

Foundation's RD Fund Invests in SalioGen Therapeutics, Developer of Novel Gene Coding Technology for Treating Inherited Retinal Diseases

The company is currently developing programs for Stargardt disease (ABCA4), Usher syndrome, RP25 (EYS), and RP1.

The Retinal Degeneration Fund (RD Fund), the venture philanthropy arm of the Foundation Fighting Blindness, has invested in SalioGen Therapeutics, a biotechnology company developing therapies for a broad range of conditions, including inherited retinal diseases, using its novel Gene Coding™ technology.

SalioGen has received a total of \$115 million in a Series B round of financing to enable the company to continue building out the Gene Coding platform, expand the company's team, and establish manufacturing and automation capabilities critical for accelerating the advancement of its preclinical programs. In March 2021, the company received \$20 million in Series A funding.

SalioGen's Gene Coding platform works by adding new genomic code to turn on, off, or modify function of new or existing genes. Gene Coding is accomplished by SalioGen's Exact DNA Integration Technology™ (EDIT™), which is based on mammal-derived genome engineering enzymes called Saliogase™. Saliogase seamlessly inserts new DNA of any size into precise, defined genomic locations.

Continued on page 2

WHAT'S INSIDE ▾

- Pg. 3 |** Join us at VISIONS 2022, the National Conference of the Foundation!
- Pg. 4 |** Telling His Story of Resilience
- Pg. 6 |** Clinical-Trial Pipeline
- Pg. 7 |** Chapters Impact Across the Country
- Pg. 8 |** New York Young Professionals Group
- Pg. 9 |** Ocugen Launching Clinical Trial for Cross-Cutting RP Gene Therapy

RD Fund Launches Opus Genetics to Advance Gene Therapies for Inherited Retinal Diseases
- Pg. 10 |** Rocking On With Stargardt Disease

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COVER STORY **CONTINUED FROM FRONT COVER**

SalioGen's technology is designed to be more efficient and reliable than other gene-editing and gene-modifying approaches (e.g., CRISPR/Cas9) because it doesn't involve the double-stranded break and subsequent repair (a process called homologous recombination) of the targeted gene.

Furthermore, the company is developing targeted lipid-based nanoparticle formulations to deliver the therapy and its genetic cargo, DNA of virtually any size. In contrast, current viral delivery systems for gene-augmentation therapies are limited in the size of the genetic cargo they can deliver. Many retinal disease genes are too big for the viral containers used in these systems.

The company is currently developing research- and preclinical-stage programs and aims to launch future clinical trials for treatments for Stargardt disease (*ABCA4*), Usher syndrome, RP25 (*EYS*), and RP1.

"We are excited by SalioGen's promising and innovative technology for addressing the genetic causes of inherited retinal disease. Their approach overcomes many of the limitations with current gene augmentation therapies and CRISPR/Cas9 gene editing," says Benjamin Yerxa, PhD, chief executive officer, Foundation Fighting Blindness. "Our investment will help the company advance their emerging therapies into clinical trials. That is an important goal for the Foundation and the RD Fund."

The Foundation established the RD Fund in 2018 to make mission-related investments in companies with projects nearing clinical trials. Visit www.RDFund.org for more information.

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Or visit us at www.FightingBlindness.org.

Physicians differ in their approach to incorporating research results into their clinical practices. You should always consult with and be guided by your physician's advice when considering treatment based on research results.

VISIONS 2022

Join us at VISIONS 2022, the National Conference of the Foundation!

VISIONS 2022 – on June 17-18 at Disney’s Coronado Springs Resort – is a one-of-a-kind event in which people with blinding retinal diseases, and their families, have the opportunity to hear about exciting advancements in blindness research. All attendees can gain practical skills for coping with vision loss, learn about products and services that can help better manage their lives, and connect with others from across the country.

This conference is designed specifically for individuals and families affected by blinding retinal diseases such as age-related macular degeneration, retinitis pigmentosa, Usher syndrome, and related conditions.

