

“Stars of the Future” Fourteenth Annual Symposium

On Friday, August 1, 2014, S.U.P.E.R., the Summer Undergraduate Program in Eye Research presented its Fourteenth Symposium at Oakland University. Each of the seven students who took part in the program presented a paper on the research that they had carried out over the previous 12 weeks under the mentorship of six Eye Research Institute faculty. The students: Erin Feeney, Mason Geno, Naharain Putrix, Kirsten Laux, Brandon Metcalf, Nathan Spix, and Jermyn Yohannan made well-thought out, organized presentations. In addition to the proud mentors, the event was attended by family and friends. Dr. Kenneth P. Mitton, S.U.P.E.R Coordinator, presented the students with certificates. Following the presentation, lunch was served and a tour of the Eye Research Institute (ERI) at Dodge Hall took place.

“Keep Your Eye on the Ball!”

Sunshine and warm weather welcomed the seventy golfers who attended the Vision Research ROPARD Foundation’s Golf Outing on September 8th. After a box lunch, the golfers set out for their respective holes and the shotgun start. They returned exuberantly four hours later for cocktails and to take part in a silent auction of unusual items. The ‘Hope for Vision Award’ dinner followed. Michigan Golf Live Radio host Bill Hobson entertained the audience with a live auction. The weather, the entertaining host, the generous golfers and diners who came out to support VRRF guaranteed the day was a resounding success.

New Members to the Board

Charles S. Walls IV, LTC (Ret) joins the Board as a parent representative. He is the parent of four boys, one of whom, Collin, who is 11, was diagnosed with X-linked retinoschisis when he was 4 years old. Mr. Walls and his wife Donna are active in the search to find the treatment and cure for Collin’s condition.

Lisa J. Faia, M.D. is a vitreo-retinal specialist at Associated Retinal Consultants, P.C. She is involved in a wide array of both basic science and clinical studies in uveitic and vitreoretinal disease. She treats and manages both adult and pediatric patients.

Holiday Giving

Vision Research ROPARD Foundation is funded almost entirely by private donations. The funds are used to support retinal research in children and adults, the Children’s Low Vision Resource Center and education through the S.U.P.E.R Students program at the Eye Research Institute at Oakland University. As the Holiday Season approaches, we would ask that you consider supporting VRRF with a gift to continue our mission.

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Should you have any questions regarding this issue, please contact VRRF at 248-319-0161 or visit our website at www.VRRF.org or email us at info@VRRF.org.



A Letter from the Directors

Dear Friends,

2014 has been another successful year for Vision Research ROPARD Foundation. With your generous donations, VRRF has funded clinical trials for adult retinal diseases, basic scientific research for pediatric retinal diseases and the S.U.P.E.R Student program at Oakland University. Our Grant Committee has continued to search out proposals to support research that will aid in our mission to cure retinal diseases.

In September, VRRF held a golf outing to raise funds for the organization. The sunshine and enthusiastic golfers who attended ensured the success of the event and introduced VRRF to many people who had never been exposed to it before. At the reception we honored Richard and Jacqueline Skipper who have been staunch supporters of VRRF with the ‘Hope for Vision’ Award.

This edition of Sightlines discusses the experience of Ray Tienda who participated in a clinical trial to address his diabetic retinal edema. We also meet five-year-old Alaina Talbott. We share with you the amazing story of a Kalamazoo family who discovered a Bulgarian orphan with retinopathy of prematurity and have welcomed him into their family. And we wish good luck to this year’s S.U.P.E.R student participants.

As this year draws to a close, we thank you again for your continued support and wish you a happy holiday season and healthy new year.

Very truly yours,

Michael T. Trese, MD
Co-Medical Director

Antonio Capone, Jr., MD
Co-Medical Director



Dr. Michael Trese presents the ‘Hope for Vision’ Award to Richard and Jacqueline Skipper

Dear *Sight*LINES,

At a few weeks old, I felt that our baby, Alaina was not thriving as she should. She was small, a poor eater and startled too easily. At her two month check-up, the pediatrician suggested an MRI. Everything looked fine on the MRI but then the radiologist said, 'There seems to be something ocular that may need to be checked out'. Words I remember hearing loud and clear. An hour later the ophthalmologist declared: 'Your daughter has detached retinas, it's one of the worst cases I've ever seen. Your baby is blind.' This was unbelievable. The ophthalmologist said that Dr. Michael Trese, located in Detroit, sees infants with detached retinas every day whereas in Louisville, the condition may be seen once a year. After a restless night, my husband and I headed to Detroit.

