



pediatric
retinal
research
foundation



PRRF: HOPE FOR VISION

Impact Report

2022

Table of contents

3

President's
message

4-5

2022
accomplishments

6

PRRF's 2023 goals

7-8

There's something
about twins

9-10

Research update

11-12

Community
programs update

13

2022 financials

14-16

Thank you to our
donors!

President's message

Dear PRRF Community,

I am honored to present you with The Pediatric Retinal Research Foundation (PRRF) 2022 Annual Impact Report.

We continued our initiative to strengthen our foundation base at the Board level in 2022. In January, Dr. Mohamed Al-Shabrawey, Director of the Eye Research Center and Eye Research Institute, joined the PRRF board. Dr. Al-Shabrawey's Board presence is essential to fortifying our long-standing relationship with Oakland University, where our Pediatric Retinal Research Laboratory (PRRL) maintains a high degree of research activity. We also welcomed new board member Alex Dobin, the senior HR partner for Federal Affairs, FPL Corporate, and Customer Service for NextEra Energy, Inc., a leading clean energy company in Florida. Alex's input will help increase awareness of PRRF's mission and services and provide insight into further Board development.

On the research front, there has been significant progress in bringing Noregen™ to becoming an FDA-approved therapy for familial exudative vitreoretinopathy (FEVR) and other diseases. We have Investigative New Drug enabling work underway - a required step in petitioning the FDA on the path to new drug development. We are also working on drug scale-up and production, anticipating first human Phase 1 work by mid-2024. That process will be expedited by our team, having obtained Rare Pediatric Disease and Orphan Drug designations. We have also resumed supporting the win-win Super Student program which gives students exposure to retinal research, in turn providing support to PRRL's DNA sequencing initiative.

We were also very active on the community front again in 2022. We hosted our 4th annual Hope for Vision Walk, raising over \$42,000. Thanks to the generous fundraising efforts of the online leadership class of Next Level Trainings, nearly \$20,000 was raised to support the launch of PRRF's new podcast, *Through Our Eyes*. Our tremendous Family Advisory Committee hosted the 1st annual virtual Family Connection Conference in January and launched bi-monthly family-led workshops in June.

We continue to make great strides in our growth as a Foundation, furthering our dual mission to support our community and pursue the quest for a cure - thanks to the generosity of supporters like you. We look forward to an exciting and dynamic 2023.

With gratitude, on behalf of the community whom we serve,



Antonio Capone, Jr. M.D., 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.

2022 accomplishments

Hosted 4th annual Hope for Vision Walk

Over 65 participants from 11 states raised over \$42,000 to benefit PRRF programs and research! Shout-out to the top fundraising team, The Dobin Family, for raising \$7,150!



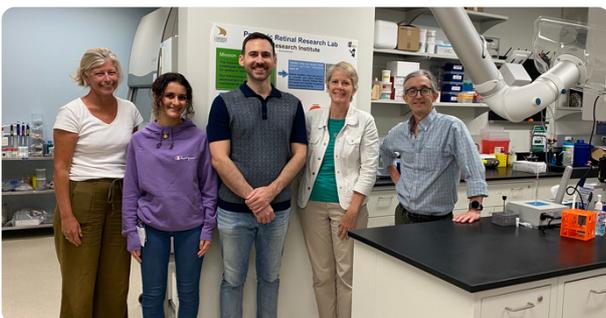
Next Level Trainings Class Raises Nearly \$20,000

Thanks to the 8th online leadership class of Next Level Trainings, nearly \$20,000 was raised in just 19 days. Funds raised supported the launch of PRRF's new podcast, *Through Our Eyes*.



Foundation Supports Funding Pediatric Retinal Research Lab (PRRL) Super Student

Thanks to funding from PRRF, the PRRL was able to hire a Super Student to assist with research initiatives. Students gain exposure to research techniques, learn about retinal diseases, and fulfill their research project requirement; while the lab staff benefit from additional assistance sequencing DNA data.



PRRF's Family Advisory Committee (FAC) hosted the 1st annual virtual Family Connection Conference in January 2022.

The Conference featured a research update, family break-out sessions, and a keynote presentation by Brandon Warner. The Conference hosted 80 registrants from 14 countries!



2022 accomplishments, cont.

Launched *Through Our Eyes* Podcast

October 2022 welcomed our new podcast which is focused on visually impaired young adults' journey's navigating high school, college, career and beyond. They share their experiences, what they've learned along the way and how sighted people can support their journey.



