

KNOW
THE GLOW[®]

BLINDNESS IS FOREVER • KNOW THE GLOW


**HOW
DO YOU
DESCRIBE THE
COLOR BLUE TO A CHILD
WHO CAN'T REMEMBER WHAT IT LOOKS LIKE?**

**SOMEWHERE IN THE WORLD, A CHILD
GOES BLIND EVERY SIXTY SECONDS**



**WHAT
IF YOUR
CHILD COULD
ONLY IMAGINE THE
BEAUTY OF A GLOWING SUNSET?**

**LEFT UNCHECKED, RATES OF BLINDNESS
WILL DOUBLE BY THE YEAR 2020**



**WHAT
IF THE LAST
THING YOUR CHILD
EVER SAW WAS THE DOCTOR
RESPONSIBLE FOR REMOVING HIS EYES?**

**EARLY DETECTION IS THE BEST STEP TO
DEFEATING DEVASTATING EYE DISEASE**

— BLINDNESS IS FOREVER • KNOW THE GLOW —

EIGHTY PERCENT OF CHILDHOOD

BLINDNESS IS PREVENTABLE.

PREVENTION STARTS BY RECOGNIZING
“THE GLOW,”
AND WE’LL SHOW THE WORLD HOW



OUR MISSION

Decreasing blindness by increasing awareness

Know the Glow is dedicated to the awareness of glow-related childhood eye diseases.



OUR VISION

Envisioning a brighter future for all children

Our vision is the global elimination of preventable childhood blindness by educating the general public and medical community on how to identify “The Glow” through simple flash photography.



The first step toward diagnosis requires something that many parents around the world already own – *a camera*.

How exactly does such a simple tool play a part in battling complex pediatric eye conditions?

Simply put, Leukocoria (“The Glow”) is an abnormal red eye reflex, common to several devastating childhood eye diseases, and is seen as a white or golden yellow “glow” in the pupil.

This ever-important photo detail led one family to seek medical attention for their son, resulting in the diagnosis and treatment of a sight-threatening disease.

“Even though the redeye reflex test is a standard part of every pediatric check up, the reality is that **80% of the time, the parents** notice ‘The Glow’ first in their child’s pictures. In this instance, the photograph becomes a medical test and the results are waiting to be found in the family photo album.”

-Dr. Thomas Lee

Dr. Thomas Lee is an Assistant Professor of Clinical Ophthalmology at the Keck School of Medicine (USC), Attending Physician-Doheny Eye Institute (USC) and Director of the Retina Institute The Vision Center at Childrens Hospital Los Angeles.



MEET BEN WEBBER

When Megan Webber downloaded her family photos from her digital camera, she found the usual problems that need touching up — some were too dark, some were grainy, and some needed red-eye removal. Also pictures of her 5-year-old son, Benjamin, had a golden glow in his left eye.

“Benjamin has always had a freckle in his left eye,” said Megan, “so I thought the flash was just a difference due to the coloring of his eye and ignored it — I even did red-eye correction to remove it from photos.” But when her sister noticed the same glow in some family vacation pictures she had taken, she gave Megan a concerned call.



“She said it was probably nothing. But she had seen on a television show that this could be a sign of a tumor in the eye and recommended I have him seen.”

Benjamin’s pediatrician found nothing, but he sent them to a specialist who urged them to come in right away. They were stunned to learn he was legally blind in his left eye.



Scans of his eye showed a white mass, which had been causing the reflection in the photograph. After testing and a tense few days, they discovered that Benjamin had Coats’ Disease, a life-long disease that can damage the eye to the point where eye removal is necessary. Fortunately, Benjamin’s problem was caught early enough for treatment.

“While Benjamin has had three eye surgeries, we were very lucky to have caught his disease in time,” said Megan. “Had it been more advanced Ben could have immediately lost his eye. We are so grateful to Dr. Tom Lee and the doctors at The Vision Center at Children’s Hospital Los Angeles. Without the work that they do so many families would not have access to the quality and caliber of care that is provided there.”

Benjamin is doing well, and is a happy, thriving first-grader. “He wears protective Nike shatterproof glasses which the other kids think are pretty cool,” said Megan. “The glasses are primarily to keep his unaffected eye safe, for without that eye he would be blind.”

Megan was determined that others learn from her experience, and is the driving force behind the “Know The Glow” campaign. “Had I known about ‘The Glow’ earlier, Dr. Lee could have saved more of Ben’s vision,” said Megan. “Knowing what it felt like to possibly face a fatal outcome and knowing that I ignored such a huge red flag that was right there in front of me, I don’t want another parent to have to suffer through that or another child to needlessly lose his or her sight or eyes due to a lack of awareness of ‘The Glow!’”



MEET JAKE OLSON



When Jake was eight months old, he was diagnosed with Retinoblastoma, a rare form of eye cancer. The disease claimed his left eye before the tender age of one, and in November 2009 Jake lost his right eye after battling the cancer for 12 years. Jake confronted many challenges during his battle and has used his experience to better himself as a person and develop a strong faith in God. Jake wrote a book when he was eight years old to uplift and encourage other children who were battling cancer and other diseases. Jake has shared his book and faith with countless others, including both adults and children that have been touched by his story. Despite this adversity, Jake remains one of the most optimistic and inspiring individuals you will meet.