Alaina was diagnosed with Familial Exudative Vitreoretinopathy (FEVR). The doctors said to remain hopeful; that predicting an infant's functional vision with partially detached retinas is nearly impossible because they learn to use what vision they have. We were vigilant, working with Alaina on her visual exercises, showing her high-contrast pictures, using lights and music and engaging her in family activities. With vision, occupational, physical and speech therapy, she soon showed signs of using vision and we focused on activities that had vision at its core.

Today Alaina uses functional vision for everyday activities but because we don't know what the future holds, she is learning Braille and uses an iPad in the classroom. She knows no boundaries, doesn't read the doctor's reports or know what the anatomy of her eyes suggest her vision to be. When she surprises us with her visual capabilities, perhaps

she is using other sensory clues or perhaps her functional vision is better than we think.

As her 5th birthday nears, our fears are replaced with enthusiasm for her future. Alaina is motivated, unstoppable with a quick wit that keeps us laughing. She enjoys life to the fullest waking each day ready to play and learn. Alaina is an inspiration and a blessing.

It is a pleasure to share our experience with you.

—Jill Talbott



Alaina Talbott lives in Louisville, KY with her Mom, Jill, and Dad, John and siblings 11 ½ year old Hannah and 9 year old Jack.

Rey Tienda

An avid boater and outdoorsman, Rey Tienda owns a paper supply company. He has had vision issues most of his life, suffering with an astigmatism and had cataracts removed a number of years ago. Two years ago, after the cataract surgery, he began to have problems with his left eye. His doctor diagnosed diabetic macular edema and referred him to a retinal specialist, Dr. Jeremy Wolfe.

Under Dr. Wolfe's care, he received laser treatments and Lucentis® shots. His vision improved but not appreciably so the doctor suggested that he participate in a clinical trial to evaluate the efficacy and safety of two doses of oral

Optina™ compared to a placebo. Rey was willing to try anything.

The study was for a 12 week period followed by a 4 week washout period to determine the regression of effect. After 8 weeks, Rey's vision showed improvement. During the next 4 weeks, the improvement continued and during the washout period, his vision stayed the same.

When the study was extended another twelve weeks, Rey was happy to qualify to participate and hopes that his vision will continue to improve.

How the Internet Brought an Orphan to a Kalamazoo Home



Zahari

Thirteen-year-old Hannah Weal loved her teddy bear. It brought her comfort when she felt lonely and sad and she felt badly for children who had none. She decided to help these children. 'Surfing the net', she found orphanages all over the world where she began to send 'beanie babies'®. In her search, she came across photos of Bulgarian orphans. One was of a small boy who desperately needed a home. Hannah was smitten. She had found her 'Soul Brother' and urged her parents, Courtney and Dave, and her sisters Stella and Emily to adopt him.

Intrigued, the family learned more about 8-year-old Zahari. According to posted information, he was blind and deaf. He suffered from a heart condition, had emotional issues and was schizophrenic. The photos showed a scared, tiny, boy who looked like a 'caged puppy'. He was obviously malnourished. Courtney and the girls were keen to adopt but Dave was hesitant. Finally, he agreed that Zahari would be good for all of them.

In January 2013, they began the process to adopt Zahari. With the help of friends, they raised money to support the application. In July, they received permission to meet and commit to him. If this adoption did not take place he would be transferred to an adult institution for the mentally ill. In September Courtney and Dave traveled to Bulgaria.

During the week they were there, they visited Zahari, for four hours each day. They knew that he was meant to be their son but they had to wait for the adoption to finalize. This process took another five months during which built a fire engine bed for Zahari.

On December 13, they received an email saying that Zahari was legally their son. In February 2014, they returned to Bulgaria. The caretaker carried Zahari to them and without a word, left him. Zahari was terrified.

In Kalamazoo, Zahari immediately saw a pediatrician and ophthalmologist. He was diagnosed with Stage 5 retinopathy of prematurity (ROP) but other than malnutrition had no other physical problems.

In his seven months at his new home, Zahari has made remarkable progress. Unschooled and developmentally far behind his 8 years, he has gained three years of skills and seventeen pounds! In May, he began at WoodsEdge Learning Center, a school for children with special needs. Therapists help him with eating, speaking, orientation and mobility and other life skills. He uses a cane to get around. Climbing is a favorite activity. Courtney thinks he has some light and dark vision because he rarely falls off the furniture. Music has become an interest and he enjoys Bible school songs. Good natured and growing less apprehensive daily, he is adapting to his new life with this remarkable family. The family love to have him around, as Courtney says, "he is a miracle unfolding."

