

The Vision of Children

Dedicated to the Eradication of Childhood Vision Disorders and Blindness

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NEW VOC RESEARCH STUDY: LOOKING BEYOND MELANIN

The Vision of Children continues to expand its research ventures by entering into an exciting collaboration with the John Alden Trust to support Suzanne Roffler-Tarlov, Ph.D. at Tufts University and Carol Mason, Ph.D. of Columbia University to study retinal and optic nerve development in albino animal models. Affecting 1/20,000 individuals worldwide, albinism is characterized by lack of pigmentation in the eyes and the skin. In the eye, there is also a misrouting of the optic nerves from the eyes to the brain. Too



many of the optic nerve axons that should follow a straight path to the brain, instead take a crossed path. The consequence of these axons taking the wrong path during the



development of the visual system is loss of binocular vision or depth perception. There are other problems, especially with photoreceptor cells (rods and cones) in the retina. Symptoms include decreased visual acuity and in some cases legal

These mice share the exact same genetic background

blindness, sensitivity to sunlight, and nystagmus.

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A MOM'S SEARCH, A DAD'S EMPLOYER, AND A CHILD'S VISION

Will Ava become blind? That's the terrifying, chilling question that Pete and Anni Basso were afraid to ask out-loud of each other the moment they realized their two-month old daughter was not focusing correctly and did not respond properly to her parents' visual tests. They simply didn't want to worry each other despite the fact that they each had the same hidden, horrifying fears.

Pete and Anni Basso, like so many parents of infants, became frozen with the fear that something was terribly wrong with their beautiful newborn. After all, she wasn't focusing on things like her two cousins were, who were close in age.

When they finally were able to discuss it, to say the words out loud, they cried. Of course they did. They loved their newborn baby and shared the same hopes and dreams that all loving parents do for the healthy future of their child.

"She wasn't really focusing on us or anybody," said Anni Basso, Ava's easy-going and patient mom. "We were filled with questions, wondering if she would ever be able to see, to drive and do things other kids with sight could do," she noted. *continued on page 5*



Ava Basso

VOC SPONSORS GROUNDBREAKING OA STUDY PARTICIPANTS NEEDED NOW!!!

In his lab, Dr. Nusinowitz hooks up wires with electrodes to two family members. The mother is a carrier for type 1 Ocular Albinism; the son has the genetic vision disorder. Although this picture resembles a scene from a sci-fi movie, the experiment is completely non-invasive and painless. The first electrophysiological study on individuals with OA1, this research will shed light on a characteristic of Ocular Albinism: the misrouting from the optic nerves to the brain.

Dr. Nusinowitz's primary research interest is the study of the sites and mechanisms of disease action in inherited eye diseases. Using electrophysiological and psychophysical techniques, he evaluates patients with retinal diseases to understand how specific gene mutations result in the wide spectrum of disease expression. In the lab, he studies mouse models of retinal disease to identify new candidate genes that may be involved in human disease. Ocular Albinism is a new area of interest for Nusinowitz. He plans to conduct a study on families with OA at the Jules Stein Eye Institute at UCLA. As he describes, "Basically what we plan to do in the OA1 study is evaluate visual function from the retina to the visual cortex in these patients, with specific reference to retinal function, because this is least understood."

PARTICIPANTS NEEDED!



The Jules Stein Eye Institute at UCLA

VOC is seeking volunteers to participate in this study. We are seeking 20 males with Ocular Albinism, as well as their 20 "carrier" mothers – females who carry the gene mutation that causes Ocular Albinism (males must be



Dr. Steven Nusinowitz

at least 10 years old at the time of the study). Tests include evaluating retinal function using the electroretinogram (ERG), which evaluates the retina. This involves recording the electrical signal generated by the retina in response to light stimulation. "Depending on how you analyze the ERG," he explains, "you can say things about different cells in the retina." Another test, the electro-oculogram, requires the patient to follow a moving light in the light and dark. To do this, he attaches electrodes to either side of the eye; the signals that he records tells him about the integrity of a different layer of the retina not evaluated by the ERG. Nusinowitz will also do VEPs to look at hemispherical asymmetries, visual acuity, etc. By evaluating visual pathways, color vision, and depth perception, Nusinowitz will gain a better understanding of the critical connection between the eye and the brain in individuals with OA.

The Vision of Children will cover all the costs of testing. At this time however, the Foundation cannot cover expenses for travel or accommodations. By participating in this study, families can directly contribute to better understanding the physiology of OA. Nusinowitz describes, "All of this is non-invasive and painless. It may actually even be fun." Interested individuals should contact the VOC office for more information. We hope that you will join us by participating in this exciting and important project.

