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Fundraiser Benefits Vision and Cancer Research

A holiday fundraising event in San Diego raised more than \$350,000 to benefit The Vision of Children Foundation (VOC) and the American Cancer Society's breast cancer research taking place in San Diego.

The event, called *Visions of Success – From Research to Reality*, featured Ann Romney, a breast-cancer survivor, health advocate and dedicated supporter of vision health. Romney spoke about the critical need for medical research to cure breast cancer and vision diseases.

More than 600 guests enjoyed the Holiday High Tea at the Grand Del Mar on December 9, 2013. VOC staff and a cadre of volunteers organized the fundraising event, which included a live auction, opportunity drawing and informal modeling of holiday fashions. The event was co-chaired by VOC co-founder Vivian Hardage and Wanda Garner.



Pictured with Ann Romney (center) at the fundraiser are several members of VOC's Board of Directors, left to right: Sam Hardage, Gregory Ostrow, Scott Glenn, Jacqueline Johnson, Kenneth Widder and Vivian Hardage.

Garner, a cancer workshop facilitator and philanthropic fundraiser, and her husband, biotech leader, Cam Garner, are strong supporters of medical research efforts in San Diego.

Hardage conceived the joint fundraiser as a way to raise money for two causes that hit particularly close to her heart. She and her husband, Sam Hardage,

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World Symposium



Eighth World Symposium Reflects VOC's Evolution

"We've come a long way from our early days, when we were focused on basic research and could only dream about a cure for hereditary eye diseases," Sam Hardage said in his opening remarks for Vision of Children's Eighth World Symposium. Hardage, VOC Chairman and Founder, welcomed 22 researchers and Family Network members to the Symposium, which took place in San Diego from November 6 -9, 2013.

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Your Donation Makes a Difference

There are so many ways to give...

Every donation to The Vision of Children Foundation helps us fulfill our mission. With proper funding, we are able to direct and sponsor scientific research that will lead to treatment, and potentially cures, for genetic vision disorders.

In addition to donating by mail or online from our website (www.visionofchildren.org), there are many ways you can directly or indirectly help VOC:

- If you shop online through iGive.com, you will trigger a donation for every purchase. Retailers affiliated with iGive donate an average of 3 percent (depending on the establishment) of your purchase price to VOC. Most major retailers contribute to charities through this website. Chances are, you'll be purchasing items from many of them anyway, so why not contribute to VOC at the same time? There's also an optional iGive Button that is a simple web browser app, easy to install and uninstall, which automatically kicks in at participating stores.
- Does your company have a Matching Gift program? Some companies will match up to 100 percent of their employees' donations. Check with your human resources department for details on how you may be able to increase the value of your gift to VOC.
- Designate VOC during annual employer-sponsored campaigns, such as the Combined Federal Campaign (for federal employees) and United Way.
- Enroll your grocery loyalty cards, credit/debit/ATM cards with eScrip (<http://www.escrip.com/>) and designate VOC as a beneficiary to which participating retailers can contribute a percentage of your card purchases.
- Supermarkets, such as Ralph's and Food4Less, will automatically donate a portion of your purchases to VOC if you register your loyalty shopping cards. For more information: www.ralphs.com/topic/community-contribution-2 or www.food4less.com/topic/community-rewards

Check out our website for other ways to fundraise for VOC.



Raffle Winner Pays It Forward

In conjunction with the *Visions of Success – From Research to Reality* fundraising event, VOC raffled off a 2014 Jeep Grand Cherokee Laredo. The Jeep was generously donated by Midway Jeep, Chrysler, Dodge and Ram of San Diego. The raffle prize also included a truckload of toys, which the winner, Beth Jupp, donated to families of Navy Seals living in San Diego and the burn unit at Rady Children's Hospital in San Diego.

Do We Have Your Latest Information?

If you are a member of The Vision of Children Foundation's Family Support Network, please take a few minutes to log in to our Member Center and make sure your data is up-to-date. That will ensure you receive our e-mail updates and other pertinent information.

October 2014 is VOC's 1st Annual Fundraising Month!

VOC Fundraising Month will be a great time to help us in the fight against hereditary childhood blindness and vision disorders. Use your creativity to come up with your own fundraising idea, or use one of ours. Encourage your friends and family to participate... get the kids involved (they can log community service hours).

