pediatric
retinal
research
foundation

HOPE FOR VISION

IMPACT REPORT

2023

Supporting the community of families impacted by blinding pediatric retinal diseases and championing the quest for cures since 1990.

PRRF.org

IMPACT REPORT

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MESSAGE FROM THE PRESIDENT

ANTHONY CAPONE, JR, MD, PRESIDENT

PEDIATRIC RETINAL RESEARCH FOUNDATION

Dear PRRF Community,

I am excited to present you with The Pediatric Retinal Research Foundation's (PRRF) 2023 Annual Impact Report.

This year was another year of significant impact as we focused on strengthening both our community programs and research investments to drive the quest for cures while also supporting children, young adults, families and loved ones.

Nicole Giudici joined the Board of Directors after having volunteered for a year on the Podcast Committee and hosting a very successful third-party fundraiser with her Next Level Leadership class. Nicole has enthusiastically joined several of our board committees and is passionate about serving the pediatric retinal disease community.

We also welcomed Breyanna ("Brey") Willitt to the team as the *Through Our Eyes* Podcast and Social Media Assistant. Brey previously served as a volunteer on the Podcast Committee as well as an on-air co-host. In her new role she has secured some amazing guests, has engaged the rare disease, blind and low vision communities on several social channels, and continues to co-host interviews.

On the research front, PRRF sponsored three Super Students at the Oakland University Eye Research Institute. The Super Students work throughout the summer on a research project aimed at advancing vision science research. Additionally, this year's year-end fundraising campaign raised funds with the goal of increasing the number of Super Students PRRF sponsors annually. Keep reading for more on these impactful programs.

As the Foundation continues to grow and evolve every year, we are inspired by the involvement of volunteers, feedback from families, and hope from research progress. Thank you for joining us on this amazing journey and cheers to an incredible year ahead.

With gratitude,

Antonio Capone

Antonio Capone, Jr, MD, President
Pediatric Retinal Research Foundation

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Heather Tull
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Breyanna Willit
Podcast & Social Media Assistant

2023
ACCOMPLISHMENTS

Hosted 5th Annual Hope for Vision Campaign

Participants from all over the country participated virtually in the Campaign, raising over $20,000! Families gathered in their local communities to walk, run, and bike to raise awareness of rare retinal diseases.

Funded Three Super Student Researchers

PRRF is dedicated to exploring ongoing research in the quest for cures. In 2023, PRRF funded three Super Students who worked throughout the summer in Oakland University's Eye Research Institute to advance research in vision sciences. Oakland University has the only lab in the world dedicated to pediatric retinal diseases!

Welcomed New Board Member Nicole Giudici

Nicole joined the PRRF Board of Directors and immediately jumped to action by growing the Podcast, participating in the Research Advisory Committee, as well as helping the Fundraising Committee establish clear goals and programs.

Nicole's professional background includes work as a physician assistant and, most recently, as a Senior Medical Science Liaison with expertise in neurology. Nicole loves to run and is training for her first marathon in fall 2024.

2023
ACCOMPLISHMENTS CONT.

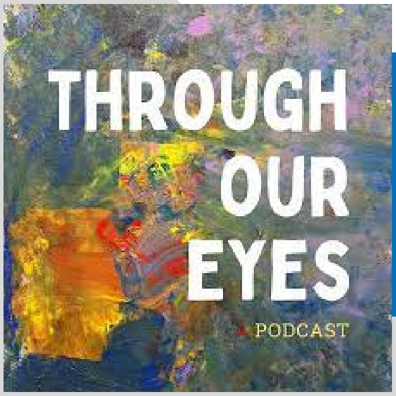
PRRF FAMILY CONNECTION
CONFERENCE 2023

Hosted 2nd Annual Family Connection Conference

The Family Advisory Committee hosted a very successful free conference in January 2023 that featured Q&A with doctors, a research update, a captivating keynote and breakout sessions. The conference welcomed 85 guests from 14 countries and 26 states!

Completed the First Full Season of the *Through Our Eyes* Podcast

Launched in October 2022, the *Through Our Eyes* podcast interviewed guests and published 23 episodes featuring topics ranging from navigating college blind to autonomous vehicles & the visually impaired to cooking as a blind person.



