Letter from the President

Dear PRRF Community,

Welcome to another issue of Sightlines.

The world was very different when I was writing this letter at the same time last year! The PRRF has nevertheless maintained focus on our community. Kelli Matthew – Strategic Development Chair for the PRRF Board - describes our 2020 Year-end Capital Campaign to expand family and patient support programs in 2021 and beyond. An example of this is a conference with both science-based and community-based/networking components for the Spring of 2021. Your support is invaluable to our ability to support our community.

On the 2020 fundraising front to date, the 2nd annual “Hope for Vision Walk” went virtual in September, on a rather acrobatic last-minute August pivot. It was a wonderfully successful event which expanded the Walk from local to national and international (see the story by the Walk Coordinator, Stephanie Saville, below). We look forward to next year’s Walk event, as well as the 2nd annual “Cars for a Cause” fundraiser under the leadership of Board member Dr. Patrick Droste and his team in 2021.

Getting a child to and through school is so cumulative a process that optimization requires intervention at many different stages. In this issue, PRRF Board Member Charles (Chuck) Walls expands on our series devoted to facing the challenges to equipping students with the tools they need to learn and thrive.

The research initiatives supported by the PRRF continue to produce meaningful results. In this issue Dr. Kimberly Drenser expands on the practical clinical relevance of ongoing work at the Pediatric Retinal Research Lab (PRRL) conducted on the Oakland University Campus.

We are also building up the Foundation’s infrastructure. Very exciting news – more on that next issue! Look forward to more frequent Sightlines updates in 2021, with roundups of the latest news, clinical studies of broad interest, and links to publications out of the PRRL.

During this season of gratitude, the PRRF thanks you for your membership. Our global community is stronger because of your dedication to our profession. We appreciate your continuing support and thank you again for being part of the PRRF. We are optimistic that the new year will bring opportunities for growth for us all. Meaningful change comes when we work together!

I close with a heartfelt “thank you” to the PRRF Board, our dedicated and enthusiastic PRRF volunteer community, and to our many generous contributors.
From all of us on the Board of the PRRF, best to you and yours for Happy Holidays and a healthy, peaceful and prosperous New Year.

Sincerely,

Antonio Capone, Jr. MD
President, The Pediatric Retinal Research Foundation (PRRF)

PRRF Launches 2020 Year-end Capital Campaign!

Consistent with our mission, PRRF is committed to expanding our family and patient support programs in 2021 and beyond. In a recent survey, our parents and patients requested additional resources. Many of our families and patients have benefitted tremendously from our current initiatives and believe we are uniquely positioned to continue to provide the information and connections that have been critical to overcoming many of the challenges they face.

By building upon our network of resources, enhancing our online informational portal and by offering virtual parent and patient support programs, we know we can provide the help and the hope our PRRF families need. Will you join with us? Please consider making a financial contribution today at https://www.pediatricrrf.org/donate.

Because this support is so vital to our PRRF family, we are thrilled to announce that an anonymous donor is offering to match every donation we receive from now until December 31. Thanks to their generosity, your contribution will be matched dollar for dollar, up to $40,000. That means your gift will be doubled!

Your donation will make real, lasting change for those living with pediatric retinal diseases. Thank you for your consideration.

~ Respectfully, Kelli Matthew, on behalf of the PRRF Board of Directors
Hope for Vision Walk Update

While this year has been a challenge for so many, we find ourselves extremely grateful for the tremendous support and involvement of individuals, families, and companies throughout the country in our second annual Hope for Vision Walk. In September, we launched the Walk virtually and invited participants to walk, run, or bike in their neighborhood and raise funds for the Foundation's mission.

Over 85 participants rose to the challenge and joined 20 Walk teams from 17 states for this year's event. The committee was not sure what to expect and was completely blown away by the incredible support and involvement of the participants and donors, who raised almost $30,000 at this year's Walk!

The photos, videos, and stories shared were a true testament to the ability of people to come together to make a difference, even when spread throughout the country and during a pandemic. We hope each of you who were involved or donated to the Walk found this year's event to be just as exciting and inspiring. We look forward to continuing a virtual component in 2021.

~ Stephanie Saville, PRRF Walk Manager
Educational Advocacy

COVID Impacts with our Low Vision Teenagers

As we remember, once COVID hit and kids were sent home to learn virtually this past spring, IEPs in our local county were basically frozen as schools struggled to develop plans for their teachers to continue teaching virtually. During the summer, the school system planned for the fall, and our county decided to keep schools physically closed for the first 9 weeks and students would learn virtually, but with a new plan and curriculum. Many IEP updates and adjustments were not started until after the school year began so student accommodations for virtual learning were delayed or there was a gap from the start of the new academic year. This was frustrating for us as a parent of a low vision teenager, but understanding the COVID environment, we adapted.

One example that should have been obvious from the start was virtual learning on a laptop. The school did a mass purchase of laptops to issue to students and these all came with small 12” screens. We asked about the size of the screen and let our case manager know that it would be too small of a screen size and extremely difficult for our son. We expanded our request to the Assistive Technology Specialist and Low Vision Specialist who worked with us to get a laptop with a larger screen, but that was going to take 2 weeks and school had already started. Again, we adapted, I grabbed our large 24” screen for our home desktop computer, went and bought a SVGA-to-HDMI adapter and we used this system until his larger laptop came in mid-September.

My challenge and encouragement to parents with middle school and high school age students is what I call the “Triple A” or “AAA”. This acronym stands for “Adapt, Advocate, and Avant-garde”. Now the term “avant-garde” fits nicely into the acronym and I had a layman’s understanding of the term until I looked it up. “Favouring or introducing new and experimental ideas and methods...” This was perfect! Thinking outside-the-box is a critical skillset for parents of students with low vision needs. While the school’s legal advisors won’t let the faculty and staff team members participating in the IEP comment on available budget or budget constraints, it is the “elephant in the room” at each IEP meeting. You, as the parent, must adapt, advocate, and be the avant-garde promoter for your child.

Another small tip that I feel is part of advocating is to get emails and cell phone/text numbers for all of the IEP team members rather than let the case manager contact them. Read more at https://www.pediatricrrf.org/facilitating-learning-and-employment-with-technology

~ Chuck Walls, Parent and PRRF Board Member

On the Research Front

Biobank Research Note

One of the challenges of research is to bridge bench-to-bedside evolution. In this regard, the Biobank has served the premature infant community in elucidating an exciting correlation. To summarize, we were able to compare genetic changes in premature and full-term infants and look at factors associated with Retinopathy of Prematurity (ROP) and pre-term labor. We found that the same pathway that regulates the development of the retina also plays a role in a healthy placenta. When the placenta fails to grow properly, it is unable to support the needs of a growing fetus, resulting in pre-term labor. On their own, these same pathway alterations may not be severe enough to cause eye disease, but when coupled with prematurity (the “second” hit), these alterations make these infants vulnerable to developing ROP. This is the first genetic link to help us understand the link between miscarriages, pre-term labor, and eye disease (ROP).

I am excited to start 2021 with a research drive to identify mothers who have had difficulty carrying an infant to term and develop an early diagnostic marker that would allow for improved pre-natal care
that could prevent pre-term labor and ROP. With the help of the PRRF community, I look forward to offering parents an opportunity to participate in this exciting development. Please follow the PRRF website for details on the project and how to participate in 2021. If we can prevent pre-term labor, we can stop ROP!


~ Dr. Kim Drenser MD PhD