Letter from the President

Dear PRRF Community,

This issue of *Sightlines* is full of news about PRRF’s efforts in support of our community.

On the fundraising front, Dr. Patrick Droste provides an update on the very successful inaugural **CARS FOR A CAUSE** fundraiser. The event was great fun for all who attended. It also provided an opportunity to meet with the research team from the Pediatric Retinal Research Laboratory at Oakland University. Our next event – the first **HOPE FOR VISION WALK** - is coming up on Saturday, September 28, 2019 in Birmingham, MI. All are welcome: music, pre-walk Zumba session, the walk itself, auction items - will be a great way to spend a Sat a.m. with family/kids. If you can’t attend, please consider **contributing**. If you can attend - **walk and contribute**. If you can’t walk - please join us for the fun anyway! Hope to see you there - it’s sure to be a fun fall event!

The PRRF’s social media initiative is underway – our new **Facebook** page just went live, under the leadership of Courtney Birchmeier. Our community is already connected in many ways, often on disease-specific social media groups. The new website will serve as a central location for information and community support.

We continue our **Sightlines** series on educational advocacy - you can find even more information on our new **Educational Advocacy page**.

The PRRF continues to grow and thrive thanks to the efforts of dedicated and talented members of our PRRF community. We are deeply grateful to all who work to make it possible.

Sincerely,

Antonio Capone, Jr. MD
President, The Pediatric Retinal Research Foundation (PRRF)
Mark your calendar to join us for our inaugural Hope for Vision Walk benefiting PRRF on Saturday, September 28, 2019 in Bloomfield Hills, Michigan. All proceeds from the Walk will fund continued research efforts to discover treatments or cures for retinal diseases which affect infants and children daily. Click here to register or donate. We hope to see you there!

Cars for a Cause Fundraiser Update

Successful Inaugural Event

Cars for a Cause West Michigan took place on July 20, 2019. It was met with tremendous success for a first-time event by enthusiastic car devotees from west Michigan reaching as far as Flint. Garage Kept Motors partnered in this event to host the car show at their new location. They had 100 cars located in their facility and another 80 cars showed for the event. A rough count of 280 patrons took part in the event which included entertainment and booths (cookies, puppies and T-shirts) by blind and visually impaired young adults, as well as a local DJ and food trucks. The 100+ degree weather and storms that wreaked havoc the night before and the afternoon of the show in Grand Rapids, didn’t hamper the energy of the event. The gross profit of approximately $28,000 was an incredible indication of first-time success - half of which will be directed to the PRRF. Cars for a Cause West Michigan is deeply grateful to all those that participated and financially supported the event. We are planning to repeat the event on July 25, 2020. We are requesting support for additional donors to raise funds for much needed equipment for the pediatric retinal genetic research laboratory.

~ Patrick Droste, MD
On the Research Front

The New NexGen Sequencer Is Up And Running!

The pilot test was flawless and the new Wnt-pathway gene panel is expanded to cover 10 genes associated Familial Exudative Vitreoretinopathy, Osteoporosis Pseudoglioma Syndrome, and Norrie Disease. In addition, this can be helpful in better understanding and diagnosing Coats’ Disease, Persistent Fetal Vasculature Disease, and Retinopathy of Prematurity. The high-through put technology allows for faster gene analysis and more samples to tested simultaneously. Our pilot run showed extremely valid sequence analysis and is an exciting first step to an improved Biobank sample analysis. The goal is to continue providing Wnt-pathway gene testing while expanding our ability to test for other rare disorders, such as those affected by changes in collagen. Many of these vitreoretinal disorders result in retinal detachments, such as Stickler’s, Wagner’s, high myopia, and congenital retinal detachment. As we gather genetic and pathway information on these samples, we will be able to direct new research for disease identification, patient management and new therapies.

~ Kim Drenser, MD, PhD

On a Personal Note

An Interview With Ben Conti

Ben is a senior at Cranbrook School and busy with all the activities that the last year of school includes, especially tennis and hockey.

But Ben has had vision problems all of his life, including multiple eye surgeries and patching for stabilization. Now he wears both contact lens and glasses all day, every day, and is comfortable doing everything using these tools to help him see well.
Ben was aware that his family was able to afford the treatments for his sight and wanted to help other children with the expenses of vision problems. He organized three tennis tournaments as fundraisers for VRRF. The biggest challenge was figuring out how to organize the tournaments, but once he decided that they should be fun and inclusive, the rest fell into place. About 80 kids participated and these three tournaments raised $18,000.

