Letter From The President

Dear PRRF Community,

Welcome to the September edition of Sightlines. In this issue, I’d like to address the power of community.

We talk about community a lot among Board members and administrative staff at the PRRF. Those who have been part of our Foundation for decades know that we transitioned from an organization highly focused on research to one that also focuses on our community.

The first question is why – what drove the shift? The answer has several parts:

- **Timeline for curative treatments.** Our quest for a cure is aspirational. It motivates us all and inspires hope. Yet cure isn’t proximal. It’s on the horizon.
- **Day-to-day life.** Next, as we move with determination in pursuit of curative therapies, our families are tasked with the daily challenges of raising their children. Unique, often emotional, highly impactful life-impacting challenges.
- **The rarity of pediatric retinal diseases.** Given that conditions which impact our community are rare, our families often find themselves alone. There typically isn’t another child like theirs in their school, often in their town, county, and even state.
- **Shared challenges.** Yet each family faces similar challenges. Will my child attend a mainstream school? What about high school? Driving? College – online, on campus, close to home? What measure of independence after school - job, a family?
- **Power of community.** The parents/caretakers of older children and young adults have a wealth of information to share with those of a newborn with the same condition. Our community has terrific, thoughtful, and generative
parents/caretakers. Several have entered the school system to serve as teachers, advocates, or paraprofessionals who support students in and outside the classroom.

The pieces were in place for a rich exchange of ideas and information. Operationally, all that was left to do was to engender connection and provide a structure. We convened a meeting with several family members to learn what issues mattered to them and how we could better serve our community. They were enthusiastic about the opportunity to engage, and their response was thoughtful, passionate, and direct. That experience affirmed to the Board the importance of giving our community a forum to express its voice. We are committed to establishing a Family Advisory Council (FAC) and providing support to build initiatives aligned with our community’s needs. As many of you know, Luisa Recchia joined the PRRF as Community Outreach Coordinator and has been critical in helping us develop a sense of a village. The FAC continues to keep us mindful of those whom we serve.

We’ve learned a great deal since tilting strongly toward our community. Learning more about our audience, hosting events rich with content, offering opportunities to connect, celebrating success stories, and embracing the power of positive messaging are a small sample of the learnings. Drawing on the strength of the community has allowed the PRRF to be more positively impactful. Fueled by the momentum of the FAC, the PRRF sponsors an annual Family Connection Conference, which has drawn attendance from across the country and the world. We have established a regular workshop schedule on family issues unique to our community. Soon we’ll launch a podcast initiative to give voice to the visually impaired young adults in our community.

Building community takes creativity. We have drawn on those of you who have engaged for that creativity and the inspiration and hard work to execute. The most significant learning is that we are limited only by our energy and enthusiasm.

With gratitude to all in our community,

Antonio Capone, Jr. MD
President, The Pediatric Retinal Research Foundation (PRRF)
2022 Hope for Vision Walk/Run Recap

Thank you to everyone who participated in this year’s Hope for Vision Walk/Run. Seeing many of you in person this year after a two-year break was fun. Collectively we raised almost $38,000 to date! The [website](#) will remain open until the end of October if walkers & runners want to continue fundraising.

A special shout-out to our top fundraisers!
- The Dobin Family $6,500
- Kelli Matthew $5,000
- Team Collin $2,325

Watch the video of the program, which includes research lab and community programming updates on our Facebook page [here](#).

There's Something About Twins

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—I 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.

Read more...
The PRRF Family Advisory Committee invites you to join us on October 11th at 7:00 pm ET for a virtual workshop featuring high school senior Jennifer Zuckerman. Jennifer will share her story of life with retinopathy of prematurity (ROP) and her relationship with her sighted twin sister Ashley. There will be time for Q&A after the presentation.

Register for the Workshop
PRRF is excited to help launch the "Through Our Eyes" podcast on Thursday, October 13th, which is also "World Sight Day." Join visually impaired young adults Brendan, Shelby, and Breyanna as they discuss what it’s like to navigate through high school, college, career, and beyond. They tap into their experiences and cover a wide range of topics providing listeners with actionable tips and strategies they can implement into their own lives.

Subscribe wherever you listen to podcasts on Thursday, October 13th!
SAVE THE DATE!

January 21, 2023
10:00 am - 1:00 pm ET

- Virtual Conference
- Research Updates
- Keynote Speaker
- Breakout Rooms
- Participants from around the US and the world

www.pediatricrrf.org/events

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