Letter from the President

Dear PRRF Community,

Welcome to the spring edition of *Sightlines*. We have been busy this spring and are excited about this inspirational and aspirational issue.

In this issue, we feature three young adults in the PRRF Community who share their journeys with us. We begin with two extraordinary young adults. Jules is a powerful young woman whose story of grit, determination, and inner strength that you will undoubtedly want to share. I won’t say anymore here, as no one says it better than Jules. Tanis is an exceptional young man who is the star of this installment of our Fish Ladder series. Dr. Droste shares the story of this brave, barrier-busting athlete, and entrepreneur. And Anthony and his family share their poignant journey in our video series on members of our community who have been impacted by the PRRF.

Next is the amazing story of the Next Level Trainings Class 8. This group of high-energy, high focus, reach-for-the-stars philanthropists ran a highly successful fund-raising blitz. Thanks to the dedication of Nicole Giudici and her team not only for the considerable funds raised but for the example of what can be achieved with passion and purpose.

We’re looking forward to our 4th annual Hope for Vision Walk. We will bring the best aspects of both the virtual and in-person events to this year’s Walk on Sunday, September 11, 2022.

I know you’ll enjoy this issue of *Sightlines* packed with the power of positivity. To those of you in our community who make this all possible with your generous gift of time, energy, and financial support we extend our heartfelt thanks.

Sincerely,

Antonio Capone, Jr. MD
President, The Pediatric Retinal Research Foundation (PRRF)
The Resilient Miracle: Jules Hoogland

Becoming a parent is such a gift. Parenting a blind child is difficult, but one thing I've discovered is that I was definitely equipped with an extra pocket of hearts! My daughter, Jules, has taught me patience, compassion, understanding, persistence, determination……the list goes on! I am absolutely honored to be her mom! ~ Karen Hoogland

“The journey of life is not meant to be feared and planned; It is meant to be traveled and enjoyed.” —Unknown

Jules also had an exciting day on the basketball court in March. Read the article and watch the video here.

Here's Jules' article “The Resilient Miracle”

I was fifteen. It was the first day of my freshman year of high school. I was nervous, overwhelmed, and stressed out. I wasn't confident in finding my way around quite yet.

My name is Jules, and I am blind. I was born as a triplet, with my brother and sister. To top it off, I was born three months early. Instead of being born in November, I was born in August. Because I was born premature, I had to be put on a ventilator. I could not breathe on my own. After I graduated from the ventilator, I had breathing assistance with CPAP. My extremely early arrival in life led me to a realm of issues. I had heart surgery when I was just less than 2 pounds. My heart was the size of a pea. A typical full-term baby's ductus arteriosus naturally closes on its own. Mine, of course, did not. After my surgery, I was put on a jet ventilator. This puffed 425 puffs a minute into my tiny, fragile lungs. As a result of this life-saving technique, it punctured a hole in my left lung. The doctor was able to seal the hole. My uphill journey continued on to more threatening issues. I developed a sepsis infection that most adults can die from. Luckily, my tiny, resilient body tolerated the antibiotics and responded well to them. I then developed Necrotizing Enterocolitis. This is an infection of the bowels that took my triplet brother's life at 4 weeks old. Read more...
Fish Ladder Story: Tanis Hooker

By Dr. Patrick Droste

Tanis Hooker was born three months premature. He weighed one pound nine ounces. During his 99 days stay at the Blodgett Hospital Neonatal Unit, he developed severe proliferative retinopathy of prematurity that required cryotherapy to each eye. Tanis subsequently came under the care of Dr. Michael Trese at William Beaumont Hospital where he received multiple surgeries and frequent office visits, over many years, to retain vision.

Despite his visual and fine motor challenges, Tanis always remained positive through school. He was one of the first prematurely born blind children in the East Grand Rapids Public School System. He blazed the trail for many similarly affected students who would follow him.

Tanis and his family were one of the original contributors to the Visually Impaired Sports and Activity Day (VISD) held annually in Grand Rapids, Michigan. He loved to ride the tandem bike with his father; they can be seen regularly riding the streets and bike trails in Kent County. Tanis also “anchored” the Tandem Bike and Soccer venues at the VISD for many years. Tanis excelled at swimming. He was active in the Special Olympics swimming team and raced competitively on the East Grand Rapids High School swimming team. Tanis is a student at the Noorthoek Academy at Grand Rapids, Community College. The Academy provides a college experience, offering continuing education and inclusion opportunities in the arts and sciences for adults with intellectual disabilities. Tanis is an avid reader, swimmer, hiker, and skier. He is also a participant at Ready for Life, a life and work skills program. Read more...
Thanks to Next Level Trainings Leadership Class 8!

The 8th online leadership class of Next Level Trainings raised $19,294 in just 19 days to support the Pediatric Retinal Research Foundation (PRRF) and its work toward the prevention and cure of vision loss in young children caused by a rare genetic disorder.

Next Level Trainings provides experiential leadership programs that support people in unlocking their passion, power, and purpose.

During the course of the 8th online leadership training program, student Nicole Giudici lost her father. The family’s request was to donate to the PRRF in lieu of sending flowers for his funeral, hoping that the Foundation will find a cure relatively sooner, to benefit 3 of his 4 grandchildren who are experiencing several degrees of vision loss. Standing in solidarity and love for Nicole’s family and as part of their Community Service Project, the 11-member class of students unanimously voted to support the PRRF. It launched its “Vision for Vision” Campaign on February 12, 2022.

The “Vision for Vision” fundraising campaign included efforts by each team member who personally reached out to families, friends, and corporate offices. They also shared social media posts and inspirational videos highlighting life experiences by people with vision loss.

The campaign culminated on March 2nd, 2022, in a very moving and inspiring online celebratory event uniting friends and families from across the globe, members of the PRRF, parents from the Foundation’s outreach programs, and people who are passionate about supporting early intervention and prevention of vision loss in children.

"Nicole and her family were a huge inspiration for this campaign. As a team, we wanted to rally around her and support." – Dan Iza, VP Kasasa Loans Client Success, and Next Level student

We are SO grateful to the Next Level Trainings Class 8 for not only their fundraising efforts, which are tremendous, but for their passion, advocacy to support rare diseases, and level of enthusiasm for PRRF’s mission. We are beyond humbled and appreciative.
Patient Video Series: Featuring Anthony

Thanks to a very generous and passionate PRRF family, we were able to develop a video series highlighting the impactful stories of children and families affected by rare pediatric retinal diseases.

The second of four videos highlights Anthony and his family as they discuss his FEVR diagnosis at age 8 and the help that Dr. Trese and PRRF were able to provide.

PRRF FAMILY ADVISORY COMMITTEE
INVITES YOU TO JOIN US FOR

Perseverance

WITH JULES HOOGLAND
AND HER MOM KAREN

TUESDAY, JUNE 7, 2022
7:00PM ET - 8:00 PM ET

The PRRF Family Advisory Committee invites you to join us for a workshop on June 7th featuring Jules Hoogland and her mom Karen. Jules, a teenager with ROP, will share her story of resilience, her challenges, and many obstacles over the years that have made her the strong person that she is today. There will also be a Q&A session after the presentation. Questions? Email Luisa Recchia at lrecchia@pediatricrrf.org.

Register Here
Save the Date!
Sunday, September 11, 2022

This year’s walk will be in person and the location is TBA. We will also have a virtual component to the event. More to come!

Help sustain the work of the PRRF by signing up to be a monthly donor! A gift of just 65¢ per day ($20 per month) will allow the Foundation to increase community programming and advance further research.

Donate Now