Welcomed New Team Member Breyanna Willitt

Brey has volunteered on the Podcast Committee since the very beginning and has been instrumental in bringing the *Through Our Eyes* podcast to life. Recently, PRRF hired Brey as the Podcast and Social Media Assistant. She has secured some incredible guests and has promoted great content on our podcast socials.

Brey shared: “I have a deep passion for helping people, especially those in my community. I am blind, being diagnosed with Familial Exudative Vitreoretinopathy when I was nine years old, however, I do not let my vision hold me back. I enjoy hiking, reading, and being surrounded by my friends and family.”

OUR VISION

PRRF 2023 Impact Report

In the next three to five years, we aspire to achieve the goals below with the involvement and support of the PRRF community.

We will lean into the PRRF community of children and young adults living with rare retinal diseases, their families and loved ones, donors, volunteers, strategic partners and the medical community to bring our strategic vision to life. If you would like to get further involved or learn more, visit pediatricrrf.org/volunteer.

OUR MISSION

1

Expand our reach. The PRRF community and volunteers have created and curated tremendous resources to support families, young adults and loved ones as they navigate the journey from diagnosis through adulthood. **We will focus on expanding our reach to ensure these resources are available to those who may benefit**.

2

Grow our services. PRRF is dedicated to listening to the community impacted by rare pediatric retinal diseases to identify services and resources that will provide support and hope for the future. **We will grow our services to meet the needs of people living with rare disease through various stages of their lives.**

3

Strengthen fundraising programs. The PRRF Board is committed to ensuring the Foundation's sustainability so we can continue to offer support services and pursue the quest for cures for the next 30 years. **We will increase fundraising revenue through strategic and focused outreach and cultivation.**

4

Fortify organizational infrastructure. As the Foundation grows and evolves, we are dedicated to fortifying a structure that will bring focused energy with a growth mindset to the organization’s future. **We will elevate our operational and leadership structure by filling staff positions, restructuring executive board roles and planning for succession.**

HONORED HEROES

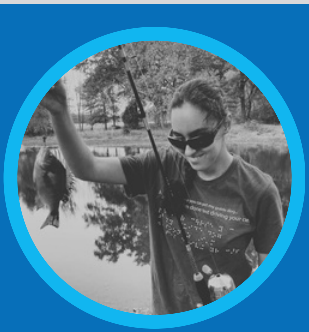
Children, young adults and families living with rare pediatric retinal diseases are at the heart of everything we do! We celebrate their bravery, tenacity and inspirational outlook on life by sharing a few of their stories.

IN HONOR OF DEZ

Dez's story started shortly after he was born when we noticed his nystagmus. We started with an MRI of his brain which came back perfect! We left the doctor's office then with no answers but continued to follow up with our optometrist.

A couple years later he was put into glasses and eye patches. It wasn't until 2017 after seeing a retinal specialist that he was diagnosed with Familial Exudative Vitreoretinopathy (FEVR). His diagnosis was then later genetically confirmed.

Even with his diagnosis he continues to persevere and not let it hold him back. He's a very active young man who loves doing taekwondo and playing video games.



IN HONOR OF GRETCHEN

"I was born 18 weeks premature and was diagnosed with Retinopathy of Prematurity (ROP). My parents weren't sure how to raise a blind child and growing up in a rural area gave me many experiences that I would not have had growing up surrounded by other blind people in an urban area. Though I did not learn all the blindness skills that I would have learned in a big city, growing up where I did taught me how to be creative and resourceful. I learned how to advocate for myself and how to work hard for what I wanted in life.