Learn about the Keynote Speakers that attendees will hear from at VISIONS:

Chad E. Foster



Chad is a motivational keynote speaker, sales/finance leader, and inspirational change agent who works at Red Hat/IBM. He was the first blind executive to graduate from Harvard Business

School’s Program for Leadership Development. Despite going blind while attending college in his early twenties, Chad started at Accenture and built a career in the technology industry, where he has directed financial strategies and decisions, resulting in more than \$45 billion in contracts. He speaks to corporate audiences and professional athletes to help them develop resilience in the face of uncertainty. He has been featured in *Forbes*, the *Atlanta Journal Constitution*, *USA Today*, *Harvard Lifelong Learning*, *BuzzFeed*, *Yahoo*, *Chief Executive Mag* and continues to inspire audiences across the world with his personal story.

Marsha Link, PhD



Marsha is an innovative and seasoned professional with a broad range of expertise as a clinician, executive coach, human resource professional, and educator. She is

Principal of Link Consulting, providing services to clients in the profit and not-for-profit sectors. Her background includes working in the medical field for decades, first as a psychiatric social worker at Indiana University Medical Center and then as a co-founder of Chiron Vision, an ophthalmic medical device company. She has been involved in the ophthalmology sector, not only as a businesswoman, but served as President for three years for OWL (Ophthalmic World Leaders). Marsha has served on a variety of not-for-profit organizations and has a strong sense of philanthropy. She is especially eager to find cures for retinal diseases since a family member has retinitis pigmentosa.

VISIONS Keynote Speaker, Chad E. Foster: Telling His Story of Resilience

by Lauren Reeves

Chad Foster is a successful corporate dealmaking executive, motivational speaker with worldwide invites, and the Atlanta Opera is commissioning an opera inspired by his life. With all these impressive achievements, Chad's most important goal now is to use his story with blindness to help others live their most fulfilled life too.

Chad was diagnosed with retinitis pigmentosa (RP) at three years old after his parents noticed he was having trouble navigating in dim lighting. But growing up, Chad's parents didn't treat him any differently because of his RP, channeling his energy into playing sports such as soccer, football, basketball, and even wrestling.

Chad's sight loss remained steady most of his childhood, but while attending college at the University of Tennessee, Chad noticed a severe drop-off in his eyesight. The first year after Chad's rapid decline in vision, he recalls pretending to see well and feeling bad for himself. But eventually, Chad came to realize this was an opportunity to own his true self.

"My blindness really forced me to reexamine my focus and perspective on life," says Chad. "I think I'm a better person today because of my blindness, not in spite of it. At only 23 years old, it forced me to be unapologetically authentic."

The major turning point in Chad's mindset was when he was training for his guide dog. At his Leader Dogs for the Blind month-long orientation, Chad met other people from all walks of life who inspired him and made him feel fortunate for what he had. From then on, Chad felt determined to show the



Chad and his guide dog, Sarge, in the snow at Snowmass.

world his resilience.

"I went there to get a guide dog but ended up learning lessons that have carried me through my entire life," Chad recalls. "It's natural to feel bad about the situation, but it's up to you how long you're going to give those feelings airtime. You've got to make a decision to be happy."

Now living in the metropolitan area of Atlanta, Georgia, with his wife and children, 45-year-old Chad currently works for Red Hat, the world's largest open-source software company that was purchased by IBM for \$34 billion. After succeeding in the corporate world for the last 20 years, Chad now enjoys helping others through motivational speaking, which is why he's working with Les Brown to bring his message to the world, and other avenues, like his new book, *Blind Ambition*.

Chad was inspired to write his own book after taking the "Authentic Leadership" course with Bill George at Harvard Business School. The *Discover Your True North* book and teachings of Bill George underscore that being a leader is more than management skills; it's instead

a question of who we are as human beings—connecting our core emotions, beliefs, and experiences to our purpose, passion, and profession. It was here that Chad had an epiphany that his purpose in life could be to empower others by sharing his journey of sight loss. Then, after being elected as the graduating speaker of his class and seeing firsthand how impactful sharing his story could be, it solidified his decision to write his book.

“It was on the flight back home from Boston when I realized that helping others in a meaningful way makes going blind worth it,” says Chad. “Now, I know that I lost my vision to help others find theirs.”



Chad rowing on the Charles River with his Harvard Business School classmates.

