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Saker ShopRites' Donations Exceed \$1.1 Million



Vision of Children is proud to announce that it recently received a \$177,000 donation from New Jersey's Saker ShopRites

grocery stores through their community outreach program. This year's donation is the third best yet since 2007, and puts their total giving at a remarkable \$1,152,000.

For one month each year for the past seven years, the cashiers at all 29 ShopRite stores have asked customers if they would like to donate to Vision of Children at the point of purchase and the company matches what is raised at the registers. Each store also has the ability to get creative to raise even more money. These additional efforts have included carnivals in their parking lots (complete with pie throwing contests), associates participating in "Mud Runs," and bake sales.

This year, Vision of Children month was June 9 - July 6 — right in the heart of "shore

season" in central New Jersey. Despite the after-effects of Hurricane Sandy in the fall of 2012, the shore communities bounced back and had a great summer season. VOC co-founders, Vivian and Sam Hardage, received the donation in person in New York from Laura and Richard Saker and the Triebenbacher family, long-time supporters of VOC. "The Sakers are wonderful people and it was our pleasure to have the chance to see them while we were in town," said Sam Hardage, VOC chairman. "It is only through support from organizations like this — and people like the Sakers — that our mission of curing hereditary childhood blindness and vision disorders will be fulfilled."

Coincidentally, there are at least two VOC supporters who both live in Manasquan, NJ and shop at the Wall Township ShopRite. One is Jake Whalen who contributed an article in this newsletter (see page 4). As a direct result of the Saker's support, Whalen has offered to help VOC by volunteering as a writer and editor.

The other supporter in is Gordon Stake, who went above and beyond to help VOC during a staff member's visit last fall. We wanted to visit New Jersey to see the "Top 10" fundraising stores in two days' time. Stake not only created a schedule for our staffer based on his knowledge of the region, but he also took the day off and drove her to seven of the stores in one day. He and his family also provided dinner, lodging, and a car so she could visit the remaining three stores on the second day. Anyone who has driven the parkways in New Jersey can appreciate what a huge help this was. It was his way of supporting VOC, and it was priceless.

When people and organizations "do good," it makes others want to the same. That's why the Saker's support extends beyond financial donations, and why there are not sufficient words to show just how grateful Vision of Children is for everything they have done for the Foundation.

World Symposium



Book Your Tickets

The 8th World Symposium on Ocular Albinism & Other Vision Disorders

Where: Hilton Mission Bay - San Diego, CA

When: November 6 - 8, 2013

Who: Vision Researchers and Parents/Members

See back page for more information about the event and how to register.



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Retailers Support VOC



Walgreens August was Vision of Children month at the Walgreens store in Encinitas, CA. We wish to thank all of the Walgreens customers who donated to Vision of Children.

JIMBO'S ...Naturally! Jimbo's, a natural foods grocer with locations in San Diego/Del Mar and Escondido, CA, selected VOC as its Children's Charity" for the third quarter of the year. Through its "Wooden Nickel" program, shoppers who brought their own bags had the option of either saving five cents or dropping a wooden nickel into a donation box for charity. VOC received all the nickels received from July 1 – September 30th.

OPTOMETRY CABANA Located in the Del Mar Highlands in San Diego, this recently opened optometrist and retail store has a donation box by the register and has been collecting donations for VOC. Be sure to stop by if you're in the mall.

MIRA∞FLEX® Maker of top-quality children's frames sold throughout the world, Miraflex has once again signed on as one of our "Partners in Vision." For more than 20 years, Miraflex has dedicated itself to developing the most suitable children's frames, assuring the best mix between the practical and the aesthetic for all ages. We're grateful that they've once again decided to partner with us by becoming a corporate donor.