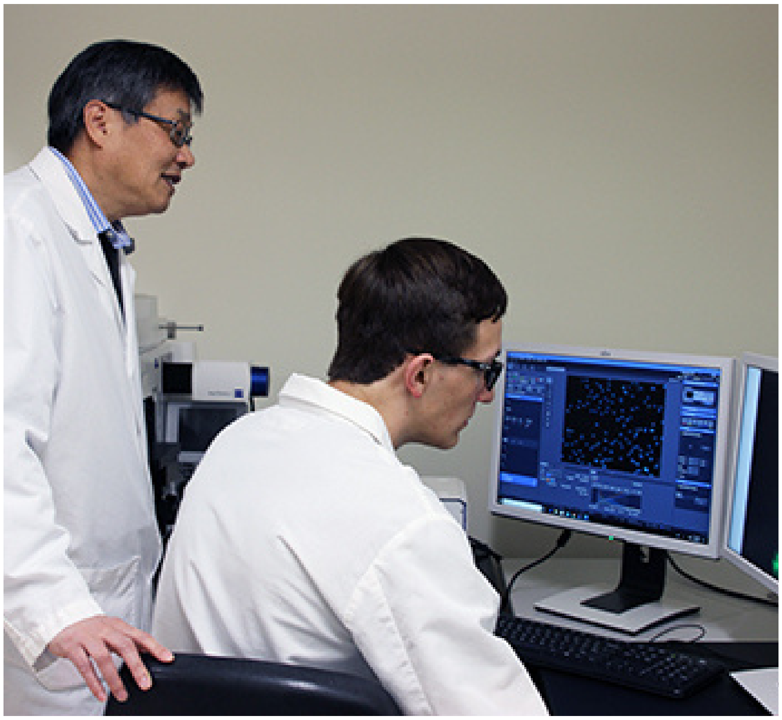
Growing up blind with ROP has taught me how to think creatively about various ways to bring accessibility to the forefront of conversations. I have learned to educate the general public who might not have much experience dealing with people with disabilities, instead of getting frustrated, I invite them to ask questions and become allies to the disabled community."

IN HONOR OF JULIANNA

"I grew up in a small town and was the only visually impaired person ever to attend my school. Being born with FEVR and not meeting anyone like me for years was difficult. At a very young age, I didn't understand why people treated me differently or judged me for who I was. Once I did understand, it became my mission to prove to my community that I could do anything they could, and I would do it with the added challenges of visual impairment.

When I reached middle school, I joined the drama club. Performing gave me a purpose and strength I didn't know I had. Performing made me a stronger person. I was able to love myself and finally accepted my place as a disabled person, which I had always felt ashamed of before."

RESEARCH UPDATE



RESEARCHERS AREN'T BORN, THEY'RE MADE

PRRF is proud to have funded three Super Students in 2023. Undergraduate Super Students work in Oakland University's Eye Research Institute throughout the summer. Each student is paired up with a faculty member and works alongside them to advance an eye research initiative. Students learn how to perform academic research, analyze the results of various experiments, troubleshoot problems, and summarize their findings. Several students have also presented their work at national industry conferences.

> I will graduate in 2026 from Oakland University. Currently, I am a sophomore majoring in Biomedical Sciences. I am a current student researcher in Dr. Zhang's lab and hope to one day become an ophthalmologist. Before entering college, I was always interested in the field of ophthalmology. Being granted this opportunity to look into real-world diseases, through the field of research, and understanding the various associated functions that the eye performs was truly an astonishing step towards becoming an ophthalmologist that I will never forget. I am truly grateful for this experience and the support that the PRRF has given me and other Super Students, and I look forward to the future of research at the Eye Research Institute.
>
> - Adam Schmitz, 2023 Super Student

PRRF is dedicated to investing in this initiative every year to not only advance vision research, but also to develop the careers of future researchers – because researchers aren't born, they're made. Additionally, it provides tremendous value to future doctors who will have a better understanding of how their clinical work may impact the pursuit of cures for their patients. PRRF has supported 128 Super Students since 2001. Thank you to the many supporters who give year after year to support advancing vision research!

RESEARCH UPDATE CONT.

NOREGEN™ UPDATE: PROMISING PATH CONTINUES

Many people in the PRRF community and beyond have been closely following the development of Noregen™, a regenerative therapy to heal diseases of the retina. To learn more about the drug and its potential impact on Familial Exudative Vitreoretinopathy (FEVR) patients, visit Caeregen.com/noregen.

In October 2023, Walter Capone, CEO and President of Caeregen Therapeutics, presented to the PRRF Board of Directors the latest progress in the drug's development. Walter shared breaking news that the Food & Drug Administration (FDA) confirmed a Pre-IND meeting in January 2024. This is the next major milestone in the drug commercialization timeline to bring the drug to clinical trials.