Through Jim Whitehurst, CEO of Red Hat at the time, who had recently written and published his own book, Chad was connected with a literary agent who soon linked him up with HarperCollins Publishers. Within a year, *Blind Ambition* was written and published in February 2021. Chad describes *Blind Ambition* as deeply personal, anecdotal, and overall, a memoir with a purpose.

“It’s terrifying to be so vulnerable with people you don’t know,” says Chad. “But then you see how much it can help, and that gave me the courage to step through the fear of sharing my story. By focusing on how you can impact

others, you can move beyond yourself to reach your full potential.”

Clearly, Chad is no stranger to taking risks. Chad’s adventurous soul has taken him around the world to downhill ski, white water raft, and zipline, all of which push him outside of his comfort zone.

“I want to live my fullest life and not make decisions based on fear,” says Chad. “It’s natural to feel fear about some things, but at the end of the day, it’s not about how long we live, but it’s about the experiences we have and the steps we take to help other people.”

Currently, Chad keeps up with advances in technology to help with his day-to-day life, both personally and professionally, using iPhone accessibility features and the JAWS screen reader for computers. With so many new accessibility tools and innovative research being discovered in recent years, Chad feels optimistic for the future of finding treatments and cures for blinding diseases.

“We’re at such an exciting time with advances in research and our vast understanding of genetics,” says Chad. “Very soon, I think we’re going to see blindness is a thing of the past.”

Chad’s ability to visualize greatness and reimagine the future is beneficial wisdom for anyone facing adversity at any stage of life.

“When I first lost my vision, I could have told myself I went blind because I have terrible luck, but all that does is frame me as a victim,” says Chad. “Instead, I told myself that I went blind because I’m someone that has the strength and toughness to overcome it. The stories we tell ourselves about our circumstances are way more important than the circumstances alone, and now my blindness is my greatest asset. It’s ironic that my loss of eyesight enabled me to see life more clearly, but the best way to improve your vision is to stop looking all around you and start looking deep inside you.”

CLINICAL-TRIAL PIPELINE

Retinal-Disease Therapy

Inherited Retinal Diseases and Dry AMD: 44 Trials (select) | Updated March 2022

GENE THERAPIES (GENE TARGET)	PROGRESS
Achromatopsia (CNGB3) – AGTC	Phase 1/2
Achromatopsia (CNGB3) – MeiraGTx/Janssen	Phase 1/2
Achromatopsia (CNGA3) – AGTC	Phase 1/2
Achromatopsia (CNGA3) – Tubingen Hosp	Phase 1/2
AMD-dry – Gyroscope	Phase 2
Choroideremia (REP1) – 4DMT	Phase 1/2
Choroideremia (REP1) – Spark	Phase 1/2
Choroideremia (REP1) – Tubingen Hosp	Phase 2
LCA (GUCY2D) – Atsena	Phase 1/2
LCA (CEP290, CRISPR) – Editas	Phase 1/2
LCA and RP (RPE65) – MeiraGTx/Janssen	Phase 1/2
RP (PDE6B) – Coave	Phase 1/2
RP (RLBP1) – Novartis	Phase 1/2
RP (NR2E3, RHO) – Ocugen	Phase 1/2
RP (PDE6A) – Tubingen Hosp	Phase 1/2
Retinoschisis (RS1) – NEI	Phase 1/2
X-linked RP (RPGR) – AGTC	Phase 1/2
X-linked RP (RPGR) – MeiraGTx/Janssen	Phase 1/2
X-linked RP (RPGR) – 4DMT	Phase 1/2

RNA/OTHER THERAPIES (MECHANISM)	PROGRESS
AMD-dry (CB inhibitor) – Ionis	Phase 2
AMD-dry (C5 inhibitor) – Iveric bio	Phase 2
LCA (CEP290, AON) – ProQR	Phase 2/3
RP (RHO, AON) – ProQR	Phase 1/2
RP, Usher, others (optogenetic) – Allergan	Phase 1/2
RP, Usher, others (optogenetic) – Bionic Sight	Phase 1/2
RP, Usher, others (optogenetic) – GenSight	Phase 1/2
RP, Usher, others (optogenetic) – Nanoscope	Phase 2
Usher syndrome 2A (AON) – ProQR	Phase 2/3

