



## ‘I See 20/20 In My Dreams’ VOC Vision Hero Ambassador Shares His Story

When he became legally blind at 19, Jeremy Poincenot withdrew from school and stopped participating in almost everything he enjoyed, including golf, which had been his passion. “I felt sorry for myself, and spent most of the day sleeping,” he recalled. “I told my dad that I was happier in my dreams, where I could still see perfectly, than when I woke up to the harsh reality of being legally blind.”

Eventually though, Poincenot decided to find ways to overcome his vision limitations, focus on his strengths and ultimately turn his life around. A year later – with help from his dad, who serves as his guide – he won the World Blind Golf Championship. Today, six years later, Poincenot is a popular inspirational speaker and is partnering with the Vision of Children Foundation as a Vision Hero Ambassador.

The San Diego native eagerly shares his story of perseverance in an effort to help others overcome their challenges.

Poincenot was a sophomore at San Diego State University when he noticed that his eyesight was deteriorating. “I thought I’d need big Steve Urkel glasses,” Poincenot said, “which would have been OK because Martin Scorsese makes them look cool.”

However, neither glasses nor any other treatment currently available would help Poincenot see again. He was diagnosed with Leber hereditary optic neuropathy, a rare and untreatable genetic eye disease. Within two months, he lost his central vision.

“I’ve learned to appreciate what I have rather than dwell on what I don’t have,” Poincenot said. “I could still be at my parents’ house sulking and complaining, but when I started thinking about my challenge with a positive mindset, I gained a purpose in life.”

That purpose is to to inspire people of all ages to become more resilient when faced with adversity and to turn challenges into opportunities. He does so through an honest, moving and sometimes lighthearted account of his story and his unique ability to play golf with his dad.

Poincenot recently shared his journey with VOC donors at the Foundation’s donor appreciation luncheon in San Diego, as well as with a group of elementary school children. During his remarks, he uses a unique style to compare the impact of his vision loss to a doughnut. “I can see peripherally, but nothing in the middle,” he says, as he asks the audience to place their hands in front of their eyes to experience what it’s like. Then, responding to a standing ovation from the audience, Poincenot quips:

“I wonder if the people in the back are thinking, ‘Does the blind guy even know I’m standing?’”

**Do You Know A Vision Hero?**  
VOC is on the lookout for young people who have overcome their vision challenges and being told that they can’t do what others can do. By featuring new Vision Heroes regularly, VOC hopes to inspire children to overcome their challenges. If you know a Vision Hero, consider nominating him or her by filling out the application on the VOC website, [www.visionofchildren.org](http://www.visionofchildren.org).



World Blind Golf Champion and popular inspirational speaker, Jeremy Poincenot, recently entranced elementary school children when he shared his journey from being fully-sighted to being diagnosed with a rare genetic disease for which there is no treatment and no cure. Poincenot is featured in the first of a series of VOC Vision Hero videos. Watch the video at: [www.visionofchildren.org](http://www.visionofchildren.org)

**For information on booking Jeremy for a speaking engagement or for a local VOC fundraiser, call 858-314-7916.**

Helping Children Now



### Project Vision Aid Program

Five-year-old Rowan Sumner is thrilled with her new handheld video magnifier. The Vision of Children Foundation donates vision aids to help children who are visually challenged see better and achieve their full potential. For more info, go to:

[www.visionofchildren.org/project-vision-aid](http://www.visionofchildren.org/project-vision-aid)



THE VISION of CHILDREN  
FOUNDATION

#### Board of Directors:

Honorary Co-Chairman  
**Senator Elizabeth Dole**

Founder & Chairman  
**Samuel A. Hardage**

Chief Scientific Advisor  
**Debora B. Farber, Ph.D.**

**Vivian L. Hardage, Co-Founder**  
**Daniel W. Gil, Ph.D.**  
**Scott L. Glenn**  
**Jacqueline Johnson, Ph.D.**  
**Gregory I. Ostrow, M.D.**  
**Richard A. Schatz, M.D.**  
**Kenneth J. Widder, M.D.**

