VRPF
The Association for Retinopathy of Prematurity and Related Diseases

2013 Annual Report
The Vision Research ROPARD Foundation is a merger of two established eye research 501(c)(3) philanthropic organizations. ROPARD was established to carry out informational and other services to families about pediatric retinal disease, as well as to support original research for pediatric retinal problems. The Vision Research Foundation was established to accomplish similar goals for adult retinal issues.

This union allows us to reduce the cost of administration and maximize the benefit for funds donated for retinal research. Funds will be used only for the pediatric or adult purpose for which they are donated.

We believe that the merger of these two philanthropic organizations will lead to a new level of patient information and to funding clinically relevant research which will bring “hope for vision” for children and adults and their families.

Our Mission

The Mission of the Vision Research ROPARD Foundation is to support research, programs and services designed to prevent, treat and provide adaptive resources to patients of all ages affected by vision threatening retinal disease. We carry out this mission through clinically relevant research, educational programs for patients, family members and the general public, physician educational programs, and community support programs, including the Children’s Low Vision Resource Center.

Where your contributions go:

Your donations support:
• Children’s Low Vision Resource Center
• Educational DVD: FEVR: Past, Present and Future
• Pediatric DNA Registry
• Photo ROP Internet Screening Program
• Research at Pediatric Retinal Research Laboratory (PRRL Lab), Oakland University, MI
• Website: www.VRFR.org
• Research to cure Adult Retinal Diseases
• Super Student Program at the Eye Institute, Oakland University, MI
• Grants to support research in Adult and Pediatric Research
• Publications:
  Pamphlet: Parent’s Guide to Their Premature Baby’s Eyes
  (both publications are available in English and Spanish)

Vision Research ROPARD Foundation

47% Research
6% Administrative Costs
5% Children’s Low Vision Resource Center
42% Research Grants Awarded
Scientific Research and Projects

Current research projects and disease models

- To establish a diabetic retinopathy model, a diabetic rat model, and to characterize the relative timing of vascular changes and inflammatory gene expression changes.
- To determine peripheral capillary dropout in diabetic retinal disease with hyperbaric oxygen treatment.

VRRF funds and/or provides grants for research at the Pediatric Retinal Research Laboratory (PRLR) at Oakland University. Although originally established to carry out research projects for children, under its new mandate, it has expanded research into adult retinal diseases.

During the past year many research projects were undertaken. Those included:

- Installation of Optical Coherence Tomography
- Establishment of international collaboration: China in ROP research
- Research training program with Visiting Fellows
- Undergraduate biomedical research training: SUPER Students 2013
- PRLR related publications
- Significant applied research findings: Blyea, Norrin, Retinoid Acid, VPA, VEGFα

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As the boys developed at home, their parents, Jalil and Mua, noticed that Neil had a different look than Rayan. His eyes were not tracking like Ryan’s; he did not watch his parents in the same way. When questioned, their pediatrician advised that since all children are not the same, they should not expect the same development. When the boys were four months old, they insisted that Neil be examined by a pediatric ophthalmologist. Neil was diagnosed with Stage 4B retinopathy of prematurity (ROP) in both eyes. Arrangements were made to see Dr. Michael Tres in Michigan, and within the month, Dr. Tres scheduled vitrectomies on both eyes.

When Neil’s right eye was operated on, it was found to be too damaged, and a lensectomy was carried out. In December 2009, a vitrectomy was carried out on his left eye. Since the surgeries, Neil has seen Dr. Tres twice a year - in Michigan and in Italy. As Jalil said ‘we will go to Dr. Tres wherever he is’. Now living in Chicago, Neil had one more operation on his right eye in October 2013, to keep it healthy and prepared, should future research find a way to improve his vision.

Neil has no vision in his right eye, but has functional vision in his left - he can see 10-15 feet in front of him. It does not keep him from being as active as Rayan. He attends two different schools. In the morning he goes to a school for the visually impaired and in the afternoon, to a local Montessori school with Ryan. In Chicago, the family has found a strong support system. A state vision specialist evaluated Neil and provided an individual program to develop social as well as practical skills. When in Michigan, the family visits the Children’s Low Vision Resource Center, where Paula Kuretz provides them with guidance and tools to help Neil grow and develop.

