Letter from the President

Dear PRRF Community,

Welcome to the March issue of Sightlines. The PRRF has been busy through the grey of our Midwest winter, and we’re delighted to share some of what we’ve been up to.

One of our initiatives for 2022-2023 is expansion of the PRRF Board. It is an honor and privilege to welcome Dr. Mohamed Al-Shabrawey as a Board member. His background as an ophthalmic researcher and Director of the Eye Research Institute at Oakland University adds depth to our research initiatives in the Pediatric Retinal Research Laboratory (PRRL). We look forward to his strategic input as well.

The Board has been acutely aware that the energy, experience, and insights of the families of children impacted by pediatric retinal disease were among the Foundation’s most valuable assets – as evidenced by our Educational Advocacy series. Stephanie Brennell provides the latest installment in that series in this issue of Sightlines with her article “What to Expect When You Don’t Know What to Expect.” It is a poignant and practical perspective on the journey she and her family have been on since the day her amazing son Sean arrived.

You’ll see in Stephanie’s byline that she is a member of our PRRF Family Advisory Committee (FAC). In January of 2021, Luisa Recchia joined the PRRF as Community Outreach Coordinator with the express purpose of deepening our connection to our parent/caregiver community. Over the last year, partnering with Board member Maj. Chuck Walls, Luisa and Chuck have worked to engage parents in the Family Advisory Committee. That initiative is beginning to bear fruit. Our first annual Family Connection Conference was very successfully received, including another installment of “Ask the Doc”, as you will read below.

No issue of Sightlines is complete without a heartfelt expression of gratitude. As you’ll read below, our 2021 year-end fundraising campaign was tremendously successful. The PRRF continues to grow and 2022 is shaping up to be our best year yet. Thanks to all of
you for making it possible.

Sincerely,

\[signature\]

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

**New Board Member Welcome**

The Pediatric Retinal Research Foundation is pleased to announce the appointment of Dr. Mohamed Al-Shabrawey, MBBCH (M.D.), M.Sc., Ph.D. as a new board member. Dr. Al-Shabrawey joined Oakland University William Beaumont School of Medicine in August 2021 as a Professor in the Department of Foundational Medical Studies and a Founding Director of the Eye Research Center.

His extensive research and success in receiving NIH funding as well as other agencies will bring extensive value to the Board as we continue to grow and expand. A forward and positive thinker, Dr. Al-Shabrawey will no doubt be an asset between the PRRL and PRRF Board. We are looking forward to doing great work together.

Dr. Mohamed Al-Shabrawey earned his medical degree (MBBCH), M.Sc., and Ph.D. from Mansoura University in Egypt. He moved to Michigan from Georgia with his wife and children upon accepting his new role with Oakland University.
What to Expect When You Don’t Know What to Expect

By Stephanie Brennell, PRRF FAC Member, Proud Mom of Sean

Has anyone out there with children not heard of the book “What to Expect When You’re Expecting?” Written by Heidi Murkoff during her first pregnancy in 1984, the original edition has been updated five times over the years. Numerous spinoff works include titles such as “What to Expect When Your Wife is Expecting” and “What to Expect the First Year.” The website www.whattoexpect.com proclaims to be the most trusted pregnancy and parenting “brand.”

I never read “What to Expect When You’re Expecting,” or any other baby book for that matter. My approach to most things in life has always been to sort of wing it…and hope for the best. Perhaps by the grace of a higher power, I’ve done pretty well so far - though there are days I wish a guidebook existed for those of us raising a child with a rare and unexpected diagnosis.

I remember the shock and the crushing weight that came with our son Sean’s diagnosis of Norrie Disease when he was four months old. I felt like my brain was melting down; I couldn’t comprehend any information we were receiving from specialists. What in the world is Norrie Disease? I’ve never heard of it. How can our child have this unfamiliar condition that I’ve never heard of? How did he end up with it? And most importantly, how do we fix him? The unexpected diagnosis of a severe visual impairment in your infant is beyond life-altering.

We are now seven years into our journey and one of the most important lessons I’ve learned is that there is no easy “fix” for Norrie Disease or any of these rare retinal diseases, but that’s okay – our children were not born broken. There is no need to try to fix anything. You quickly realize that different does not equate to less. A child with a disability (or multiple disabilities) can be an amazing teacher for those who are willing to be
receptive. There is certainly no one-size-fits-all approach when it comes to offering advice to other families. I’m sure there are many helpful books out there written by parents or experts on disability. I haven’t read any, though I would be curious to know if anyone is promoting the #1 “brand” on disability parenting…

In this house, we march on – learning as we go, trusting the guidance from many experts in our circle, and loving our child fiercely. Below are just a handful of the lessons we have learned along the way that I offer as advice to someone new to the journey. Read more...

https://www.pediatricrrf.org/personal-stories

**Family Connection Conference**

To say that our very first annual Family Connection Conference was a success would be an understatement. The Family Advisory Committee comprised of families and patients affected with rare eye diseases put on an event touching families from around the world. Of course, this would not have been possible if the event was held in person. Our team pulled it off virtually!

The day began with answers from our very own renowned physicians, Dr. Capone and Dr. Drenser, to live Q&A from the participants. The participants then joined break-out rooms. Each room was led by a member of the Family Advisory Committee with rooms organized by age groups (Birth-Pre-K, K-6, 7-9, 10-12, and College). The rooms offered a forum for participants to ask questions and receive answers from parents and caregivers with real-life experience.

The highlight was our guest speaker, Brandon Werner, who is currently working as an Accessibility Analyst focused on making websites and software easier to use and accessible for everyone at the University of Michigan. A true success Story! Our day ended with an additional Q&A with our expert doctors.

Our goal is to build a community of people to share their experiences in a safe place for those just beginning their journey. While we knew the community could not come to us in person during these difficult times, we brought the community together from locations throughout the world. The conference had representation from Saudi Arabia, United Kingdom, Belarus, Italy, India, Panama, Australia, Canada, Indonesia, Greece, Lecco, Malaysia, Jamaica, Singapore and the United States.

Now we are off to planning the Family Connection Conference 2023. Look for a save the date in the coming months!
Year End Campaign

We are thrilled to share an update on our 2021 year-end fundraising campaign. This year's campaign focused on the tremendous need for continued research funding to expand upon the initiatives at the Pediatric Retinal Research Lab at Oakland University. In 2023, the Foundation is proud to announce that the first therapeutic drug treatment for FEVR will be entering Phase I clinical trials! In addition to this effort, we’re excited to kick off concurrent research into other therapeutic options for pediatric retinal disease patients.

With the support of our amazing donors, we raised $41,347 - which will be DOUBLED by two very generous anonymous donors!

We look forward to sharing updates about the impact these donations have made to research projects.

Patient Video Series: Featuring Aria L.

Thanks to a very generous and passionate PRRF family, we were able to develop a video series highlighting the impactful stories of children and families affected by rare pediatric retinal diseases. This video of Aria and her family is the first of four videos that take you on a journey with Aria’s mom and dad as they first learn of their child’s diagnosis to challenges along the way. Aria’s story also shows how they’ve persevered and always encourage a positive outlook. https://vimeo.com/663131592
Help sustain the work of the PRRF by signing up to be a monthly donor! A gift of just 65¢ per day ($20 per month) will allow the Foundation to increase community programming and advance further research.

https://secure.givelively.org/donate/pediatric-retinal-research-foundation/prrf-donations

The PRRF Family Advisory Committee Community private Facebook group is designed to provide community, support, education, news, and links for families with children touched by retinal diseases.

https://www.facebook.com/groups/423667939118420

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STAY CONNECTED

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