



SIGHTLINES | The PRRF Newsletter

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

Ready to get involved? PRRF could use your help in a variety of ways. Take a look at the options and pick one that interests you.

[Volunteer](#)

Letter from the President

Dear PRRF Community,

In the last year the PRRF has strung together an impressive list of accomplishments. In the last 12 months we have:

- launched the Foundation's new website www.pediatricRRF.org
- resumed publication of this, the Foundation's quarterly newsletter **Sightlines**, with Dr. Lisa Faia at the editorial helm
- deepened our engagement with families of the children for whom we care
- begun our focus on educational advocacy as suggested by our parent community, with Karen Hoogland authoring our *Focus on Advocacy* series - soon to be joined by Donna and Chuck Walls
- developed and refined the PRRF "brand" - logo and color schematic for the website and letterhead
- developed fundraising materials (introductory fund-raising letter, brochure, envelopes, donor cards) to support such initiatives

For all of these accomplishments we are deeply grateful to our dedicated PRRF Board, the hard work of Andrea Bennett (for design of the website and **Sightlines**), Rachel Decker (for spearheading our year-end fundraising campaign), and especially, the support of our PRRF community.

To top this all off, we undertook a year-end capital funding campaign hoping to raise \$50,000 for purchase of a new gene sequencing technology. Through the incredible generosity and initiative of our PRRF community we have raised nearly \$80,000. This purchase greatly expands what we are able to offer our families in terms of free genetic testing and significantly broadens the PRRF's research capabilities at the Pediatric Retina Research Laboratory.

As you can see from what we have all been able to accomplish together in 2018, we are on a roll. It has been an extraordinary year, and we are not stopping here. We are doubling down. In 2019 we seek to continue to inspire emotional connection to the mission of the PRRF and strengthen our infrastructure. If you have the time and energy to volunteer – we need you! We can use help in the following areas:

- anchoring our social media initiative
- shoring up our contact database
- staffing our crisis support team
- serving as a liaison to donors and those interested in fund-raising

To connect with us about volunteering visit pediatricrrf.org/volunteer or email us at info@pediatricrrf.org.

Heartfelt thanks to all who have been involved in making 2018 such a success. Enjoy this issue of **Sightlines**, as we set our sights on an even better 2019.

Sincerely,

Antonio Capone Jr. MD

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

On the Research Front

With the great news about raising money for a new generation sequencer, I thought it would be a good time to better explain how this technology helps develop new treatments. Starting in 2003, the first ophthalmic biobank was created with the help of ROPARD and the Margaret Walters Foundation. An automated sequencer (a machine that evaluates one gene at a time) was purchased, and the DNA of hundreds of patient samples were analyzed. The genetic information from this database identified a pathway that is specific and necessary for a developing retina. More importantly, it looked like we might be able to turn this pathway back on and treat children and adults with Familial Exudative Vitreoretinopathy, Norrie Disease, and Osteoporosis Pseudoglioma Syndrome. The goal is to have this therapy in clinical trials in the next 12-18 months.

NextGen sequencing allows for multiple genes to be tested simultaneously. We now will have the capability to screen more genes and query more pathways faster and more effectively. The goal is to identify new treatments in different diseases through the continued growth of the biobank. This includes Congenital X-Linked Retinoschisis, Coats Disease, Sticklers Syndrome, Best Disease, and others. Only by having a concentration of rare vitreoretinal diseases samples that are safely warehoused can this kind of discovery and research occur. I am excited to start our new NextGen sequencing and sharing our findings, and hopefully, new treatments, with all in the future.

~ Dr. Kim Drenser

On a Personal Note



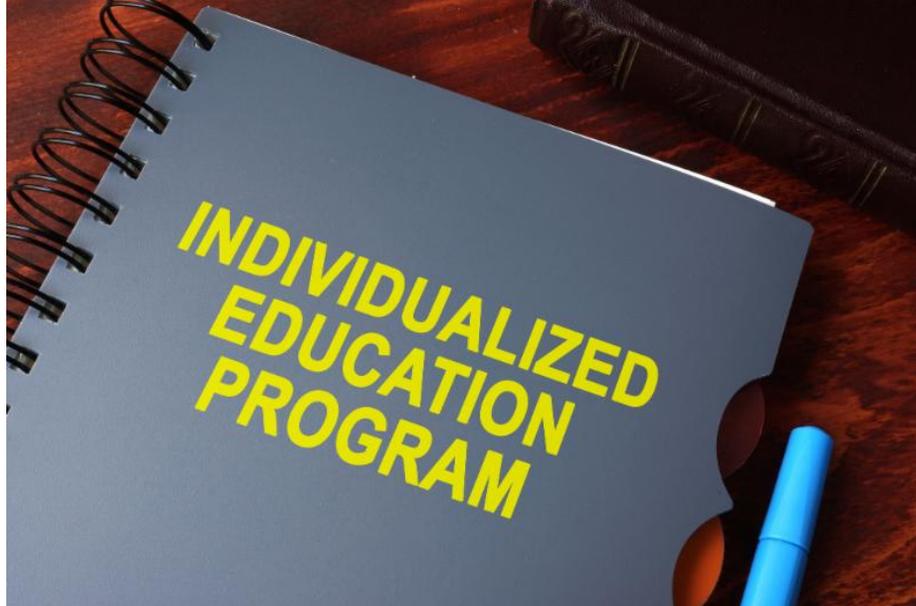
Meet the PRRF Board

Kay White Meyer joined the ROPARD board in 1995 after chairing ROPARD's major fundraising event, "The Artful Garden", for three years. "I became interested in ROPARD because of Dr. Trese's passion for research to prevent blindness in small babies, especially premature infants. I realized that "The Artful Garden" combined two of my main passions – art and gardening- as well. The idea that children could someday also see these beautiful creations as well as I do made volunteering to help an easy choice."