CELL-BASED THERAPIES (CELL TYPE)	PROGRESS
AMD-dry (RPE) – Astellas	Phase 1/2
AMD-dry (RPE) – Cell Cure	Phase 1/2
AMD-dry (RPE from iPSC) – NEI	Phase 1/2
AMD-dry (RPE on scaffold) – Regen Patch	Phase 1/2
RP, Usher (retinal progenitors) – jCyte	Phase 2b
RP, Usher (retinal progenitors) – ReNeuron	Phase 2
Stargardt (RPE) – Astellas	Phase 1/2

SMALL MOLECULES (MECHANISM)	PROGRESS
AMD-dry (C3 inhibitor) – Apellis	Phase 3
RP (NAC-anti-oxidant) – Johns Hopkins	Phase 2
Stargardt disease (emixustat) – Acucela	Phase 3
Stargardt disease (deuterated vit A) – Alkeus	Phase 2
Stargardt disease (C5 inhibitor) – Iveric bio	Phase 2
Stargardt disease (anti-RBP4) – Belite Bio	Phase 1
Stargardt disease (anti-RBP4) – Stargazer	Phase 2
Stargardt disease (metformin) – NEI	Phase 1/2
Usher syndrome (NACA-anti-oxidant) – Nacuity	Phase 1/2

For more details and trial contact information, visit www.FightingBlindness.org/Clinical-Trial-Pipeline. This document is for informational purposes only. Information is subject to change, and its accuracy cannot be guaranteed.

COMMUNITY SPOTLIGHTS

Chapters Impact Across the Country

As the Foundation's Chapters continue to grow, so does the impact that the local leaders are having on the mission of the Foundation Fighting Blindness.

Longtime advocate and national trustee Judy Kahl, from the Pittsburgh Chapter area, is making strides to help fund research in honor of the Foundation's 50th Anniversary. Judy has created a DIY Raising Our Sights Campaign to unite all the Chapters across the country in this fundraising effort that brings the communities together as we collaborate to move the mission forward.

Another Chapter is focusing on the impact that networking can have on those in our communities. Our Los Angeles Chapter hosted its first virtual West Coast Community Connections event. This provided a safe space for those impacted by low vision to come together to share resources, experiences and to meet others who have gone through similar situations as them.

This was the first of many opportunities that will be hosted by the Chapters to provide a place for those with low vision to come together.

The Chapter network not only helps fund research and connects people to resources, but it also provides educational opportunities. Recently the Foundation hosted a Para Nordic webinar that featured the U.S. Paralympics Nordic Skiing athletes Pearl Outlaw, Liza Corso, and Owen Cravens. This virtual educational experience offered a glimpse into how athletics helped open a new world of opportunities for these three low vision athletes. It provided attendees a place to ask questions and learn about not letting their low vision keep them from participating in activities they enjoy.

To get more involved with your local Chapter or to start a Chapter in your area, reach out to: Chapters@FightingBlindness.org



Judy and Joe Kahl from the Pittsburgh Chapter.

Shop the Foundation Merchandise Store

The Foundation Fighting Blindness has an official merchandise store – designed to raise awareness and support the Foundation's mission! Show off your support of the Foundation with various branded merchandise and apparel, like t-shirts, hoodies, hats, YETI® tumblers, and more.

Check out the website by visiting: www.ShopFightingBlindness.org

COMMUNITY SPOTLIGHTS

New York Young Professionals Group

The New York Young Professionals Group began in 2019 with the goal to provide and foster meaningful connections among young professionals impacted by vision loss through networking opportunities, volunteerism, fundraising events, and educational resources.

“The Young Professionals Group is made up of both affected individuals and family members of those who are affected,” says Josh Steinberg. “Over the years, the group has organized fundraising events and formed a VisionWalk team targeted toward young professionals in the New York City area. It has also been a forum to meet and socialize with those in the inherited retinal disease community.”

“When I was diagnosed three years ago, I had never met anyone who was openly blind or low vision, let alone any young people in the community,” says Jenna Desmarais. “The Young Professionals Group has provided me with a network of incredible people who have been more welcoming and supportive of me in my vision loss journey than I thought possible. Whether it’s speaking with affected individuals who understand the vision loss experience or grabbing dinner with people who have affected family members, I have found people to be great.”

