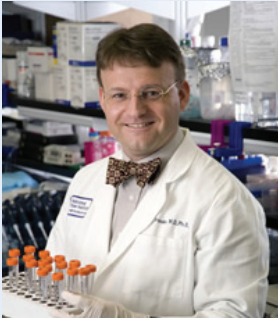




Our mission is to cure hereditary childhood blindness and vision disorders, and to improve the lives of visually impaired individuals and their families.

Patient Registry

Advancing our Understanding of Inherited Eye Disease



Dr. Brian Brooks

When scientists proposed the Human Genome Project in the 1990s, the goal was to identify all human genes. With that roadmap in hand, doctors would be able to identify mutations that cause or increase the risk of certain diseases. Scientists also believed that understanding the human genome would lead to individualized treatments. While much of the promise of genetic-based medicine has not yet been fulfilled, our understanding of inherited disease continues to grow. Today, over 500 genes have been identified as causing vision disorders.

In 2006, the National Ophthalmic Disease Genotyping and Phenotyping Network or eyeGENE® was launched. Based at the National Eye Institute in Bethesda, it has a dual mission. It offers families, free of charge, genetic testing to confirm a diagnosis. (The cost of the blood draw and shipping is borne locally.) After submitting a blood sample, family history and exam results are collected, and sent to one of the country's top labs for definitive genetic testing. The results are sent back to the ophthalmologist, who can arrange for a counselor to explain the results and what that means. Remember, genetic testing cannot forecast the severity of the condition, but can help make a definitive diagnosis when the symptoms don't appear to match the common presentation of a disease. The added benefit is that these DNA samples and results, with all identifying information removed, are made available to the research community. For diseases that may only impact a handful of families, this database and sample library has been extremely valuable.

Brian Brooks, MD, PhD is a researcher at the National Eye Institute, and an expert in genetic eye disease. He has worked with Vision of Children, including presenting information to participants at VOC Scientific Symposia. Dr. Brooks is one of the scientists managing eyeGENE®, an important collaboration between families affected by inherited vision disorders, their eyecare providers, and researchers.

According to Brooks, "The goal of eyeGENE® is to accelerate the rate of scientific discovery for a number of inherited eye diseases, including X-linked albinism, while at the same time providing useful clinical genetic information to patients and their physicians. It is our hope that eyeGENE® will enable the entire vision research community to work towards better prevention and treatment of inherited eye disease."

In the six years since eyeGENE® was launched, over 3,350 DNA samples have been collected. For many diseases, including ocular albinism, there are only a few samples on file. We encourage families who are interested in learning more about eyeGENE® to contact VOC. You can also find information at www.nei.nih.gov/resources/eyegene.asp.

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A special thank you to the Delta Gamma Fraternity and the Harriet E. Pflieger Foundation for helping to make this newsletter possible!



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Jeans for Genes

Jeans Day has been a longstanding tradition with some Vision of Children supporters. Employees make a contribution to come to work casually dressed. In the Big Apple, employees from Ally Financial took the opportunity to dress down for a cause. Family Network member George Triebenbacher gets credit for bringing VOC to the attention of Ally employees!

Jeans Day at Ally raised more than \$8,500 including donations from staff and a matching gift from Ally. The money raised in our Jeans for Genes program goes to support our medical research program.



Thanks to George and the team at Ally for helping us find a cure for genetic eye disease. If your company is interested in hosting a Jeans for Genes Day to benefit VOC, contact info@visionofchildren.org. We'll supply you with information about this FUNdraiser.

Project VisionAid

Our Goal is 200 Magnifiers

Did you know that Vision of Children supplies portable magnifiers – free of charge – to students with low vision? Since 2010, VOC has donated more than 75 of these adaptive devices to school districts requesting them.



Some children with genetically caused vision disorders encounter difficulty trying to keep up in the classroom. Students seem particularly reluctant to use assistive devices that set them apart from their classmates. VOC looked for ways to help and consulted several experts. A small, handheld magnifier seemed to be the most useful. With a generous starting grant from the Alcon Foundation and the Harriet Pflieger Foundation

in 2010, we were able to make our first purchase of 25 units that Vision of Children donated to school districts.



