
 THE VISION of CHILDREN
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Our mission is to cure hereditary childhood blindness and vision disorders, and to improve the lives of visually impaired individuals and their families.

Dedicated to finding a CURE for hereditary childhood blindness and vision disorders since 1991!



Saker ShopRites Continue to be TOP Supporter

The term "community spirit" doesn't begin to scratch the surface of what the Saker stores do for Vision of Children and countless other organizations. New Director of Development & Communications, Megan Powers, had the chance to visit the Saker headquarters in Freehold, NJ in July. For five years, the Saker ShopRite stores have been dedicating the month of August to VOC, and with the sixth year approaching, we thought it was important to share our successes and let them know what a difference they are making in our efforts. Megan met with all 29 human resources managers and all 29 customer service managers and had the opportunity to answer questions about the organization and thank them personally.



Although we have previously shared the stories about ShopRite's tremendous support, we want to share the latest figures with you. This August they raised \$170,000, bringing the six year total to **\$975,000!**



It is our hope to implement this program with other grocery stores and drug stores throughout the country. Not only does it increase recognition of the Foundation, but the money raised in this way adds up quickly. If you have any connections or suggestions for ways we could expand this program, please contact Megan directly.

A special thanks go to Laura and Richard Saker (pictured left) whose continued support is such a blessing to VOC. They are absolutely our SUSTAINING "Vision Heroes"!

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GIVING Grandparents Expectations Exceeded as Vision CHAMPIONS Emerge

Historically it has been individual members and families of Vision of Children who have emerged as an incredible source of inspiration and financial support for the organization. Well, this September was no different. Stephanie and Seth Polevoy have a daughter named Erika who is 8-years-old and has OCA. They also have Stephanie's incredible parents—Marv and Lois Plansky (pictured right)—as part of their support system.



The Planskys live in Monroe Township, New Jersey, in a special community called The Regency at Monroe. A few years ago their community Tennis Committee began allowing their residents to vie for the opportunity to hold a fundraiser there on Hy Levy Day. The Planskys gave a presentation explaining why VOC is an organization worthy of this event and they won out over much larger, better known charities. The community then pulled together to provide strong support throughout the planning and execution of the event.

How much did they raise, you ask? Close to \$50,000!

How did they do it? In short, they got creative! They sold flags at different levels of sponsorship. Attendees paid an entrance fee and had a fun-filled day with many activities including tennis, golf, cycling, shuffleboard, and bocce ball. As a part of the event, they held a luncheon where there was an opportunity drawing and silent auction, which also helped raise thousands for the event. VOC co-founder, Sam Hardage, attended the event and was able to share VOC's progress with the attendees and to thank them for their participation.

Marv Plansky said he and his wife were motivated to support VOC since their granddaughter, Erika, is affected by a vision disorder and they feel that VOC needs to be better recognized. They wanted to "give back" in hopes that VOC will find a cure for Erika's disorder. When asked how he felt the event turned out, Marv responded by saying: "The entire event went WAY beyond our expectations! This is a small charity that our community wanted to support even more as they learned more about it... it pulled on their heart-strings." He went on to say "Our friends and family were SO generous! It really was inconceivable that we would have raised this much money and we are so grateful for all of the support."

Undoubtedly, this was no small feat for Marv and Lois Plansky and VOC has recognized them with the "VISION CHAMPIONS" Award. Words cannot express how incredibly grateful we are to the Planskys and Polevoys and their huge support network. All of the effort will make a tremendous difference in the lives of the children who are affected by vision disorders. This fundraiser will go a long way towards our research efforts and we thank you!!



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Message from the Co-Founder & Chairman

Dear Friends,

The Vision of Children Foundation thanks you all for your continued support to fulfill our mission of curing hereditary childhood blindness and improving the lives of the visually impaired and their families.

