

'Don't Ever Think You're Less Than Anyone Else'

Teen With OCA Visits Research Team Working On Cures

Born with several vision challenges, Heidi Ansonge faced many obstacles growing up. What for most people would be considered run-of-the-mill daily experiences – such as reading restaurant menus and seeing classroom boards – were always a struggle for her. Moreover, she was not able to experience one of the most anticipated rights of passage for most teenagers: getting a driver's license.

"I was definitely sad," Ansonge said. "But, I was motivated to do better in other areas to overcompensate for what I couldn't do."

Ansonge, a California resident, was born with oculocutaneous albinism

(OCA) — a condition affecting the pigmentation of the eyes, as well as the hair and skin. As a result of this genetic condition, she has difficulty perceiving depth and seeing far distances. She also has nystagmus (rapid involuntary eye movement) and astigmatism (which causes distorted or blurry vision).

In school and at home, she relied on technology such as a laptop, iPad and a closed-circuit television to help her read. But she didn't let her disability and associated challenges hold her back. Instead, she relied on her "never-make-excuses" and "will-to-succeed" attitude to excel. Even summers were no break, as



Heidi Ansonge visits with researchers Drs. Alejandra Young and Debora Farber at Jules Stein Eye Institute, both funded by The Vision of Children Foundation.

she completed summer classes at the University of Southern California and Boston University in international relations, infectious diseases and neurobiology, ultimately sparking an interest in science.

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When Vision Becomes Reality

Celebrating 25 Years of Funding Research to Help Kids See Clearly

We are celebrating and YOU are one of the reasons. *Your support – as a donor, researcher, Family Network Member or friend has been essential to our success.*

The Vision of Children Foundation (VOC) was founded by Sam and Vivian Hardage in 1991, after their son was born with a rare genetic vision disorder, ocular albinism type 1. They were shocked to discover that there were no researchers studying these types of vision issues. Since then, VOC has encouraged scientific exploration in genetic vision disorders by supporting researchers at leading institutions worldwide.

"Our researchers have made extraordinary progress," said Sam Hardage, VOC Board Chairman. "Among many breakthroughs, they have isolated genetic mutations for eye diseases and developed genetic tests." Current research focuses on induced adult stem cell therapy, genetic reprogramming and medication trials.

We need your help to unlock the secrets to cures for genetic eye diseases. In honor of our 25 years of commitment, please consider a gift of \$25, \$250, \$2,500 or any amount you choose. Our goal is \$25,000. Please use the envelope included in this newsletter or donate online: www.visionofchildren.org

A cure is within reach. Help us give kids the gift of sight. Thank you for your support!



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#VOCvisionheroes

New Team Members



Emily Coring, our new Director of Development, has spent her career in the healthcare sector, serving in various roles including marketing and sales. More recently, she managed a customer service team at Cardinal Health. Coring graduated from the University of North Carolina at Chapel Hill, where she majored in Journalism and Mass Communications with a focus in Public Relations.



Nancy Montejano, our new Director of Operations, began her career in Oceanography after graduating from the University of California, San Diego, with a BS in Biology. She continued her science career, working at several biotech companies in San Diego. After years in research, Montejano worked in the financial services industry, coordinating educational marketing events and managing the firm's relationships with clients.



Elizabeth Berg comes to us as a Development Consultant with 17 years of experience helping non-profits succeed through fundraising, communications and partnership building. She is a Certified Fund Raising Executive (CFRE) and has a Master's Degree in Journalism. She is also a native San Diegan.

Upcoming SYMPOSIUM Encourages Scientists to SHARE WORK IN PROGRESS

The Vision of Children Foundation will host some of the world's top vision research scientists at its 9th World Symposium on Ocular Albinism & Other Vision Disorders in San Diego November 16-18, 2016.

Over the past two decades, VOC has sponsored eight World Symposiums, where top vision researchers from around the world share and discuss their latest discoveries and research efforts involving ocular albinism and other genetic vision conditions.

The Symposiums have stimulated innovative approaches to difficult problems, and have had a far-reaching impact in the vision

research community, partly because of the unique format. 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. Each symposium has accelerated the pace of vision research.

Vision care providers and families are welcome to attend.

Details about the hotel and registration information will be posted on the Foundation's website, www.visionofchildren.org, by early September.

WHEN VISION BECOMES REALITY.