CONTACT VOC to sign-up: 858-799-0745.

...Research, continued from page 1

To date, scientists have believed that lack of the pigment melanin causes the abnormal development of the optic nerves and photoreceptors in albinism. Doctors Roffler-Tarlov and Mason will investigate other possible factors that contribute to the disorder. Understanding the routing mechanism of the optic nerves and the point at which this pathway is disrupted in albinism is essential to understanding the condition and eventually reversing the effect with therapeutic models.

VOC is very excited about this collaboration with the John Alden Trust and its strong support of our East Coast research at Tufts and Columbia. The John Alden Trust provides grant support toward organizations providing care and administering to the needs of children who are blind, disabled, mentally or physically ill, or, organizations engaged in medical and scientific research, directed toward the prevention or cure of diseases and disabilities particularly affecting children. We look forward to sharing the results of this study upon its completion.

VOC COMPUTER MONITOR SYSTEM

The Vision of Children continues to make strides to help the visually impaired through our computer monitor system program. Several generous grants this year have allowed us to grow the program and set even greater goals. Started as a pilot program in San Diego, we now have expanded across the country and have donated systems to schools in Arizona, California, Florida, Georgia, Massachusetts, North Carolina, Virginia, Washington, West Virginia, and Wyoming. Our goal is to have our computer monitor systems placed in every school that has visually impaired students.

VOC developed this system in response to feedback from parents and teachers who reported that low vision and visually impaired students were leaning overly close to the monitor in order to see it better. This awkward posture results not only in eye strain, but neck pain and back aches. Furthermore, it was also compromising the student's ability to type properly. In an increasingly hi-tech society, students use computers on a daily basis. By not being able to type properly or see the screen clearly, visually impaired students can fall behind in computer classes, as well as struggle through general class assignments that require the use of a computer.



The VOC computer monitor system provides the perfect solution: a flat-screen monitor coupled with an articulated arm which enables the user to bring the monitor to the user's face, rather than leaning the face toward the monitor. It can be easily tilted up, down, backward,

forward and side to side without tools or difficult adjustments. This benefit allows each student to adjust the monitor to their own individual viewing position. In addition, it can be used with or without other low-vision software. Many students have even remarked how their need for magnification software has decreased because they are able to view the entire screen and prefer to move their head back and forth rather than scroll through the page with a magnifier. With the use of this special monitor system, students have reported a 50-85% improvement in their typing abilities and have expressed a new found sense of enjoyment in using computers.

We hope that by providing this technology to schools that serve the visually impaired we can help these students succeed. If you know of a school that could benefit from a computer monitor system, please contact the Vision of Children for a request form.

VOC'S PATIENT DATABASE REGISTRY



The Vision of Children continues to build its Patient Database Registry to further genetic vision research and promote accurate diagnosis. Directed by Vision of Children Scientific Advisory Board member, Richard Lewis, M.D., M.S., at the Baylor College of Medicine in Houston, Texas, the registry gathers information on patient history and family inheritance and also supports current research. For example, researchers have collected skin cells from registry participants to establish a skin cell culture line being used in current research studies. The registry will also provide a list of individuals to access for future clinical trials testing potential therapies. Scientists predict that gene therapy treating hereditary eye diseases may be ready to test in humans in the next few years with adequate funding and progress.

Please sign up for the VOC registry! The registry questionnaire has basic questions about you or your child's vision disorder – symptoms, diagnosis, testing, and family history. Information and records are kept confidential. Submitting information does not automatically sign you up to participate in research; you will, however, be one of the first to find out about our research updates, especially if you are interested in volunteering for any future studies.

If and when VOC research reaches human clinical trials, volunteers will have the opportunity to fully participate in our research efforts. YOU may have the unique opportunity to be a part of history! Sign up for the registry today! Questionnaires are available online or by request at the VOC office.

NEW BROCHURE ON OCULAR ALBINISM



The Vision of Children Foundation has a new brochure about OA. This brochure "Ocular Albinism: A Resource for Doctors and Families" was developed with the idea of continuing to educate the medical community and general population about OA. OA is often misdiagnosed due to the fact that many optometrists and ophthalmologists have never seen a patient with the disorder.

This brochure contains information about proper diagnosis and testing available for OA, as well as the difference between OA and OCA, and ways to improve the quality of life for children and adults with vision problems. If you would like a copy of this brochure or have information about doctors or facilities that you would like to distribute the information to, please contact Stephanie Durso at sdurso@visionofchildren.org.