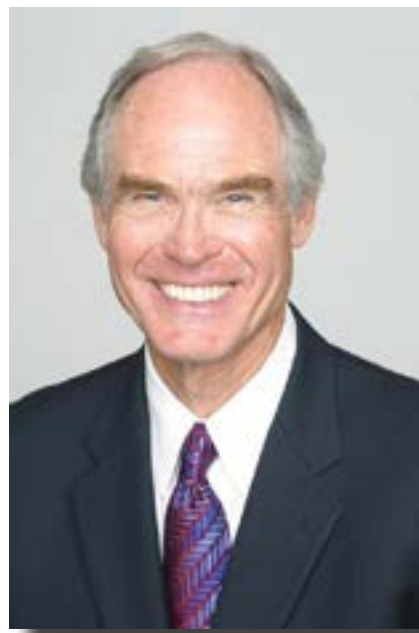
VOC provides funding to researchers around the world focused on finding the genetic pathway to various retinal eye disorders. We know that gene therapy is the solution which has been proven to work. This is a very exciting time in eye research! We feel we are closer than ever to finding the pathway for OA and other vision disorders. In this newsletter, we have featured Dr. Brian Brooks from the NEI, in which he explains a proposed clinical trial where researchers will give an oral medication, nitisinone, to people with OCA-1B to see if it improves their melanin pigment.

Our goal at The Foundation this year is to expand the number of research centers and researchers working on a vision cure. This can be achieved with increased funding from our supporters, which will enable us to fund cutting edge research, like that of Dr. Brian Brooks and others.

With your continued support, we will find a cure for hereditary childhood blindness!

Gratefully,

Sam Hardage
Co-Founder & Chairman



THANKS
to our VOC
Sponsors!

Ally Financial remains a consistent supportive sponsor of VOC, year after year. Each year they hold a VOC "Jeans Day" during which their employees pay to wear jeans to work and they are incentivized further to donate more... Ally then matches all donations! If you think your company might implement this program, please let us know and we will put together a "pitch" to encourage GOOD corporate citizenship.



GRANTMakers

Many thanks also go out to organizations that have granted VOC monetary awards in 2012 (waiting on results from five others):

- * Allergan Foundation
- * Delta Gamma
 - SD Alumnae Chapter &
 - Chapman U. Chapter
 - Foundation
- * Gold Diggers Foundation
- * Harriet E. Pfleger Foundation
- * WD-40 Corporation

Historically, a good deal of time has been spent applying for various grants for the Foundation. This past year was no different and it has paid dividends. We ask if you know of an organization or foundation that has a grant we should apply for, to please let us know. With such a small staff, having other eyes and ears out there is very helpful!

New Team in Place

By now you might have gathered that the word "new" is being used quite a bit in this newsletter. We have a renewed vigor and desire to accomplish our mission—sparked in part by a new team.

Megan Powers joined the VOC team in May as Director of Development and Communications. Her primary duties are fundraising and marketing & outreach. She has a professional background in writing, marketing, event planning & production, and business development. She has volunteered for Delta Gamma for the past 18 years, which has included service hours and fundraising for the blind and visually impaired. She started a charity event in 2005 called Race for Sight and Vision of Children has been a beneficiary since its founding. Sam and Vivian Hardage believed Megan would be the perfect fit for this position based on work experience, her philanthropic spirit, and can-do attitude. She has several other volunteer activities she enjoys, mentoring and giving back to the community.



Megan considers it an honor to be on staff at VOC and helping the organization exceed its goals.

Andria Kinnear joined the team as Executive Director in September and is excited to be a part of the Vision of Children team. After receiving dual degrees in Molecular and Cellular Biology and Psychology from the University of California at Davis, she began her career in the lab. She then moved her focus to the pharmaceutical industry, and spent more than 10 years as a highly ranked sales representative. Her last position was as a Senior Ophthalmic Specialty Representative with Bausch + Lomb, where Andria first became interested in ophthalmology. This led to her desire to do more for those living with vision disorders, and ultimately to her position as Executive Director with Vision of Children. With scholastic and professional experience in related science and ophthalmology, the VOC Board of Directors resoundingly agreed Andria is the right person for this important position.