Innovation @ Work

Updates on VOC Featured Researchers



FOLLOWING THE PATH OF A MALFUNCTIONING GENE

M. Vittoria Schiaffino, MD, PhD., San Raffaele Scientific Institute, Milan, Italy

Dr. Schiaffino's research on the changes taking place at the subcellular and molecular level that ultimately cause ocular albinism type 1 (OA1) could lead to targeted drug treatments. Individuals with this genetic disorder carry mutations of the OA1 gene and, as a consequence, loss-of-function of the OA1 pathway, which is necessary for normal vision. Understanding the molecular players acting within the OA1 pathway is an important step in developing treatments.

SEARCHING FOR CLUES TO WHY RETINAL NERVES TAKE A WRONG TURN

Sonia Guha, Ph.D., Jules Stein Eye Institute, University of California at Los Angeles

Dr. Guha's research on how the gene for OA1 works, and how its mutation affects the functioning of the retina, could lead to new therapeutic approaches. Individuals with OA1 display a number of abnormalities in the eye, including the misrouting of the optic nerve fibers that extend to the brain. Dr. Guha is examining the development of the retina during early embryonic stages to determine precisely what type of malfunction leads to this misrouting.



IT'S ALL IN THE GENE DELIVERY

Alejandra Young, Ph.D., Jules Stein Eye Institute, University of California at Los Angeles

Gene therapies are an exciting new method for the prevention and treatment of blindness caused by a variety of ophthalmic disorders. For gene therapies to work, scientists must find proper methods for transferring normal, functioning genes into the cells containing the incorrect genetic material. Recent approaches, like using viruses, are often inefficient and appear to have limited therapeutic benefit. Dr. Young is researching the use of microvesicles, released by the body's own stem cells, as an alternative delivery vehicle for gene transfer.

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A call from her mother to The Vision of Children Foundation staff led to several visits to the lab of the very team researching the optic nerve and the use of gene therapy to potentially treat and cure genetic eye disorders like the one affecting Ansorge. The team at UCLA's Jules Stein Eye Institute is led by Dr. Debora Farber, Director of the Biochemistry Laboratory. Funded by VOC for nearly two decades, the scientists are working on cutting-edge research that could lead to clinical trials in the

near future. "It was an amazing opportunity to be able to spend time with such incredibly brilliant scientists in a field that is close to my heart," Ansorge said. "It solidified my interest in studying neuroscience in college."

Ansorge graduated from high school with an A+ average and will attend the University of Southern California in Spring 2017. An ex-flier for her competitive cheerleading team and avid water skier, wake boarder and surfer,

she didn't let anything keep her from living a normal life. "My dad treated me like I was a normal kid and taught me to think the same," she recalled.

"A lot of people doubt you and what you can do," she said. "My advice to others with a disability is don't ever think you're less than anyone else. It doesn't matter if you have to work harder to achieve your goals."

By Kristin Butler
Vision of Children Intern

New Partnership Program Engages Optometrists in Working Toward CURES

Optometrists devote their lives to improving people's vision. But there is little they can do for people whose vision disorders can only be minimally improved with glasses or contact lenses. Until now...

Vision of Children is launching an innovative new cause marketing program, called the Vision Hero Network. It is designed to engage Optometrists in the effort to fund vision research. The goal is to ultimately help the millions of people suffering from genetically caused blindness and vision disorders for which there is currently no cure, and often no treatment.

For the past 25 years, VOC has been at the forefront of unlocking the secrets to cures for hereditary

blindness and vision disorders, such as ocular albinism, oculocutaneous albinism, blue cone monochromacy and myopia. "We're in the early stages of the roll out, and it's exciting to see that optometrists are seeing the positive potential they can have by partnering with us," said VOC's Director of Development Emily Coring. "It can be an important part of their marketing strategy, enhancing their social responsibility profile, building goodwill with patients and employees, and increasing customer loyalty."

The program launched in San Diego earlier this summer. Coronado optometrist Stephen J. Moffett, OD, was the first to sign on as a partner and strategic advisor. "This is a great opportunity to make an impact on the lives of people tomorrow, in

addition to the work I do to take care of their vision needs today," Moffett said. "My patients are thrilled to know that I am investing in cures for tomorrow, in addition to providing families with clear vision today. And my staff is also energized knowing they are playing a role in helping to discover cures for genetic blindness and vision disorders."