The (FAC) Launched Bi-Monthly Family-Led Workshops

Beginning in June 2022, the FAC began offering free, virtual workshops on a variety of topics including perseverance, sibling relationships, life as a twin with ROP, the loneliness of an orphan disease, and navigating high school and college with your young adult low-vision child. All sessions are hosted by individuals with rare retinal diseases or their parent(s) and encourage connecting families with one another.



PRRF Welcomed New Board Member Alex Dobin

Alex is the senior HR partner for Federal Affairs, FPL Corporate, and Customer Service for NextEra Energy, Inc., a leading clean energy company in Florida. He also serves on several other boards in Florida and is president of two associations. Alex brings a passion for increasing awareness of PRRF's mission and services to all families as they learn about pediatric retinal disease diagnoses.



PRRF's 2023 goals

1

Increase Family Engagement

Increase engagement of families as advisors to PRRF, particularly in determining how best we can serve the rare retinal disease community. This includes expanding the diseases represented on the Family Advisory Committee (FAC) and continuing to offer quality community programming; including FAC-led workshops, the annual Family Connection Conference and the *Through Our Eyes* podcast. We are also dedicated to connecting families - including in person and through our various online channels. Lastly, we are excited to formalize a volunteer engagement program.

3

Shift Fundraising Approach

Shift our fundraising initiatives from episodic events and appeals to include ongoing, year-round fundraising. This includes launching a Giving Circle campaign, growing the Hope for Vision Walk throughout the community, and increasing support of community-hosted fundraising events.

2

Support the Pediatric Retinal Research Lab

Sustainably support the Pediatric Retinal Research Lab (PRRL) at Oakland University and its research initiatives. This year's goals include providing funds to hire three or four Super Students in the PRRL and funding a summer lab technician. As well as launching and funding a pilot study program out of the PRRL to encourage novel research ideas that will benefit rare retinal diseases.

4

Strengthen Policies & Best Practices

Continue to build infrastructure, strengthen Board governance and set policies to execute PRRF activities efficiently and consistent with best practices for non-profit organizations. As the Foundation continues to grow, the need for organizational policies and best practices also increases. We will also refresh marketing materials and the website to reflect the Foundation's growth and expansion of programs.

There's something about twins

By Jennifer Z.



Jennifer and Ashley Z.

There seems to be something about twins that never fails to draw intrigued glances and the question, "Identical or fraternal?"

Some claim it is that famed "twin telepathy," others their shared birthday, age, and grade in school, and still others the relative rarity of birthing multiples. But being a twin myself, and one in especially unique circumstances, know that the bond I share with my twin sister means more to me than any of this.

As is somewhat common for multiples, my twin sister Ashley and I were born three months premature in October 2004. I quickly developed retinopathy of prematurity and subsequently underwent numerous surgeries to prevent blindness, and now I possess about 20/300 vision in both eyes, with correction. Meanwhile, though Ashley also underwent eye surgery at a young age, she now possesses excellent vision. In a previous article written for the January 2022 "Sightlines" newsletter, I discussed my own challenges, goals, and personal growth as a teenager with visual impairment, but now I wish to pay homage to my sister, for much of what I have accomplished in my lifetime would not have been possible without her unwavering support.

In my time working with the Pediatric Retinal Research Foundation, I have come to realize that, in families such as mine, there can be a certain amount of alienation between siblings when one has a prevalent disability, no matter their age or other similarities.

The disabled sibling may, for example, be excluded from certain activities in which the non-disabled siblings can participate. Stephanie Brennell wrote a wonderfully inspiring article for the July 2022 newsletter that highlights her own young sons, two of whom are twins, and the success they have had in dealing with this very fact. Still, when it comes to such families, any number of scenarios are possible, and they can greatly affect the growth of all siblings involved and the relationship that they develop as they grow older. As Ashley and I are now seniors in high school, I hope that I can offer some insight into how we have both grown as best friends and as individuals and how our relationship remains as strong as it was ten years ago.

Aside from the obvious advantages of being the same age and gender, there are many factors to which I can attest that have allowed Ashley and I to grow so close. For one, my parents have always treated Ashley and me in the same way—they have afforded us the same opportunities, encouraged us to do the same activities, and pushed us toward the same goals. As children, we never stopped to consider how we were different; it was more about how we were similar, how we shared the same likes and dislikes, the same friends, the same teachers, and the same experiences. We spent nearly every waking moment together, and (barring the occasional sisterly argument), we always got along.

There is much to be said about this kind of constant interaction. The hard truth is that visually impaired children are growing up in a world of sighted people, and it is imperative that they be afforded opportunities to interact with and share the same experiences as sighted children.

(continued)

There's something about twins, cont.