While she spends most of her free time driving her two young children to soccer practice and dance lessons, Andria spends what little remaining free time she has volunteering at her children's elementary school, and challenging herself with new and creative physical endeavors (think trapeze lessons!).

Megan and Andria already make a great team. Please feel free to reach out to either of them at any time!

FAMILY NETWORK UPDATES

New Admin System Implementation

Within our current systems—all intended to give us low overhead costs—we have a different program for everything we do, which is actually cumbersome, allowing for more errors. We have a database, an e-mail system, a Web site CMS, and PayPal for online payments. Changes must be made manually within each program. Our new system will enable us to accept online donations, automatically updating the database records. If you unsubscribe from receiving e-mail from us, your record will be instantly updated. If your contact info changes, you can update your own member record! This system is Web-based, so everyone on staff can access it remotely. Best of all, the system comes with a reasonable monthly fee. As a member, you can track your donor records and members will have a private community forum in which to communicate and trade ideas/stories with other member parents, which is so important to our Family Network Members.

The conversion process is tedious, but we hope to have it up and running before the end of the year.



Get Social

Social Media continues to grow at Vision of Children. Please take the time to “like” us on Facebook, follow us on Twitter (@VOC_Foundation), subscribe to our YouTube channel, follow our boards on Pinterest, and join our group on Linked-In. We’re constantly posting tips on eye health, letting you know about events coming up, posting links to the latest research, and more. This is also a crucial, low-cost way that YOU can help US get more exposure... Ideally, with more exposure comes more financial support!

Dollars & Sense

We are at a crucial point in the history of this organization. At no other time in our history has the potential been SO great as it is right now to achieve our mission. It is through financial support from our members and donors—and others you all connect us to—that we’re able to fund such exciting research! Please take a moment to give what you can or to share the work we are doing with those who you think can help. Also, be on the lookout for another note from us at the beginning of December.



Making Meaningful Connections

Part of our mission is to support the families whose children have been diagnosed with vision disorders. More than likely, you know the routine—your child is diagnosed and you’ve been given very little hope from your physician. Where to turn? Well, thankfully, you have turned to Vision of Children. We are a small organization, but we try to be big in impact, and we believe we have done that with a recent family network connection in Mississippi.

Melinda Sanderson's 3-year-old daughter Savana (both pictured here) was recently diagnosed with a vision disorder, though the “official” test results are not back yet, she appears to have OCA and nystagmus. She set out on the Internet to see what she could find out and came upon the VOC Web site. We asked Melinda if she would like to become part of our Family Network and she jumped at the chance. We connected her as quickly as we could with the person in closest proximity to her home in Mississippi—Patty Fant. To our delight, they became fast friends. They e-mailed quite a bit and then

became Facebook friends, making contact just about every other day since getting connected.



When asked what she hoped to get out of her membership, Melinda shared that she is looking for ideas from other parents regarding how she can help her daughter through daily life with low vision. “I am just SO grateful to have found Vision of Children and I’m thrilled with the relationship I’ve developed with Patty,” she shared, “It’s so helpful to know I’m not alone and I have a resource whenever I have questions.”

This was the first time Patty Fant had been asked to connect with another member and she was happy to do so! Her son was diagnosed at the age of one and he is now a senior in high school and doing very well. When asked what she wants for her son, she had this to say: “They are just like any other child and want to be treated as so. Children with visual disabilities have a hard road to follow, but with the help of organizations like VOC, it is possible for them to grow to be hard-working adults.”

Facilitating connections like this is at the heart of what our Family Network Membership is all about. Thank you to both Patty and Melinda, and all members who have done the same for another.