Neil has many interests, including swimming and gymnastics, and has his yellow belt in Taekwondo. He also has a strong interest in music, and takes piano and guitar lessons, as well as dance. He is a thoughtful boy who enjoys meeting new people. Rayan depends upon Neil, as the twin who will open doors and pave the way before he enters. Bright and cheerful, innovative and caring, Neil is thriving.

Neil Mekour

Neil and his twin Rayan are 4½ years old. They were born in the American Hospital in Dubai, prematurely at 28 weeks, and weighed less than two pounds. During their two-month stay in the NICU they had eye examinations at two weeks and four weeks of age. They were told that there was no sign of ROP and to return in six months.

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Micah Wong is an active six year old who loves music. Weighing in at five pounds, he was born in Melbourne, Australia, on January 15, 2008, two weeks earlier than his parents Elaine and Ray expected. Because he was almost a term baby, they did not consider eye problems and were devastested to learn, when he was two months old, that he had familial exudative vitreoretinopathy (FEVR). He was blind in one eye with little vision in the other.

Elaine and Ray did their research and learned that the pediatric ophthalmologists in Michigan could help. The family visited Michigan and Micah was treated by Dr. Antonio Capone. They also met with Paula Kornitz at the Children’s Low Vision Resource Center. They learned of the “Little Room”, by Lilli Nelson, which helped Micah deal with spatial recognition.

The first year was very difficult because, with a lack of visual stimulus, Micah’s gross motor skills were slow in developing. Even though he was small when he was born, his size was in the normal range for his age but his development was behind other children of a similar age. In the end, he rolled over, sat up, crawled and walked, all from 11 to 14 months.

Today, Micah’s vision is stable, but the family must be vigilant during growth spurts. They return to Michigan for periodic examinations under anesthesia. Micah reads very well - he holds his books close to his eyes. He is also learning Braille. To promote gross motor skills, he is enrolled in gym class and takes swimming lessons. His major love is music, with Frankie Vallie and the Four Seasons being his favorite group. He loves to sing, harmonizing on the bass line. He plays the piano and plans on taking violin lessons.

### Adult Clinical Studies/Trials

The Vision Research ROPARD Foundation sponsors protocol supervised studies of new therapies for age-related macular degeneration (AMD), both wet and dry, as well as diabetic retinopathy, ocular inflammatory diseases and other retinal vascular diseases.

**In 2013 new studies were undertaken and some are ongoing.** These included:

- **A study to establish the safety and efficacy of Squalamine Lactate Ophthalmic solution 0.2% on wet AMD (Oculus).**
- **A study to establish the changes in retinal morphology and retinal vascular oxygen content in patients with disease states using a non-interventional oxygen imaging device called OxyCam (D.I.R.D.S.).**
- **A study to evaluate the efficacy and safety of two doses of oral Optimax™ in patients with diabetic macular edema (Ambig-DME).**
- **A study to establish the safety and efficacy of intravitreal administration of Fovista™ administered in combination with Lucentis® in subjects with subfoveal neovascular AMD (Ophthotech).**
- **A study to compare Emixustat-Hydrochloride with a placebo for the treatment of geographic atrophy associated with dry AMD (Acucela).**
- **A study to evaluate the safety and efficacy of lontophoeretic dexamethasone phosphate ophthalmic solution compared to prednisone acetate suspension 1% in patients with noninfectious anterior segment uveitis.**

Some studies came to a close, including:

- **A study to establish whether to use Foreshine to monitor visual perception in patients at risk of developing choroidal neovascularization (CNV).**
- **A study to establish the efficacy of the AREDS2 vitamin formulation;**
- **An Allergan study to evaluate the biodegradation of the brimonidine tartrate posterior segment drug delivery system in AMD.**

Some are in follow up:

- **A study to evaluate the efficacy and safety of monthly injections of Sirolimus vs. sham for geographic atrophy.**
Carol Berge was waiting for an appointment with Dr. Capone, when she was surprised to meet babies and children in the waiting room. Twelve to fourteen years before, she had been diagnosed with dry age-related macular degeneration (AMD) in both eyes. Because her father had AMD, her diagnosis did not come as a surprise but she was unaware of vision problems that children have.

For several years after the diagnosis, her vision was stable at 20/25 in both eyes, but it then began to deteriorate, particularly in her left eye, which developed wet AMD. She received Lucentis® injections in her right eye and eventually had a vitrectomy.

