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THE VISION of CHILDREN

SEVENTH WORLD SYMPOSIUM:

"Understanding the Pathway - Discovering a Cure"

The Vision of Children Foundation is proud to announce the successful conclusion of the Seventh World Symposium on Ocular Albinism. Twenty-five prominent scientists, many international, travelled to San Diego for the two day conference where each presented and discussed their latest research into the genetics and treatment of vision disorders. The researchers were welcomed to San Diego by County Supervisor Bill Horn, a long time friend and supporter of VOC, who was quite heartened at the remarkable progress that has been made. "These researchers are indeed closer than ever to finding a cure," Horn said.

Topics covered were as diverse as the scientists themselves, who were affiliated with many of the world's most prestigious research institutions. Participants discussed such subjects as visual functions in infants and young children with Nystagmus, the role of the OA type 1 protein in regulating melanosome transport in pigment cells, and potential use of stem cell microvesicles in the treatment of genetically caused vision disorders. Each talk was guided by the conference's theme of collaboration and mutual assistance. Questions and clarifications after the presentations enriched not only the presenting scientist's research, but the work of all Symposium members. At the close, several Symposium presenters enthusiastically endorsed the unique, iterative format of the meeting. "It was the best discovery session I have ever attended," remarked one scientist from Europe. 😊



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AAPOS

The Vision of Children Foundation grows by expanding through research and networking. And at the recent American Association for Pediatric Ophthalmology and Strabismus (AAPOS) convention, we accomplished both. The convention reviewed current therapies and new advances in the diagnoses and management of both adult strabismus and disorders that are treated within the field of pediatric ophthalmology.

Our researchers were on hand to present their newest findings and, in addition, add to the VOC's own technical resources. But equally as important, the VOC was there to network. For this year's AAPOS, that meant informing doctors of our new Sponsorship Program. By giving a "Vision, Passion, Hope, or Cure" level donation to become a member, physicians receive benefits that help us better reach their patients. The program is a wonderful way to inform families who aren't yet aware of us and the services we provide.

The program works because doctors are trusted and vital sources of healthcare information for families. Their referrals go a long way towards guiding patients to the support that they need. For parents of children with vision disorders, this guidance can mean the world! With our program, the VOC Sponsorship doctors link families to the Foundation's network through recommendations, informational material, and the VOC endorsement that they give by simply being members. So, if you know a physician who might be interested in our new Sponsorship Program, we encourage you to tell them about it. You never know who else you might be helping!

At a minimum level, physicians receive waiting room materials such as brochures, newsletters, bookmarks, and the book, "All Children Have Different Eyes," as well as use of the VOC logo on their personal website, recognition of membership on the VOC website, and additional benefits. ☺

NEW CORPORATE PARTNERS

Support for The Vision of Children Foundation comes from many sources, among which are partnerships with our forward-thinking sponsors. This month we have the pleasure of introducing two new partners: MIRA FLEX and The Medi-Kid Co. Welcome to the VOC!



The Medi-Kid Co. designs and delivers custom pediatric and adult immobilizers for every requirement—from therapeutic exercise to night splinting to post-surgery recovery. With more than two decades of experience, Medi-Kid provides comfortable and convenient immobilizers to hospitals, doctors, and parents. Visit them at: www.medi-kid.com



MIRA FLEX provides top-quality pediatric lens frames to customers throughout the world. For over 20 years their high standards have produced a combination of safety, durability, and aesthetic design that satisfies both the demanding requirements of professionals and the unique needs of every child. Visit them at: www.miraflexglasses.com ☺



RETINAL GENE THERAPY

Retinal gene therapy is going from bench to bedside. The team coordinated by Alberto Auricchio at TIGEM in Napoli and Francesca Simonelli at the Dept. of Ophthalmology of the Second University of Napoli, Italy, in collaboration with Drs. Jean Bennett and Katherine High at the University of Pennsylvania and Children's Hospital of Philadelphia, has initiated a clinical trial testing the safety and efficacy of subretinal administrations of a small vector derived from the adeno-associated virus (AAV) in the retina of patients with a rare form of childhood blindness, Leber's congenital amaurosis (LCA). Very promising data on 3 Italian patients treated one year ago in this trial were recently presented at the 7th World VOC Symposium. The patients had significant and stable improvement in both subjective and objective measurements of visual function in the absence of serious adverse events. The persistence of efficacy at one year after a single administration of the vector in the LCA patients strongly supports the retina as a target organ for gene therapy. ☺