SYMPOSIUM UPDATE:

*The 6th World
Symposium on
Ocular Albinism will
be held in Spring
2007 in San Diego.*

SPACE CAMP FOR VISUALLY IMPAIRED STUDENTS



Have you ever dreamed of blasting off into outer space in a space shuttle? Do you wonder what it's like to float around in zero gravity? Well here's your chance to find out! The Vision of Children is now accepting applications from students (grades 4-12) who are interested in attending Space Camp during a specially designed program for visually impaired students. Students can participate in orbit simulation and astronaut training; learn how to pilot a jet fighter and how to eat, sleep and walk in space. In addition, campers have the chance to make new friends and learn more about science and math.

Students can choose between 4 programs depending on their grade level:
 Space Camp (Grades 4-6)
 Space Academy (Grades 7-12)
 Advanced Academy (Grades 10-12)
 Aviation Challenge (all grades)

Space Camp for Interested Visually Impaired Students (SCIVIS) will be held September 23-28, 2006 in Huntsville, Alabama. Space Camp will be covering the tuition costs and The Vision of Children Foundation will cover travel costs. Please contact Stephanie sdurso@visionofchildren.org, at VOC for more information about this exciting opportunity.





The Basso Family

...Basso, continued from page 1

“Sure it was scary, but we believe that God makes no mistakes and we know that Ava is how she is for a reason and we wouldn’t want it any other way,” Anni stated. Ava’s father, Pete, added, “Man sees the condition Ava was diagnosed with as a type of flaw, to me it’s just a characteristic, something original about my little girl and it’s the one thing, the characteristic I love the most about her; it truly sets my heart on fire.”

So it was with Anni, Pete, and little two-month old Ava. At age seven months, Ava was finally diagnosed with Oculocutaneous Albinism. Their first attempt at medical intervention left the Basso’s frustrated with the medical community. Ava’s pediatrician “did not know anything—he didn’t know anything about Albinism,” according to Mrs. Basso.

This led her to the internet. She was told something about a disorder called Albinism. She found the NOAH website, filled with information and answers to the Basso’s many, many questions. Armed with new information and a hunch that Albinism may well be the proper diagnosis, Ava returned to the pediatrician who, with the consultation of a genetics specialist in Iowa City, made the proper diagnosis.

With continued need for more answers and information, the Basso couple was directed to the Vision of Children website—an oasis for the highly anxious, worried, young parents. They were destined to find something they never would have imagined, however.

“Pete, you’ve got to see this! You just won’t believe this.” exclaimed Anni. With Pete running into the computer room from his home office, the Basso’s lives were about to be changed yet again. What he saw, he thought, was nothing short of a miracle.

There on the Vision of Children website was a link. “Oh my gosh, this is Dimension One Spas...” said Anni. Dimension One Spas is Pete’s employer.

Pete and Anni Basso’s personal tie to the Vision of Children through Dimension One Spas is “nothing short of extraordinary” according to Pete. He added, “I just praise God that we were able to be a part of this wonderful organization, and benefit from its remarkable amount of information and support.”

Pete beamed when he said, “Now I know that when I go to work everyday, I’m not just going to work to make money – I’m also going to work to further a cause and I dig that. To me that is truly a part of my passion.”

Anni, in describing Pete as a, “great husband, a great Dad, and a great family man,” shared that Pete and Ava enjoy going to the park and taking long walks. The family enjoys the special moments that real quality time bring, watching Ava, now twenty months, climbing into cabinets, playing with dishes and pots and pans and other kids.

The prognosis looks very good for Ava. She has a 90% chance of being able to drive when she reaches driving age. Her eyesight is getting better all of the time. The doctors tell the Basso’s that Ava’s eyesight “may be fairly normal, meaning a ‘regular person’s vision’, but maybe to the point where she’ll need glasses...” according to Pete.

The Vision of Children has assisted the Basso’s in finding medical care for Ava. For this and so much more, the Basso’s are grateful. “Just so you know, God’s interwoven into this and it’s been a wonderful sentiment of this organization that I’m part of. I just feel blessed everyday that we contribute to the Vision of Children,” Pete said.