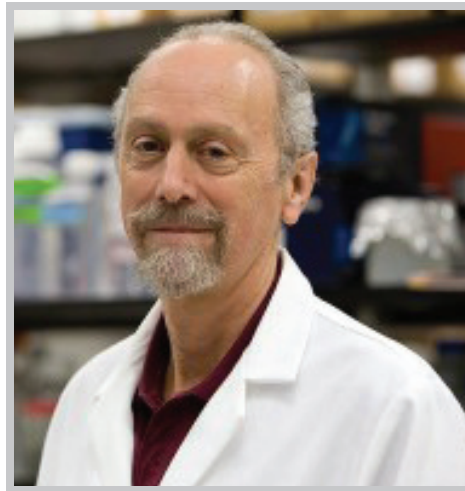
VOC has made these magnifiers available to school districts in Texas, California, Florida and Michigan. If you believe your school-aged child would benefit from the device, which magnifies images up to 15x and permits close-up viewing of books, worksheets and handwritten material, complete the parent request form available on the VOC website. A school district official will also need to complete part of the form and return it to VOC. We ask that families and teachers complete a questionnaire after one month and six months so that we can assess the benefits of this program.

Research

Delivering Improved Genes

Dr. William W. Hauswirth is Professor of ophthalmic molecular genetics at University of Florida College of Medicine. He has also developed a reputation as the 'go to' scientist for vision-related gene therapy experiments. With more than 200 scientific publications, he has been a critical member in some of the most promising recent vision research.

Hauswirth played a role in the 2009 trials at U. Florida and U. Penn that helped individuals who were blind due to Leber's Congenital Amaurosis type 2 (LCA) regain eyesight. A 3-year follow-up of these patients recently reported that study participants show no ill effects from the gene therapy and that vision in their treated eyes remains improved. Hauswirth developed the viral injection that delivered a normal copy of a gene, giving the patients improved vision for the first time in their lives.



Dr. Bill Hauswirth

Hauswirth was awarded a grant from Vision of Children in 2010 to expand and accelerate experiments on Blue Cone Monochromacy (BCM), a severe blinding form of color blindness. We asked Dr. Hauswirth about his research:

How can you correct a defective or missing gene?

WWH: We use a non-disease causing human virus, Adeno-associated virus (AAV), remove its normal DNA and replace it with the gene the patient is missing. This new virus (called a vector) is then injected into the eye near the retinal cells that are affected. The vector delivers the therapeutic gene to the affected cells and, if all goes well, these nonfunctional cells regain vision function.

There has been some remarkable success with gene therapy for vision disorders, but less so in treating other inherited diseases. Is there a reason?

WWH: In many ways the eye is the perfect organ for gene therapy. It is external, so it is relatively easy to precisely deliver the vector. It is small, so only a little vector is needed in a limited area. And many noninvasive techniques are available to test vision, so the outcome of the therapy can be measured precisely. There is no other organ or tissue in the body that possesses all these properties.

It's been three years since the LCA study which gave hope to so many families dealing with genetic vision disorders. Have you been surprised that the gene therapy you've been involved with seems to have a permanent – or at least long-term – improvement?

WWH: No, earlier studies in a dog model with the same disease showed that a single treatment lasted for more than 10 years, the life of the animal.

Is there anything about the results of that study that surprises you?

WWH: All treated patients saw vision improvement within a few weeks, more quickly than we had expected. Also, some patients acquired new vision abilities that took many months to become apparent, more slowly than we expected.

You also had success curing monkeys of their color-blindness. Now, for Vision of Children, you are determining the proper doses and the optimal age to treat BCM. What is the next step?

WWH: Unlike the monkey experiments, for humans we are not developing a gene therapy for the common forms of color blindness, but for Blue Cone Monochromacy (BCM), a rare genetic form that causes severe vision loss and functional blindness.

We are working with rodent models of BCM to optimize the AAV vector design to efficiently and effectively supply the missing gene to the cone cells of the retina. Once the vector design is firmly established we will carry out the formal safety studies required by the FDA before a human clinical trial is initiated.



Team VOC

Join the Race – Until Children See Clearly

Earlier this year, Vision of Children launched Team VOC, our grassroots effort to raise awareness and funds to support eye research.

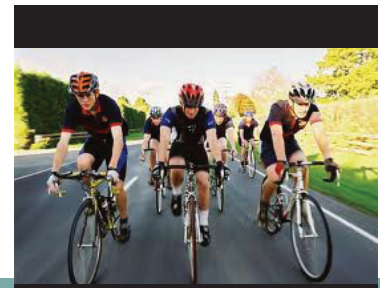
“Our friends wanted to bring Vision of Children to their hometown,” said Karla Readshaw, VOC Marketing & Development Coordinator. “Team VOC lets people participate in local events and be a part of our national efforts.”

Becoming a member of Team VOC is easy. First, find a local event like a fun run or walk, bike ride or canoe trip. (One of our supporters turned his wrestling season into a fundraiser – see story on Joe Arellano on page 7).

