Letter from the President

Dear PRRF Community,

In a speech in June 1966, Robert Kennedy said: “There is a Chinese curse which says 'May he live in interesting times.' Like it or not we live in interesting times. They are times of danger and uncertainty; but they are also more open to the creative energy of men than any other time in history.”

While the 1960s were interesting times, the 2020s are giving them a pretty good run for the money, and we are barely getting started. My favorite part of Kennedy’s quote is the focus on creative energy. As much “corona chaos” as there has been, many things will be better on the other side of this.

A positive consequence of our current circumstance is that the PRRF Board has had the opportunity to devote time to implementing a strategic vision for the next 3-to-5 years. We continue to grow. With this growth come new infrastructural needs required to support our goal to “build community and build capacity”. To that end, we have brought on talented individuals in the areas of digital media/communications, development/fundraising, and finance/administration. These initiatives allow us to leverage our talented and dedicated volunteer community to further facilitate getting the PRRF message out to families and the broader community.

During times like these, our Foundation looks to provide our community with care, support, leadership, and guidance. Our strength comes from our ability to unite with compassion and solidarity. We strive to model the change we wish for the world.

As always, sincere gratitude to our Board and the PRRF community for all you do on the behalf of the Foundation.

Sincerely,

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

The Pediatric Retinal Research Foundation has played a key role in supporting translational research with the goal of moving promising treatments from the bench to the bedside. One of these projects aims to restore healthy retina in cases where the retina did not develop normally (e.g. Familial Exudative Vitreoretinopathy (FEVR)) or when healthy retina has been injured (e.g. Diabetic Retinopathy). The discovery of this promising therapeutic dates to the beginning of the Biobank. FEVR is a vitreoretinopathy that is caused by a change in genes that turn on Wnt signaling in the eye. The data collected from the various genetic alterations in these patients identified a protein that is specific and necessary for retinal development. When combined with the clinical course of the patients, a new understanding of how Wnt signaling works in the eye was elucidated. Many years later, and after testing in the lab and in rodents, this protein has been engineered to restore healthy retinal tissues.

We are excited to report that we are entering the commercialization phase of this treatment. The next step is human trials. This requires several steps to achieve, such as manufacturing the final product, completing toxicity and safety studies in animals, and filing with the FDA. Once that is completed a Phase 1 (safety) trial may begin to enroll human patients. Although we are a long way from a final product which is available in the clinic, we are embarking on the next steps to bring this treatment to patients.

~ Written by Kim Drenser, MD, PhD

Focus on Advocacy

Parent Support

We felt very lost when our daughter was little. We didn’t know anybody else in our community who had a blind child. We were confused, scared, and uncertain as to how we could help her adapt to a sighted world.

Every year, my daughter’s pediatric ophthalmologist puts on an event called Visually Impaired Sports Day. There are bounce houses, beeper baseball, therapy dogs, crafts, a rock-climbing wall, and lunch. The kids also put on a talent show that includes singing, playing instruments, telling jokes, or storytelling. There is also a table set up every year that highlights a camp for kids who are visually impaired. The wonderful and kind-hearted lady who runs the camp became our mentor. She could take the title of angel, lifesaver, and friend. She told us about a parent group, which she was president of at the time, called Michigan Parents of Children with Visual Impairments (MPVI).

MPVI is a group of Michigan parents who are raising kids who are visually impaired. There are two retreats a year. Some of the places we have been include an indoor water park at a hotel, Greenfield Village, a “tactile” tour of the Henry Ford Museum, Art Prize, the capital building in Lansing, and Mackinac Island. There is one standing retreat that we have every year. It is at Challenge Mountain (Petoskey area). It is an adapted ski hill for people with unique challenges. The kids ride up the ski hill on a snowmobile and ski down with a guide if preferred. There are also scoop chairs with skis on them that people with physical challenges can use with a human ski guide.

Jules, 15 skiing with her dad at Challenge Mountain. She was only 3 years old when her love of skiing began.
What we love about this parent group is that our whole family is included, and the trips are very affordable. We love that our sighted kids can bond with other sighted siblings and form their own support group. There are always lessons that our low vision/blind children learn. One time the kids learned how to fold their money to identify the correct currency. The kids have also cooked and served the parents and siblings food as if they were at a real restaurant. They learn self-advocacy skills at these retreats. The kids love to get together because they all have at least one thing in common that others in their community do not - vision loss. Our daughter has often said that she feels “at home” when she is with these friends. They often end up sharing adaptive technology tips with each other.

Try to find a group like this in your area. We have met so many great people at these gatherings. Most of the people we have met through this group have become our closest friends. They have taught us what tools to have in our toolbox when it comes to advocating for our kids in school. It has been very encouraging to see how successful the older kids are and listening to their stories about how they pushed through school.

~ Written by Karen Hoogland

Upcoming Event: Hope For Vision Walk – September 13, 2020

Save the date and mark your calendars! Our second annual Hope For Vision Walk will be on Sunday, September 13, 2020 in Birmingham, MI. It’s sure to be a fun fall event, with a Zumba warm-up, music, food, and a chance to walk through a lovely neighborhood in Bloomfield Village. Keep a look out for more details to follow.

Help us support families impacted by blinding pediatric retinal diseases and champion the quest for a cure. Visit https://www.pediatricrrf.org/donate.

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