Letter from the President

Dear PRRF Community,

January is a time to look both back at accomplishments, as well as forward to aspirations. It is remarkable to consider how far we have come as a Foundation in the last year. The year began with the PRRF welcoming Stephanie Saville as Foundation Manager, and Luisa Recchia as Community Outreach Coordinator. Stephanie has fortified our infrastructure in many ways - our social media presence, IT infrastructure, contact database, development initiatives – and much more. Luisa has nurtured our connection to the PRRF community, most notably our Family Advisory Committee and this month’s inaugural Family Connection Conference (see below). They have helped meaningfully further our dual mission to support our community and further the quest for a cure.

Speaking of the quest for a cure, I am delighted to report that we have been successful in moving vital research forward despite the COVID headwinds. There has also been significant progress along the pathway of bringing Noregen from a potential therapy developed in the lab to phase 1 clinical trial, on the way to being an FDA-approved therapy (from “bench to bedside”) for familial exudative vitreoretinopathy (FEVR) and other diseases. The addition of the optical coherence tomography (OCT) device in the operating suites – thanks to the 2020 year-end funding initiative - to our diagnostic armamentarium this past September will further advance clinical research.

Looking over this last year, I’m reminded of how challenging things seemed last year at this time due to limitations borne of the pandemic. I am grateful for the progress in this last year – progress made possible by the generous support and hard work of people like you. We look with an eager eye to the challenges and achievements that await us this year in 2022.

As this very successful year comes to a close, all of us on the Board of the PRRF join to extend our best wishes to you and yours for a healthy, peaceful, and prosperous New Year.
Sincerely,

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

Board Member Recognition

Congratulations to PRRF Board Member Dr. Michael Trese who is the recipient of the American Academy of Ophthalmology 2021 Laureate Award. The Laureate Award recognizes individuals around the world who have made exceptional scientific contributions to the betterment of eye care leading to the prevention of blindness and restoration of sight worldwide. Dr. Trese has done just that. His accomplishments and practice are used worldwide. We are not only proud but privileged to be amongst such genius as Dr. Trese. This award is the single highest honor of the American Academy of Ophthalmology.

Congratulations Dr. Trese!

Year-End Campaign

We are thrilled to share an update on our 2021 year-end fundraising campaign. This year’s campaign focused on the tremendous need for continued research funding to expand upon the initiatives at the Pediatric Retinal Research Lab at Oakland University. In 2022, the Foundation is proud to announce that the first therapeutic drug treatment for FEVR will be entering Phase I clinical trials! In addition to this effort, we’re excited to kick off concurrent research into other therapeutic options for pediatric retinal disease patients.

With the support of our amazing donors, we raised $41,347 - which will be DOUBLED by two very generous anonymous donors!

We look forward to sharing updates about the impact these donations have made to research projects. We’re still accepting donations for the year-end campaign! If you wish to donate, visit www.pediatricrrf.org/donate.
Please join us in a few weeks for the Family Connection Conference 2022. This conference is made possible by our generous PRRF Donors.
This year’s virtual conference will focus on education for parents and caregivers. The doctors of Associated Retinal Consultants will discuss research updates and will be available to answer your questions. If you haven't already done so, please register and submit question(s) for the doctors today!

I’m also excited to announce that Brandon Werner will be our keynote speaker. If his name is familiar to you, it is because he is featured in this issue’s Ladder Story.

Brandon received his master’s degree in Vision Rehabilitation Therapy from Western Michigan University. He is currently working as an Accessibility Analyst at the University of Michigan focused on making websites and software easier to use and accessible for everyone at the University. Brandon will be sharing with us what it has been like for him to navigate through college, the choices offered to him and the many more options available for those who persevere. I hope you join us on January 22, 2022. I am confident you will walk away enlightened.

~ Luisa Recchia, Community Outreach Coordinator.

**Ladder Story: Brandon Werner**

When Brandon Werner was born on January 26, 1992, everyone commented on “his beautiful blue eyes.” However, around 6 weeks of age, Brandon’s mother noticed jiggling of his eyes “in different directions”. After seeing several eye doctors, a retinal specialist in their area identified retinal hemorrhages in each eye. He immediately referred Brandon to Dr. Michael Trese at Beaumont Hospital in Royal Oak, Michigan. Dr. Trese felt that the bleeding was caused by a condition called Familial Exudative Vitreoretinopathy (FEVR).

FEVR is an inherited, progressive bleeding disorder of the retinal vessels characterized by abnormal growth of the blood vessels and ultimate retinal detachment. Many cases of FEVR respond to medical and surgical treatment resulting in variable degrees of visual function. However, in Brandon’s case, despite multiple surgeries and pharmacologic treatments, he became totally blind/no light perception in each eye by eight years of age.

Brandon’s mother, Alissa, made sure that he remained active in all areas. Brandon mastered Braille at a very young age, excelled in school, and became actively involved with sports for the visually impaired such as Beep Baseball, Goal Ball, and rock climbing. His mother organized a Goal Ball team that attracted visually impaired players from all over Michigan. Brandon and his family participated in every Visually Impaired Sports and Activity Day (VISD) held in Grand Rapids, Michigan, during the first week of June from 2001-2019. When in high school, Brandon traveled with the marching band to different venues including the state competition. Read more...

**Seeing the Possibilities: Jennifer Zuckerman**

The Roman poet Horace once said, “Adversity has the effect of eliciting talents which in prosperous
circumstances would have lain dormant.” Ever since I stumbled across this quote in my English class, I have contemplated its meaning and all the ways in which it relates to me.

Recognizing that everyone’s situation is different, I share with you how these words have inspired me with the hope that others may find some inspiration in them, too.

I am seventeen years old and a junior in high school. I focus much of my energy on school and my possible future career as a classical singer. I have a loving, tight-knit family, including a twin sister who is basically my other half. On most accounts, I could be considered a typical teenager, but that description omits what is perhaps my most defining characteristic.

I have about 20/300 vision after correction. Shortly after my birth, I was diagnosed with retinopathy of prematurity or ROP, and suddenly the question of whether or not I would grow up with any vision wasn’t set in stone. I have heard stories of what it was like for my parents, traveling back and forth from New Orleans to Detroit with two small infants, one of whom was in and out of surgeries and examinations for the next few years. I can’t imagine the things they must have been feeling--was it fear? Desperation? I’ll never truly know. Read more...

If you love our work then tell the world! You have an opportunity to help us make even more of a difference in our community. GreatNonprofits—a review site like TripAdvisor—is honoring highly reviewed nonprofits. Won’t you help us raise visibility for our work by posting a review of your experience with us? All reviews will be visible to potential donors and volunteers. It's easy and only takes 3 minutes!

Go to https://bit.ly/3yYaBS4 to get started!
PRRF earned a 2021 Platinum Seal of Transparency! Now everyone can see our strategy, metrics, and achievements.

Learn More

This is a private Facebook group designed to provide community, support, education, news, and links for families with children touched by retinal diseases.

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