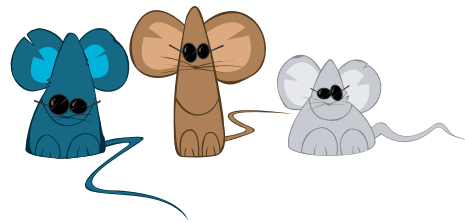


Dr. Alberto Auricchio

THREE BLIND MICE

This nursery rhyme and song was first written down 400 years ago and is sung everyday by countless children (and adults). The refrain also figuratively echoes through the hallways of

research labs around the world as mouse models for human diseases have become the single most powerful method for understanding how genes affect our health.



The common laboratory mouse originated in the parlors of mouse fanciers in the 19th century – people who collected mice as pets! The mouse fanciers all over America, Europe and Asia collected and traded mice with different coat colors, eye colors, behaviors, etc. Some of the fancy mice were blind, others deaf, some “danced” due to inner ear abnormalities.

At the beginning of the 20th century, the science of genetics was in its infancy, but a few scientists recognized that these fancy mice might be more than just pretty to look at. Mice began to move from parlors into laboratories. As part of this early work, among the first genetic mutations identified in mammals was the gene for albinism, a condition that results in a lack of pigmentation in the skin and eyes. Albinism, as is found in mice, humans, and virtually every other mammal, turns out to have a common cause: the gene that codes for an enzyme (tyrosinase) that is needed to make melanin is mutated. If the mutated gene is 100% inactivated the result is complete absence of melanin in hair, skin and eyes. Sometimes (in both mice and people) the albino gene is only partially inactivated and some pigment is formed. Scientists now know dozens of other genes that contribute to skin, eye, and hair color, and thousands of genes for other traits.

Near the end of the 20th century, the Human Genome Project gave genetics a major revolution as the DNA of the entire genome was sequenced. The first two mammalian species to be sequenced were humans and mice! Now, we have the complete DNA sequence and know that there are 4 billion letters in the genome which encode for about 25,000 genes. We know that most of the genes of mice and humans are almost identical, and we can use studies of mice to develop treatments for human disease.

Gene sequencing has also given scientists the ability to engineer mouse mutants to create a disease model when one has not occurred in nature. For example, the human gene for ocular albinism type I (OA1) exists in mice but a mouse mutation did not exist until the Vision of Children Foundation funded the research that made a mouse model for OA1 and research for a cure possible. Similar projects for other eye diseases such as blindness and glaucoma, and other diseases of vision are now all being studied in laboratories and more are planned.

So the next time you hear someone sing “Three Blind Mice,” smile not just because it’s cute but also because it reminds you that scientists around the world are using mice to help make and keep people healthy. ☺

Dr. Richard S. Nowakowski is a Professor of Neuroscience and Cell Biology at the Robert Wood Johnson Medical School in Piscataway, New Jersey.



HEALTHY EYES - EATING RIGHT FOR THE EYES

An essential part of preventative eye care is eating the right foods that contain the right vitamins to help keep your eyes healthy.

HEALTHY EYES - ANTIOXIDANTS

Antioxidants help prevent many diseases affecting all the organs of the body including the eyes. Antioxidants work to scavenge free radicals that circulate throughout the body and can cause inflammation. Antioxidants include Vitamin C, Vitamin E, and Vitamin A. These antioxidants have been shown to prevent progression of certain types of Age-Related Macular Degeneration, cataracts, and several other eye diseases. Good sources of antioxidants include fruits and vegetables, with the highly pigmented ones often having higher concentrations. When picking fruits and vegetables notice the color and chose the ones with more color to them. Concentrations of antioxidants are more abundant in raw form and are sometimes lost through cooking, canning, drying, and freezing.

ANTIOXIDANTS - VITAMIN A FOR HEALTHY EYES

Vitamin A is a type of antioxidant found in many foods which is essential to proper functioning of the retina. Vitamin A comes in many forms, some of which appear particularly beneficial to eye health. Lutein, which is found in high concentrations in leafy green vegetables, including spinach and kale, appears particularly helpful in reducing the rate of Age Related Macular Degeneration (ARMD).