Contribute to VOC Through Combined Federal Campaign & United Way

If you or any of your friends or family contribute to the Combined Federal Campaign, please let them know that they can give to Vision of Children through Medical Research Charities (MRC). VOC's CFC Designation Code is 10206. The CFC campaign takes place from September 1 – December 15 and all federal employees may

participate in this campaign nationwide. If you aren't a federal employee, you can also give to VOC through the United Way. Contact your human resources representative and provide them with the nonprofit code 95-4271785. Please ask if VOC may be listed on your employer's web site and encourage your co-workers to contribute to VOC.

RESEARCH - Update from Dr. Alejandra Young

Protein Research Yields Promising Results

Alejandra Young, Ph.D., a doctoral research scientist with the Jules Stein Eye Institute at University of California Los Angeles, has been a Vision of Children researcher since 2008. Our Board of Directors selected her as a VOC Fellow and she served in that capacity from 2011 to 2013. She has dedicated a big part of her career to solving the mysteries behind ocular albinism type 1 (OA1).

Dr. Young shared with us the following summary of her recent research paper, which will be published in PLOS One, an open access, peer-reviewed scientific journal published by the Public Library of Science.

Ocular albinism type 1 (OA1) is a disease caused by mutations in the OA1 gene and characterized by the presence of giant melanosomes in the retinal pigment epithelial (RPE) cell layer just outside of

the retina. Melanosomes are organelles where melanin, the most common light absorbing pigment, is synthesized and stored. Other characteristics of OA1 are abnormal crossing of the optic axons projecting from the retina to the brain, involuntary eye movement (nystagmus) and crossing of the eyes (strabismus), all conditions that reduce and limit vision. We have previously shown that OA1, the protein encoded by the gene that is mutated in ocular albinism, in normal conditions activates another protein, Gai3, which is responsible for regulating the size and number of the RPE melanosomes. In our recent studies, we used a mouse model for ocular albinism that exhibits many of the same features of the human disease, including the presence of the RPE giant melanosomes and the misrouting of the visual projections to the brain. We investigated whether incorporating an already active Gai3 into the RPE of these mice could restore the normal size and number of melanosomes. We found that this was the case, and that the active Gai3 circumvents the need for a functional OA1



protein. This also confirmed that Gai3 is essential in the OA1 signaling cascade. The results of these studies, currently in press in *PLOS One*, increase our understanding of ocular albinism and might open possibilities to developing therapeutic strategies for this disease.



Event to Raise Medical Research Funds for Vision of Children & American Cancer Society

Dear Friends,

On behalf of The Vision of Children Foundation, I thank you for your support over the years. It is because of you and other generous donors, that we've been able to provide critical funding to vision researchers around the world in order to create a broad foundation for further scientific discoveries, including treatments and cures for several genetic eye disorders. Research is the route to a cure!

Most of you are probably unaware that my wife, and VOC co-Founder, Vivian, is also a three-time breast cancer survivor. We are blessed to have her with us today, thanks to the incredible innovations that have come from groundbreaking research — research that we must continue to champion.

In support of our continuing cutting-edge research, let me tell you about an exciting holiday event, "Visions of Success – From Research to Reality," on December 9th at The Grand Del Mar, featuring Ann Romney as the keynote speaker. Ann will be joining us for a Holiday High Tea, which will also feature a live auction, and holiday fashion show compliments of Fashion Valley. This event will benefit both the Vision of Children and the American Cancer Society. Ann, a breast cancer survivor, health advocate, and dedicated supporter of vision health, will address the critical need for medical research to cure breast cancer and genetic vision disorders.

I hope that you will join us in our endeavor to find cures for two diseases that matter to us the most. If you would like to be a sponsor, live auction donor, or attendee, we would be honored to have you as part of the event.

Thanks again for your wonderful support.
Sam Hardage



For additional information, please visit: <http://www.visionofchildren.org/holiday-high-tea>.

Scott Glenn Rejoins VOC Board



Vision of Children is honored to welcome Scott Glenn back to the Foundation's Board of Directors. Glenn previously served Vision of Children from 1991-1999.

"Vision of Children is doing such important work in vision research — they've made great progress in my absence

and I look forward to helping them achieve even more as we move forward together," Glenn said.

