group for parents** and caregivers to share ideas, questions, feedback and build camaraderie.



An inaugural **Ask the Doc webinar** was hosted in May which featured a recorded and live Question and Answer session for families across the globe to get answers to their disease related questions from our panel of expert doctors. Additionally, we created eight follow up mini-Ask the Doc videos to answer additional pressing audience questions.

In an effort to connect families and share the hopes, struggles and accomplishments of children and young adults with vision loss, and their families, **life journeys** were incorporated into the Sightlines newsletter and on the PRRF website.



We **formalized our organizational structure** through the establishment of policies and procedures, streamlined activities, and expansion of IT software and security protocols.

The PRRF community rallied behind fundraising initiatives to support the third annual **Hope for Vision Walk** (virtual), as well as the **year-end campaign**, raising over \$86,000 for community programming and research initiatives.



Family Connection Conference 2022

The FAC and staff laid the groundwork for the first annual **Family Connection Conference** (hosted in January 2022).

Finalized a **four-part video series** highlighting PRRF families and team members to tell the PRRF story to the community and garner additional awareness and advocacy for rare pediatric retinal diseases. Additionally, a **PRRF LinkedIn** page was developed to share the PRRF mission, vision and story.

The PRRF board reviewed and quantified the **annual budget required to run the Pediatric Retinal Research Lab (PRRL)** to ensure sustainability of the program and adequate resources to further research initiatives and goals.



Research Update

Pediatric Retinal Research Lab Discoveries

PRRF continued our investment in research initiatives in 2021 at the Oakland University (OU) Pediatric Retinal Research Lab (PRRL). Despite the challenges of 2021 from the global pandemic, the PRRL and Associated Retinal Consultants completed the first analysis of FEVR patients using the new Next Generation Sequencing panel, which sequences eight genes involved in Norrie Disease, FEVR and Retinoschisis. **In addition to finding the likely genetic cause of FEVR in several families, this research project revealed that FEVR patients have changes impacting more than just one FEVR-related protein at a much higher incidence than expected in the general population.** The PRRL researchers hope this will lead to more insights on the variable nature of FEVR severity – even within members of the same family. This DNA sequencing was made possible because of donors like you investing in the research, expertise and equipment needed!

Additionally, PRRF welcomed the newly appointed Director of OU's Eye Research Institute (ERI), Dr. Mohamead Al-Shabrawey, to our board of directors. This partnership is the first step to expanding the collaboration efforts between PRRF and OU's ERI with a new fellowship program in development that will support future researchers, as well as bringing back the super student program in the PRRL to educate and encourage future ophthalmologists.

We look forward to seeing how this collaboration continues to grow and expand in the coming years.

Commercialization of Noregen™

Noregen™, the drug therapy currently being researched to treat FEVR, continues to make tremendous progress in the lab and offers promises of hope. In 2021, researchers initiated the FDA processes and protocols so the innovative drug therapy could enter Phase I Clinical Trials in 2022. It is the goal of PRRF and Noregen™ researchers for the drug to become available for patient use within five years.

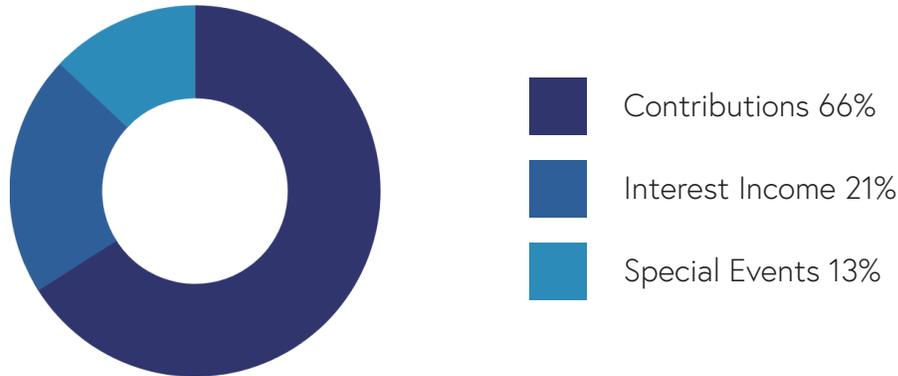
Community Outreach Update

This year was a tremendous year of growth for PRRF's community outreach initiatives. In addition to the accomplishments highlighted previously, the Foundation has laid the groundwork that will allow the team to expand educational resources and events even further in 2022. We are continually looking to provide answers to critical questions, as well as highlight trends and innovative opportunities on the horizon.

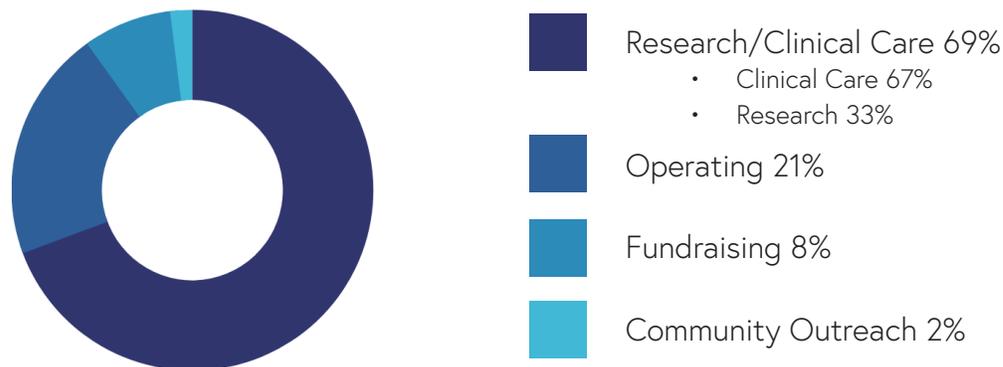
In addition to continuing the Family Connection Conference and webinars in years ahead, the purpose of the Family Advisory Committee is to identify unmet needs of the pediatric vision loss community. The PRRF board and staff want to hear from the people served and supported by PRRF to better understand how we can continue to offer services and programs for needs including reviewing and procuring accessible devices and technology, offering educational advocacy support, and how to best tell the stories of people served through PRRF. The FAC has kicked off their first year of service by developing the Conference content and will look to achieve the other goals outlined above in the coming year.

2021 Financials

2021 Revenue \$184,075.00



Total Expenses \$123,658.48 (67% of revenue)



PRRF is very excited to introduce our Community Outreach program in 2021. We look forward to the expansion of programs and services that meet the needs of the PRRF community today, while we continue our long history of investment in research efforts to discover opportunities for the future. Spring of 2022 marks a decade since the PRRL first opened. To date, pre-Phase-1 milestones were met in the research and development of Noregen™ and late 2022 will hopefully introduce researchers to Phase-1 Clinical Trials where researchers will administer the drug to assess its safety and provide in initial data regarding efficacy. We are excited to share updates of all activities happening in the PRRL and with the Foundation in the year ahead.

Thank you to our tremendous donors

This list represents gifts ranging from \$100 and up giving in 2021. An asterisk (*) denotes a Board Member and a caret (^) denotes a Staff Member.

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