The Vision Hero Network offers Optometrists several options for supporting VOC. They can elect an annual partnership or they can donate a portion of the proceeds from certain eye exams, such as digital retinal imaging. In addition, they can encourage their clients to contribute directly to VOC.

Jason Tu, OD, is another San Diego Optometrist who was among the first to sign on. "Our profession is one of passion... helping patients see the world through clear vision no matter what the issue may be," Tu said. "We strive to provide thorough eye examinations, using the latest in technology, with attention to personal service and products that make our patients' lives better and more enjoyable. The Vision of Children Optometric Program has inspired my team, my patients and my family."



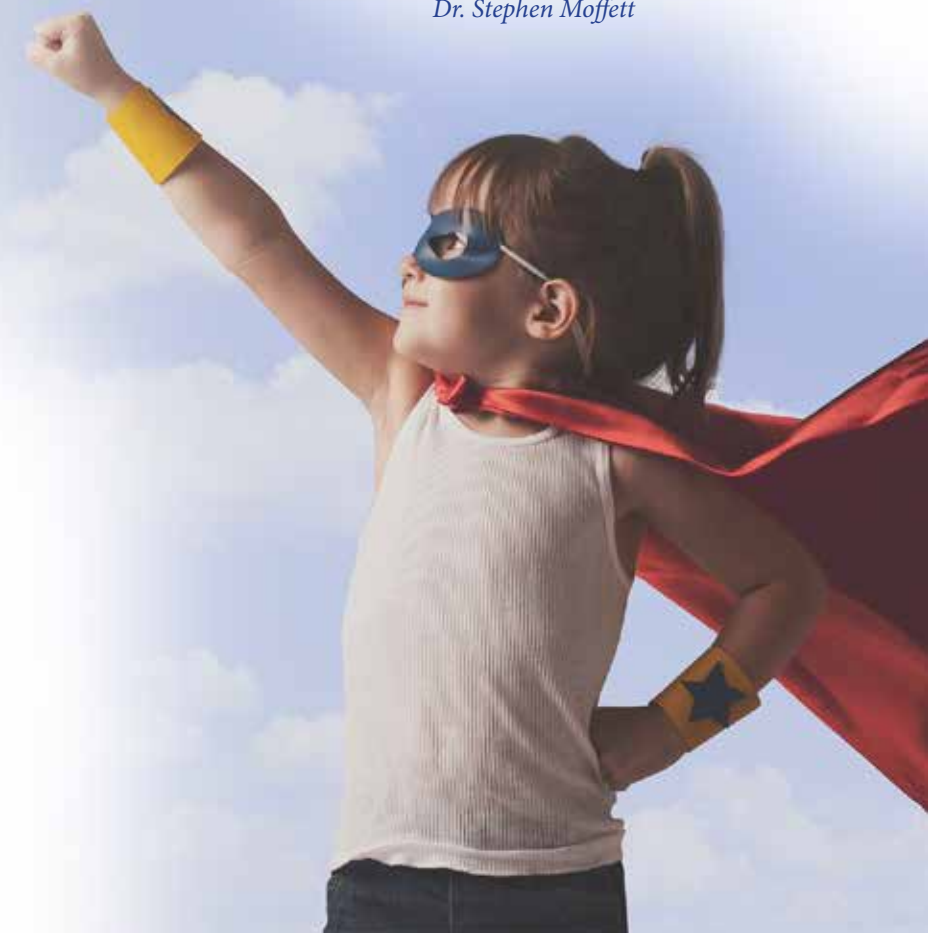
Dr. Stephen Moffett



The San Diego Downtown Optometry Team: From left to right: Allen Tu, Carolyn Razoky, Nicole Cristofari, Kyla Allen and Dr. Jason Tu.

Providing Clear Vision
TODAY
Investing in CURES for
TOMORROW

Do you know an Optometrist who you think would partner with us to fund our research and find cures? If so, send an email to emily@visionofchildren.org. If your Optometrist signs on, we will give you one of our new VOC T-shirts as a token of our thanks!



VOC Vision Heroes provide *Inspiration* to



Vision of Children's Vision Heroes are young people who have pursued their talents and dreams despite their vision challenges. Our latest two Vision Heroes, who are legally blind, epitomize the essence of what it means to persevere.