Keep an eye on our website for more information, including guidelines and ideas for fundraisers and third-party events. We'll also provide updates via e-mail. In the meantime, take a look at some of our preliminary ideas below and feel free to send us your suggestions so we can share them with other VOC fundraisers. Importantly, remember to have fun!

Fundraising Ideas

USE THE WEB:

- Create an online fundraiser through crowdrise.com for just about any event (run/walk, birthday, wedding, memorial). Check out crowdrise.com for more great ideas. (VOC is already an approved Crowdrise charity.) Then ask everyone you know for donations using e-mail,

Facebook, Twitter and everything else you can think of. Be relentless.

- Shop online through iGive.com and trigger a donation for every purchase. (See more about iGive on page 2.)

GET ACTIVE:

- Turn any 10K, marathon, bike tour, triathlon, or sports event into a grassroots Team VOC fundraiser. VOC will help you create your own personal fundraising page. Not the sporty type? Then consider a bowl-a-thon, bake-a-thon, dance party... the possibilities are endless.
- Ask your gym to host an exercise class to benefit VOC.
- Host a tournament – golf, tennis, volleyball, ping pong... any sport.

GET THE KIDS INVOLVED:

- Lemonade stand/bake sale.
- Refreshment sales at sporting events.
- Halloween party – Trick or Treat for VOC.
- Create and sell crafts.

ON A GRANDER SCALE:

- Host a game night at which your guests make a donation to play.
- Collect quality items from friends and



local retailers and host a silent auction at your home.

- Organize your own or neighborhood garage/tag sale.
- Plan a fundraising tea party/dinner/gala.
- Encourage your friends to "Give up their latte" for the month and donate those daily expenses to VOC.

RECYCLE:

- Work with an electronics recycler to start a local collection.
- If you live in Southern California, work with www.rippletextilerecycling.com to start a used textile collection.

Congratulations Team VOC Runners!

Three runners raced to the finish line for Team VOC in Southern California on Sunday, March 9, 2014, raising more than \$2,800 for vision research. In San Diego, Cyndie Schade ran her eighth ½



Left to right: Cyndie Schade, Riley Segel, Monica Amin.

Marathon (and second one as a Team VOC member). Joining her in the race this year was her daughter Riley Segel, who trained hard for her first ½ Marathon.

Riley, who has a vision disorder, will benefit from the research VOC

is funding. In honor of Riley's 15th birthday, the mother-daughter team hoped to raise \$1,500, a goal which they easily surpassed. "I am so proud of Riley," said Schade, who is already talking with both her daughters about doing the race next year.

In Los Angeles, Monica Amin finished her first ASICS LA Marathon. "With the training of my first marathon, I am continuously challenged every week to run distances I never fathomed and test my abilities mentally and physically," she wrote on her Crowdrise fundraising page. "There are numerous moments where I would rather quit than endure another mile, however, during those occasions I am quickly reminded that I am not running this race for self-achievement but rather for children who have been stripped of their capability to see."

Team VOC was created to give supporters a way to fundraise for VOC while participating in an event they might already plan to do (or might be inspired to do). Instructions for becoming a member of Team VOC are on our website under the Fundraise tab.

Eighth World Symposium Reflects VOC's Evolution *(Continued from page 1)*

The feeling of optimism was evident throughout the Symposium, as the scientists reported on their ongoing research. Presentations included several that focused on the pathogenesis of the various types of ocular albinism, the function of retinal pigment epithelium and the mechanisms of melanogenesis. In addition, several researchers discussed



VOC research scientists Drs. Debora Farber (left) and Carol Mason.

studies on various treatment approaches, including gene and stem cell-based therapies and the use of two different drugs. And, four different new human clinical trials were announced!

The human clinical trials are in preliminary stages and it will be some time

before the results will be formally presented to the medical community. Nonetheless, the fact that scientists now have enough information to conduct trials on people with albinism is extremely encouraging and satisfying to Hardage and his wife, Vivian. The couple founded VOC more than two decades ago precisely to heighten researchers' focus on genetic vision disorders at a time when there was almost no one studying this group of rare diseases.

"Each of our Symposiums has accelerated the pace of vision research and brought us closer to our goal," Hardage said, adding that the unique format of these meetings has encouraged new research projects that would not otherwise be possible. Unlike most other scientific conferences, where researchers only present the results of completed research, researchers at VOC's Symposiums typically share incomplete and ongoing work. "We are very grateful for their willingness to do so, since this type of open forum stimulates new research ideas and refines current research methods," he said.

