

# 2017-18 IMPACT REPORT

Leading Research... Saving Sight

#### **DEAR FRIENDS,**

Your commitment to our mission to prevent vision loss and restore sight through innovative research and treatment is greatly appreciated and vital to all we do at the Retina Foundation of the Southwest. By all accounts, this past year the Retina Foundation reached important milestones and celebrated a number of achievements. Among the significant accomplishments was the discovery of a specific gene causing blindness in Hispanic families residing in Texas, Arizona, and Southern California, the initiation of several ground-breaking clinical trials for pediatric eye disorders, inherited eye diseases, and age-related macular degeneration, and the further development of a novel drug delivery approach for the treatment of age-related macular degeneration.

The Retina Foundation of the Southwest family grew this past year with the addition of seven new employees, several new members who joined The Phyllis G. and William B. Snyder Legacy Society, and the newly formed Retina Foundation of the Southwest Auxiliary. Our Legacy Society and Auxiliary members are vital to us in achieving our goal to make a lifetime of good vision a reality for everyone.

On March 2, 2018, we hosted the inaugural Visionary Luncheon with special guests President and Mrs. George W. Bush. It was an overwhelming success! The funds raised from this event, along with other grants, allow us to stay on the cutting-edge of vision research. We are revolutionizing the way children with lazy eye are treated and developing a new drug to treat older adults with age-related macular degeneration.

In the years to come, the Retina Foundation of the Southwest plans to continue identifying vision research priorities and advancing treatment for individuals with pediatric eye conditions, inherited eye diseases, and age-related macular degeneration. We always look forward to participating in clinical research studies and to providing more than 2,300 vision assessments each year for children and adults completely free of charge.

On behalf of the Retina Foundation of the Southwest, thank you for your generous support over the past year. We hope that this year's Impact Report will serve as an educational piece for you to learn more about the impact you have on each and every one of our patients. As we begin our 36th year, we want you to know how grateful we are for your contribution to leading research and saving sight!

With gratitude and appreciation,

David Callanan, M.D. Chairman of the Board

Karl Csaky, M.D., Ph.D. Managing & Medical Director

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David Callanan, M.D. Chairman of the Board



Karl Csaky, M.D., Ph.D Managing & Medical Director

The Retina Foundation of the Southwest is leading the way the world understands, prevents, and treats vision loss caused by pediatric eye conditions, inherited eye diseases, and age-related macular degeneration.

Our vision is clear:

### Leading Research. Saving Sight.



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#### The Dallas Morning News By Anna Kuchment

# ASPIRING DOCTOR HOPES GENE THERAPY WILL SAVE HIS SIGHT



Mason Two Crow, 22, has X-linked retinoschisis, an inherited eye disease for which he is being treated by Dr. David Birch at the Retina Foundation of the Southwest in Dallas. XLRS is characterized by the abnormal splitting of the retina's layers. (David Woo/Staff Photographer)

When he was 9, Mason Two Crow learned he could be legally blind before he turned 18. A few years later, his doctors told him something else: Researchers were working on a treatment that could save his vision. But the therapy would have to arrive before Mason lost his eyesight.

Now 22, Two Crow received an injection in July 2017 that he hopes will allow him to look through a microscope and fulfill his dream of becoming a doctor. For many years, his plans including marrying his high school sweetheart and applying to graduate school — rested on the uncertain future of his eyesight.

The doctors who treated Two Crow are affiliated with the Retina Foundation of the Southwest, a nonprofit vision research institute that sits just off Central Expressway in North Dallas. The doctors used a pioneering treatment known as gene therapy, which has the potential to fix mistakes in patients' DNA.

#### **BLURRY BLACKBOARD**

Two Crow, who is a member of the Mandan, Hidatsa and Arikara Nation — also known as the Three Affiliated Tribes — grew up in Sachse, about 30 miles northeast of Dallas. He first noticed he was having trouble seeing in second grade.

He couldn't make out the letters of the alphabet hanging by his teacher's blackboard. He begged his parents for an eye exam and finally received one at a Wal-Mart. By luck, the optometrist had just returned from a conference on rare diseases and diagnosed Two Crow on the spot.

He has a condition called X-Linked Retinoschisis, or XLRS, which is passed from mothers to sons and affects between 1 in 5,000 and 1 in 20,000 people.

Patients with XLRS lack a protein that helps maintain fluid balance in the retina, a group of cells at the back of the eye. As a result, fluid accumulates between the retina's layers. The same protein, retinoschisin, also plays a role in transmitting signals from the eye to the brain. XLRS patients see a warped, blurry image that glasses can't correct.