Register for the event and let us know you’ll be participating as a member of Team VOC. Invite your friends and family to also join Team VOC. We’ll set up your personal page on the VOC website where your friends can read your story and contribute to your efforts. Team VOC offers a Vision of Children t-shirt to anyone who links their event to our website, and we have additional prizes for individuals who raise money for research.

We’ll supply you with information about VOC to share with your friends, suggestions about fundraising, and tips on how to train for events. If you are not an athlete, ask a neighbor or co-worker to join Team VOC when they compete in local races.

For more information about Team VOC, contact info@visionofchildren.org or visit Team VOC on the Vision of Children website.



Welcome to our

Vision of Children reconfigured its website in the way that you’ll participate.

“Blog” is a wonderful noun and verb that combines the best of our favorite blogs are “A Parent’s Voice” sponsored by the National Association of the Deaf (www.familyconnect.org/blog.aspx) and the National Association of the Visually Handicapped (www.thewilltosee.org) whom have ocular albinism (www.thewilltosee.org).

VOC will be linking to other blogs, and putting you in touch with Network members. Your insights about family life and the diagnosis for their child. The doctors are generally a difficult time. Sharing tales of big challenges and successes with the Network, or a question, please feel free to use our

Delta Gamma

Our Sorority Sweetheart

The women of Delta Gamma have a passion to end blindness. The motto for the 200,000 strong women's fraternity is, "Do Good" and their philanthropic efforts fall under the umbrella of "Service for Sight".

The Chapman University DG chapter held a holiday party, "Deck the Halls with Delta Gamma" at their campus in Orange, CA. The event came together quickly and within 2 weeks, they distributed 25 Christmas trees to other sororities, fraternities, sports teams and campus clubs. The decorated trees were auctioned off and the proceeds donated to VOC. They raised \$4,300 and promised to turn it into an annual event! Sara Nininger, VP Foundation, deserves a special thank you for her hard work in putting the event together. And a big thank you to the ladies of Chapman DG for their enthusiasm and for creating a truly memorable event!

At the Delta Gamma Founder's Day luncheon in San Diego, 250 collegians and alumnae invited VOC founder and Board President Sam Hardage to be their keynote speaker. He challenged them to become active in VOC's efforts to find a cure for childhood blindness, and shared the inspirational story of the gene therapy successes for LCA (Leber's Congenital Amaurosis). Hardage told the guests there would be more cases of eyesight restored and vision regained because of the dedication of scientists worldwide.



Sam Hardage, Founder's Day



SDSU DGs, Spike for Sight!



*Miss California
Deck the Halls with Delta Gamma*

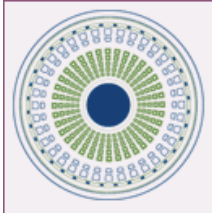
Our On-Line Neighborhood!

In the Spring, making room for more interaction among our Family Network members. We'll be hosting a Blog and hope

combines Web and Log. It's an online journal that records opinions and observations and invites readers to comment. Two sponsored by the American Foundation for the Blind and the National Association of Parents of Children with Visual (.asp) and "The Will to See" – a blog documenting the life of Seattle mom Sarah, raising her boys, Jackson and Will, both of see.com).

ing topics on our blog and asking you to respond. We also would welcome the comments and questions of our Family ily life coping with a vision disorder are priceless. At the VOC office, we get calls from parents who have just received a nerally not very encouraging and the perceived future appears bleak. Your stories encourage these families during their most s and small victories will help. If you have a story about your family, an opinion about a topic that will interest our Family e our blog. To read the VOC blog, visit www.visionofchildren.org.

Resources



The National Alliance for Eye and Vision Research (NAEVR) wants to hear your story. Vision of Children is one of the 55 professional, consumer and industry organizations involved in eye and vision research that make up this consortium. NAEVR advocates for increased federal funding for eye-related research and increased awareness of the impact of eye disease on Americans. There is nothing more compelling when budgets are being prepared than telling your story to those in Washington. If you are interested in learning more about how federal funds are allocated for eye research, or if you would like to testify about the impact of research on you and your family, contact NAEVR at www.eyeresearch.org.



Blazing the Trail

Travel to the heart of America this summer and take part in NOAH's yearly meeting. The **National Organization for Albinism and Hypopigmentation** will hold its 14th Annual conference entitled "Blazing the Trail" from July 12-15, 2012. Families affected by OA and OCA will find sessions run by professionals and other families. The meeting will also provide networking opportunities and social gatherings. Consider a trip to St. Louis this summer! Visit www.albinism.org or call them at 1-800-473-2310 for more information.



