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. Visit https://www.pediatricrrf.org/volunteer/, take a look at the options and pick one that interests you.

Letter from the President

Dear PRRF Community,

In this issue of Sightlines we continue to extend our focus on supporting both our community and our research initiative.

We are very excited about our upcoming inaugural CARS FOR A CAUSE fundraiser (see below), spearheaded by long-time Board Member, Dr. Patrick Droste. This event will raise funds to support research conducted by the PRRF with a fun-filled and informative day for members of our PRRF community and our supporters. The Grand Rapids Lions Club is the 501(c)3 organization sponsoring the event, and we are also generating funds for Opportunities Unlimited for the Blind (OUB), whose mission is to create independent productive members of society who integrate in a sighted world. Please join us for this very special family event!

The PRRF is also expanding its social media initiative under the leadership of our newest PRRF volunteer, Courtney Birchmeier. With Courtney’s help we are looking to forge a social media strategy, create a new Facebook page to post events and other information, and evaluate analytics - all in the interest of communicating as effectively as possible with the PRRF community.

In the next few weeks, look for a new Educational Advocacy page on our website, the information-rich culmination of a collaborative effort of deeply dedicated PRRF parents and Board Members.

We are also excited to announce our first HOPE FOR VISION WALK fundraiser on Saturday, September 28, 2019 in Birmingham, MI. More to come on that fun fall event as well!

There is a lot happening! The PRRF continues to grow and thrive thanks to the efforts of dedicated and talented members of our PRRF community. 2019 is looking to be a very exciting year for our Foundation. Thanks to all of who work to make it possible.

Sincerely,

Antonio Capone, Jr. MD
President, The Pediatric Retinal Research Foundation (PRRF)
Cars for a Cause Fundraiser

Saturday, July 20, 2019 | 11 am - 4 pm
Garage Kept Motors, 460 36th St. SE, Wyoming, MI
Sponsored by the Grand Rapids Lions Club

Cars for a Cause will be a fun filled day for the whole family!

View Classic, Collector, and Specialty Cars
Food
Entertainment
Silent Auction
Educational Programming

This inaugural fundraising event is designed to raise funds to support research conducted by the Pediatric Retinal Research Foundation (PRRF). Genetic research for blinding pediatric retinal disease requires tremendous capital to purchase equipment, maintain funding for current studies, and research grants. With well done research, we hope to find ways to diagnose and treat pediatric retinal diseases such as, familial exudative vitreoretinopathy (FEVR), Norrie disease, congenital X-linked retinoschisis (CXLRS), retinopathy of prematurity (ROP) and other pediatric retinal diseases.

For more information about the event and how you can support the initiative click here.
New Social Media Focus

Within the next several weeks the PRRF will be launching a new Facebook page to help support and expand our community and strengthen the relationships we’ve formed so far. We know that many Facebook groups exist around the topics of pediatric retinal diseases and we hope our new page will add to your social experience surrounding these topics. We'll share information about the foundation, the diseases themselves, personal stories of those affected, PRRF events, research, and so much more.

Whether you’re affected by a pediatric retinal condition yourself, are a parent or family member to someone who does or are simply interested in helping PRRF further its mission, we invite you to “like” our new page once launched. We welcome your feedback and can’t wait to connect with you on Facebook soon.

~ Courtney Birchmeier

On the Research Front

Regenerative Medicine

Regenerative Medicine is a concept that has been discussed for many years. Usually it has been around the thought that a "stem cell would be introduced, and it would take over the lost function of that tissue or organ." The thought of the stem cell being able to regenerate tissues or organs has shown very little success. In fact, several charlatan stem cell centers have been harming patients and eyes for several years and now at least in the United States these centers are being policed.

In 2017 the then Commissioner of the FDA issued a statement in which he said, “the ability to regrow organs is no longer science fiction and is within the scope of modern medicine.” Well, how is that being done? There are at least three areas of interest when it comes to regenerative medicine:

1. The genetics of the tissue or organ are such that they can support growth of a healthy structure,
2. The proper cell type be supplied, and these cells introduced from outside the body or they maybe progenitor cells (a cell which is dormant in your body and can be awakened to differentiate into the cell that is needed), and
3. An appropriate microenvironment is needed to support the growth of these structures and perhaps appropriate reactivation of genetically corrected cells to form working organ systems.