Lutein is also found in high concentrations in egg yolks since farmers often feed their chickens marigolds to increase the color of the yolk. This has an added benefit of increasing the lutein concentration in the yolk. Zeaxanthin (also found in leafy green vegetables and in orange bell peppers) appears to help prevent ARMD as well. Several large scale epidemiologic studies suggest that both lutein and zeaxanthin can help to prevent the onset of cataracts.



THE BENEFITS OF OMEGA-3'S AND CHILDREN

Omega-3 fatty acids are essential to human health and cannot be manufactured by the human body so they must be obtained through diet. The three major dietary omega-3's are alpha-linolenic acid (ALA), eicosapentaenoic acid (EPA), and docosahexaenoic acid (DHA). The omega-3 fatty acids have been shown to have numerous beneficial health effects, most of which appear to revolve around their anti-inflammatory properties.

Several recent studies have shown other remarkable benefits attributable to DHA (and likely EPA) in developing children. Pioneering work over the last 20 years at the University of Texas Southwestern has shown that DHA is associated with better vision during infancy and better vision and cognitive function during infancy and early childhood. These NIH funded studies were actually used in the development of DHA supplemented infant formulas. A number of studies have shown that incorporating DHA in the diet of growing children helps to support both eye and brain development.

DHA and EPA are found most commonly in fish and there have been concerns about possible harmful effects from the heavy metals including methyl mercury that is found in fish products. Several large scale reviews articles have shown that the benefits of eating low-mercury fish (wild caught salmon, sardines, small oily fish) outweigh the potential risks. For those still concerned, there are numerous purified fish oil supplements that come in flavored chewable or liquid forms. ☺

Dr. Gregory Ostrow is the director of Pediatric Ophthalmology and Adult Strabismus under the Division of Ophthalmology at the Scripps Clinic in San Diego, California.

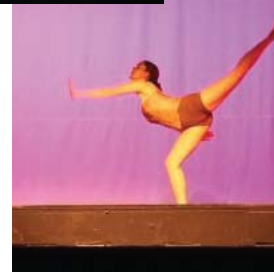


FAMILY NETWORK

FANCY FEET

Sometimes fundraising is just a matter of keeping your eyes open for opportunities; longtime Family Network member Ashly Stohl certainly did, and it paid off with over \$5,000 raised for the VOC!

Every year, Fancy Feet Dance Studio puts on a variety show for charity-and by chance-one of their dance instructors is a high school friend of Ashly's. When the pair struck up a conversation, the charity show and the VOC was mentioned. A short time later, Palisades High School had donated the space for ballet and hip hop dancers, singers, and more! Ashly's nieces and their three friends helped with ticket sales, concessions, and t-shirts. It was a great success, with many people giving more than the cost of their ticket. Thank you Ashly and company for all of your hard work! ☺



KIDS OF THE MONTH

Each issue we highlight the accomplishments of an outstanding junior member of our Family Network. This issue is unique because two exceptional kids share that distinction. They are fundraising go-getters, Mack and Jordan Portnoy. The children of longstanding VOC Family Network members Greg and Hillary, helped raise \$300 for our foundation!



Jordan and her twin-brother, Mack, are honor roll students and active young achievers in dance and baseball. They are also the warm-hearted older siblings to Lucas and Dylan, identical twins who have Ocular Albinism(OA). Jordan personally understands their OA because she was born with a cataract and has almost no vision in one eye. Mack is no less supportive of Lucas and Dylan than his sister. When their school asked their sixth-grade class what organization they would like to see receive the proceeds from their student fundraiser, Mack and Jordan immediately

thought of the Vision of Children Foundation. It was their perfect chance to do something extra special for Dylan, Lucas, and all the other children and families that the VOC reaches.

Each Wednesday the twins and their spirited schoolmates manned a snack stand for charity. At the end of the fundraiser, their class had sold enough snacks to present the VOC with a check for \$300! Jordan and Mack's wonderful suggestion ultimately raised not only money, but awareness of the VOC within their community. Needless to say, we are grateful for their outstanding, selfless support.

We also extend our gratitude to the twin's fellow sixth-graders, their school, and all others involved with the fundraiser. Thank you everyone!

And don't forget to wish Mack and Jordan good luck! Mack and his baseball team will be trying for another championship win this fall, and this summer Jordan is performing her dance at Pace University. We know they'll do just fine! 😊

NIGHT FOR A CURE

Marissa Makram is a longtime member of our Family Network and the loving mother of two sons who have Ocular Albinism(OA). Thanks to her efforts, as well as those of her friends and family, late last year New York's historic Oheka Castle was host to an event as inspiring as the estate itself, Marissa Makram's Night for a Cure fundraiser. This special evening raised \$8,000 for the Vision of Children Foundation. Thank you!