To that end, if it is possible, building supportive relationships with siblings who are near in age should be encouraged, for it can greatly alter the way the visually impaired child perceives the world and the way the world perceives him or her. During my childhood, for example, I was never without Ashley, especially when it came to school—we had classes together, ate lunch together, and played with friends together. As the years went on, I became known not as the girl with large papers and strange magnifiers but simply as one half of the Z. twins. In short, Ashley was the one who made me feel “normal,” and—early on at least—I imagine she was also the one who made me appear “normal” to other kids. She saw past my visual impairment and treated me as she would any other sister, and in doing so she helped other kids to treat me as they would any other elementary-school-aged girl.

That is not to say that helping visually impaired children meet and interact with one another cannot also be immensely beneficial, for it can relieve feelings of loneliness and isolation and offer some reassurance that one is not alone in facing the challenges of visual impairment. In fact, I wonder how my perspective might be different had I met someone like me as a child. That being said, I personally do not recall ever longing to meet another visually impaired girl when I was younger. Instead, I was content to know that I had my twin sister, who understood my disabilities and my insecurities, and I was—and still am—more focused on adapting to the sighted world and interacting with sighted people.

Now, as Ashley and I enter our senior year of high school, our relationship has taken on a whole new meaning. We still have some classes together, we still eat lunch together, and we still have

many of the same friends, and still Ashley remains my biggest supporter and most trusted confidant; yet our lives are swerving in very different directions as we build our own identities and pursue our own goals. Though part of me knows that I cannot afford to be so dependent on her any longer, I still cannot imagine what my life will be like in a year; for then I will be in college, confronted with new surroundings, new people, and new challenges, and—solely because of my visual impairment—nothing terrifies me more. Truthfully, for as long as I can remember, it has been a dream of mine to share a dorm with Ashley; and that is not only because of how much fun it would be to decorate our room together. As this is not likely to happen though, it will be up to me to establish my own identity at the school of my choice, in addition to tackling practical challenges that come with learning a new environment. That being said, whether I am preparing for my first day of college classes or my first day at a new job, I know that Ashley, who has never failed to understand—or, to the best of her ability, attempt to understand—and support me when I find myself in an unnerving situation, will be merely a phone call away.

I truly feel that, were it not for Ashley—and for my parents, who encouraged Ashley to help me in these ways—I would not have been so readily accepted among my peers throughout my school career and would not have adapted to the sighted world so easily. I hope that every child who is disabled in some way can develop this sort of relationship with a sibling, for it is perhaps the most valuable—or invaluable—relationship that I have. I can honestly say that I would not be the person I am today without the incredible friendship and steadfast support that Ashley has given me over the years.

Research update

Pediatric Retinal Research Lab Discoveries

The world of research in the Pediatric Retinal Research Lab (PRRL) has been busy with a flurry of activity since returning to “normal” operations after COVID. To understand the work in the lab, it’s first helpful to understand the relationship between the Oakland University Eye Research Institute (OU ERI) and the Pediatric Retinal Research Foundation (PRRF).

In 2011, the Pediatric Retinal Research Foundation launched a capital campaign to fund a state-of-the-art retinal research lab on the Oakland University campus in Rochester Hills, Michigan. The Virginia and Clarence Clohset Family Pediatric Retinal Research Lab (pronounced PEARL) is the first of its kind solely dedicated to pre-clinical development of therapy for regeneration and repair of the retinal vasculature; and well as performing DNA-sequencing for children and families affected by inherited eye diseases.

Dr. Kimberly Drenser, PRRF board member and internationally recognized pediatric retina specialist, serves as the Scientific Director. Dr. Drenser, with full-time faculty member Dr. Ken Mitton (Associate Professor of Biomedical Sciences, Eye Research Institute) oversee the conduct of the research in the PRRL with the help and expertise of Wendy Dailey, Research Assistant and DNA-Sequencing Technician.

Oakland University supports the PRRL by providing salaried staff to manage the program, animal care, ensuring compliance with regulatory boards, and maintaining the equipment, lab and utilities. In January 2022, Dr. Mohamed Al-Shabrawey, Director of the Eye Research Center and Eye Research Institute, joined the PRRF board.



This collaboration is not only critical to a healthy partnership between the Foundation and Oakland University, but it is allowing research to thrive as new ideas and opportunities are pursued. Dr. Al-Shabrawey is the successor to long-time, dedicated board member Dr. Frank Giblin.

In June 2022, PRRF funded a Student Lab Technician to work in the PRRL throughout the 16 weeks of summer break. The Student Lab Technician helped improve lab research outcomes while the experience provided expertise to a student pursuing a career in the sciences.