Pete Basso recently visited San Diego on business, and during a dinner meeting one night experienced everyone stepping forward with spontaneous donations to Vision of Children, “It just struck a chord with me,” Pete said. Pete has been a long-time sales employee of D1 Spas. Back in 2002, D1 Spas became the first corporate sponsor of the Vision of Children. For more information on how to become a corporate sponsor go to: www.VisionofChildren.org



VOC Founder Sam Hardage visits Dimension One Spas

A special thank you to the following groups who have provided generous funding for The Vision of Children in the last six months:

John Alden Trust
 Teammates for Kids Foundation
 Las Patronas
 Thomas C. Ackerman Foundation
 Morongo Band of Mission Indians
 Country Friends
 Cush Family Foundation
 Dimension One Spas
 Woodfin Suite Hotels
 American Express
 IPAK Printing
 Silpada Designs
 San Diego Delta Gamma Alumnae
 Century Club of San Diego

RACE FOR SIGHT

After a month of intensive training for my new position as the director of VOC, former director Erin Eriksson was prepared to pass the torch and put me in the driver's seat of Vision of Children.



VOC Racing Team

Imagine then my shock when I found out on a Sunday afternoon she meant it literally! The driver's seat was real, and it was attached to a go-kart racing 40 mph around an indoor track. And so our transition took on a literal sense as Erin came tearing into the pit area, jumped out of her kart yelling "Go, go, go!"

Now you're probably wondering what in the world are the incoming and outgoing directors of Vision of Children doing in a relay race with indoor go-karts? Raising money for VOC of course! The Second Annual Race for Sight organized by the San Diego Delta Gamma alumni once again designated Vision of Children to be one of the official beneficiaries of this event. The go kart relay races were a huge success with over 100 in attendance and several thousand dollars raised for vision-related organizations. Thanks to Delta Gamma and the Miramar Speed Circuit for their efforts and continued support of VOC.

CHIP-IN FOR CHARITY-- A HOLE-IN-ONE FOR VOC!

Sponsored by the Century Club and the Buick Invitational, VOC joined 60 other charities this year to sell discounted tickets to the 2006 Buick Invitational. The "Chip-in For Charity" fundraiser is one of the only fundraisers in San Diego that has no upfront or backend costs, allowing charities to receive 100% of the money they raise. With diligence and hard work, VOC raised \$2,580! We thank all of those who supported us through donations and ticket purchases.

Tiger Woods grabbed his fourth Buick Invitational trophy in a sudden-death play-off at Torrey Pines Golf Course in La Jolla, California. Erin Eriksson, former VOC Director, has organized ticket sales for VOC for the past two years. "The golf tournament is a huge crowd-pleaser for golf fans and newcomers alike," she expressed. "VOC loves being involved with the Buick Invitational. Because our programs focus on research, education, and outreach

in the visually impaired community, this event enables us to interact with new supporters who may not have otherwise heard about our organization."

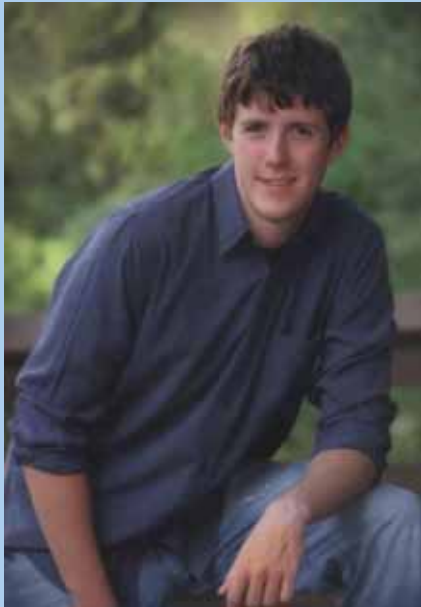
"In just three years, a very simple program has raised \$350,000 for local nonprofit organizations. The premise behind the program is so simple that organizations are

limited only by the amount of energy they put into the fundraiser," said Casey Dillabaugh, Chip-in for Charity's Programs Coordinator. "We see the Chip-in for Charity program continuing to blossom in San Diego and more and more charities getting involved in this unique program."



Be there when Tiger Woods tees it up to defend his title again in 2007!! Tickets for the 2007 Buick Invitational, January 22-28, go on sale in October 2006. Contact VOC at (858) 799-0810 for upcoming announcements.

OA SPOTLIGHT: DANNY CHRISTOPHER



"All I have done is live my life the only way I can – as a 'normal' person. In my mind, I don't have other options. Vision has nothing to do with how successful a person will be, or how fulfilling a person's life will turn out. We all have the option to make our lives great, no matter what the handicap or hardship may be, and the only factor that decides how your life will be lived is your attitude. Everybody has something to overcome in their life, whether it be low vision or otherwise, and the only thing that makes one person's problems more pertinent than another's is the outlook they have."