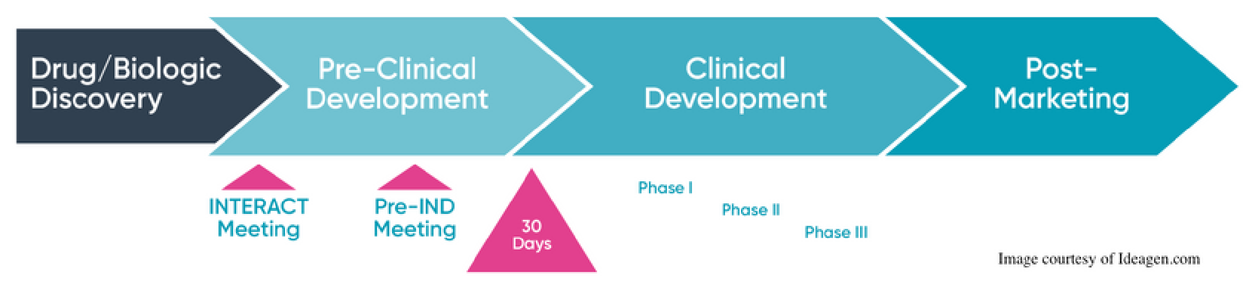


Image courtesy of Ideagen.com

The Pre-IND meeting with the FDA allows for Caeregen Therapeutics to discuss the development and review of their application. This opportunity allows the team to talk through any scientific, regulatory, manufacturing or safety issues related to the development of the drug. This meeting can help improve the speed of the drug making it to market because the FDA can help the team complete the IND application properly, avoid common mistakes, and mitigate the possibility of clinical holds.

Above is a visual timeline showing where the IND meeting fits into the drug development process. We will closely follow the progress in the commercialization of Noregen™ and will be sure to share updates with you along the way!

COMMUNITY UPDATE

BUILDING COMMUNITY

In 2023, PRRF was proud to support the community of children, young adults, parents, caregivers, medical providers, and loved ones effected by rare pediatric retinal diseases and beyond. Below we've highlighted the impact of 2023 programs by the numbers. We look forward to growing awareness of rare pediatric retinal diseases, the impact of vision loss and blindness, as well as lifting up families through meaningful connections.

Family Connection Conference

The PRRF Family Advisory Committee (FAC) hosted the 2nd annual conference, "Family Dynamics: Bridging the Gap," in January 2023.

- 84 Registered attendees
- Guests from 14 countries & 25 states

Guests enjoyed a research update, live Q&A session with expert doctors, breakout sessions, and an amazing keynote from Wallace Stuckey, a recent college graduate living with Retinopathy of Prematurity.

Through Our Eyes Podcast

2023 hosted the first full season of the *Through Our Eyes* podcast with 16 episodes ranging in topics from inspirational stories of young adults living with vision-related diseases, to parent journeys, to genetic research and autonomous vehicles.

- Total of 1,528 downloaded episodes
- Downloads in 27 countries
- Engagement on four social media platforms

Launch of PRRF Blog

Thanks to passionate volunteer Jeanne McClellan, the PRRF blog was launched in March 2023. Jeanne has researched fascinating histories of tools and programs related to vision loss, including how Braille started and the history of White Cane Day, to personal experiences living day-to-day as an adult who battled with vision loss her whole life. The articles are captivating!

Sightlines eNewsletter

Every other month, the PRRF team invites contributors to provide insightful articles to be shared in Sightlines, PRRF's bi-monthly eNewsletter. The goal of Sightlines is to share exciting updates, opportunities for engagement, as well as resources for those impacted by retinal diseases and vision loss. 2023 featured:

- Six "Minute with the President" episodes
- Six "Understanding Rare Disease" videos
- Launch of new monthly blog

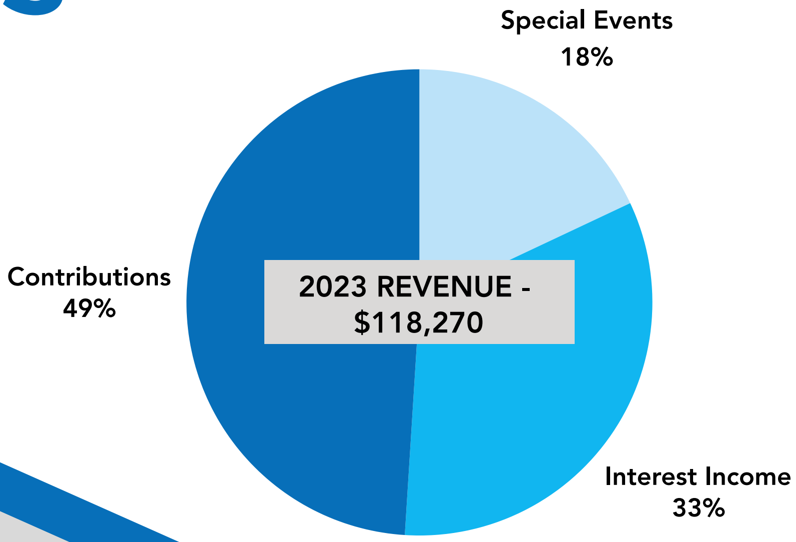
COMMUNITY UPDATE CONT.

