SIGHTLINES | The PRRF Newsletter

Supporting the community of families impacted by blinding pediatric retinal diseases and championing the quest for cures.

Visit our new website www.pediatricrrf.org

IMPORTANT NOTICE

With this issue, we are transitioning our newsletters to email versions. If you would like to continue receiving SIGHTLINES, please provide your name and email address by emailing info@pediatricrrf.org or go to our website www.pediatricrrf.org and click on the “Sign Up Now” button at the bottom of the home page.

Letter from the Directors

Community and Cure

Welcome to the inaugural Pediatric Retinal Research Foundation (PRRF) newsletter. The PRRF is built on a foundation of 20 years of outstanding research outcomes of the Vision Research ROPARD Foundation ("VRRF"). Our work has helped substantially reduce blindness in premature infants due to retinopathy of prematurity. Our mission is to support the community of families impacted by blinding pediatric retinal diseases and champion the quest for cures. Each SIGHTLINES will feature one of the exciting projects we’re actively developing. While the work we do is serious, there is great joy and fulfillment in impacting the lives of children and families. There is much work to be done as we seek cures for pediatric retinal diseases. We are excited to have you join us as we embark on the journey ahead!

Antonio Capone, Jr., MD, President | Michael T. Trese, MD, Chairman

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Medical Research Review

Clues Toward a Cure

We are excited to introduce the Ophthalmic Biobank, the first database to specifically bank tissue from patients with a wide variety of vision disorders. A biobank allows for the collection of large numbers of samples from those affected with rare diseases. From these tissues, targeted research can be directed as new technology becomes available. The samples have no patient identifying information making a safe repository of valuable data that opens the door for researchers with specific interests and skill to study these diseases.

An example of how a large biobank database helps improve research was our discovery that a specific gene expression pathway, seen in the inherited eye disease Familial Exudative Vitreoretinopathy, is also involved with premature birth. Newer technologies allow for even more associations between vision threatening diseases and genetic pathways using Next Gen Sequencing, done at the Pediatric Retina Research Laboratory at Oakland University. This exciting technique allows for whole genome sequencing, uncovering clues in the DNA and their genes, looking for suspected genetic alterations.

Links to both the Ophthalmic Biobank and the Pediatric Retinal Research Laboratory are available on our new website www.pediatricrrf.org.

Community Review

Meet Board member Charles “Chuck” Walls

When Chuck’s third child, Collin, sat too close to the TV, he and his wife thought that was merely unusual. The day after Christmas, when Collin was around 5 years old, the family learned that he had congenital X-Linked retinoschisis, splitting of the retinal layers, and there was no treatment and no cure. It was predicted that Collin would eventually be blind.

Chuck immediately took a leave of two weeks from the army where he was serving as a LT. Col. as an experimental test pilot and sat at the computer to find out what could be done to help his son. Dr. Michael Trese’s name continued to pop up and soon the Walls had an appointment with him. Dr. Trese evaluated Collin and discussed research that was ongoing with a synthetic schisin that he was hoping might lead to a treatment. Two years later they met with other staff to learn about working with children with vision problems because his wife is a special needs teacher and could put to good use information on helping children with low vision. Then he joined the PRRF Board.

Chuck said they have struggled with finding a balance of letting Collin do all the contact sports he so loves and yet protecting his vision. He feels there is so much research to do which will help prevent or cure pediatric vision problems and wants to do more, faster.

For that reason, he is reaching out to families with children who have vision impairment in order to connect and inform them of the advances which are happening. He wants to build teams of families and invites parents to contact him at (757)338-1775 or cdwalls@yahoo.com.