Glenn is the founder and managing partner of Windamere Venture Partners. Over the past 15 years, he has raised or invested over \$500 million in emerging medical and technology businesses. As

Managing Director of Windamere, he currently serves as a director of Evoke Pharmaceuticals. He also was a founder of several successful biomedical companies, including Prometheus Laboratories (sold to Nestle), Santarus (Nasdaq: SNTS), DexCom (Nasdaq: DXCM), SpineWave, Conception Technologies (sold to Vitrolife), Novacardia (sold to Merck) Planet Technologies, (sold to ARES), Cadence Pharmaceuticals (Nasdaq: CADX) and SkinMedica, Inc. (sold to Allergan). Mr. Glenn holds a Bachelor of Science degree in Finance and Accounting from California State University at Fullerton.

"Scott Glenn's depth of experience in bio-technology and pharmaceuticals makes him the perfect addition to our board," said VOC Executive Director, Andria Kinnear. "We are fortunate that he has volunteered to help us once again."

How Not to See the World by Jake Whalen

I approached the checkout counter in my local ShopRite just as I had done a thousand times over the years. The beeps from items being scanned from a dozen checkout lanes bounced in one ear (and rattled around a few times in the void, my wife would add) and out the other.

But this particular experience was different because today the checkout counter was lined with little pieces of white paper with "ONE DOLLAR" written across the top. I've seen these types of cards many times before, but this one was different: The Vision of Children Foundation. Not only did it concern children, which for me, is the greatest concern on the planet,

but it related specifically to vision disorders from which I have been suffering since age nine.

It was around that time that I realized I had a hard time seeing the blackboard in class and also began experiencing extreme sensitivity to light. Thus began my lifelong acquaintance with Keratoconus (KC), a condition which misshapes the corneas and, in most cases, is not correctable with glasses. The corneas often deteriorate to the extent that they can develop fissures and cracks at which point transplants are typically suggested.

Squinting at the blackboard seemed to rectify the situation as did moving closer to the front

of the class. The added benefit to the latter was that I could more clearly see Miss Maxon, undoubtedly the hottest teacher that fifth grade student had ever laid his visually challenged eyes upon. Unfortunately, Miss Maxon soon began to blur into that same blackboard and, whereas I wouldn't lose any sleep over not being able to see the various types of triangles clearly, not being able to see Miss Maxon undoubtedly was completely unacceptable. Within the week, I was wearing glasses.

For the next 20 years or so, prescription changes in the lenses desperately tried to keep up with the shape changes that were occurring in my corneas, but they finally lost

that battle when I was 28. I was told that the KC had worsened and that hard lenses would be the only option — glasses would no longer offer any help.

In reality, the contact lens doesn't actually sit directly on one's eye, but on the layer of tears that coats the eye. In practice, however, not only did my hard lenses feel like they were sitting directly on my eyes, they felt like some sadistic hunchbacked lab technician in a dark, dank lair giddily fashioned them from tiny pieces of sandpaper, which rubbed across my corneas every time I blinked.

I learned to just endure the pain, and try to function as a human being as best as I could although on most days, I felt like ripping the lenses out after just a few hours and lying on the couch for the rest of the day with a warm compress over my eyes. On more than one occasion, I actually did just that.

After consulting with several eye specialists — none of whom could help — a coworker mentioned that she'd heard about someone in Harrisburg, PA, who had helped a friend with a difficult condition. The good doctor experimented over the next several years with hybrids, Rose K, and other



Not until the malformed corneas are removed and replaced with what is referred to as "cadaverous tissue," can a normal life ever be enjoyed.

After putting up with this for several

solutions until we finally agreed that the piggyback, which is wearing two lenses in each eye — a hard lens over a soft lens — provided the best compromise in vision and comfort... until the abrasions started.

... I'll never, ever take my vision for granted.