Although limited vision has affected her golf game, it has not prevented her from enjoying herself. She is an accomplished pianist, loves to travel and spends time with her family - her husband, Frank, daughter Catherina and her husband, and their 3½ year old son Kyle. Today she has 20/25 and dry AMD in her right eye, where a cataract is forming. She gets injections of Eylex® in her left eye, which has limited vision at 20/70. She also takes supplemental vitamins.

It was at one of her more recent doctor’s visits when she shared the waiting room with the children that sparked her interest in retinal problems of children. Curious, she spoke with Dr. Capone about issues with children and, later, visited Paula Korellitz at the Children’s Low Vision Resource Center. On seeing the remarkable resources available at the Center, she arranged for the local Optimist’s Club, of which she is a member, to hold their November meeting there. Carol’s enthusiasm about the Center is infectious and she looks forward to raising funds for the Center and research in retinal diseases.

Musician, world traveler and linguist, Victor Hickman has not stopped since he retired fifteen years ago from Birmingham Public School where he taught music. Already fluent in Italian, on retiring, he began studying other romance languages and joined an orchestra where he plays the viola. Travel became a major pleasure. Six years ago, during a routine eye examination, his ophthalmologist noticed signs of age-related macular degeneration (AMD) in his right eye. Victor’s father had AMD so he was aware of how this could affect him, particularly reading and playing music.

When he was first diagnosed, Victor was told of an eye study comparing new AMD treatments. He was referred to retinal specialist Dr. Tarek Hassan. The two year study, called the Comparison of AMD Treatment Trials or CATT, sponsored by the National Eye Institute, compared the effectiveness of two anti-VEGF drugs, Lucentis® and Avastin®. These drugs reduce blood vessel growth. At the beginning of the study, Victor’s vision in his right eye was 20/100, but a month later, after treatment, it was 20/60. It has continued to improve and is holding steady at 20/30-20/40. After Victor exited the study, his left eye began to show signs of AMD, and today both are being treated with Lucentis®. He also takes PreserVision®.

Victor’s greatest concern is his ability to read music. He has special glasses, but lately he has been having more trouble following the notes across the page. He has an appointment with Dr. Susan Hahn, a low-vision specialist, and hopes that she can help him.

Victor still performs in two orchestras, the Macomb Symphony and the Groovi Pointe Symphony. He also works out at the YMCA several times a week and continues to practice his new languages by travelling the world.
Future Research and Projects

Two grants have been approved by the Board of Directors for future projects:

- A grant for $7,300 to Dr. Michael Trrese. This is a three-month study to determine if hyperbaric oxygen helps or worsens peripheral capillary drop-off in the retina in diabetics.

- A grant for $26,000 to Dr. Kim Drsense. This is a one-year study to engineer a recombinant Norrin protein which behaves as endogenous Norrin does in activating Wnt-signaling for use in treatments of neovascular disease (i.e., retinopathy of prematurity, ROP).

The eye Research Institute, Oakland University, Michigan

The Vision Research ROPARD Foundation supports the Summer Undergraduate Program in Eye Research (SUPER) at the Eye Research Institute (ERI) of Oakland University in Michigan with grants. This program allows undergraduates to participate in NIH (National Institutes of Health) and other externally sponsored research under the mentorship of six ERI faculty. SUPER scholars obtain research training in the disciplines of biochemistry, cell biology, physiology, molecular biology and neuroscience. Scholars use the latest research methodologies and equipment and receive training in professional speaking and presentation. There are also opportunities for students to co-author publications in scientific journals and to participate in presentations at future national meetings. The program offers an opportunity for students to pursue a career in ophthalmology and/or research. All SUPER scholarships include a Research Fellowship.

Eight top achieving undergraduate biomedical science students were selected for the 2013 summer program. This was the largest SUPER class since the program was formalized in 2001.
The Children’s Low Vision Resource Center is the first facility of its kind in the world. It was created to address the developmental and educational concerns of families with children who are visually impaired. Families from more than 50 foreign countries and the United States and Canada have visited the Center. Many come from areas where there are no local resources to assist in the development of their child. Doctors from Lithuania, Italy, Puerto Rico, Columbia, India and Taiwan have visited the Center, with the hope of replicating it in their own countries.

