Letter from the President

Dear PRRF Community,

Life has changed since the beginning of the year. Despite the many challenges, or perhaps because of them, it is likely many things will be better. For starters, there is now a greater emphasis on personal connections and quality of life outside of work. We are also compelled to innovate; to find different ways to work that are complementary to our prior routines, to find ways to leverage our efforts to increase effectiveness, and many more. And above all, to be resilient.

On that theme, faced with the challenges of social distancing, we have re-invented and re-tooled the annual Hope for Vision Walk. COVID-19 has brought us a unique opportunity to come together to make a difference in a new way. We have elected to take the walk virtual. As a result, this year's Hope for Vision Walk is now open to everyone AROUND THE GLOBE!

This is an example of COVID-propelled innovation. For some time, the PRRF Board has been reflecting on how to expand the reach of the Hope for Vision Walk's fund-raising and community-building initiative. This virtual initiative will have as its legacy that all future walks will have a virtual component in parallel.

We encourage all members of our PRRF community to gather friends, family, and co-workers and form a virtual walk team. Walk, run, or bike (socially distanced and wearing a mask, of course) a 1.5–mile route in your neighborhood, on a scenic trail, or at a local park anytime between Sunday, September 20th through Saturday, October 3rd. Take photos and videos along the way and share them with our team! We will host a live stream program on Saturday, October 3rd at 11 am. Join us as we share our progress toward our fundraising goal. Hope to “see” you on the virtual trail!

Sincerely,

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

Unprecedented

Unprecedented … how many times have we heard that word since March? COVID-19 will be in our history books! These times have been very trying for so many. Unemployment, limited groceries, running out of toilet paper, people contracting the virus, quarantining, social distancing, wearing masks, sitting in your car until it’s your turn to see the doctor, no pop can returns, coin shortage, no dentist appointments, NO HAIR SALONS (that one about killed me as a woman who HAS to cover her silvers)!

But … our kids with special needs! That, by far, has been the most challenging in our family. Learning virtually, especially so abruptly, not having a solid plan in place with accommodations for kids with IEP’s. My daughter was busy every minute of the day during virtual learning. All her services kept rolling via zoom, of course. I was actually impressed with a lot of service provider’s creativity. Her orientation & mobility specialist would zoom with her and play car noises. Jules would have to tell the instructor when she thought it was safe to cross the road. They talked about self-advocacy, role played some scenarios, and discussed situations at grocery stores requesting personal shoppers. They even discussed topics such as Instacart, which seems to be the popular way to get groceries during these times. She also zoomed with her paraprofessional and resource teacher to get assistance with Geometry and other subjects. It wasn’t easy, but she kept busy and kept going. She definitely shed tears at times.

Going into this school year, I have so many questions. I just had a meeting with her team. I asked for an amendment to her IEP going into this new COVID school year in case the students end up learning online. I wanted to make sure that if an assignment is too visual, the teacher makes accommodations. An example would be instead of watching a simulator video and explaining what you “see”, the teacher could give her a paragraph or two to read with a question and answer type of assignment that pertains to the content being taught. If our school district scales back to learning online, the teachers will be allowed to teach virtually from their classrooms. After hearing this, I asked permission that Jules learn at school next to her paraprofessional where all her adaptive tools are. Her Teacher Consultant for the Visually Impaired and O&M specialist will also service her at school. I was told this would be allowed.

I’m so thankful for a great team. It’s a team that was built by being a respectable parent advocate. Advocacy can be done with graceful persistence. Parents - don’t give up! Advocating for your child can be challenging, especially when not many educators have had a VI/blind student before. Please remember that you have the right to request a school meeting for your child at any time. Establish great relationships with your child’s team members. Remember to always praise them if they go above and beyond for your child. And also remember … these are unprecedented times. Not just for our kids but for everybody. Try to give grace to educators who are trying their hardest because this pandemic will end … eventually.

~ Written by Karen Hoogland
The Fish Ladder of Life for the Visually Challenged Individual

Fall is the time of year when shorter days, cooler nights, and lower water temperatures are accompanied by the annual migration of lake trout, salmon, and other species to return to their streams and estuaries of origin to spawn and complete the circle of life. The fish begin their return and encounter many obstacles on their way home, such as predator fish or birds, hydroelectric plants, locks, dams, and fishermen. In order for the species to survive, government organizations like the Army Corps of Engineers, Department of Natural Resources (DNR) as well as state and private corporations, have worked together to develop ways that allow the fish to overcome these barriers and flourish. These structures take many different forms and are sometimes referred to as a fish way, fish pass, fish steps, or fish ladder. Most fish ways enable fish to pass around the barrier by swimming and leaping up a series of relatively low steps (hence the term ladder) into the waters on the other side to reach their final destination. Since fish may need to climb many ladders, these fish ways are constructed with circulatory pools that allow for rest before continuing.