Alone we are rare. Together we are strong. Those words guide the **National Organization for Rare Disorders (NORD)**, a nonprofit that serves the rare disease community. Rare Disease Day is an annual effort to increase awareness of the challenges faced by individuals living with an orphan disease. NORD estimates there are more than 7,000 diseases (including several vision disorders) that impact fewer than 200,000 individuals. That translates to more than 30 million Americans – one in ten – living with a rare disease. Vision of Children was honored to be an ambassador for the 2012 Rare Disease Day held on February 29. Mark your calendar for next year's event. For information, visit www.rarediseaseday.us

Family Network

New Jersey Event

We invite all of our friends in NJ/NY/PA to mark their calendar for a special event on September 11, 2012. Marv & Lois Plansky will be hosting an event to raise funds for VOC at their community, the Regency at Monroe Township. The Planskys are grandparents to Erika Polevoy who lives with OCA. Golf, tennis, card games, music and food will be offered. If you are near Central New Jersey, plan on attending and supporting vision research. For details and directions, contact the VOC Office.

Keep in Touch

Remember to send VOC your new email address or your new home address. We'll update our records and we'll be able to include you in future mailings. Also, ask your family members and friends to join our Family Network. Send changes to info@visionofchildren.org

**THANKS
to our
Donors!**

Vision of Children is supported by many dear friends. Most notably, Richard & Laura Saker lend extraordinary support to our cause each year. We salute these wonderful philanthropists. You truly make a difference!



Thanks also go to some of the other organizations, foundations and corporations who supported our programs during 2011, including:

*Alcon Foundation
Ally Financial
Bunker Charitable Fund
Clayman Family Foundation
The Country Friends
Cubic Corporation
Del Mar Highlands
Delta Gamma Fraternity
The Gold Diggers
Johnson Family Foundation
Harriet E. Pflieger Foundation
Polevoy Family Foundation
Simon-Strauss Foundation
Stein Family Foundation
Zable Family Foundation*

VOC Spotlight



Vista Murrieta Wrestling Team

Joe Arellano, a senior at Vista Murrieta High School in Riverside County, California, uses his skills on the wrestling mat to raise awareness and funds to battle genetic eye disease.

Joe's little brother, Jonas, was born with oculocutaneous albinism, and suffers from low vision and photophobia (discomfort in sunlight and bright light). After learning about the

growing popularity of running marathons to fundraise for charity, Joe wanted to find a way to get involved. "Suddenly, I began to try to make it work in my head. Jonas has albinism. I can't run 26 miles, but . . ." The idea of turning his senior year as a wrestler to a season-long fundraiser seemed possible.



Joe Arellano

Joe and his Bronco teammates sold t-shirts at wrestling meets, and friends and family committed to make a donation to VOC for every win during the season. Joe had an outstanding year, finishing as League Champion and Riverside County Champ at 195 lbs. He was invited to the state championships and completed the season with a record of 45-10. Joe was inducted into his high school's Hall of Fame at the end of the year.

Congrats to Joe, Jonas and the Vista Murrieta Bronco Wrestling Team on a very successful season and their efforts to raise awareness of eye disease. Together we will find a cure!

Be A Medical Hero

Behind every new treatment are volunteers who participate in clinical research studies. The mission of Vision of Children is to eradicate inherited vision disorders, and that can't be done without research. We encourage our friends to find out about on-going research.

The Center for Information and the Study on Clinical Research Participation (CISCRP) and the NIH both maintain clinical trial databases. Studies can be found by diagnosis or by geographic location. The National Eye Institute also has a helpful booklet entitled, "Clinical Trials in Vision Research" available on their website www.nei.nih.gov/health/clinicalstudies/.

Here are three studies that are currently recruiting participants:

Retinal Imaging in Patients with Inherited Retinal Degenerations

University of California, San Francisco

Study coordinator is Arshia Mian, 415-476-0444 (miana@vision.ucsf.edu)

Clinical, Cellular and Molecular Investigation into Oculocutaneous Albinism

The National Human Genome Research Institute, Bethesda

Lead Investigator is Dr. David Adams 443-254-3376 (dadams1@mail.nih.gov)

Trial of L-Dopa as a Treatment to Improve Vision in Albinism

The University of Minnesota, Minneapolis

Lead investigator is Dr. Gail Summers 612-625-4400 (summe001@umn.edu)



Spike for Sight! *Charity Beach Volleyball Tournament*

VOC organized and sponsored a beach volleyball tournament on San Diego's Mission Beach on March 24, 2012. The event raised money for eye research. Fifty of the area's top amateurs competed during the all-day contest. Congratulations to our players and our generous sponsors. A special thanks to Ophthonix, Barbara Worth Country Club and Resort, Kona Ice, and Trader Joe's, who helped make the event a success, and especially to the San Diego State Delta Gamma sorority members who volunteered!



Tournament Winners!



Spike for Sight Participants



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