#### Staff:

**Jim Mullen**  
Director of Development  
jim@visionofchildren.org

**Fran Goldstein**  
Development Consultant  
fgoldstein@visionofchildren.org

**Kenny Liles**  
Communications & Operations  
Coordinator  
kliles@visionofchildren.org

---

**The Vision of Children Foundation**  
12555 High Bluff Drive, Suite 330  
San Diego, CA 92130  
T: 858.314.7916  
F: 858.314.7920  
info@visionofchildren.org  
www.visionofchildren.org  
#VOCvisionheroes

# Honoring Our Donors

*A special gift for our generous donors*



Vision of Children recently honored one of the Foundation's top supporters, **Laura and Richard Saker**, with a personalized painting created by **VOC Vision Hero Lauren Mills**. For the past eight years, the owners of New Jersey's Saker ShopRite grocery stores have devoted

one summer month to raising money for VOC. Cashiers at all 29 stores ask customers if they would like to donate to vision research at the point of purchase, and the company matches donations raised at the registers.

"We are tremendously grateful to Laura and Richard, and all the ShopRite employees, for their long-time support and dedication to our cause," said Sam Hardage, VOC Founder and Chairman. With total giving already topping \$1.3 million, the ShopRite stores are wrapping up the 2015 Summer Campaign for VOC, which started in June.

Lauren, the 14-year-old artist from Ypsilanti, MI is legally blind. She has been drawing since she could pick up a crayon at 10 months of age and painting since she was 11. She has garnered worldwide recognition for her artwork. To learn more about how Lauren has overcome her vision challenges, visit: [visionofchildren.org/voc-vision-heroes](http://visionofchildren.org/voc-vision-heroes)

Help discover a cure for childhood blindness and vision disorders. Fund a VOC researcher this summer!

## Three Ways to Get Involved:

**1 CHAMPION** the cause by creating a fundraising page to share with your network. **Go to: [www.visionofchildren.org/fundraise](http://www.visionofchildren.org/fundraise)**

**2 INVITE** your company or business to be a 2015 VOC Partner. Contact **Jim@visionofchildren.org; 858-314-7916** for partnership opportunities

**3 INVEST** in funding innovation @ work and donate today. Donate online at: **[www.visionofchildren.org/donate](http://www.visionofchildren.org/donate)** or **send a check in the enclosed envelope**

**\$25** — Funds a day's supply of one chemical reagent

**\$50** — Funds 3 pairs of custom DNA primers for genotyping

**\$100** — Funds a lab assistant for a day

**\$150** — Funds a Ph.D. fellow for a day

**\$300** — Funds the use of imaging microscopy for a day

**\$1,000** — Funds the work of a small lab for a day

**\$5,000** — Funds the work of a small lab for a week

# Innovation @ Work

## VOC Featured Researchers



### COULD A NATURALLY OCCURRING FATTY ACID TREAT NYSTAGMUS?

*Joost Felius, Ph.D., Visual Disorders and Eye Movements Laboratory, Retina Foundation of the Southwest, Dallas*

- People with albinism typically suffer from nystagmus, which causes their eyes to constantly move back and forth. There is no cure for nystagmus, and currently available therapies lead to only moderate improvements.
- Dr. Felius and his team are measuring the docosahexaenoic acid (DHA) content in the blood of children with nystagmus. DHA, an omega-3 fatty acid naturally found in the human body, is known to have several benefits. Giving children DHA supplements has been shown to benefit both eye and brain development. Showing a correlation between DHA levels and the severity of nystagmus could lead to clinical trials on the therapeutic benefits of DHA supplementation.