The Center is located at 3412 W 13 Mile Road, Royal Oak, Michigan, 48073 across the street from Beaumont Hospital. The comfortable atmosphere puts families at ease and allows them to explore the Center’s many resources at their leisure. The Center is staffed by Paula Korell, Outreach Director, and Rosemary Blaszkiewicz, Parent Advisor, who help families understand how best to provide appropriate stimulation for their child. Many of the materials and tools can be taken home. Because of the generous support of the friends of Vision Research ROPARD Foundation, there is no charge for the services or materials provided at the Center.

The Center also has a large meeting room, and organizations are encouraged to gather and tour the facilities to increase awareness. In 2013, two groups, the regional Optimists Clubs and the Delta Gamma Society held meetings at the Center.

The new combined website, www.VRRE.org was established in 2013. It incorporates the best features of both the ROPARD and Vision Research Foundation websites and more! There are new ideas that will lead to better information about many pediatric and adult retinal diseases for patients and families.

On the Pediatric Retinal Information page, parents, families and friends will continue to have access to the Bulletin Board, News Flashes, Technology Information, Living Skills, Telemedicine and Pediatric Retinal Diseases.

The Adult Retinal Information page provides a wide array of information on diseases, research and current studies concerning adults. It also provides information for adults who are interested in becoming a study participant.

See our Pinterest page at www.pinterest.com/VRRF/
Vision Research ROPARD Foundation Events

Fundraising and Volunteers

VRRF is supported by incredible groups of fundraisers and volunteers who have devised unique methods for not only raising funds but increasing awareness of its mission. Golf tournaments were hosted by the Skipper family in Texas and the Bonitz family in Ohio.

The Bruno family continues to bring VRRF awareness to Pennsylvania. With Cassie Bruno, who has ROP, as the focal point, many members of the family have arranged interesting events with dedication and ingenuity. Cassie’s parents, Mike and Jennifer arranged “Volley for Vision,” a Volley Ball Tournament at Point Park University where Mike teaches. “The ROPARD Cup,” a soccer tournament, arranged by Casey’s cousins and uncle Anthony, at the Bethel Park Soccer Association was received with enthusiasm by children and adults. An enthusiastic scrapbooks, Cassie’s grandmother, Kathy Bruno holds scrapbooking events to raise funds. Cassie’s dad, Mike ran in the Pittsburgh marathon blindfolded so “that in this one event I can experience what Cassie experiences every day”.

Jennifer Abbruzzese in New York held a successful soup tasting for the benefit of VRRF.

The Delta Gammas continue to contribute time and resources to the Children’s Low Vision Resource Center.

Vision Research ROPARD Foundation is honored to have the support of these generous organizations and individuals.

The Hope for Vision Award (Formerly The Children’s Vision Award)

The Children’s Vision Award was established in 2000 to honor individuals who have made a significant contribution to improving children’s vision through support for pediatric retinal research and education.

It is awarded every two years. Past recipients include: Frank Kelley, a founding member of ROPARD; Dr. John D. Baker, who has devoted his career to pediatric eye disease and vision problems and is also a founding member of ROPARD; Teresa and Sergio Nascimbene who have contributed tirelessly to improving children’s vision in Italy and the US; Erik Weihenmayer, who has overcome his blindness to become an athlete, author, and inspirational speaker; to Dr. Mark Humayun for his research in developing a retinal prosthesis and his devotion to helping the blind to see; and to Dr. Jean Bennett and Dr. Albert Magueiro who have used gene therapy to reverse near blindness in people with Leber’s Congenital Amaurosis. The 2012 Award was presented to Paul and Colleen Ziegler who through their generous support have been instrumental in making ROPARD and the Children’s Low Vision Resource Center a success.

In 2012, when ROPARD and Vision Research Foundation merged, it was established that the Award should recognize those outstanding individuals who contribute to retinal research and education in both children and adults.

In 2014, the Vision Research ROPARD Foundation will honor Richard and Jacqueline Skipper in recognition of their outstanding contribution to pediatric and adult retinal research and education. The presentation will take place at VRRF’s golf outing and dinner, on September 8, 2014 at the Shurf Golf Course at Oakland University in Rochester, Michigan.

Funds raised at each event to honor these outstanding individuals are used to fund research grants and other projects.

Delphi Gammas make Bibs – Delta Gammas make out at the Children’s Low Vision Resource Center to make bibs to be given to children with low vision.
Individual Donors

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For information, contact info@VRRF.org or call 1-800-788-2020.