Letter from the President

Dear PRRF Community,

Welcome to our first issue of Sightlines for 2021. A lot has happened since the December issue!

First and most exciting - we have made great strides in building the Foundation’s infrastructure. In this issue we have the distinct pleasure to introduce you to Stephanie Saville and Luisa Recchia (see below). Stephanie assumes the role of Foundation Manager for the PRRF, and brings experience in non-profit strategic planning, volunteer management, and fundraising. Luisa will serve as Community Outreach Coordinator, drawing on her experience in team building, operations and strategic development. Together, they position us to more effectively impact the children and families we serve.

Expanding our family and patient support programs in 2021 is made possible by the generosity of the PRRF community. Kelli Matthew, our Strategic Development Chair, reports on our successful 2020 Year-end Campaign.

Also, in this issue, PRRF Board member Dr. Droste expands on our series devoted to facing the challenges to equipping students with the tools they need to learn and thrive - swimming up the “Fish Ladder of Life”- by introducing us to Miles Scharfenberg. This inspirational profile highlights Miles’ gift of artistic expression.

Lastly, in 2021 Sightlines, will be coming your way bi-monthly. We look forward to connecting more consistently with you, and keeping you abreast of scientific developments in the field of pediatric vitreoretinal disease.

Heartfelt thanks to the dedicated and talented members of our PRRF community who share the passion for working on behalf of “our kids”

Sincerely,

Antonio Capone, Jr. MD
President, The Pediatric Retinal Research Foundation (PRRF)
Introducing Stephanie Saville, Foundation Manager

I am thrilled to be working with the team at the Pediatric Retinal Research Foundation in an expanded capacity. I have had the pleasure to work with some of you on the annual Hope for Vision Walk for the past two years. In this new role as Foundation Manager, I look forward to supporting the Foundation's important work in pediatric retinal research and community support programs through expanded fundraising efforts and day-to-day operations. I am passionate about the work of the Foundation because of their history and dedication to improving the lives of children in a meaningful way, as well as the opportunity to connect with and support so many wonderful families.

My first order of business is to get to know YOU - our community of supporters. I would love to have virtual coffee with you and learn what you love about the Foundation, why you choose to support us, and your thoughts on where we can improve and grow going forward. Let's talk soon: [schedule a 30-minute virtual coffee chat today](#)

Introducing Luisa Recchia, Community Outreach Coordinator

My name is Luisa Recchia and as the Community Outreach Coordinator for the Pediatric Retinal Research Foundation (PRRF), it is my privilege to serve both the Board and its Community. My goal is to add value to you, collaborate with you with the intent to work towards making change happen one life at a time.

I look forward to meeting and getting to know you.

Another Successful Year-end Campaign

Thanks to you, our generous PRRF community, our year-end 2020 campaign raised more than $50,000! This year’s funds will be committed to expanding our family and patient support programs in 2021 and beyond. More to come in future issues as to new initiatives designed to build upon our network of resources, enhance our online informational portal and offer virtual opportunities for parents and caregivers to connect. We know that this past year has been financially challenging for many people; but because of your support, we will provide lasting change for those living with pediatric retinal diseases. To all of our donors, we express our sincere appreciation and gratitude.

~ Kelli Matthew, on behalf of the PRRF Board of Directors

On A Personal Note
Miles Scharfenberg was born on May 18, 1994 in Kalamazoo, Michigan. He was 15 weeks premature and spent his first three months of life in Neonatal Intensive Care Units in Kalamazoo and Royal Oak, Michigan.

Like many premature children, Miles had challenges from Retinopathy of Prematurity (ROP) and neurologic development. He underwent many vitreo-retinal procedures, on both eyes, by Dr. Michael Trese and his colleagues at William Beaumont Hospital. The most recent procedure was a difficult lens extraction in the left eye during the summer of 2018. Miles also endured challenges from spastic cerebral palsy, which has confined him to a wheelchair and severe delays in speech, hearing and cognition. Miles is non-verbal because of his hearing impairment.

Through the years, the biggest challenge Miles’ eye doctors faced, was a constant struggle to keep his pupils from closing over due to chronic inflammation of the eyes. He underwent many operations to remove scar tissue from the pupils so that “The light could get in.”

Miles has viewed his world from two pupils about one millimeter in size. From an early age, he was always attracted to light and colors. He liked to “splash” colors on white paper and, as he grew, he started to place the colors on poster boards, sheets, walls, table cloths and whatever else he could find. Not being able to speak, he expressed himself with his colors and others noticed his expression and creativity.

Miles’s mother is an occupational therapist and she insisted that he get as much occupational and physical therapy as possible. Many of his therapists recognized Miles’ talent for putting colors together and as Miles grew, so did the complexity of his “splashing.”

Miles came under the tutelage of Mr. Ken Freed at the Kalamazoo Institute of Arts. Mr. Freed spent his life teaching students how to make art. Miles presented unprecedented challenges to Mr. Freed and his team of talented occupational therapy students and physical therapists. The team developed special painting innovations which they termed “adaptations”, such as a tennis ball attached to a stick that would allow Miles to paint designs on canvas. Some sticks were long which allowed him to reach high areas of the painting from his wheelchair. Other sticks were shorter for closer distances.

People began to appreciate Miles' expressions of color on canvas. His largest painting is a 7ft. by 5ft painting entitled “Emotion” that is currently displayed at the Public Media Network building in Kalamazoo, Michigan. He also has several smaller paintings displayed on the walls of Mary Free Bed Hospital in Grand Rapids, Michigan. Miles spent many of his early years in the Outpatient and Inpatient departments at Mary Free Bed Hospital. In 2013, at 18 years of age, one of Miles paintings was featured on the cover of the Open Journal of Occupational Therapy; a follow up painting was published in the same online Journal in the fall of 2019. In 2018, Miles received recognition for his entry in to the Grand Rapids Art Prize Exhibition.

Showcased in this article are just a few of the painting by Miles. One is entitled: “There is a Crack in Everything: That is How the Light Gets In.” These words are part of Leonard Cohen's song “Anthem.” Carole Scharfenberg, Miles’ mother, felt that this title most closely conveyed Miles message in the painting. “I felt that the painting looked like Miles retina that had a little window of light coming through”, Carole said. From an eye doctor's point of view, the bright “splash” in the center of the painting, represented Miles' one millimeter pupil, in his left eye, that allowed light to get into his world. A very gifted occupational therapy student, Laura Weincek, helped Miles make this painting in 2018.

Miles has been swimming up the Fish Ladder of Life since the very beginning. He continues to rise up the ladder to higher waters; Miles is still on his journey and he is lending his gifts of expression for all of us to enjoy and look at in amazing wonder! Every time one looks at one of his paintings, the individual leaves with a different interpretation, not only of what message the painter is trying to convey, but also what we, as observers, interpret in his creativity.

To learn more about the incredible journey of Miles Scharfenberg, his adaptive equipment and how he works with his “innovators”, we encourage you to look at his biopic on...
and how he works with his innovators, we encourage you to look at his biopic on YouTube "Uncovering Creativity: Miles Scharfenberg." You can also communicate electronically at scharfenberg.art@gmail.com.

~ Patrick J. Droste MS, MD