### 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 ocular albinism type 1 (OA1) works, and how its mutation affects the functioning of the retina, could lead to a new therapeutic approach for ocular albinism in humans.
- Individuals with OA1 display a number of abnormalities in the eye, including the misrouting of the optic nerve fibers that extend to the brain. When the fibers coming from each eye cross incorrectly or not at all to the opposite side of the brain, vision is negatively impacted. Dr. Guha is examining the development of the retina during early embryonic stages to determine precisely what type of malfunction leads to this misrouting.



### DO L-DOPA LEVELS IMPACT ALBINISM?

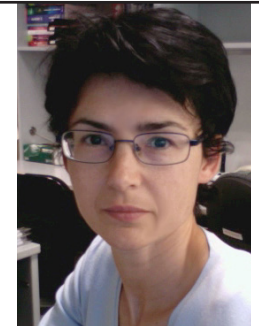
*Carol Mason, Ph.D., College of Physicians and Surgeons, Columbia University, New York City  
In collaboration with Suzanne Roffler-Tarlov, Ph.D., Tufts University School of Medicine, Boston*

- L-Dopa, a chemical normally produced in the body, plays an important role in many functions, including melanin development. Scientists have shown that L-Dopa levels are critical to the synthesis of the normally pigmented retina. Albino mice have little to no levels of L-Dopa during the early developmental stages of the retina.
- Drs. Mason and Roffler-Tarlov are examining whether giving pregnant albino mice water enhanced with L-Dopa improves the retinal development in their fetuses. This is a critical step in determining whether or not L-Dopa can treat vision disorders in people with albinism.

### 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 cellular and molecular level that ultimately cause ocular albinism type 1 (OA1) could lead to targeted drug treatments.
- Affected individuals carry mutations of the OA1 gene. This means they also lack the OA1 protein, which is a G protein-coupled receptor that, when functioning normally, regulates cellular functions necessary for vision. Since many drugs currently on the market (including anti-histamines) target the same type of receptors, this research raises the possibility that treatments similar to already available therapies may be useful in treating albinism.



### 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 (MVs) released by stem cells as an alternative delivery vehicles for gene transfer. MVs can transfer their genetic contents to other cells in a different manner than viruses and with potentially less drawbacks.
- Dr. Young is using MVs to repair the retinal defects of mice that are missing the OA1 gene. If successful, her next step would be to try to repair human cells missing the OA1 gene.



THE VISION of CHILDREN

12555 High Bluff Drive, Suite 330  
San Diego, CA 92130

Nonprofit Org.  
US Postage  
PAID  
San Diego, CA  
Permit No. 59



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

## Innovation @ Work

See page 3 for a look at VOC-funded  
pioneering research  
toward discovering cures.



**Learn more about**

**Dr. Sonia Guha's innovative work  
at UCLA's Jules Stein Eye Institute.  
Go to: [www.visionofchildren.org](http://www.visionofchildren.org)  
to watch the video.**

## Getting CLOSER to the CURE

**Viral vector gene therapy**, considered a breakthrough in treating many diseases, has helped many physicians offer hope to their patients, including those with genetic eye disorders. "We're actually starting to repair genes and restore vision," said Gregory Ostrow, MD, Director of Pediatric Ophthalmology at Scripps, San Diego, and a Vision of Children (VOC) Board member. Speaking at a recent VOC Donor Recognition event in San Diego, Ostrow was referring to groundbreaking advances in the treatment of Leber congenital amaurosis and other genetic eye diseases.

Ostrow noted that until recently he has had to deliver the same disappointing news to many patients during his many years of practice. "It's very painful to tell a parent that their child is losing his or her eye sight and at this time we do not have a cure or treatment," he said. "But all that is changing with new developments in medicine and gene therapy, some spurred by recent VOC contributions." Ostrow is optimistic that there will be several treatments for genetic eye disorders in the near future.

"The Vision of Children Foundation is funding cutting edge research that is expected to cure certain types of genetic eye disease and blindness within our lifetime," said Vivian Hardage, VOC co-founder and Board member. "We are able to do this thanks to the generosity of the donors in our community," she said.