Letter from the President

As 2018 quickly comes to a close, PRRF is looking towards 2019 with a renewed focus on helping support families who have been impacted by blinding pediatric retinal diseases.

One way we hope to advance our efforts is by purchasing new gene sequencing technology. As many of you know, we currently offer our families free genetic testing at our one-of-a-kind lab, which focuses on translational basic science research targeting pediatric vasoproliferative disorders. However, our current methods of genetic testing are slow, limited in their gene sequencing range, and costly for PRRF to perform.

In 2019, we seek to remedy those limitations by providing faster and more comprehensive genetic testing that will increase our research capabilities. In fact, the new gene sequencing technology we hope to purchase will:

- Enable high throughput data acquisition (96 samples as opposed to 16)
- Cut the costs associated with testing by nearly 80%
- Help uncover new genetic mutations and clarify the important pathways in retinal development and healing

While the benefits of this new technology are vast, PRRF has not yet been able to purchase it because of the daunting $50,000 cost. But you can help! We’ve been lucky to have an anonymous donor step forward to help defray the costs with a matching challenge, but we still need you.

Every gift you make from now until December 31 will be matched dollar for dollar, up to $20,000. That means your gift will be doubled!

To support our research advances and help us one-day champion a cure, please visit us at www.pediatricrrf.org and click on the ‘Donate’ button. You can also mail a check made payable to PRRF to 39650 Orchard Hill Place, Suite 200, Novi, MI 48375.

Thank you and happy holidays!

Sincerely,

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

On the Research Front

Noregen a Regenerative Therapeutic Option for Pediatric Retinal Disease

As many of you know Drs. Drenser, Capone, and myself have been working on a medical therapy for Familial Exudative Vitreoretinopathy (FEVR) for several years. Noregen is an analog of the protein Norrin that is missing in Norrie Disease and altered in FEVR. The presence of the Norrin protein is what makes the vessels and neurons of the brain, ear, and eye develop in the proper way. We have now been able to make the Noregen protein in the Pediatric Retinal Research Laboratory. We have used Noregen to produce the elements of cell junctures missing or damaged in both of these pediatric retinal diseases in small animals and human adult tissue cultures models and are on own way to developing a therapeutic option for damaged retinal vessel diseases.

Even more exciting news is that in these same animal models, we see regrowth of appropriate retinal capillaries and neurons. Noregen may be able to regrow functional retina in some circumstances by regenerating capillaries and neuronal cells. There has never been a therapy which has showed such hope. It will be many years and a great deal of work and money but an extraordinary goal.

This form of medical therapy is referred to as regenerative medicine and is now one of the most exciting areas of medicine. It has even been accepted by the FDA director as
"no longer science fiction but within the scope of modern medicine" to be able to build organs and organ systems. The eye is a very complicated system to rebuild and connect to the brain but there are many steps that are being pursued. Our hope is that the biochemical environment that allowed proper retinal development as a fetus and infant can be called on again to stimulate development of properly directed pluripotent stem cells from one’s own tissue with the help of Noregen to provide the proper growth environment in order to support the regrowth of functioning retina.

To a bright future and Happy Holidays!

Michael Trese MD

Focus on Advocacy

Sightlines warmly welcomes Karen Hoogland, who will be authoring a series called Focus on Advocacy. In this series, Karen will speak of her personal journey. She is a paraprofessional for the Visually Impaired and Secretary for the Michigan Parents of Children with Visual Impairments. Through this series, she will share the wisdom she acquired along the way to learning how to most effectively advocate for her visually impaired daughter Juliana.

Here is her story …

Much to our surprise, we were having triplets. How on earth were we going to raise triplets? We were already blessed with a 2-year-old son. We knew the risk we faced having multiples. After letting this news absorb for a bit, we got used to the idea of this being fun… challenging, but fun! The next six months were very risky. I was able to carry them to 26 weeks gestation. Due to complications with our baby boy, we had no other decision but to deliver all three so extremely early. We had no idea the roller coaster we were about to ride! They were born at 26 weeks gestation - one boy, two girls. Our little boy passed away at one month due to complications from prematurity. Our two girls survived.