The group will be hosting a fundraiser in September 2022. The event will be an opportunity to spread awareness of blinding diseases and the Foundation, as well as providing a space for community members to come together for a good time.



The New York Young Professionals Group at the 2022 New York VisionWalk. From left to right, in the back, Mike Hannon, Josh Steinberg, Ally Fox, Jennie Russnow, Henry Russnow, Nick Martucci, and in the front, Rachel Steinberg, Blair Hudgins.

Join Us for a Spring VisionWalk!

The Foundation is excited to be hosting our VisionWalks this year and look forward to seeing you again in-person. Join us at one of our upcoming local VisionWalks by registering at: www.VisionWalk.org

RESEARCH HIGHLIGHTS

Ocugen Launching Clinical Trial for Cross-Cutting RP Gene Therapy

Ocugen, a developer of gene therapies targeting eye diseases as well as a vaccine for COVID-19, has received authorization from the US Food & Drug Administration to launch an 18-participant, Phase 1/2, *NR2E3* gene therapy clinical trial for the following conditions:

- Retinitis pigmentosa caused by autosomal dominant mutations in *NR2E3*
- Retinitis pigmentosa caused by autosomal dominant mutations in rhodopsin (*RHO*)
- Retinitis pigmentosa, enhanced S-cone syndrome, and Goldmann-Favre syndrome caused by autosomal recessive mutations in *NR2E3*

Additional information on trial sites and participant enrollment is on clinicaltrials.gov.

RD Fund Launches Opus Genetics to Advance Gene Therapies for Inherited Retinal Diseases

The Retinal Degeneration Fund (RD Fund) has launched Opus Genetics, a patient-focused gene therapy company targeting inherited retinal diseases. Seed financing of \$19 million was led by the RD Fund with participation from the Manning Family Foundation and Bios Partners.

The company's lead programs will focus on treatments to address mutations in genes that cause different forms of Leber congenital amaurosis (LCA). Current programs are for LCA5 (lebercillin), LCA13 (*RDH12*), and LCA9 (*NMNAT1*). Opus expects to enter a clinical trial in 2022 for LCA5.

This is the first spin-out company internally conceived and launched by the RD Fund to further the Foundation's mission. The initial seed funding will enable Opus to advance the preclinical research of its scientific founders, Jean Bennett, MD, PhD, the F.M. Kirby Emeritus Professor of Ophthalmology at the Perelman

Known as OCU400, the emerging gene therapy uses a human-engineered adeno-associated virus (AAV) to deliver copies of the *NR2E3* gene to retinal cells. OCU400 is designed to potentially slow disease progress for many inherited retinal diseases, independent of the mutated gene causing the patients' retinal condition.

Known as a "modifier" gene therapy, OCU400 targets nuclear hormone receptors, which regulate multiple important functions within the retina, giving it the potential to address retinal disease caused by many different gene mutations. A single subretinal injection of OCU400 is designed to be effective for many years, perhaps the lifetime of the recipient.

School of Medicine at the University of Pennsylvania; Junwei Sun, chief administrator of Penn's Center for Advanced Retinal Ocular Therapeutics (CAROT); and Eric Pierce, MD, PhD, William F. Chatlos Professor of Ophthalmology at Harvard Medical School and Massachusetts Eye and Ear.

Want to learn more about the latest from the world of vision?

Check out our Eye on the Cure Podcast, hosted by Ben Shaberman, senior director scientific outreach. Stream the Podcast on SoundCloud, Spotify, Audible, Pandora, and more:

www.FightingBlindness.org/Podcasts



Scan the QR code to go directly to the web page on your device.

DIY CAMPAIGN SUCCESS STORY

Rocking On With Stargardt Disease

Miles Hoyt is famous in his small beach town, known as the guitar prodigy. At only 12 years old, Miles can be found playing in one of his two bands in the local restaurants and pubs.

Adopted into a musical family, his mom, Renee, and dad, Mike, met doing musical theater in Long Island, New York. And after they got married, Renee and Mike adopted Miles when he was four days old. Miles picked up a guitar at just four years old, and he hasn't stopped playing since.