**Family Network Kid,
Erika Tess Polevoy
at the Hy Levy Day Fundraiser**

Membership – With a WHOLE New Meaning

We are in the process of executing a calling campaign in an effort to reach every one of our Family Network Members. If you haven’t been called yet, you will! Our intention is to check-in with you, see how you and your children are doing, and to find out what else we can provide for you as an organization. We have had several parents tell us we should charge a membership fee, so we also want to speak with you about that. At the same time, we will provide you with a bit more for that fee. The new administrative system that we’re implementing will come with a private forum/community area for our members only. You all will have an environment that’s more personal and private than Facebook in which to ask questions of other parents, exchange ideas, stories, and photos. You will control how much contact information you share with the other members and you will have access to your own records to view and make changes, as needed. This membership is about YOU and we hope you understand the fee will support our administrative costs, while helping us dedicate more of our fundraising dollars to the research. Our primary concern remains funding research to find a CURE for OA / OCA and now BCM also... We’ve made tremendous progress and we are very grateful for your continued support. Our intention is to offer the opportunity to pay for your membership between now and the end of the year and your fees will be renewable on the first of each year, so this first payment will carry you through the end of 2013.

NOTE: Family Network Members have a different remit envelope within this newsletter. We look forward to your continued membership!



Replacing our regular "Kid of the Month" column, we are presenting our "Young Adult" article in this issue.

Many of our readers and supporters have been following our progress as a foundation for many years and know that we were formed when Chase Hardage was born with ocular albinism (OA1). When our founders Vivian and Sam Hardage were told by doctors that there was no treatment and no cure, they were inspired to start the VOC with the goal of finding a cure for Chase's and other children's genetic vision disorders. Throughout the years, we have presented a few updates about Chase and we'd like to share the latest news with you on what Chase is doing these days.

Chase graduated in May 2012 from Southern Methodist University in Dallas, Texas, with a double major in Economics and Markets & Culture. He was awarded an academic scholarship which he was able to maintain throughout his four years there as a student. He participated in a variety of organizations, including Delta Sigma Pi Business Fraternity, Economics Club, and Kappa Sigma Fraternity. He was involved in numerous charitable and philanthropic events during this time and enjoyed trying to make a difference on his campus. He spends much of his spare time weightlifting and watching Football games with friends.

Upon graduation, Chase began the "much dreaded," but highly anticipated, job hunt and was happy to find employment within a few weeks in Dallas. He is currently employed by Energy Brokers and is adjusting to the rigors of full-time employment.

He recently was recorded on our current VOC video that is available on our YouTube page (there's also a link to it from our Web site home page). Chase wanted to take the opportunity to thank all of our VOC friends for their support throughout the years. His statement from the video:

"To the people who have been there from the beginning, and the ones who have always been supporting us and helping us through many years and a lot of struggles and tough times, I just want to say thank you from the bottom of my heart. It really does mean the world to me. And I can't thank you enough for just the thought that maybe one day my kid's or my eyes will be better and that I won't have to deal with this anymore. It's just pretty amazing. So, I want to say thank you for all of your support and everything that you've done for us and just keep having faith, and keep moving forward, and we will find a cure."

As you can see, despite some challenges over the years due to his vision disability, Chase is thriving and grateful to our VOC family for the many years of encouragement and for sharing his "vision" of a world, hopefully in the near future, where he and others with OA can see clearly.



Albinism: Can It Be a Treatable Disease?

Brian P. Brooks, MD, PhD

Albinism is an inherited condition characterized by a reduced amount of melanin pigment in the hair, skin, and eyes. Most patients with albinism have some degree of visual impairment, which can extend up to legal blindness. The precise reasons why vision does not develop normally in people with albinism is complex. However, a major contribution to the vision loss in albinism is foveal hypoplasia. The fovea is a highly specialized area of the neural retina that gives humans their high degree of visual acuity (i.e., "20/20 vision"). In people with albinism, the fovea does not form completely, if at all. Scientists do not understand exactly what the link is between developing eye melanin pigment and development of the fovea. However, because the fovea continues to develop in humans after birth, it raises the important question: "If we had a way of improving melanin pigment in the eyes of children with albinism at an early stage, could we improve their vision?" My research, one day, hopes to answer this question.