She is active with several Oakland County organizations, including volunteering for 35 years on a crisis hotline and also serving as board chair of the same organization. She was president of the Village Club Foundation.

Kay feels she brings a layperson's point of view to "a group of highly talented doctors". She is very excited about the new research which PRRF is funding and nurturing. Kay has seen the progress which was made in treating retinopathy of prematurity and is looking forward to the same success from the current projects which are sponsored and supported by volunteers, parents, and the physicians themselves.

Focus on Advocacy



What is an IEP?

There are many important acronyms involved when discussing special education, but the first one that you will get familiar with is an IEP. This stands for Individualized Education Program. An IEP is a 10-15 page (or more) legal binding document that is a mutual agreement between parents and educators that blueprints your child's educational pathway and progress every year. It includes all the names of your child's service providers. You and all these educators attend the IEP meeting that is held at the same time every year.

There is a section in the IEP that is titled, "Special Education Services." For example, on my daughter's IEP, it states that she has a TCVI (Teacher Consultant for the Visually Impaired) and O&M services (Orientation and Mobility Instructor) for properly learning how to use her cane. She also is in a resource program for Math. It states specific amounts of time and frequency of her sessions. Another section in the IEP is Supplementary Aids and Services. An example from my daughter's IEP would be that she has a one-on-one paraprofessional to braille all her materials for her and be her school advocate. More examples are that she needs a bigger desk in math class for all her math tools, more time to travel the hallways, and reduced homework assignments. With her being in middle school now, an accommodation that I voiced my concern about was that she had one hour of an academic support class/study hall so that time/class can be used for catching up on work and for scheduling her outside service time with her TCVI and O & M. I personally feel this is very important so that she is not missing instruction during her academic core classes. Your child's IEP may look different because it will be their own map of their specific needs.

Honestly, for years I was very overwhelmed with all the paperwork involved in an IEP. I did not understand what it all meant and just trusted the team to carry us through her plan. Finally, when my daughter was in fourth grade, a friend of mine sat down with me and explained to me page by page what it all meant. She pointed out to me that Section 4 (Schedules) could be very beneficial to me as a parent by stipulating that I wanted weekly reporting from her service providers. It says "Grading Period" by default, but you can request it to be daily, weekly, monthly, etc. This was very helpful to me as my daughter had two service providers who were not showing up for their service time and were not following the IEP plan. Needless to say, they both got in trouble for the IEP being out of compliance. This is the school year I finally "wised up" and dug into the fine details. It is very important to have both parents present at the IEP meetings. If that is not possible, I recommend having a family friend or special education advocate attend with you. Sometimes these meetings can be very overwhelming.

The advice I would love to share with you is to have an education advocacy binder for your child. My daughter's binder is tabbed in this order: IEP's (all of them in order by year), medical concerns, technology concerns, school concerns, email-paper trails (promises from educators), calendars (to keep track of outside services), progress reports, achievements/certificates, and highlights. I bring this binder with me to every IEP meeting. If there is ever a question at the meeting regarding any of these subjects, the answers are right at your fingertips. It is also very effective to email the team or send a follow up email to a phone call. Paper trails are powerful!

To conclude, you are your child's biggest advocate. It is so important to study their education plan and ask questions if you do not understand it. I have been present at other IEP's as an advocate and it puzzles me as to why some of the parents do not talk at the meeting. You know your child more than anybody else in that room. You are their voice. As your child gets older, they can also attend the IEP meetings. It is important to be that role model to them as they hear you speak on their behalf so they can learn how to properly start advocating for themselves.

Car Show And Silent Auction To Benefit PRRF

Saturday July 20, 2019
11 am - 4 pm

Garage Kept Motors, 420 36th St. SE, Grand Rapids, MI 49548
Cost: \$10/Person or \$25/Family - Free Parking



The purpose of this fundraiser is to:

- Generate funds for research in pediatric retinal disease performed by the Pediatric Retinal Research Foundation (PRRF) centered at Oakland University in Rochester, Michigan.
- Provide a forum for car enthusiasts to interact with visually challenged patients of all ages.
- Provide a morning educational session with brunch to explain about the studies being performed at the PRRF research laboratory.
- Provide a forum for visually impaired children and adults to interact with trained mechanics from Garage Kept Motors to learn about engines and car design and hands-on interaction with classic and new automobiles.
- Provide an exhibit with military and public safety vehicles for visually and non-visually challenged participants to interact with.
- Have a live and silent auction of automobile related activities, adventures (race tracks) and items/memorabilia to generate funds for the Research Laboratory of the PRRF

Anyone interested in registering a car, (we are looking for all kinds, old and new) sponsoring an event or workshop (oriented to the visually impaired population), or donating auction items, please contact Heather Raschke at:

Pediatric Retinal Research Foundation
39650 Orchard Hill Place, Suite 200 Novi, MI 48375
(248) 319-0161 x1026 | hraschke@arcpc.net

We are also looking for contacts that can help us provide military vehicles of all types, police, emergency/riot vehicles, etc.

We are hoping to make this a very special event. Please contact the foundation with any recommendations or ideas. Thank you!

Help us support families impacted by blinding pediatric retinal diseases
and champion the quest for a cure.

Donate

STAY CONNECTED