For most of the population whose extent of eye discomfort involves a wayward eyelash, I'm here to tell you that a corneal abrasion makes most other eye issues seem like a Swedish massage in comparison.

A healthy cornea is a perfectly smooth parabolic shape. A cornea with KC is more like a Thomas's English Muffin with nooks and crannies. Those nooks, (or is it the crannies — whichever one sticks out,) can come in contact with the contact and therein lies the rub — literally. That rubbing action causes a corneal abrasion, which in turn causes extreme pain that doesn't go away until the cornea heals. During the healing time, I couldn't see since I couldn't wear the lens.

years, the final straw occurred during The Masters Championship. I had abrasions in both eyes at the same time. Not able to wear any contacts, and with earth-wobbling pain, I was lying on the floor in front of the TV, a hot compress over my eyes, occasionally peaking out from under the towel to watch only when seeing another great shot was worth the agony. I called my doctor the next day and asked about the cadaverous tissue.

Cornea transplants are among the most successful. I had them done about a year apart and I'm extremely grateful to the donors. The most arduous part was going back in for the removal of the stitches, which takes place gradually over time. After receiving a drop to numb my eye, my doctor would hold his knife in place next to the stitch, touching my eye, and then would tell me to look in a specific direction. Upon his three-count, I moved my eye and the stitch would be cut as it passed over the blade.

I've not had any more abrasions since the transplants about 10 years ago, but the vision and sensitivity issues remain, and I'm still wearing hard lenses.

I'll manage as I've always done. But I'll never, ever take my vision for granted. It's been said that the eye is the most spectacular device in all of God's creation. I think He must have been so impressed with this beautiful world He put us on, it was His desire to give us the ability to see it for ourselves. Thank God that Vision of Children has that same desire.

VOC supporter Jake Whalen lives in Manasquan, NJ.

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For more information go to visionofchildren.org

Tickets are available by mail until December 2, 2013, by phone until December 5, 2013, or in person until December 9, 2013. Winner need not be present to win and may purchase additional vehicle upgrades as available. Winning ticket will be drawn December 9, 2013 at

Visions of Success – Holiday High Tea with Ann Romney. Estimated vehicle value \$30,000. Winner is responsible for tax, title, license and registration. Car is donated by Midway Jeep Chrysler Dodge & Ram San Diego to benefit Vision of Children & American Cancer Society.



Jeep GRAND CHEROKEE LAREDO RAFFLE

Option 1: You may order by phone, by providing the same information on this form by calling 858-314-7927

Option 2: Complete and return this form to: Vision of Children, 11975 El Camino Real, Suite 104, San Diego, 92130

Name _____

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I would like to purchase _____ raffle tickets x \$100 = Total \$ _____

Enclosed is my check for \$ _____ payable to Vision of Children

Please charge \$ _____ to my credit card: Visa Mastercard American Express

Account number _____ Expiration date _____

Signature _____ Name on card _____

This raffle is registered with the Department of Justice under Raffle Reg. #RF0008238.

Medtronic Twin Cities Marathon Brings VOC Triple the Assistance

“Team VOC – Racing for Research” brings us to Minnesota this fall. VOC is one of the participating charities in this fall’s marathon on October 6th. We are fortunate to have three people running for us. Even more extraordinary is that, prior to now, they knew nothing about our organization. Each of these individuals has a different reason for running. Melody is a running’ grandma, participating in her second marathon, and fundraising for VOC because children’s charities are close to her heart. Erick grew up with very poor vision and loves running for a cause — “I feel illnesses and disorders will limit us in many things in life, but with the right motivation and help, one can accomplish so much more than expected.” Our third runner is Terry, who lives in Wisconsin, but will travel for this race. He is involved in his local Lions Club and selected Vision of Children to support because of our similar mission to fight childhood blindness. His club was supportive of his family during tough times, so he feels compelled to give back. If you would like to support any of these individuals who are supporting VOC, please visit our Crowdrise page and select one of them (or more) to support. Every dollar makes a difference! <http://www.crowdrise.com/visionofchildren>



Racing for Vision – More Great Results

Nearly 100 participants maneuvered and raced high-speed GO-Karts around gut-wrenching twists and turns as part of a fundraiser for three vision-related organizations. The event, called Race for Sight, benefited Vision of Children, the Delta Gamma Foundation, and the Braille Institute (San Diego) — all charities that fund vision-related research or services.