Indeed, throughout the Symposium, there was a sense of camaraderie as the researchers collaborated on different approaches to the common goal: finding a cure for hereditary childhood vision disorders and blindness.

The scientific agenda was developed by Drs. Debora Farber and Esteban Dell'Angelica, from the David Geffen School of Medicine at the University of California, Los Angeles.

"This Symposium was particularly exciting since it was attended by quite a few researchers new to our group who are interested in ocular and oculo-cutaneous albinism, as well as other pigmentation deficient disorders," said Dr. Farber, who is also affiliated with Jules Stein Eye Center and has attended every VOC symposium. "It was also thrilling to see that some of the basic work we are doing is leading to the development of possible therapies."

The Symposium concluded with a presentation by Baylor College of Medicine's Dr. Richard Lewis to family network members. Dr. Lewis provided an in-depth look at the genetics and manifestations of various types of albinism. He also noted that the attendees of this year's symposium represented the greatest collection of talent researching ocular albinism and related disorders.

Family Network Moms at Symposium

Heather Benedetti, from Richmond, VA., and Sarah De Nike, from Sammamish, WA, got a first-hand look at the latest VOC-funded research when they attended the Eighth World Symposium. Both said they found the experience very valuable.

"It is heartening to know that this wonderful and diverse group of researchers are working hard to find a cure for so many vision disorders," said Benedetti, who also attended the 2004 Symposium in New York City. "I have always heard that the research community is competitive and secretive, so it is remarkable to me that these scientists came together to share their ideas and push each other further."

De Nike was particularly excited to hear about the clinical trials. "Hopefully this will lead to some way to help my children in the future," said the mother of two young boys diagnosed with ocular albinism (OA). She also suggested that future symposiums include a parent presentation, so the researchers could better understand families' day-to-day challenges.

Both moms encourage Family Network members to attend future symposiums to share ideas and support each other. "For us, VOC has been a tremendous source of hope for more than 15 years, since our son was diagnosed with OA as an infant," Benedetti said.



Heather Benedetti (left) and Sarah De Nike.

Fundraiser Benefits Vision and Cancer Research

(Continued from page 1)

founded VOC in 1991, after their son, Chase, was diagnosed with ocular albinism type 1. And, she is a three-time breast-cancer survivor who recently was diagnosed with a recurrence, this time with a particularly aggressive form of the disease, Inflammatory Breast Cancer. The money raised will directly fund important medical research to find cures for hereditary childhood blindness and rare and aggressive breast cancers.

Hardage felt compelled to organize the fundraiser in order to raise awareness about the importance of medical research. "Without research there are no cures... without money there is no research," she said. "We have to raise people's awareness about donating funds to medical research."

In her remarks at the fundraiser, Hardage said, "I am grateful for each new day. I tell my story to pretty much anyone who will listen. In doing so, I hope people will understand the critical need for medical research to cure both breast cancer and vision disorders. It has become my passion... in my mind at least, my reason for still being here. My Vision of Success is translating research into reality... I will persevere until people who are diagnosed with a disease they've never heard of will also be told that there's a cure."

Romney, the wife of presidential candidate and former Massachusetts Governor Mitt Romney, wrapped up the event, and captivated the audience with

Modeling the latest fashions...



Guests raise their paddles to bid on high-end items during the auction.

stories about her family and her own personal health issues. In addition to battling breast cancer, she has learned to live with multiple sclerosis since 1998. Like the Hardage family, she and her family are dedicated to vision health and research, and she described their recent mission trip to Peru, where they worked with eye doctors conducting vision screenings in remote villages.



The event's Diamond Title Sponsor Papa Doug Manchester with Vivian Hardage.

"None of us really escapes a lot of pain when we live on this earth," Romney said, and added that raising money for health care research "is a great way to pass on how we need to care for one another."

Several of the other event organizers, including honorary co-chairs Susie

Spanos and Bill Griffith, also have personal connections to the causes. Spanos, wife of San Diego Chargers President Dean Spanos, was diagnosed and successfully treated for early stage breast cancer over 10 years ago. Griffith, co-anchor of 10News Live in San Diego, battled male breast cancer — an extremely rare disease in men, and one which is often fatal. Griffith also has personally dealt with a rare vision disorder, making the event doubly important to him. Both Spanos and Griffith have been outspoken advocates of the importance of early detection and breast cancer research. In addition, nine of the 10 models at the event's fashion show were breast-cancer survivors, and one of them has a family history of breast cancer and carries the BRCA gene, which very frequently results in breast cancer before the age of 50.