In September 2022, we toured the PRRL where they make the Norrin protein for research purposes, as well as targeted DNA-sequencing for patients and families with rare retinal disease; such as FEVR and Norrie Disease. Rima, OUWB graduate student and Super Student, worked in the lab throughout her summer break. Videos of the tour, what the summer students worked on, various equipment (including the DNA sequencer) and more can be found at <https://www.pediatricrrf.org/our-lab>.

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Research update cont.

Concurrently, tremendous progress has been made with Norrin-derived growth factor, Noregen™, managed by the Caeregen Therapeutics leadership team: Dr. Kimberly Drenser, Dr. Antonio Capone, Jr., Walter Capone, and Wendy Dailey. Initial drug research started in the PRRL in a collaborative effort with Dr. Mitton and has evolved into a commercialization process to bring the FEVR-treating drug to patients. In 2022, Caeregen Therapeutics received United States Food & Drug Administration (US FDA) and European Union European Medicines Agency (EU EMA) Orphan Drug Designation Acceptance. FEVR achieved US FDA Rare Pediatric Disease Designation and identified a commercial manufacturing partner, and began preclinical animal testing.

In 2023, Caeregen Therapeutics is raising additional funding needed to continue the commercialization process, including further preclinical testing, conducting toxicology studies, and beginning drug product manufacturing.

It is anticipated that Phase I and II clinical trials on patients could begin as early as the first quarter of 2024. It is important to note that the designations listed above are allowing the process to move at an expedited pace compared to non-rare disease designations.

The success of the progress of the Noregen™ development and commercialization was made possible by the families who agreed to participate in DNA-sequencing, which allowed Dr. Drenser's lab to analyze enough samples to learn and understand FEVR at a molecular level. The success was further made possible through PRRF donors that supported funding designated to the PRRL research studies. It is rare in disease research for donors to see the impact of their giving from start to end! But we are hopeful Caeregen Therapeutics and PRRF can share such a tremendous success as early as 2026.



Community programs update

2022 was a year of tremendous activity for PRRF community-related programming! We are so grateful to all of the amazing volunteers that have helped bring these goals to life this past year.

We'd like to recognize the members of the **Family Advisory Committee (FAC)**, led by board member Chuck Walls:

- Joanna Askenazi
- Stephanie Brennell
- Caroline Halbert
- Karen Hoogland
- Lisa LoVasco
- Tracy Shafizadeh
- David Stevens
- Natalia Stevens
- Donna Walls
- Jennifer Z



In January 2022, the FAC sponsored the first annual **Family Connection Conference**. The conference invited people from all over the world to gather for the only family-centered conference dedicated to pediatric retinal diseases.

The committee created the agenda, which included: a research update from Dr. Kimberly Drenser, a live question and answer session with Dr. Drenser, Dr. Antonio Capone, Jr., and Dr. Michael Trese; a pre-recorded question and answer session from questions registrants submitted; breakout sessions focused on unique challenges that face each age group from birth through college; and a keynote by Brandon Werner that introduced the audience to various assistive technology resources.

The conference was well-received with over 80 registrations and participation from 14 countries around the world.

In June 2022, this committee launched a **bi-monthly free virtual workshop series** led by family members (parents, teens, and young adults) of the FAC. The workshops aim to introduce topics relevant to all families facing a rare retinal disease, build community and support, and provide resources to one another based on lived experiences.

Every other month an FAC member writes an article for the Sightlines eNewsletter. The article serves as the inspiration for the following month's workshop.

(continued)

Community programs update, cont.

Also, focusing on supporting the community of young adults living with rare retinal diseases, the Podcast Committee launched *Through Our Eyes* in October 2022.

We'd like to recognize the members of the **Podcast Committee**, led by board member Dr. Patrick Droste:

- Haven Capone
- Brandon Werner
- Shelby Craig
- Breyanna Willitt
- Nicole Giudici



The committee released six episodes before year-end and plans to release two episodes each month thereafter. Listeners can find the podcast on Discord, Facebook, Instagram and TikTok. The purpose of this podcast is for the Visually Impaired Young Adult (VIYA) community to have an open and accessible forum to share their physical, emotional, and educational challenges and to collectively become active and successful contributors to society.