Two Crow was told to stay away from football and all contact sports, because an injury could further damage his eyes. If he roughhoused with his friends and cousins, his parents would yell at him to just sit still. He stood out in a community of teenagers who circled their schedules around sports. Two Crow focused on his studies instead.

### **A TURN TO SCIENCE**

Four years ago, he traveled to the University of California, Berkeley as part of a study to better understand XLRS. There, he met with researchers and sat for a series of eye exams. That moment marked another shift in his life.

Two Crow enrolled at Oklahoma State University and majored in pre-medical studies. Two years ago, when he was a sophomore, he visited the Retina Foundation of the Southwest. Lea Bennett, a postdoctoral fellow, told him he'd been officially selected for the clinical trial.

"I knew it was on the table, but to be told it was going to happen was groundbreaking," he said.

With a brighter future seemingly at hand, he married his fiancée, Lydia, whom he has known since elementary school.

For now, Two Crow is mostly independent despite his impaired vision. He drives and reads, though his eyes fatigue easily, which makes it difficult to study. When he has trouble making out cells under a microscope, his lab partner pitches in to help.

Lydia helps him navigate crowds and helps him recognize the faces of friends they run into. Those closest to him know not to yell, "Hey look at that!" — because he probably won't be able to observe small or faraway objects.

Dr. David Birch is the director of the Rose Silvert-THE EXPERIMENTAL DRUG horne Retinal Degeneration Lab at the Retina Foundation of the Southwest in Dallas. On the monitor In July, an eye surgeon collaborating with is an image of the retina of a 50-year-old man with Birch's team injected one of Two Crow's eyes XLRS. (Rex C. Curry/Special Contributor) with the experimental drug. If the drug is FDA-approved, doctors will be able to inject the other eye. The drug consists of healthy versions of Two Crow's defective genes hidden inside a virus's outer shell.

The virus delivers the healthy gene to Two Crow's retinal cells, which should then begin manufacturing the missing protein. In animal studies, the gene and the protein helped close gaps in the retina and improved communication between the eyes and the brain.

But no one knows how much vision Two Crow and other patients will regain or for how long the benefits of the one-time treatment will last.

The Two Crows are moving ahead with their lives. In May, Mason graduated from OSU and is applying to medical school. They hope that this therapy, regardless of how much it helps Two Crow, will one day cure his 3-year-old nephew, their only other family member with XLRS. Perhaps he'll have the chance to play sports his uncle never did.



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# **ADVANCE OUR MISSION**

The mission of the Retina Foundation of the Southwest is to prevent vision loss and restore sight through innovative research and treatment. We see all infants, children, and adults free of charge for in-depth vision evaluations.

Strengthen your commitment to our mission by joining the newly established Retina Foundation of the Southwest Auxiliary or by becoming a member of the Phyllis G. and William B. Snyder Legacy Society.

For more information, please call 214.363.3911.



ABOVE David Gamm, M.D., Ph.D. was the guest speaker for the first talk in the Keeping an Eye on Innovation lecture series sponsored by The Rosewood Foundation. ABOVE RIGHT Karl G. Csaky, M.D., Ph.D. is pictured in the middle between Jean Broughton-Powell, Honorary Chair, and her husband, Darryl Powell at the 20th Anniversary Racing for Sight. **RIGHT** Clint McDonnough and Carol Greene at the March 2, 2018 Visionary Luncheon where ORIX Foundation was presented with the Visionary Award for outstanding commitment to the Crystal Charity Ball Pediatric Vision Laboratory. **BELOW** Faye Briggs and Vinette and Mike Montgomery hosted the 2017 Patron Party for sponsors of the 20th Anniversary Racing for Sight. BELOW RIGHT Event co-chairs, Lisa Hewitt and Brian Tibbs, M.D. and Therese and Chris Rourk are pictured with guest speakers, President and Mrs. George W. Bush at the inaugural Visionary Luncheon.



Your dedication to our mission comes alive through our activities in Texas to raise funds for vision research and awareness of the Retina Foundation of the Southwest.



# MEET GIGI

## age 72 | age-related macular degeneration

Gigi was always a creative and adventurous woman who had aspirations to travel the world after retiring. She was not prepared for the day in June 2016 when she learned she suffered from an irreversible eye disease called agerelated macular degeneration.