Among the notable guests were California State Senator Mark Wyland, San Diego Mayor Kevin Faulconer, San Diego County Supervisor Dave Roberts, San Diego County District Attorney Bonnie Dumanis, San Diego County Sheriff Bill Gore, and former California State Assemblyman Martin Garrick. The event was sponsored/underwritten by more than 40 companies and individuals, including Papa Doug Manchester, real estate developer and publisher of the *U-T San Diego*, who was the Diamond Title Sponsor.

New Video Showcases VOC & Finn Boyle

A newly produced video highlights The Vision of Children Foundation's crusading work and research funding. The video features Sam and Vivian Hardage, scenes from the Eighth World Symposium, and the Boyle family from Ontario, Canada, whose older son, Finn, was born with oculocutaneous albinism 1B.

"We created the video as a way to give people a current, in-depth look at VOC," said Executive Director Andria Kinnear. The video is available on the VOC website (www.visionofchildren.org/media), and will be used for education purposes and to highlight the need for expanded vision research.

The Boyles, who have been loyal VOC supporters, donors and Family Network members since 2004, eagerly agreed to participate in the video. Nine-year-old Finn and his family are very excited about the research being done by VOC researchers. The fourth-grader had encouraging results when he participated in a clinical trial testing the effects of dopamine replacement on the vision of individuals with oculocutaneous albinism (OCA). VOC is funding this trial, conducted by Dr. Michael Struck at the University of Wisconsin, Madison. Finn attended VOC's Eighth World Symposium with his parents Roben and Feidhlim and his little brother, Oscar.

In the Q&A below, Roben Boyle shares some more details about her family's experiences with OCA.

Tell us about how Finn was diagnosed.

Finnegan was three months old when we noticed his nystagmus. We were living in New York City at the time, so we had access to lots of doctors. However, the first three doctors told us that Finn would be "legally blind, there was nothing they could do, come back in five years." We rejected the idea of doing nothing, and we kept looking for the experts in this area. Luckily we found Vision of Children Foundation and Dr. Terri Young, a pediatric ophthalmologist (who was previously with The Children's Hospital of Philadelphia and is now with Duke University Eye Center). Dr. Young ordered genetic testing for both Finn and for us, and an MRI to look at Finn's optic nerve to rule out anything other than OCA or OA. When she

Finn (at right) and his brother, Oscar.

presented her findings from all the tests, it was pretty clear she had the correct diagnosis. More importantly, she had ideas to help Finn.

The early diagnosis made a difference to Finn's eyesight because we were able to start treatments at a young age. The eye and brain develop together up until around the age of five, so early intervention is critical. We started patching his strong eye every day (from age of 3 months to 4 years). And by the time he turned three, we decided that he should undergo the operation for correcting his "null point" (by tightening his eye muscles) so he didn't continue tilting his head to get the best point of vision.

How did you hear about VOC?

The day we received the diagnosis from the first doctor, my husband, Feidhlim, spent all night online researching pediatric ophthalmologists. In the process, he came across Vision of Children's website. Through the Vision of Children, we found lots of information and a community of people. I was able to make contact with other moms who had children with OCA or OA. And, as luck would have it, just a few months after learning Finn had OCA, Vision of Children was hosting a Symposium on Ocular Albinism in Capri, Italy. Feidhlim and I attended that Symposium and learned a great deal about OCA/OA.

What was the key message you took away from VOC's recent Symposium?

The key message for us was that the Symposium brought together, in one room, the greatest minds working on solving OA/OCA. And these scientists and researchers were tackling the problem from many different angles: stem cell research and genetics to clinical trials involving dopamine replacement. We think it's useful for parents to attend these Symposia because you can meet the scientists, doctors and researchers who are working to find cures.

What are Finn's limitations?

Finn has to be extremely careful of sun exposure, and his photophobia causes reduced vision outside so he must always have sunglasses. We also find that he gets tired more than other kids. We think this is because he has to work so hard to see everything.

Does he get accommodations at school?