Now we had to figure out how to “do life” with our triplet survivor daughters … one sighted, one blind. Juliana had many surgeries as an infant into her toddler years to keep the retinas attached. Retinopathy of Prematurity is her eye condition (ROP). The surgeries were always a success, but the healing process was not.

As soon as we faced the realization that she would live a life of complete darkness, our first worry was how she would be able to go to school. I’ll never forget the sweet kisses and cuddles I gave her, rocking her while whispering in her ear, “I will never let you down!” I was determined to never break that promise to her because I knew that as her mom, I would be her biggest cheerleader and advocate!

Juliana’s Special Ed Team

Her services began with Early On coming to the home when Juliana was an infant. I believe the social worker from the hospital got these services rolling. From Early On’s observations, they assigned her to a Teacher Consultant for the Visually Impaired (TCVI), Physical Therapist, and Occupational Therapist. She got these services at home until she was 18 months old. I then had to take her to a class to continue to receive these services 3 times a week. At age three … here we go … she started riding the special ed bus to the Early Childhood Center to start attending Early Childhood Special Education (ECSE). Buckling her in the bus seat for the very first time and watching that bus roll out of our driveway carrying my blind child was excruciating to my mom’s heart. It was terrifying learning that my daughter would be the first blind student to attend our school district. It was so hard to put my trust in the school system when it was an “unvisited avenue” for them. It took everything I had to not jump in my car and follow that bus to her new school! I had many sleepless nights leading up to her first bus ride to school. I often thought to myself, “How is this going to work? And how will they know what to do?” As her mom, even I was still figuring out what to do!

Being the nervous and anxiety driven person that I am, I decided that I wanted to learn Braille. I knew this would be her only form of literacy. I took a 16 week course through Michigan Department of Education Low Incidence Outreach (MDE-LIO). This was the best decision ever! I started introducing Juliana to it. I made it fun. I ordered the cute Braille board books from www.seedlings.org that had the print and pictures. I was diligently reading to her while running her finger over the bumps. I knew that if my other children enjoyed books by looking at the pictures and associating the words to each page, Juliana needed to be introduced to books in her form of literacy.

As time went on with her in the ECSE program, I started to trust a little more. She had an amazing teacher who was very compassionate about her job, new at teaching a blind child, and absolutely grew to love my daughter. She and I had many conversations about what would work best for her learning environment. Juliana hated having sticky hands. I told her teacher to make sure she does the most sticky crafts possible to get her little “tactile feelers” acclimated. I remember having a conversation about fruit. Her teacher
was discussing different kinds of fruit to the class. I mentioned to her that she should have some tactile play fruit or real fruit that Juliana could feel because she could not see the pictures. The fact that her teacher valued my insight, strategies, and suggestions gave me so much hope for Juliana’s future in school.

At this point, I decided that I needed to really get to know her Special Ed Team. This consisted of the Special Ed Director, Principal, Teacher, Occupational Therapist, Physical Therapist, Speech Therapist, Teacher Consultant for the Visually Impaired, and O&M Specialist. I wanted to know everybody, communicate regularly, compliment them on my daughter’s successes and have a great relationship with them all. I knew that we would be working with these professionals all throughout her schooling. I kept reminding myself, at times of anger and frustration, to do some deep breathing and to think before I spoke. As the saying goes, I did not want to “bite the hand that fed us” and be “that” mom that always jumped across the table at the IEP meeting in a fit of rage. I knew that I had to keep my composure, be mature, and be my daughter’s best advocate!

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**Upcoming Events**

**My Cause, My Cleats Raises Money for PRRF**

In recent years, the NFL has dedicated one week of the regular season for the players to wear cleats aimed at promoting causes important to them called “My Cause, My Cleats.” Each team designates a home game to showcase the effort. Players are permitted to auction their cleats, with 100 percent of the proceeds going to the player’s selected charity. Indianapolis Colts defensive tackle Margus Hunt is auctioning his cleats in week 13 in honor of Presley Halbert (featured with her parents Caroline and Michael in the September issue of *Sightlines*), with proceeds to benefit the PRRF!

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**Fundraiser for the Pediatric Retinal Research Foundation**

**First Car Show and Auction at the Gilmore Car Museum**

Hickory Corners, Michigan  
Saturday July 20, 2019  
10 am - 5 pm
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 the Gilmore car museum 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-visualy 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) 318-0161 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