A Letter from the Directors

Dear Friends,

For the last six months, we at VRRF have continued to carry out our mission: to fund research, programs and services designed to prevent and/or treat retinal disease in adults and children. Clinical trials for adults are ongoing and research to treat and cure pediatric retinal diseases continues. We are optimistic that these studies will lead to more effective treatments of retinal diseases.

In this edition we introduce two study participants one with Diabetic Macular Edema and one with Age Related Macular Edema. We also explain how soup can be a great fund raiser for VRRF.

This year, we will be holding our biennial Hope for Vision Award (formerly Children’s Vision Award) dinner, where we will honor Richard and Jacqueline Skipper in recognition of their outstanding contribution to adult and pediatric retinal research and education. It will follow a Golf Outing and Silent Auction at the R & S Sharf Golf Course, Oakland University, Rochester Michigan.

All of the research projects and accomplishments are due to your generous support for which we are most thankful. We look forward to seeing you at the Golf Outing and Award Dinner on September 8, 2014.

Very truly yours,

Michael T. Trese, MD
Co-Medical Director

Antonio Capone, Jr., MD
Co-Medical Director
Eye on the Future Soup Cook Off

My name is Jennifer Abbuzzese. My husband, Julio “Chris” and I live in Cooperstown, NY. We have two wonderful daughters, Marissa and Juliana, ages 10 and 9. Both girls have Familial Exudative Vitreoretinopathy (FEVR) and are patients of Dr. Antonio Capone. They are monitored by Dr. Sam Spalding in Syracuse and their condition is currently stable.

Marissa has little vision in her left eye (she can’t see the big “E” on the eye chart) but with corrective glasses, she has almost 20/20 vision in her right eye. A good student, she has just completed the 5th grade. Her interests include basketball, Girls on the Run, swimming and riding her razor scooter. She is a funny, loving big sister with an infectious laugh.

Juliana’s vision acuity is 20/400 with blind spots. Her left eye is more involved. A graduate of 3rd grade, she has a one-on-one aide at school and on the bus. She does her schoolwork using a CCTV and an iPad. Juliana is involved in Girl Scouts, ballet and Girls on the Run. She listens to books on her iPad, plays with her American Girl dolls and sings. Her latest passion is horses and recently she had her first assisted horseback ride—she loved it!

About six months ago, Juliana asked, “Mommy because I am legally blind, when I have kids will they be blind too?” She reminded me that FEVR is a genetic disease and can affect generations of our family. Although we have no knowledge of other members of our family with FEVR, I thought we should try to help prevent blindness in our family and in others.

On November 16, 2013 my family and I held a fundraiser on behalf of VRFF. We hosted the first annual “Eye on the Future” soup cook-off and basket raffle. We asked family and friends to make a soup with an enticing name to be judged by the people who attended. We received soups from family, friends, neighbors and even Juliana’s teachers. A local restaurant donated tossed salad and rolls, another donated drinks and an Amish family donated pumpkin and apple pies. Perfect fall foods!

Many local businesses made donations for the basket raffle. These included gift certificates, a snow blower, a power washer, tickets to “Spank” from a local theatre, lotto tree and holiday baskets full of goodies... we raffled off over 50 baskets. As our guests tasted soup and chose a basket, they were served cheese and crackers donated by a local farm and Chobani yogurt donated by Chobani employee.

Marissa and Juliana sold “Eye on the Future” T-shirts, light up glasses and popcorn. We ran a slideshow and the YouTube video from ROPARD’s 2010 FEVR conference.

Our goal was not only to raise money for research, but also to educate others about FEVR.

We planned a small event so we set a modest goal of $500. The outcome was overwhelming. In the end we sent a check to VRFF in the amount of $3,800.47, vastly exceeding our goal, due to the support of family, friends and community.

As a family we try not to let Marissa and Juliana’s vision limit their daily lives. With a little creativity and help from our community, we try to adapt to all activities. Although I hesitated at first when Juliana wanted to see the movie “Tangled,” we took her anyway and she loved it. She didn’t need to see it with her eyes, she listened and knew more about the movie than we did. We learned that we couldn’t feel sad for what we think they are missing because they are, in fact, seeing differently. To appreciate life fully you need to open your eyes to everyday miracles and keep your “Eye on the Future”!

Grand Rapids, Michigan: Sports Day for the Visually Impaired

On May 31, 2014 the Vision Impaired Sports and Activities Day (VISID) was held. The purpose of the event which began fourteen years ago, is to expose visually impaired children to new sports and activities and challenge them to move out of their comfort zone. It also brings together parents and siblings of these children from different areas of Michigan to interact and share resources for education, recreation and other forms of development. Organized by a group of dedicated volunteers including Dr. Patrick Droste, Dr. Brooke Geddle, Amy Welcots, Gwen Botting of Opportunities Unlimited for the Blind and Scott Embrute from the Grand Rapids Lions Club, the day was a great success. The Helen DeVos Children’s Hospital Foundation is the major sponsor of the event.

Children of all ages took part in “Beep Baseball”, Rock Wall Climb, Bouncing Fun House, Cody’s Ride (tandem tricycles) and crafts. East Grand Rapids Public Safety brought a fire truck and police cruiser for the children to learn about. Michigan Therapy Dogs attended to the delight of everyone. A delicious barbecue was provided and served by the Grand Rapids chapter of the Lions Club. Susan Campbell of the Vision Research ROPARD Foundation setup a booth to explain the purposes and achievements of the VRFF and the resources available to the visually impaired and their families. The event culminated in a group photo of the enthusiastic participants.

Stephanie Hamilton

Stephanie Hamilton lives in Oxford, Michigan with her husband Bill and her six-year old daughter. She works as a Title Clerk at a local car dealership. When Stephanie was twelve years old, she was diagnosed with Juvenile Diabetes. Now twenty years later, she is suffering from Diabetic Macular Edema. Stephanie’s problem was first identified by her primary care doctor. Eventually, she was referred to a retinal ophthalmologist, Dr. Jeremy Wolfe. Stephanie has diabetic retinopathy in her right eye.

Dr. Wolfe is conducting a clinical trial to evaluate the efficacy and safety of two daily doses of oral Opti-Ex™ in adult patients with diabetic macular edema and suggested that she enroll. Stephanie was enrolled in the trial for seven months, during which time, she took four pills a day—two in the morning and two at night. She experienced no side effects to the drugs and at the end of seven months noticed an improvement in her vision. She was told that there was a reduction in the swelling causing her vision to improve. Stephanie was seen ten times during the period of her enrollment and was kept informed about her progress. Once the study is complete, results will be sent to the FDA for evaluation.

Stephanie enjoyed being in the study and hopes that her participation will benefit not only herself but others with the same problem. Unfortunately for Stephanie, the oral Opti-Ex™ medication will not be available until the trial is concluded and receives FDA approval. In the meantime, she hopes to be able to participate in more clinical trials.

Become a Study Participant

A clinical study, clinical trial or a clinical protocol all mean the same thing— a scientific study of how a new medicine or treatment works in people. There are many benefits in participation in a study. The treatments may be more effective than those currently available. Participants are closely monitored by doctors and other experts and are promptly informed of the outcome. Study results may help others with the same eye problems. If you wish to participate in a clinical study, contact your ophthalmologist to see if one is available for you.