Joel Gomez has been a musician since he first picked up a violin at age 5. Since then, he's added the piano, ukulele, guitar and vocals to his repertoire. He has also won several track competitions in his age group, and recently broke his own record, running the mile in 5 minutes 9 seconds. Gomez, who is now 12, was born with Blue Cone Monochromacy, a genetic vision disorder that causes color blindness, photosensitivity and nearsightedness.

Lauren Mills has been drawing since she could pick up a crayon at 10 months of age. She began painting when she was 11, and creates works of art inspired by her favorite artists, Salvador Dali and Picasso. The 16-year-old was diagnosed with nystagmus and other vision disorders when she was a baby.

In addition to their remarkable talents, both Gomez and Mills have excelled academically. But they each have faced their own unique challenges.

"My vision has contributed to many struggles that I have experienced," Gomez said. "When I mistake colors and have to tell people I am color blind, sometimes kids will ask what they would think is a funny joke, testing me, 'What colors am I wearing?' or 'What color is this?' These are some of the worst things about having a visual impairment. However, I have learned to be patient and just answer their questions or make a joke back. I also think dealing with these questions has helped me learn to be more understanding about other people's problems when I hear about them."

For her part, Mills said, "As a young girl, other kids teased and physically bullied me, and even adults did

ALL

not appreciate my visual disability. Many people would become frustrated with me because I needed to be very close to them, or to inanimate objects, in order for my eyes to settle down enough to focus. People did not understand me, and I didn't understand them and their cruel, hurtful responses to me."

Neither has let such challenges stop them from achieving their dreams and goals, relying instead on their inner strength, conviction and talents.

"It can take a lot of courage to make new friends," Gomez said. "My vision challenges have helped me have a positive perspective on life because I have gained confidence by overcoming many obstacles, and each setback that was meant to knock me down would push me up." The gifted musician has his own YouTube channel, where he features covers of his favorite musicians. Track has also enabled him to show his best side. He likes to quote Jackie Robinson: "Above anything else, I hate to lose."

After all, everyone gets knocked down, the strong get back up."

Mills, an award-winning artist, transfers what she can identify through minimal vision and a vivid imagination to the canvas. "I know my art brings joy to people, and that makes me happy," she said. She also likes to write poetry, and plays the saxophone. She advises others not to be ashamed of their disabilities. "Your disabilities do not define you. Love yourself for who you are and live your life," Mill said.

Watch Gomez and Mills showcase their talents and discuss what it's like to live with a genetic vision disorder in their Vision Hero Videos: www.visionofchildren.org/voc-vision-heroes

The VOC Vision Hero Video Series was made possible through a generous grant from the Harriet E. Pfleger Foundation.

Do you know a VISION HERO?

We are seeking inspiring young people who have overcome their vision challenges despite being told they have limitations that may hold them back from achieving their dreams. By spotlighting new Vision Heroes regularly, we hope to encourage young people to realize their talents and reach their full potential in life! If you know someone who we should consider, send us an e-mail at info@visionofchildren.org.





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We are dedicated to treating and curing children's vision disorders so kids can see and live better.

Your Donation Makes a **Difference**

YOU can have an impact on the lives of Vision Heroes like Joel and Lauren, and many more children who navigate the world without the benefit of sight as most people know it. YOUR donation to The Vision of Children Foundation helps create a better future for children with genetic vision disorders... a future in which they can read a book, participate in any sport, and drive a car. Help us help kids see and live better!

There are so many ways to give...

- ⇒ Donate directly to us by mail or online from our website (www.visionofchildren.org).
Help us meet our 25th Anniversary goal of \$25,000!
- ⇒ Trigger a donation for every online purchase you make at retailers affiliated with iGive. Visit www.igive.com to download the iGive Button to your Internet browser.
- ⇒ AmazonSmile will donate 0.5% of the purchase price from your eligible AmazonSmile purchases. Visit www.smile.amazon.com and select VOC as the charity to receive donations from eligible purchases.
- ⇒ 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 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 (www.escrip.com) and designate VOC as a beneficiary.
- ⇒ Supermarkets, such as Ralph's and Food4Less, will automatically donate a portion of your purchases to VOC if you register your loyalty shopping cards.
- ⇒ Create a fundraiser for your next running, cycling or endurance event.



Check out our website www.visionofchildren.org for other ways to fundraise for VOC.