Race for Sight was created in 2005 by an alumna of San Diego State University’s Delta Gamma women’s fraternity. May 2013 was the sixth time this event was held, netting a record return, with Vision of Children receiving a check for \$3,350 — almost \$1,000 more than in previous years.

Participants registered in teams — each team got one kart and team members took turns driving it several laps around the indoor track, with quick switches in the pits essential to success. Along with the racing, participants — and spectators — enjoyed dinner provided by Jimbo’s...Naturally! and

Noodles & Co., free arcade game use, an opportunity drawing and a silent auction. The silent auction packages included an all-inclusive package to Cancun with two round-trip tickets on JetBlue; a trip to New York, along with tickets to see the Yankees and the Broadway production of Spiderman, with a backstage tour; and tickets to the Del Mar Racetrack with brunch in La Jolla.

“With a staff as small as ours, third-party fundraisers like this really help to bolster our fundraising efforts,” said VOC co-founder, Vivian Hardage. “Thank you to the Delta Gamma alumnae in San Diego for continuing to include Vision of Children in this great fundraiser.”

If you would like information about holding an event like this for VOC, we have a “how-to” package with all the tools needed to be successful. For more information, contact Kenny Liles at 858-314-7916 or kliles@visionofchildren.org.

We Need Runners!

Races Coming Up...

October 13, 2013

Long Beach Half or Full Marathon

November 17, 2013

Silver Strand (Coronado) – Run or skate the 1/2 Marathon, 10-mile or 5K

January 4, 2014

San Diego Resolution Run – 5K & 15K @ De Anza Cove

January 19, 2014

Carlsbad Half or Full Marathon (Flat course with an amazing view!)

February 16, 2014

California 10/20 – 10 miles, 20 bands — Del Mar-Solana Beach-Encinitas

March 9, 2014

ASICS LA Marathon (full / relay) – VOC is a designated charity for this one and we need 10 runners!

March 9, 2014

San Diego Half Marathon – ends with a party in the Gaslamp Quarter

For more information, contact Kenny Liles at 858-314-7916 or kliles@visionofchildren.org. He will set-up a fundraising page for you and provide you with all the tips and tricks to get started. Perhaps this is just the motivation you need to check off that distance race from your bucket list!



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Presenting: The 8th World Symposium on Ocular Albinism & Other Vision Disorders



Vision of Children is hosting some of the world's top vision research scientists at its 8th World Symposium on Ocular Albinism & Other Vision Disorders at the Hilton San Diego Resort and Spa November 6-8, 2013. This year, 30 scientists from Europe, Asia, and North America

are scheduled to attend and present updates on their cutting-edge projects. It is unusual for researchers to share their work while still in progress, but this format, organized by VOC, has proven to be very popular with researchers around the world. Parents are welcome to attend the symposium. In addition to being able to sit in on the researchers' sessions, there will be a special session for parents led by Dr. Richard Lewis, who will share highlights from the latest research and answer questions. Dr. Lewis has been a strong advocate for translation of genetic research back to patient care and has shepherded

the establishment of the clinical DNA testing for OAI at the Baylor Diagnostic Laboratory. For more information on the symposium and to register online, visit www.visionofchildren.org/2013-symposium, or RSVP directly to Andria Kinnear at 858-314-7917 or akinnear@visionofchildren.org. If you need a hotel reservation, please call the Hilton San Diego Resort and Spa directly at 877-313-6645 or 619-276-4010. Inform the reservation agent that you are with the Vision of Children group in order to ensure the \$155/night group rate.