The Night for a Cure was a wonderful experience from beginning to end. Guests responded at the evening's auction with a spirit of generous giving. The event began in an elegant ballroom where a local High School Chamber

Orchestra entertained guests while they bid on over 100 beautiful gifts and baskets. Later, they dined on a magnificent buffet that was donated by local restaurants. The evening was topped by the music of DJ Doug and gourmet desserts.



Everyone went home happy, especially Marissa: "As a parent of two boys living with Ocular Albinism, I am truly grateful for the work of Sam and Vivian Hardage and the staff at The Vision of Children." Well Marissa, we are truly grateful to you and everyone

else involved. We hope that your plans for the next Night for a Cure will be as successful as this one. 😊



IT'S IN THE BAG

If you are interested in helping raise money for the Vision of Children Foundation, you may want to know what wooden nickels, groceries, and the VOC have in common. Recently at Jimbo's, a San Diego organic and natural foods grocer, they were all part of the "It's in the Bag" program! "It's in the Bag" is Jimbo's regular charity drive, which collected \$1,200 for VOC this April.

For three months, shoppers could receive a wooden "Jimbo's" nickel for each recycled bag that they brought and used. They then "donated" the wooden nickels to a Jimbo's organization of their choice; their donation to the VOC

represents 22,000 recycled bags! That's a lot of recycling, and a lot of support for research toward curing hereditary childhood blindness. Thank you so much to Jimbo's and everyone who participated, because programs like this greatly help children who need us.

You can help as well! If you are asked to donate to a cause on your next shopping trip, please suggest adding the VOC to your store's program. It can be as easy as giving the manager a VOC newsletter like this one and telling them what the VOC means to you personally. Remember: every nickel, whether wooden or real, truly counts! ☺

PAST EVENTS

SAN DIEGO COUNTY DECLARES "SAM AND VIVIAN HARDAGE - VISION OF CHILDREN DAY!"



November 18th, the County of San Diego honored Sam and Vivian Hardage for their tireless work with the Vision of Children Foundation. The award was presented by County Supervisor Pam Slater-Price, who proclaimed November 18th as Sam and Vivian Hardage Day. We all

congratulate the dedicated pair for their achievement!

The recognition comes as no surprise to those who have followed the Hardage's efforts to provide outstanding service and leadership for both the VOC and the San Diego community. Through their guidance, the Vision of Children Foundation has produced promising research towards the elimination of genetically caused childhood blindness, while improving the quality of life for visually impaired individuals and their families. Thank you, Sam and Vivian! ☺

WEARING JEANS REPAIRING GENES

There are hundreds of ways to raise money for your favorite cause, but not all are as comfortable as Jeans Day. In December, George Triebenbacher of GMAC Corporate Finance and his assistant Athena Ziakos used this fundraiser to raise \$6,000 for The Vision of Children Foundation! Way to go!

George and GMAC are longtime supporters of the VOC. Just a year and a half ago, they lent their leadership to the VOC Andrea Bocelli event in New York. Twelve months later, with Athena Ziakos, they've led the way in organizing a fundraiser that many of us can do as well: Jeans Day. Details vary, but the heart of the fundraiser is that employees pay \$5 each day that they want to wear jeans to work. It's simple, fun, and effective. And for GMAC, it was a huge success- the jeans option was given to three offices, which resulted in employee gifts totaling \$3,000! Even better, GMAC was generous enough to match the donation for a total of \$6,000! As a show of gratitude to everyone who "bought" jeans for our foundation, VOC T-Shirts were given out to those who gave \$25 or more, and everyone who gave more than \$75 was entered in a drawing to win a beautiful pearl necklace. This was our way of saying thank you for supporting such a worthy cause.



At the end of Jeans Day at GMAC, we hope that everyone in the office knew that they had helped to bring us one step closer to clear vision for every child. Thank you George, Athena, and GMAC - the VOC very much appreciates you!

Jeans Day is easy and fun. If you would like to raise funds for The Vision of Children Foundation in your own office and need help, we invite you to email Executive Director Kristy Winters at kwinters@visionofchildren.org ☺