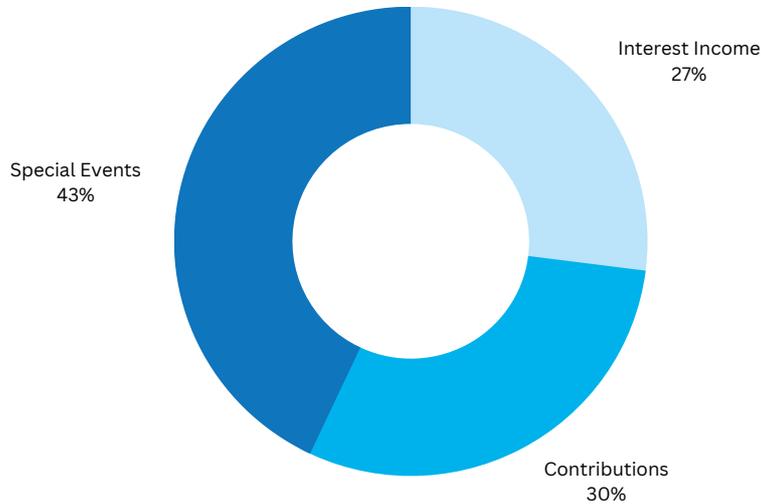
Last, but certainly not least, dedicated volunteer and passionate supporter, Richard A. Deyo, hosted a free webinar titled "Build Your Legacy, An Overview of Legacy Giving Strategies" in April 2022. Rick is a Financial Consultant and Chartered Advisor in Philanthropy Wealth Management. The webinar was really well-received by donors and supporters; and Rick will continue to offer two free, virtual webinars to the PRRF community in 2023.

We look forward to continuing these efforts in 2023, as well as inviting new speakers to motivate, educate and inspire the PRRF community; expand our resources page on the website to be more family driven with content that is helpful and relevant to challenges families face regularly; and expand networking opportunities between families around the world.

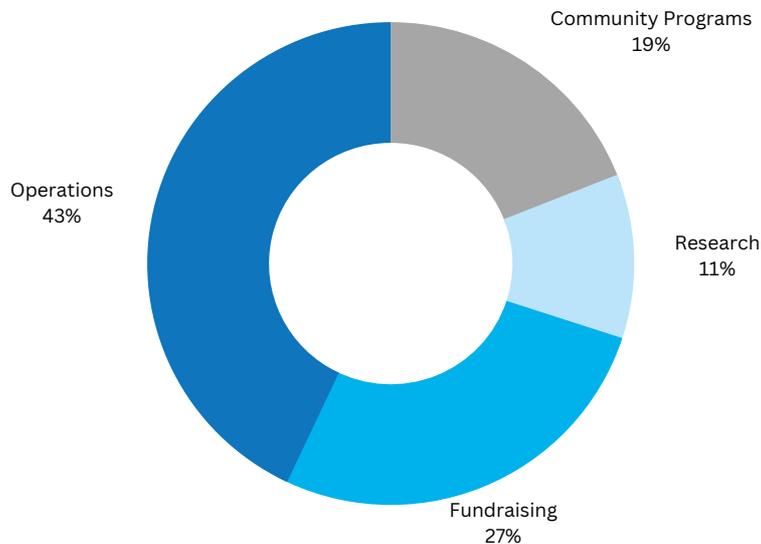
If you would like to get involved in our community programs, please contact Luisa Recchia at lrecchia@pediatricrrf.org.

2022 financials

2022 Revenue - \$146,311



2022 Total Expenses - \$72,269 (49% of revenue)



In 2022, the Foundation placed a great emphasis on expanding current and launching new community programs. While progress continues to move forward with Noregen™ drug development and the Pediatric Retinal Research Lab gets back to DNA sequencing and research discoveries after the COVID shift, the Foundation is investing in supporting children and families with challenges they're facing today.

The Foundation continues to support both research and community programming, while also growing engagement, support and awareness in the community about pediatric retinal diseases. We are enthusiastic about the progress made in all three initiatives this past year and look forward to continuing our efforts in the year ahead.

Thank you donors!

This list represents gifts given in 2022. An asterisk (*) denotes a Board Member and a caret (^) denotes a staff member.

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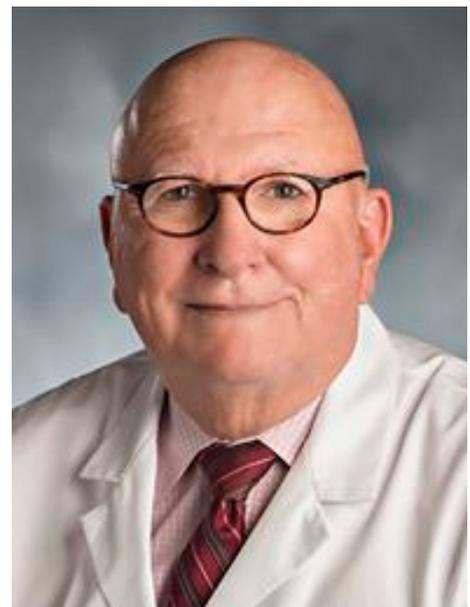
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