Dear PRRF Community,

These are exciting times as the PRRF continues to grow in both size and scope. In this issue of Sightlines, I'd like to provide some insight into the activity and engagement of our Foundation.

Our Family Advisory Committee (FAC) has grown to be an active group, with regular meetings and at our annual Family Connection Conference and workshop offerings sharing real-life experiences and stories from the family, and children/adults impacted by pediatric retinal diseases. This committee serves as the voice of our constituency, helping the Board and staff to stay focused on the needs of the children and families whom we serve. By virtue of their input, we don’t have to intuit or divine which direction to move in. The FAC is our partner in the directional leadership of the PRRF.

As part of the PRRF’s Strategic Plan for 2022, we convened a Research Advisory Committee (RAC). Research is a core mission of the Foundation, and we have a long and robust relationship with Oakland University’s Eye Research Institute where the Pediatric Retinal Research Laboratory (PRRL) is housed. The mission of this committee is to provide the Board with an opportunity for input into the PRRL’s research activities and means for the Board to stay abreast of ongoing research activities. Look for quarterly research updates here in Sightlines.

We are also working on an exciting new podcast initiative. In the last 2 years, we have increasingly focused on the challenges many young adults with pediatric retinal diseases face in transitioning from high school to college, and then from college into the working world and society generally. On the initiative of Board member Dr. Patrick Droste, whose passion for this issue has guided our focus on the topic, we are sponsoring the development of a podcast by and for those in our community from when they enter high school through to their late 20’s. This is an exciting project with a dyad leadership model, with Board members partnering with our bright and talented young adults to bring this project to fruition. Look for more news on this topic in the months to come.

Our staff and Board family continue to grow as well. Heather Tull joins us as of July 1 to
provide sorely needed administrative support to our Foundation Director Stephanie Saville and Community Outreach Coordinator Luisa Recchia as they continue to power the growth momentum of our Foundation. Additionally, we are thrilled to announce the newest member of our board, Alex Dobin, highlighted below.

We are also growing on the development front. New for 2022, we are expanding our giving programs. Below you’ll also read about the 2022 Hope for Vision Walk/Run. This year’s event features a new venue to allow in-person participants to make a day of it with their families if they wish, a run as well as a walk, and the opportunity for both in-person and remote participation will combine for a memorable event.

We thank those who support, fund, and donate to help us in this work. If you’ve not contributed, please consider joining us to whatever degree you can. If you’d like to volunteer, you can see from the above that we can use your energy and input! And if you have any friends or family whom you think would be excited by our mission, vision, and values - it’s an inspiring time for the PRRF - invite them to join us and share this issue of *Sightlines*.

With gratitude,

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 Alex Dobin as a new board member. Alex is the senior HR partner of Federal Affairs, FPL Corporate, and Customer Service for NextEra Energy, Inc. (NYSE: NEE), a leading clean energy company.

Alex is based in Florida expanding the reach of PRRF outside of the state of Michigan. We are excited to add another dedicated parent to the board!

**2022 Hope For Vision Walk/Run**

*Sunday, September 11, 2022*

8:00 am ET Registration | 9:00 am ET Walk/Run

We invite you to gather your friends, family, and co-workers to form a Walk/Run team or join as an individual participant. This family-friendly fun walk/run is open to all ages and abilities. The run will NOT be timed, but race bibs will be provided to all participants.

Participants can walk or run up to 6.2 miles on a
paved trail loop at Stoney Creek Metropark. Each mile will be marked along the trail for easy tracking & turn-around points. Virtual participants can choose the distance of their Walk or Run as well.

We invite ALL participants - virtual and in person - to join the post-event LIVE program. Details on how to join will be emailed to all virtual participants in advance.

More Info & Sign Up

Donate

Sibling Revelry

"If you want to know how to treat a child with special needs, look at their sibling…they will show you." I have no idea who wrote this quote, but I really like the sentiment. At the same time, I hate the phrase “special needs” in terms of a specific population of people or description of my son, in particular. I get lazy and do use it because it is such a widely accepted term, but I don’t like it. None of us have needs that are otherworldly. We are all unique and special in our own way. Those who have disabilities or learning deficits may require an extra level of support or accommodation, but whatever their needs may be – they fall within the realm of normal human interaction in a civilized society. There is no shame in possessing a disability or differing abilities, and many experts recommend using
the term “disabled”. I’ve been pondering this issue for quite a while and haven’t come up with a brilliant new way to rephrase or re-frame things, so I’ll save that endeavor for another time and move on to the bigger picture.

The most unexpected and jarring news I’ve ever received was delivered by a medical professional, but it was not delivered by the ophthalmologist who delicately informed us our infant son was blind. It was delivered by the ultrasound technician who nonchalantly mentioned two embryos as I was lying on the exam table at the high-risk maternal medicine center. She thought our normal OB-GYN had already informed us, hence the reason for our evaluation that day. In fact, we were there because I was over 35 and considered geriatric in pregnancy terms, and because I had needed an emergency c-section when our first son was born. In any event, we were floored, and she was mortified for so casually delivering such a shock to completely unsuspecting parents. I was stunned. I was completely overwhelmed. And I was beyond excited. Twins are always best friends, right? Don’t they possess some sort of secret, mysterious, unspoken connection, or communication? These are things I thought to be true, and they are questions I get asked quite often. I always dread having to answer…no, not really. Not with all twins. Not with my twins. Read more...

2021 Tribute Gifts

We want to recognize and share an appreciation for the following generous donors that gave a tribute gift in 2021:

In Memory of Ann Abbruzzese
Arthur Abbruzzese
Cynthia M. Barton
Gloria A. Bella
Eleanor Cooper
Frederick LaCoppola
Linda Putnam
Helen Vass Burke
Gina M. Ward

In Memory of David Giudici
John N. Craig
Carol A. Rossetti

In Memory of Dr. Glen Robert Lange
Donna N. Armstrong
Joan R. Bartlett
Patricia A. Cardellio
Emily Ward-Culp

In Honor of Megan Vida
Lonny McDougall

In Memory of Michael M. Wild
The June and Cecil McDole Charitable Fund

In Memory of Dr. Paul Fecko
Katherine Burland
Consultants in Ophthalmic & Facial Plastic Surgery, PC
Joan E. Forgrave
John Michael Garrett
Joseph E. Grinnan
Bonnie Lou Gregory
Kimberly Hart
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Ralph Tyler Perkins, Jr.
Leslie A. Touma
Nancy R. Touma
Katherine White

In Honor of Guilliana
David Murphy

In Honor of Isaac Askenazi
Diana Sreter

In Honor of Megan Vida
Lonny McDougall

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Marilynn A. Jakubowski
Michael J. Kane
Ralph Tyler Perkins, Jr.
Leslie A. Touma
Nancy R. Touma
Katherine White

In Honor of Guilliana
David Murphy

In Honor of Isaac Askenazi
Diana Sreter

In Honor of Dr. Venkat N. Reddy
Victor R. Leverenz
**In Honor of Juliana & Marissa Abbruzzese**

Holly Sue Pellis

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**PRRF FAMILY ADVISORY COMMITTEE INVITES YOU TO JOIN US FOR**

**Sibling Revelry**

**Tuesday, August 23, 2022**
7:00 pm - 8:00 pm ET

Stephanie Brennell will discuss sibling relationships - how they look different in every family and the importance of educating young children about disabilities and differences in others.

Register Here!

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.

Donate Now

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PRRF | info@pediatricrrf.org | www.pediatricrrf.org

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