There are certain parallels between fish ladders and human development. Both have a beginning and an end and, in order to be successful, both fish and human need to overcome obstacles placed in their paths. Their final fate depends on a strong nurturing support system, persistence, durability, and a little bit of good fortune.

This brings us to Michael and Elizabeth. Michael Ryan Kazmierski Dunn and his twin sibling Elizabeth Madeline Kazmierski Dunn were born extremely premature at Helen DeVos Children’s Hospital (HDVCH) on March 28, 1996. Both children faced many challenges in the neonatal intensive care unit (NICU), including advanced Retinopathy of Prematurity. Despite laser treatment at 3 months of age, their disease progressed at a very aggressive rate and multiple surgeries were performed on each child during the first fifteen years of their lives. Despite best efforts, both have only light perception vision with no ability to read the printed word. The lack of vision was the largest fish ladder that both had to negotiate in their early years, but, like the fish trying to make their way home, both children had a fierce determination to excel and external support. In this case, it was from their family and friends.

Michael and Elizabeth attended summer camps for visually impaired children under the financial support of the State of Michigan, the Michigan School for the Blind, and private donations. Both children and others at the camp (affectionately referred to as Camp “T”) learned skills for basic self – care as well as creative studies, such as music and singing. At camp and home, both mastered the piano, sang duets, and performed at local restaurants. Michael also developed a love for the Uilleann Pipes (Irish Bagpipes). Unable to use traditional pipes because of his glaucoma, Michael developed his skill with an electronic version.

Nothing has stopped these two. To read more about these amazing individuals and the supportive family behind them, click here.

~ Written by Patrick J. Droste, MS, MD
Hope For Vision Walk – Virtual in 2020

We are very excited to host our 2nd annual Hope for Vision Walk - Virtual in 2020! We invite you to join us between Sunday, September 20th through Saturday, October 3rd to walk, run or bike 1.5 miles in your neighborhood, on a scenic trail or at a local park. No matter where you are in the world, you can make a difference for children with vision loss and their families!

Register your team or as an individual by visiting www.prrf.blueskysweet.com today! Send a message out to your colleagues, friends, and family asking them to support your efforts with a donation. Every individual who raises $100 or more will be mailed an official walk t-shirt!

We still want to see your smiling faces! Take a group/individual selfie and post it on social media using hashtag #HopeforVision2020 or email a video to StephaniePRRF@gmail.com. Do not forget to include where you are from - as we are excited to share the collective impact passionate supporters can have when we "come together" this fall.

Lastly, we will share a live stream program on Saturday, October 3rd at 11 am. You will be invited to join us as we share our progress toward our fundraising goal and how the funds will be used to make an impact while highlighting some amazing Walk teams!

Please join us and celebrate the important work of the Pediatric Retinal Research Foundation. For specific questions, contact Stephanie at 248-568-7545 or StephaniePRRF@gmail.com.

Hope to "see" you on the virtual trail!

On the Research Front

Ken Mitton Ph.D., FARVO, Associate Professor of Biomedical Sciences, Eye Research Institute (ERI) at Oakland University, is running a study to evaluate the reliability of a finger-tip blood test system to detect two classes of antibodies to the COVID-19 spike protein. While many tests were rushed out early in 2020 to test for antibodies to COVID-19, the majority of the tests were not specific and not even well tested by their makers before marketing their kits. Dr. Mitton is assisting a US company, Epigentek, that he knew as a manufacturer of very specific antibody-based reagents for the study of gene expression. Dr. Mitton, along with Nahrain Putris, a 4th-year OUWB medical student and an alumnus of the ERI's Summer Undergraduate Program in Eye Research, are doing a human subject study to evaluate if the Epigentek test can be used for antibody testing with a simple finger-poke drop of blood. This is done with the same finger lancets used for testing blood sugar. Volunteers from the community have been very responsive and showing up to help evaluate the test's reliability. It is important that these tests do
not have false positives and that they only detect antibodies to COVID-19 specifically. As of this reporting, about 30 persons have been tested in the study and so far it is clear that the test does not suffer false positives and both IgM and IgG classes of antibodies to the COVID-19 Spike protein have been detected in volunteers who have recovered from COVID-19 or who have also tested antibody positive from an arm-drawn blood clinical lab test. Testing continues. This project was started when non-COVID-19 research was suspended in most of the country for a few months. The expertise and equipment required to carry out the study were available in the ERI.

~ Written by Michael T. Trese, MD