The Vision Research ROPARD Foundation is a not for profit corporation registered as a 501(c)(3); all contributions are tax-deductible as allowed by law.

Teresa Nascimbeni
Vision Research ROPARD Foundation is saddened to announce the death of Teresa Nascimbeni. Teresa, ROPARD’s 2004 Children’s Vision Award co-recipient with her husband Sergio, contributed tirelessly to ROPARD over the last decade. Teresa and Sergio provided a ‘home away from home’ for Italian families who came to Michigan for treatment. They also established an educational opportunity for some of Italy’s young ophthalmologists to acquire an expertise in the diagnosis and management of pediatric retinal conditions. Teresa also served as a translator for Italian families who came to Michigan and for Dr. Tese when he operated his clinic in Italy.

Vision Research ROPARD Foundation is honored by the dedication and goodwill of Teresa and Sergio Nascimbeni.

Board Meeting at the PRRL Lab
On April 28, 2015, VRRF held it’s Board of Director’s Meeting at the PRRL Laboratory in the Eye Research Institute, Oakland University. For many members of the Board this was their first opportunity to see the state-of-the-art facility. Researcher Ken Mitton, PhD, was in attendance to provide information and demonstrations. Those who attended left with a better appreciation of the operation of the laboratory.

Upcoming Events
Ben Conit, an 8th Grader in Birmingham, Michigan, will hold a 20/20 Tourney 2015, A Charity Youth Tennis Event, on August 29th, 2–5 pm at the Bloomfield Open Hunt Club in Bloomfield Hills, Michigan.

The Trinity Rose Foundation will be holding the Trinity Rose Golf Outing on September 21st at Weymouth Country Club in Medina, Ohio. More information at www.trinityrose.org.

The Skilhi Golf Tournament will be held on September 25th at the Canyon West Golf and Sports Club, Weatherford, Texas. More information at www.canyonwestgolf.com.

Anthony Bruno and his daughter Emma will be hosting the Seventh Annual ROPARD Cup Soccer Tournament that will be held in Bethel Park, Pennsylvania. Usually in November, the date is yet to be determined.

The Abbruzzese family will be holding the “Eye in the Future” Annual Soup Cook Off on November 14th at the Lake ‘n Pines Motel in Cooperstown, New York.

Information for all of these events will be posted on VRRF’s Time Sensitive Board on Pinterest and on Facebook and Twitter.

The Gift that Gives Forever!
Have you considered including VRRF in your estate plan?
For information contact: info@vrrf.org or call 800-788-2020

Board of Directors

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Letter from the Directors
Dear Friends,
Vision Research ROPARD Foundation funds research, programs and services designed to prevent and/or treat retinal diseases in all ages. Research and development that is crucial to our success is ongoing and our Grant Committee continuously seeks out suitable opportunities that support our mission.

One ongoing study examines pharmacologic therapy for Familial Exudative Vitreoretinopathy which will be discussed in this edition. Also in this edition we will introduce you to two young people with ROP who have taken their musical talents on the road and we will meet the S.U.P.E.R. Students of 2015.

Donors and volunteers are an important part of our organization and VRRF is pleased to benefit from the proceeds of many events such as golf outings, soccer tournaments and ‘Scrapping for Sight’.

We are optimistic that these research projects will lead to more effective treatments for retinal diseases and thank you for your generous support.

Very truly yours,
Michael T. Tese, MD Antonio Capone, Jr., MD
Co-Medical Director Co-Medical Director

New Research for Familial Exudative Vitreoretinopathy
Familial exudative vitreoretinopathy (FEVR) is an inherited retinal vascular disease, which is potentially active lifelong, and can lead to blindness by leakage into and under the retina, creating an exudative retinal detachment. (See Sightlines, Dec. 2005 & 2010) People born with FEVR lack blood vessels in the peripheral retina. Children known to be at risk of having FEVR are often treated with laser that destroys the areas of the retina without blood vessels. The disease progresses into other areas with blood vessel loss or capillary drop out. The blood vessels are damaged and begin to leak.

The blood vessels are tubes of endothelial cells that are held together by adhesive proteins—the best known of which are Claudin 5 and VE Cadherins. We have recently shown that by adding the protein Norrin to retinal endothelial cell cultures we can increase the amount of Claudin 5 and VE Cadherin. This should reverse the leakage of blood vessels and eliminate the need for destructive laser treatments.

This is the first suggestion that drug therapy might be possible for FEVR, a goal we have been seeking for many years. Much needs to be done to demonstrate that this can become a mainstay of FEVR therapy, but this seems like a good beginning step.
Elizabeth and Michael Kazmierski Dunn

On May 30, at the Vision Impaired Sports and Activities Day, the participants were entertained by the ‘blind piper’, Michael Kazmierski Dunn, who played the bagpipes (in the rain). Michael and his twin sister Elizabeth have both completed their freshman year at Alma College in Alma, Michigan where they are both studying music. Both Michael and Elizabeth were born with Retinopathy of Prematurity (ROP), they are blind.