But a year later, Miles' parents took him to the eye doctor, where he was diagnosed with Stargardt disease. Renee and Mike immediately scheduled additional doctor's appointments to learn more about his condition and did their own research online, as they knew nothing about Stargardt disease. And being a closed adoption, they couldn't contact Miles' birth mother, although they did try.

From searching online, they found the Foundation Fighting Blindness, which helped to give them more insight into the research being done for Stargardt disease. They also found Stargardt groups on Facebook, which gave them a network of other people who either have



Miles sitting on stage during a performance playing guitar.

or know someone with Stargardt disease.

Miles' vision decreased quite quickly, so he and his parents had to learn to adapt fast. Luckily, Miles' natural musical talents made playing the guitar one of the many ways Miles has coped with his vision loss.

"I try to stay positive about life and to help Miles with that too," says Renee. "I always tell him to remember that we knew about his gifts before we knew about his challenges. There's no sense in wallowing about it, but instead, find a way to pay it forward and help increase awareness for such a rare disease."

Now living in Lake Worth Beach, Florida, the Hoyt family has decided to use music to bring their community together and raise funds for blinding retinal diseases like Stargardt disease. Their do-it-yourself fundraiser, Smiles for Miles, first began in 2018 as a music event for Miles to perform. Now, in its third year, Smiles for Miles has transformed into a community music festival, with blues and rock musicians performing along with Miles. Local businesses donate for the fundraising efforts and attend the gig, and the local TV stations come out



The Hoyt Family: Mike, Renee, and Miles, on stage.

to cover the event. In 2021, Smiles for Miles raised over \$13,700 for the Foundation Fighting Blindness, with more than 200 attendees in-person and donors from across the country.

“I’m not a scientist that is going to find a cure for Miles, but that’s why we want to help the Foundation who is making such a difference,” says Renee. “I love doing a DIY fundraiser because we can put our own personal touch on the event. Smiles for Miles is just one way we keep hope for a cure, and help to raise awareness for Stargardt.”

Miles is a regular performer at Rudy’s Pub, where Smiles for Miles is held. When people see Miles play for the first time, they often have no idea he is legally blind. So, his parents use his performances as an opportunity to educate the community on blindness.

“We like to share about Miles’ Stargardt before gigs to tell people about his blindness, as well to avoid flash photography since he can be so sensitive to it,” says Renee. “We’ve even gotten to know the local photographers around town, so now they know to show up before it gets dark. Everyone’s always so understanding once you explain.”

Miles’ musical talents have really blossomed in the last few years, and he’s become a much more proficient guitar player. Miles and his parents have their own blues/rock band called The Miles Hoyt Band, with Renee on vocals and Mike on rhythm guitar and vocals. Miles also plays in a jazz/blues band with other young local musical prodigies called ETA, which stands for Even Tempered Artists.

When Miles isn’t busy playing his guitar, he attends school virtually, which he’s found extremely effective with his visual impairments. In the last year, Mike has become Miles’ full-time teacher, as Miles previously had a lot of anxiety when it came to school.



The Smiles for Miles t-shirt design created by a local community artist.

“His peers in school didn’t understand that blindness is a spectrum,” says Renee. “One year, when Miles was in third grade, Mike and I, along with the school nurse, went into Miles’ school to help educate the students on his condition, and that really helped.”

Renee also highly encourages therapy as a coping mechanism for anyone with a disability.

“We think about therapy as just adding more tools to your belt,” says Renee. “It gives us and Miles different ways of coping with his blindness on a daily basis.”

Miles’ parents have made sure he has all the accommodations necessary to succeed in life and be an advocate for himself as he gets older. And no matter how much Miles’ vision loss progresses, he’ll always continue to rock on.

You can use your creativity, passions, and connections to help raise awareness and funds for the Foundation too! Start your own DIY Fundraiser at:

www.FightingBlindness.org/RaisingOurSights

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Leave Your Legacy

The Foundation is fighting every day to find treatments and cures for blinding diseases, but we can't do it without your help. Most people can make a far more significant gift by including the Foundation in their will or trust or making a gift by beneficiary designation.

For more information, visit:

www.FightingBlindness.org/legacy-giving

IN FOCUS

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