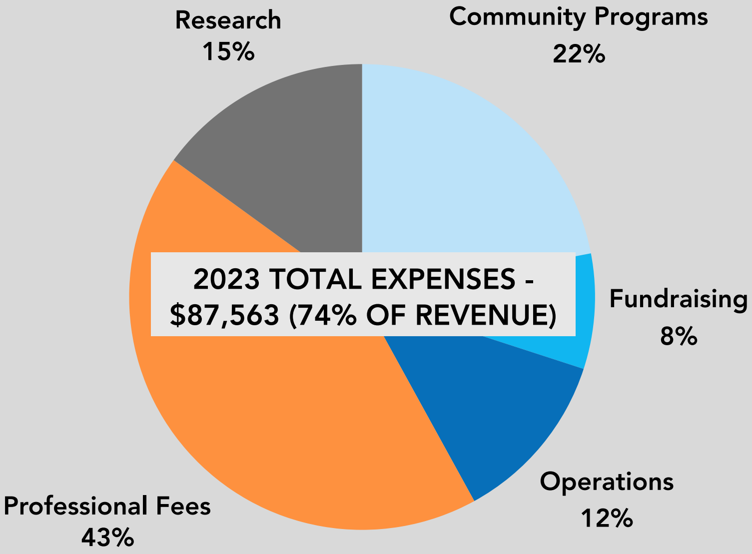
The Heart of PRRF – Our Volunteers

As a small but mighty nonprofit, we rely on the tremendous contributions of volunteers to bring programs to life. In 2023, passionate volunteers donated time, talent and treasure not only advancing the mission of PRRF, but making a difference in countless lives of newly diagnosed families, young adults seeking connection and opportunities, as well as those seeking hope for vision. PRRF is beyond grateful to the volunteers for their tireless efforts! The following list showcases members of our volunteer committees. We apologize if we accidentally omitted anyone and we extend our gratitude to **everyone** who dedicated their time and talents in 2023!

Family Advisory Committee	Stepanie Brennell, Lisa LoVasco, Natalia & David Stevens, Chuck & Donna Walls, and Jennifer Zuckerman
Podcast Committee	Dr. Patrick Droste, Nicole Giudici, and Breyanna Willitt
Family Connection Conference Volunteers	Stephanie Brennell, Dr. Tony Capone, Dr. Kim Drenser, Lisa LoVasco, Wallace Stuckey, Chuck & Donna Walls, Tracy Zhafizadeh, and Jennifer Zuckerman
Research Advisory Committee	Dr. Mohamad Al-Shabrawey, Dr. Tony Capone, Walter Capone, Dr. Kim Drenser, and Nicole Giudici
Fundraising Committee	Sally Calcaterra, Rick Deyo, Alex Dobin, Nicole Giudici, Lisa LoVasco, and Jeanne McClellan
Blog Volunteer	Jeanne McClellan
Nominating Committee	Alex Dobin, Chuck Walls, and Kay White

2023
FINANCIALS





In 2023, the Foundation was enthusiastically dedicated to growing our investment in both research and community programming. We were proud to increase the number of sponsored Super Students at Oakland University's Eye Research Institute, as well as host the podcast for an entire year - in addition to keeping the Family Connection Conference free of charge to all attendees. Additionally, we curated over twenty informational short videos to explain rare pediatric retinal diseases, how rare disease research works, and the impact of community services on families.

THANK YOU DONORS

This list represents gifts given in 2023. An asterisk (*) denotes a Board Member and a caret (^) denotes a PRRF team member.

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THANK YOU FOR YOUR SUPPORT!

The mission of the Pediatric Retinal Research Foundation (PRRF) is to support the community of families impacted by blinding pediatric retinal diseases and champion the quest for cures.

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