-Danny Christopher

Danny is graduating from Mountain View High School in Loveland, CO and will be attending the College of Business at Colorado State University this fall.

VISION OF CHILDREN SCHOLARSHIP PROGRAM

Last year, VOC provided two educational scholarships to college students with vision disorders: Brad Aldridge and Chris Benjamin. Since they were given their grant awards, these two guys have been busy!

Brad, a student at UC Berkeley, has kept himself occupied with numerous art and design projects. "The last semester has been the usual busy kind for me," he reflects. "During the first part of the year I was the assistant set designer to Kent Dorsey in the UC Berkeley production of "The Seven Lears," a prequel to William Shakespeare's "King Lear." Also, I've been working in the production department of KALX, UC Berkeley's radio station, creating public service announcements." In addition, Brad has continued his contributions as an editorial cartoonist for The Daily Californian and has had illustrations appear in Greater Good Magazine.

As for Chris, he has "taken the liberty to express personal advocacy in asking local city governments, county officials, and the governor of Florida to recognize albinism for a day, month, or week." In the City of Tarpon Springs, Florida, for example, Mayor Beverly Billiris proclaimed October 2005 as "Albinism Awareness Month." Chris is also an advocate for bioptic driving and may help Florida become the next state nationwide to allow bioptic driving.

Vision of Children is proud to support the ongoing educational and extracurricular endeavors of these

outstanding students. Based on their success, VOC is delighted to announce our second annual scholarship program for visually impaired students. In 2005, VOC launched its inaugural scholarship program. We received such positive feedback that we are delighted to offer scholarships again this year. Eligibility includes 1) high school seniors who plan to attend college in the fall, and 2) students currently enrolled in college who are continuing their undergraduate studies. Applicants must have a genetic vision disorder to be eligible for scholarship funding.

Required materials include a completed and signed application form, transcripts, a letter of support (we recommend that you contact your reference well in advance of the deadline so he/she has ample time to write the letter), and a photograph. Scholarship applications must be received by August 1st, 2006. Late entries will not be accepted under any circumstances. The Vision of Children Scholarship Committee will review applications thoroughly before making final decisions. The number of scholarships and amount of funding available is subject to change. Scholarship funding must be used toward educational purposes, including: tuition, fees, room and board, and books. Funding used for any other purpose may result in revocation of the scholarship. If you are interested in applying for a scholarship, contact Stephanie Durso at sdurso@visionofchildren.org or (858) 799-0745.

SCHOLARSHIP APPLICATIONS DUE AUGUST 1ST!

VOC WELCOMES NEW DIRECTOR

I am so pleased to join this wonderful organization as the new director for The Vision of Children. Not many people have the opportunity to go to work everyday and make a difference in people's lives. VOC has truly made leaps and bounds in the fight to eradicate vision disorders, which is why I am thrilled to join the foundation at such a cutting-edge time. Learning about all the VOC-sponsored research around the world is truly exciting!

Before joining VOC, I received my bachelor's degree from the University of California, Los Angeles and an MBA from San Diego State University. I have previously worked with several different research foundations and I am ready to put my experience and skills to work to help find a cure for genetic vision disorders. I look forward to getting to know the entire VOC family—family network members, researchers, donors, and volunteers. If there is anything I can do for any of you, please do not hesitate to call or email me at anytime. I am here for you!



New VOC Director Stephanie Durso and Development Intern Torye Nguyen



Former VOC Director Erin Eriksson and husband Bryan Jones

Our former director, Erin Eriksson, has left to attend graduate school with her husband in Los Angeles. Erin has been a fantastic director at VOC, helping to create new programs such as the computer monitor system, organizing VOC's first symposium in Europe, increasing the family network and patient database, and raising thousands of dollars for VOC through her grant writing. Erin has been dedicated and steadfast in her commitment to VOC, and she will be missed. On behalf of everyone at VOC, we want to thank Erin for all her hard work and wish her the best of success in her endeavors. We know she will always be a strong advocate of those with vision disorders and we appreciate her continued commitment to this important cause.

How You Can Help!

VOC's mission is to cure hereditary childhood blindness and other vision disorders, and to improve the quality of life of visually impaired individuals and their families. VOC depends on supporter contributions to maintain its important research, outreach, education, and scholarship programs. To make a donation, please contact VOC or enclose a donation in the envelope provided.

Every donation makes a difference in the life of a child!

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