We recently conducted some experiments in mice to look at this question for one form of albinism, OCA1. OCA1 is caused by mutations in the gene tyrosinase (TYR). Tyrosinase is the enzyme that performs the first and rate-limiting steps of melanin pigment synthesis using the amino acid tyrosine. People who completely lack tyrosinase activity have no melanin pigment and are said to have OCA-1A; people who have some residual tyrosinase activity have reduced melanin pigment compared to others in their family and are said to have OCA-1B. We have reasonable mouse models of both of these forms of albinism.

How could we improve tyrosinase activity in these mice, or—more importantly—in patients one day? One basic principal of biochemistry is that if you want to stabilize an enzyme like tyrosinase, you provide lots of its starting material (the substrate)—in this case, the amino acid tyrosine. Tyrosine is included in most proteins and is therefore part of a regular diet. So, how could we increase tyrosine in cells to help stabilize the tyrosinase enzyme? If we were to ask patients with OCA1 to eat lots of proteins containing tyrosine, this probably would not work, as the tyrosine would not get completely absorbed. Even that tyrosine which got into the blood stream would not necessarily make it into cells and would be excreted by the kidneys.

Another possible way it might work would be to inhibit the breakdown of tyrosine in cells, such that the tyrosine that does get there sticks around a little longer. It turns out that there is a rare inherited disorder called tyrosinemia, type 1, (HT-1) where children cannot perform the last steps in tyrosine breakdown. This has the effect of causing some toxic byproducts to build up, causing damage to the liver and other organs. Fortunately, there is a drug, nitisinone, that blocks tyrosine breakdown at a step "upstream" from the defect in children with HT-1. As such, it keeps the toxic byproducts from building up; as a side-effect, it also increases the amount of tyrosine circulating in the blood. When we fed nitisinone to mice, modeling the two forms of OCA1,

we found that over one month, melanin deposition improved in the hair and eyes of our model of OCA-1B, but not in our model of OCA-1A. We also learned that elevating tyrosine did stabilize the OCA-1B form of tyrosinase better than the OCA-1A form. Elevating tyrosine also improved melanin pigment in skin cells cultured from a patient with OCA-1B, but not a patient with OCA-1A.

Now nitisinone is approved by the Food and Drug Administration for use in humans with HT-1. We would therefore like to ask the question, "Will giving oral nitisinone improve pigmentation in humans with OCA-1B?" At the National Eye Institute, we are currently in the

planning stages of a pilot clinical trial to begin to answer this question. We will start with five adult patients with OCA-1B and follow them closely before and during treatment using a battery of tests to measure melanin pigment and to assess visual function. If, in fact, nitisinone works in adult humans without significant side effects, we plan on trying to extend this work into children, where visual benefit might be expected. I should caution that nitisinone CAN have significant side-effects and should not be taken without proper monitoring in the setting of a clinical trial for albinism. It is too early to say whether this drug will work for patients with albinism. We are also interested in extending this work in other animal models of albinism, to see if the results might be more generalizable.



Fundraising Events Coming Up...

...**TEAM VOC: George Triebenbacher** is running the Philadelphia Marathon on Nov. 18 and raising money for VOC in the process! Click the CrowdRise button in the upper-right corner of our home page if you'd like to sponsor him.

Also, the annual Ally Jeans Day was Nov. 5th! ...**Chapman Delta Gamma chapter** will be holding another fundraising event for VOC on Dec. 8th. It's called "Sail Away for the Holidays"- they will once again auction-off beautifully decorated trees.

...**RACE for SIGHT - SD Delta Gamma alumnae** will hold the 6th high-speed go-karting event in S.D. May 4, 2013.

GIVE When you are Already Shopping!

iGive Register on www.iGive.com/VOC to have a percentage of what you spend online go right to Vision of Children! It's SO easy - register now and then start shopping. Be sure that you register before you begin your holiday shopping!



Ralphs If you shop at Ralphs, go to Ralphs.com and register your Ralph's Rewards card. Once registered, click "Community," then "Community Contribution," and then under Participant, click "enroll" where you'll designate VOC as a beneficiary of your shopping. Easy stuff!

