Letter From The President

Dear PRRF Community,

Welcome to the November edition of Sightlines. In this issue’s President’s Letter, I’d like to speak briefly on the topic of leadership. The default notion of leadership for many relates to traits we associate with leaders such as charisma or the ability to summon an apt phrase for any occasion. My interest is in leadership as an opportunity to impact others.

The leader’s goal is to get things done. Different circumstances require different types of leadership – a business, a preschool, a laboratory, a family – even when the leader is the same person in two or more roles. Tom Hanks as Captain Miller in “Saving Private Ryan” was an extraordinary leader on the battlefield and a teacher at home. The most important leadership drive for me is to serve others: to create and sustain positive change in the lives of those the organization serves. I can’t think of anyone who is good at this without working at it, being deliberate about learning how to influence in the name of service to others. It’s like a muscle. Work at it and you’ll get better at it.

Yet leadership is not limited to dramatic visionary acts or exemplified only by those with titles or power. There is an opportunity to lead in humble acts like Mother Theresa, or even the mundane. A quote that speaks to the latter by the Italian writer Umberto Eco reads: “I believe that what we become depends on what our fathers teach us at odd moments when they aren’t trying to teach us. We are formed by little scraps of wisdom.” We all lead in the way we live our daily lives.

Many in our community have quietly taken on the mantle of leadership, and this issue of Sightlines is rich with the fruits of their labors. Lisa LoVasco speaks to the challenges young parents face when their child is diagnosed with a pediatric retinal disease. We also highlight the Family Advisory Committee’s December conference and the upcoming 2023
Family Connection Conference. Lastly, we proudly announce “Through Our Eyes” - an exciting new podcast initiative led by a very talented group of young visually impaired adults and anchored by PRRF Board member Dr. Patrick Droste.

With deep gratitude to all members of the PRRF community,

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

The Loneliness of an Orphan Disease Diagnosis

By Lisa LoVasco, Parent and FAC Member

A rare disease is defined as any disease that affects a small percentage of the population, often fewer than 200,000 people in the United States. Oftentimes, due to the rarity of these diseases and lack of a large patient population, gaining support and resources for treatment options is a challenge. Receiving a diagnosis of one of these rare diseases can leave an individual or family with a very isolated and lonely feeling. This was our experience after receiving the news that our daughter, Aria, had been born with a rare retinal disease.

When Aria was about two months old, we noticed that her eyes were doing a rapid back-and-forth movement that seemed to be increasing in frequency. She was so little that I simply thought her eyes were still adjusting, until one day I watched one eye drift from top to bottom, with no control. We then decided to address it with our pediatrician. Although they did not recognize any issues and seemed unconcerned, we pressed them to see a specialist, which brought us to our first appointment with a pediatric ophthalmologist. Upon her first exam, it became immediately apparent that something was very wrong. The ophthalmologist pulled up a picture of Aria’s eye on a computer screen and explained to us that all the markings we saw on the screen were areas of abnormalities in her eye. I remember saying to him “But that’s her entire eye?” He excused himself and stepped outside to make a phone call. He returned and said he was able to get us a last-minute appointment the following day at Associated Retinal Consultants to see Dr. Michael Trese. He assured us that we were very fortunate to be seeing one of the best pediatric retinal specialists in the world.

Read more...
PRRF FAMILY ADVISORY COMMITTEE
INVITES YOU TO JOIN US FOR

The Loneliness of an Orphan Disease Diagnosis

WITH
LISA LOVASCO

TUESDAY, DECEMBER 13TH
7:00 PM ET – 8:00 PM ET

Register for the Workshop

Family Connection Conference - Winter 2023
Family Dynamics: Bridging the Gap

We hope you can join us for our second annual PRRF Family Connection Conference! This virtual conference will focus on education for parents and caregivers including research updates with expert doctors, a guest speaker, and breakout sessions. This conference is made possible by our generous PRRF donors.

Click the button below for more information and to register!

Register for the Conference

"Through Our Eyes" Podcast Launched October 13th

PRRF helped launch the "Through Our Eyes" podcast on Thursday, October 13, 2022 "World Sight Day." Visually impaired young adults Brendan, Shelby, and Breyanna discuss what it’s like to navigate through high school, college, career, and beyond. They tap into their experiences and cover a wide range of topics providing listeners with actionable tips and strategies they can implement into their own lives.

Click here to learn more or subscribe wherever you listen to podcasts. Be sure to share this with someone who would benefit from this unique resource!
Whether it’s Black Friday or Cyber Monday, when you shop on Amazon, consider using smile.amazon.com to generate donations to support PRRF.

PRRF Amazon Smile

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.

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