Michael began piano lessons at age three, but a year later he and Elizabeth were enrolled in the Suzuki method, in which the music is accompanied with a CD. They had a keyboard at home, but switched to a non-digital piano because some sounds are only produced by a piano. Born with a natural talent for music, it was easy for the children to listen to the music and transfer it to their fingers.

Music presented an opportunity to explore and create without constraints. Bagpipes became Michael’s first love when he received a beginner set. He taught himself from the accompanying CD, but later took formal lessons He currently is in the Alma Pipe Band. Elizabeth began composing in 2003 after a very close friend passed away. She titled the piece “I Want to Hear Your Voice Again.” It was notated by a composer in Homer, Michigan, and performed by the Battle Creek Boychoir in Grand Rapids and later on their International tour. She has composed more than thirty pieces.

The Twin Thistle

In 2006, the owner of an Irish gift shop in Grand Rapids heard Michael playing. On learning that Michael’s sister played piano/keyboard, he invited them to play at an event he was sponsoring. The band “Twin Thistle” was formed and continues to perform at Celtic events. That same year, Elizabeth submitted a piece to ‘Very Special Arts’ (VSA) of Michigan and won 1st place. She played the piece at the State Capitol rotunda and at the gala event for VSA in Grand Rapids. In 2007 she wrote and played a piece called “Summit” for Erik Weinnmeyer at the ROPARD Children’s Vision Award gala. She submitted the piece to the NFB as a fundraiser which was published on the NFB’s ‘Sound and Sight’ CD. With their musical talents and strong academic achievements, they successfully applied for music scholarships at Alma College: Elizabeth for piano/keyboards performance with creating a new musical piece and Michael for bagpipe performance.

Michael and Elizabeth love to perform together. Depending on the venue, they play and sing a variety of music, including Classical, Pop/Rock (with songs by Coldplay and One Republic), Celtic Music (with traditional pieces as well as modern artists Enya and Van Morrison), and religious and holiday songs. While Michael plays the bagpipes and sings, he sits on a Cajon drum pounding out a supportive beat to the music. The electronic bagpipes are versatile, adapting to any keyboard sound connected to it. Elizabeth’s setup includes a full size keyboard, a synthesizer and vocal/looping device that adds to the complexity and uniqueness of their sound. Although they perform three to four times a year, they are not interested in performing professionally. Elizabeth is exploring Music Therapy and Psychology and how music interacts with the brain to overcome obstacles and create new neuropathways. Michael would like to be a professional bagpipe, but states that the job market is not the greatest, so he is studying computer science along with music. With their passion and innate capabilities, there is no doubt they will be successful in their endeavors.

Sports Day for the Visually Impaired, Grand Rapids, Michigan

This year’s Vision Impaired Sports and Activities Day (VISD) was held on May 30, 2015. The sports day, which began fifteen years ago, aims to expose visually impaired children to new sports and activities and challenge them to move out of their comfort zone. It also encourages parents and siblings of these children to interact and share resources for education, recreation and other forms of development. VISD is organized by a group of dedicated volunteers including Dr. Patrick Droste, Dr. brown Geddie, GrandVibes of Opportunities Unlimited for the Blind and Scott Embree from the Grand Rapids Lions Club. Helen DeVos Children’s Hospital Foundation is a major sponsor.

Historically the participants have enjoyed superb weather, but this year was different and Mother Nature added a new dimension. The cool rainy day resulted in some events being canceled and others like, the Bouncing Fun House moving inside Wealthy School. Michigan Therapy Dogs attended to the delight of everyone. A delicious barbeque was provided and served by the Grand Rapids Chapter of the Lions Club. Luncheon entertainment was provided by Michael Kazmierski Dunn playing his bagpipes. VRRF representatives shared information about the Foundation and the Children’s Low Vision Resource Center. The event culminated in a group photo of the enthusiastic participants and dancing in the gym.

S.U.P.E.R. Students at the Eye Research Institute (ERI), Oakland University

Seven undergraduate biomedical science students were selected for the 2015 Super Student Program (Summer Undergraduate Program in Eye Research). The students will be carrying out research under the auspices of six ERI faculty members. The research will have application to many diseases and conditions, including diabetic retinopathy, retinopathy of prematurity (ROP), Norrie Disease, familial exudative vitreoretinopathy (FEVR), glaucoma and retinitis pigmentosa. This year’s program began May 1, 2015 and will end on July 31st when the students will present their studies and findings to faculty and an audience of interested family and friends.