Is all of this available today? No, not yet, but many centers, including ours, are hard at work on this project. Our center works largely on the microenvironment and is making progress monthly. This is largely due to the generosity of donors supporting the Pediatric Retina Research Laboratory. Thank you for your support. It is making a difference we hope to be in human trials at the end of 2020.

~ Dr. Michael Trese
On A Personal Note

Meet Jules...

The first thing Jules told me was that she had joined a ski club and that she also plays unified soccer and basketball for fun. Jules, who has been blind since the age of 3 due to retinopathy of prematurity, said that she needs people on either side of her to guide her when she skies but basically, she does lots of the actual maneuvering herself.

Jules explained that she has a prosthetic eye now after one eye caused her great pain and needed to be replaced. She uses a cane and also has a full-time aid who reads braille to help in her middle school. She said that a big challenge is memorizing the routes inside her school, especially since next year she will be going to high school, which is even larger and more complicated.

In classes Jules has a variety of tools to help her, including braille math books, calculators, and braille screen tablets. She loves to read with her fingers and would like to be a writer someday.

Jules is a delightful young woman and an inspiration to all who live with vision problems. Despite being visually impaired, she continues to move on with her life, learning in every possible way with appreciation for the aids that help her navigate the world.

Jules sees Dr. Capone and Dr. Droste once a year each to make sure all is going well and is glad of their care. It is through this foundation that future innovations will be made for children and adults with her disease.

~ Kay White

Focus on Advocacy

Low Incidence Support in Your Area

Low-incidence disabilities are ones that are more uncommon such as visual impairments, hearing impairments, physical disabilities, other health impairments, autism, and multiple disabilities. The likelihood of a low-incidence disability is ½ or 1% of the school’s population of the students with a disability.

It is extremely important that you find your local low-incidence outreach program. I am located in Michigan and the Michigan Department of Education Low Incidence Outreach has been my go to place. This is where most of the braille school books in Michigan are produced. They also have a lending braille book library for home and school. They can mail the adapted academic books they will be using in class or even to read for leisure. They also offer services for the hearing impaired.

They offer many amazing classes. I have taken a 16-week braille course and a few assistive technology courses. Every time my daughter is provided with a new piece of technology to use in school, I take a beginner’s class through
MDE-LIO just to get a basic knowledge of how it works. Some of them include: BrailleNote for beginners, JAWS, Refreshabraille 18, BrailleNote Touch, Duxbury for beginners, and Tactile Graphics. Even more helpful is that a visually impaired person usually teaches these classes giving you an idea of how accessible it really can be for your own child. MDE-LIO just recently started offering an online braille class too.

Our local low-incidence outreach program also offers an extremely important service that I took advantage of. They will assess students regarding assistive technology and orientation and mobility. This service has been extremely helpful and free to us. It helped gauge what my daughter knew and did not know regarding both topics. We received a long report as to what her strengths and weaknesses were and where she should be at for her grade level. This report helps you know what to advocate for. You can request to amend or modify their current IEP with these recommended changes.

Because assistive technology is so expensive for the blind and visually impaired, it is helpful to be able to try it before you buy it! MDE-LIO will loan us these expensive devices for a period of time to see if it is easy to learn or practical. This has helped us when the school district offered to purchase the Braille Note Touch. The special education director observed my daughter using it with her TCVI first to see if it was a tool that she could easily learn to be successful in school.

Last but not least, MDE-LIO has collaborated with our Michigan parent support group. They often come to our weekend retreats and teach our kids some very beneficial life skills. Some of the things they have taught is: proper money folding to help identify currency, pouring, spreading, cleaning, self-advocacy skills, and much more.

Given these topics that a low-incidence outreach program assists with, it is so comforting to have a very supportive program that can help you with your child. Let's face it... parenting a child with special needs is not easy but knowing about helpful resources make it so much more manageable!

~ Karen Hoogland

Source: [https://www.sst16.org/content/low-incidence-and-autism](https://www.sst16.org/content/low-incidence-and-autism)

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**SAVE THE DATE! Hope For Vision Walk – September 28, 2019**

**HOPE FOR VISION WALK**

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. Stay tuned for more details about how you can participate and support this great cause!

Help us support families impacted by blinding pediatric retinal diseases and champion the quest for a cure. Visit [https://www.pediatricrrf.org/donate](https://www.pediatricrrf.org/donate).

To receive this newsletter electronically please send an email to info@pediatricrrf.org and write “newsletter” in the subject line.