Having been a dedicated prep school teacher for many years in Texas, Gigi hit the books to learn as much as possible about the research studies being done across the world for macular degeneration. Her investigations led her to a four-hour drive from Shreveport, Louisiana to Dallas, Texas for an appointment with Dr. Karl Csaky at the Retina Foundation of the Southwest.

Gigi is now participating in one of our research studies and visits the Retina Foundation every six months for advanced vision testing. She leaves every visit feeling hopeful.

"I am doing everything I can to try to prevent going blind. I am eating healthy, taking my vitamins, and staying active," Gigi said.

Her life mantra is:

## "Tomorrow is a bigger and better day".



# MEET AVERY

# age 4 | coloboma of optic nerve, nearsighted, farsighted, lazy eye

Avery is a happy and affectionate little girl who has been amazingly brave for a total of twelve surgical procedures. Avery has a syndrome known as CHARGE which has led to a myriad of issues, including poor eye-hand coordination, poor depth perception, lack of balance, and difficulty with simple tasks, such as brushing her hair.

Avery has two loving parents, a full-time care provider, a physical therapist, an occupational therapist, a speech therapist, a vision teacher, and a dozen doctors to help her overcome some of the challenges she faces. Avery's life remains very active as she enjoys playing outside. Her current eyesight allows her to maneuver both the swimming pool and the great outdoors, but her vision needs to be monitored as it develops naturally over time.

### At six months of age, Avery's local eye doctor referred her to the Retina Foundation of the Southwest, one of the only sites in the nation that evaluates the vision of special needs children.

Avery's vision assessments, which are provided by the Retina Foundation of the Southwest free of charge, allow her school to adjust her Individualized Education Program (IEP). They also help Avery's therapists keep track of any changes in her vision, so they can try new therapies more aligned with her visual abilities.

Avery's parents know her vision may change throughout her life, so they will continue bringing her to the Retina Foundation every six months. Our evaluations, and experienced and caring staff, will ensure that Avery's parents and therapists have the knowledge they need for Avery to optimize learning and growing.





to recognize individuals who have made a planned gift to ensure that future research at the Retina Foundation is possible. We are building our endowment funds for the support of our mission for generations to come.

For more information, please call 214.363.3911.

16% Individuals \$674,235

12% Government \$491,880

1% Other \$14,170

# Functional Expenses:

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> **Retina Foundation** of the Southwest

### A WORLD LEADER IN VISION RESEARCH

Everyone at the Retina Foundation of the Southwest is committed to improving the quality of life for people of all ages.

We put every infant, child, and adult at the center of our efforts to fight the conditions that steal the precious gift of sight. We are working at the cutting edge of science to discover better ways to diagnose and treat eye conditions.

#### We won't stop until a lifetime of good vision becomes a reality for everyone.

We will continue working in Dallas with partners across the nation and around the globe, sharing our discoveries as they are made so that doctors and scientists can use this knowledge toward saving sight for millions of people. Our laboratories and patients are in Dallas, but our discoveries advance eye care worldwide.

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#### **BECAUSE OF YOU, THE FOLLOWING RESEARCH PROGRAMS WERE SUPPORTED...**

In 2017, **424** donors supported...

Since 1982, 3,377 donors supported...



In 2017 2,450 vision evaluations for infants, children, and adults were completed free of charge

#### Since 1982

72,300+ vision evaluations for infants, children, and adults were completed free of charge



In 2017 219 new patients enrolled in the Southwest Eye Registry

#### Since 1982

8,516 patients have enrolled in the Southwest Eye Registry



In 2017 4 postdoctoral fellows conducted research

Since 1982 26 postdoctoral fellows have conducted research

#### In 2017

44 scientific manuscripts were published Since 1982

744+ scientific manuscripts have been published



In 2017 4 internships were completed

Since 1982 83 internships have been completed



## ANNUAL GIVING **INDIVIDUAL & FOUNDATION SUPPORT**

The Retina Foundation of the Southwest has achieved remarkable success since 1982 because of the tremendous support provided by you, our generous donors. We are pleased to take this opportunity to recognize and thank those who made gifts or provided support of \$250 or more from January 1, 2017 through March 31, 2018. Every effort has been made to ensure this list is as accurate as possible, but inevitably some omissions or errors may have occurred. We would appreciate receiving corrections, comments, or questions. Please contact the Retina Foundation of the Southwest at 214.393.3911.

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### **PRESENTATIONS & PUBLICATIONS**

#### ABSTRACTS, PUBLICATIONS AND BOOK CHAPTERS

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