Ben has plans to major in business, international relations, or chemistry when he goes to college next year, but in the meantime, he has majored in heart. His empathy for other children with vision problems meant that many others benefitted from his drive and caring.

Thanks, Ben!

~ Kay White

Photograph courtesy of Ben Conti

Focus on Advocacy

Assistive Technology and Helpful Advice As The New School Year Begins

Technology today allows low vision and blind adults to be more employable. I do not claim to know every single adaptive device that is available, but my child has used many of them. The key is to have a lot of tools in their toolbox. The more they know, the better.

In MY personal opinion, I believe Apple products are the most accessible to the visually impaired community. Apple has an option to turn voice over on their devices including iPhone, iPad, iPod, and Apple Watch. Voice over is found on the settings application of the device. It is quite comical to be around a group of visually impaired individuals when they are all swiping with voice over commands on their Apple devices. I think they have a competition as to who has the voice set at the fastest speed, and quite frankly, it drives me nuts! There are 2 finger swipes, 3 finger swipes, and so on. When you swipe the screen until you hear what application you want to open, you can double tap anywhere on the screen. There is also an option for braille screen input. You access it this way: General, Accessibility, Voice Over, Rotor, Braille Screen Input. When you go to type something, such as a text, you do a 2 finger twist to activate braille screen input. Now you can type with your braille fingers right on your touch screen! I have been fascinated watching my daughter learn all these things on her own and learning it from other blind users through the years.

American Printing House for the Blind (APH) has many adaptive devices for blind and low vision users. They are very costly! There is a new Braille Trail Reader LE. It has 14 braille cells and can be paired to use with an iPad with voice over on. It is currently $995. What parents don’t know is that most items ordered from APH are FREE! If your child has a Teacher Consultant for the Visually Impaired (TCVI), they have the authorization to order these expensive items from the APH catalog with federal quota funds. I recommend that every parent go to www.aph.org and order a catalog for home. Whatever you feel your child could benefit from, tell his or her TCVI that you would like those items ordered. APH sells many other useful items such as magnifiers, color identifiers, slate and stylus, clothing labels, and much more for all ages.

If you haven’t heard of Humanware, you will want to get familiar with their website: www.humanware.com. They sell very expensive but beneficial devices for our kids. Unfortunately, these devices are not covered by federal quota funds. My daughter uses the BrailleNote Touch. It is approximately $6,000! It is absolutely amazing! It is the size of an iPad and has braille keys with a braille display. There is also a touch screen that you can use with your brailling fingers. You need to stipulate in your child’s Individualized Education Plan (IEP) that the TCVI uses their service time to teach your child how to use this device. My daughter organizes all her classes and homework on this device. Her special education director purchased this for her to use in school. It is school owned, of course! Your school district HAS to provide assistive technology for your child to help them be a success in school. Here is your crutch …If they can provide computers,
iPads, MacBooks, etc. to sighted kids, they HAVE to provide a device that is accessible for your blind or low vision child. If your request is initially rejected at the IEP meeting when this is mentioned, all you have to do is say the acronym “FAPE” (Free and Appropriate Public Education). I have had to use this a few times! As I have said in a previous article, learn your special education acronyms in your provided special education parent handbook! Knowledge is powerful! If you have done your homework as a parent and know what you are asking for or are talking about, you are more likely to get what your child needs in school. Also, a powerful piece of advice is to not rely on your child’s paraprofessional to do all the advocating. They won’t get as far as parents will advocating for their own child.

**JAWS** is talking software to use on a laptop. As I have said before, your child needs to have a lot of tools in their toolbox. JAWS, however, is very costly! My daughter has many older blind mentors. She was recently told that it is very beneficial to learn Non-Visual Desktop Access (**NVDA**). It is similar to JAWS, but it is free! Why NVDA vs. JAWS? An employer would more likely consider them if they don’t have to purchase $1,000 software to do their job.

Lastly, and this is not related to technology, I have heard a lot of parents complaining about their kids not getting to pick electives in school because of service time with their TCVI and Orientation and Mobility (O&M) Specialist. There is a way around this! My daughter takes choir. I never allow that hour to be touched. Our kids work harder than the average student in school. They deserve a fun elective. Her other elective is guided studies or academic support to catch up or get a head start on homework. If your child is in middle or high school, typically the day ends sooner than elementary hours. The service providers in our area work until 3:45 or 4:00 p.m. You have the right to request an after school lesson. We have one after school lesson with each provider and another lesson with each provider during the guided studies hour. This way she does not miss any academic instruction, like English, Language Arts, or Math, and she gets to have at least one fun elective! You have the right to request this as the parent.

~ Karen Hoogland

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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](#)

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

[Donate](#)