Yes. Finn's school is extremely accommodating. The hard part is figuring out all the little details that could improve his life. To help Finn navigate better in the classroom and on the school grounds, we used the services of Canadian National Institute for the Blind and the W. Ross Macdonald

School for the Blind. Both organizations provide excellent in-school assessments for low vision kids. Finn's school has implemented all the suggested recommendations.

Tell us about your experience participating in Dr. Struck's clinical trial.

The clinical trial was a great experience for Finn and for us. It was well organized and efficiently run by Angie Wealti. Dr. Struck and all the doctors who collaborate with him were very kind to Finn and took the time to thoroughly explain each test. It was a wonderful learning experience for Finn. Finn is now able to tell people about his condition in more detail and advocate for himself. After the clinical trial experience, Finn has taken more ownership of his OCA.

What advice do you have for other parents?

We find it encouraging that Vision of Children is funding research that is getting very close to treating OCA. In the meantime, there are tools and technologies that children with low vision can use to help them see better. And finally, we would encourage parents to help as they can. If you take action, either by donating to VOC or by participating in a clinical trial, you help the scientist and doctors advance closer to solving OA/OCA. It makes you feel like you are part of the solution, and that has been very encouraging for us.

In Finn's Own Words

What are your hobbies and activities outside of school?

My favorite activities outside of school are playing soccer with my friends in the park and training with two different soccer clubs. I really like looking up my favorite soccer players moves on YouTube and trying to learn them. I really like to play outside with my brother. Right now we have a gigantic snow fort on our street! I also like playing board games like Monopoly and Clue.

What's your favorite subject?

My favorite subject is science. I just finished my science project on rocks and minerals. My thesis was that the metamorphic rocks were going to be the strongest because metamorphic rocks are made up of lots of rocks put together by time, heat and pressure. It turned out my hypothesis was right!

How have you learned to live with OCA?

I don't know. I wear glasses that go dark outside. I really like those. And also sports goggles that go dark too. When my teacher writes on the blackboard or smart board, I'm allowed to get up and go right up to see things if I can't see them from the front row. I memorize my violin sheet music right away so I don't have to look at the music sheets very often. My mom makes the music sheets really, really large for me. Before recess, I talk to my friends and ask them where they are going to go on the school ground so then I know where they will be. I tell everyone — like my teachers and coaches — when I cannot see and need to get closer. For soccer, I get to know my teammates and know what they do with the ball, and then I try to visualize where they are going to put the ball.

What was it like to participate in Dr. Struck's trial?

It was awesome because I got to skip a bit of school, which was pretty fun. The only part I didn't like was the taste of the pills. I liked seeing all the equipment they used and having wires attached to my head to measure my brainwaves. I also liked going to Madison, Wisconsin.

Did you notice a difference with the treatment?

Yes, I noticed a difference. I moved to the second row at school to sit with my friends. But now I'm back in the front row because I think the medicine wore off. Also, I was able to see the rabbits in my backyard. They are brown and were hard to see before. I will have to see if I can see them again in the spring.

What advice would you give to other kids with OCA or similar vision disorders?

If you don't want people to ask questions about why your eyes move side to side, then just keep your eyes moving. Advocate for yourself. Don't be shy if you can't see the board. I used to be like that, but once I learned to speak up, it was so much easier.

Indigo's Vision of the Future

More than 200 people enjoyed a beautiful afternoon of art, fashion, food and a chance to bid on unique auction items at a fundraiser for The Vision of Children Foundation hosted by Indigo Salon and Spa in San Diego.

Indigo's owner Randi Hosking marshaled dozens of individuals and retail establishments to donate services, time and goods for the November 3, 2013 event, which also featured an exhibit of paintings by San Diego artist Ann Golombok. Salon Manager Carrie Daly, hair stylist Michelle Ward, and the rest of Indigo's 40 staff members planned and volunteered for all aspects of the fundraiser. Le Bel Age Boutique lent exquisite clothing for the fashion show, while local restaurants donated food and beverages.

Hosking, along with her business partner Phyllis Strauss, host about three fundraisers each year for local charities. "This is my way of giving back to my community for all the support I've had during my own battle with breast cancer," Hosking said. "I choose to share my gratitude by paying it forward."



(Above) Indigo Salon and Spa staff members promote Vision of Children at their fundraiser, which featured a fashion show (below).





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