Jake is also a life-long University of Southern California® (USC) football fan. He had the opportunity to meet the entire coaching staff and team as well as spend precious moments with them leading up to his surgery and the weeks that followed. Meeting Coach Carroll and the team was a special experience not only for Jake, but the Trojans as well. Jake leaned heavily on these relationships during some of his most trying times, and a few have become very special friendships. During the Trojan season and leading up to Jake's surgery, ESPN®'s Shelly Smith captured his story along side the Trojans. Aired on ESPN®, Good Morning America®, and ABC®'s Evening News, the short documentary has won an ESPY® award. Jake has also appeared as a guest commentator on ESPN's College Game Day.

Jake's recent fame has given him the opportunity to speak about his experiences and faith in front of corporations, schools, service organizations and congregations. Jake had a busy 2010 with speaking engagements for the Fellowship of Christian Athletes®, The American Cancer Society®, Dick Vitale's 5th Annual V Foundation for Cancer Research®, and Melaleuca®'s National Convention. During the summer, he accompanied his twin sister Emma on a mission to Costa Rica to help build houses and encourage less-advantaged children.

Jake attends Huntington Christian School and continues to maintain straight A's despite his blindness. He also plays on the school football team, enjoys golf, skiing, surfing and playing the guitar. Ignoring conventional boundaries, he has set a personal goal to become the first blind golfer to play in the PGA®.

Jake's faith and attitude are an indelible source of inspiration to all those he touches, and his belief in making the most out of life continues to motivate those around him.





Blindness is one of the most feared and devastating disabilities in the world. It is even more tragic when it strikes children. Almost everything we learn and experience comes through seeing the world around us. Vision impairment is indeed life-altering in every way.

80% of childhood blindness is preventable or curable.

- Somewhere in the world, a child goes blind every 60 seconds.
- Rates of blindness will double by the year 2020 unless prevention efforts are intensified.

In addition to the life long impact of a child going blind, the social and economic costs are also enormous. Children who become blind face significant obstacles as adults, facing continuous issues in health care, employment and engagement in society in general.

- 62% of adults who are blind in the United States are unemployed.
- It costs more than \$4 billion annually in benefits and lost income.
- It adds \$10,500 annually to the cost of any individual's healthcare.



"The Glow" can be found in a typical flash photograph. Rather than the normal red reflection from a healthy retina, there is a golden white or golden yellow "glow" that can be a sign of an eye disease or disorder.

"The Glow" is an indicator of 16 potentially devastating childhood eye diseases as well as the leading preventable cause of Amblyopia, monocular childhood blindness. Vision disorders are the fourth most common disability among children in the United States and the most prominent handicapping condition in childhood, according to the National Eye Institute.

Up to one in 80 children will exhibit "The Glow."

- Parents can easily recognize "The Glow" in flash photography of their children.
- Over 80 percent of Retinoblastoma and Coats' Disease cases are first diagnosed by a parent or family member through "The Glow."
- Once detected, specialists can determine the cause of "The Glow" and begin treatment early enough to ensure the best possible results.

Diseases common to "The Glow":			
Amblyopia	Congenital Cataract	Retinal Dysplasia	Toxocariasis
Cataract	Norrie's Disease	Retinopathy of Prematurity (ROP)	Trauma
Choroidal Osteoma	PHPV	Retinoblastoma	
Coats' Disease	Refractive Error	Strabismus	
Coloboma	Retinal Detachment		

SEE THE GLOW

“The Glow” is easy to detect.
These case studies show what to look for!



Jake
Disease: **Retinoblastoma**
Diagnosed: **8 months**



Gavin
Disease: **Amblyopia**
Diagnosed: **20 months**



Jake
Disease: **Coats' Disease**
Diagnosed: **5 years**



Hannah
Disease: **Cataract**
Diagnosed: **3 days**



Disease: **Amblyopia**
Diagnosed: **1 year**



Francois
Disease: **Coats' Disease**
Diagnosed: **10 months**

BLINDNESS IS FOREVER • KNOW THE GLOW

None of the family photographs shown have been retouched, and have only been used with permission.

WHO WE ARE

We are building a coalition of people who “Know The Glow.” Each of our board member’s personal journey’s have led them to take an active role passionately spreading awareness about Luekocoria.

Know The Glow also strives to support glow-related disease research, medical treatment and therapies in order to prevent childhood blindness. With your assistance and support, Know The Glow will achieve its vision and ensure children everywhere will forever see their loved ones’ faces.

FOUNDING MEMBERS



Co-founder

Megan Webber was introduced to Children’s Hospital Los Angeles in September of 2009 when her second son, Benjamin, then age five, was diagnosed with Coats’ Disease. His journey would ultimately sparked the Know The Glow campaign, which Megan is Co-Founder. She is also on the Advisory Board of The Vision Center at Children’s Hospital Los Angeles and Co-Chair of BrightEyes, a volunteer organization dedicated to supporting the doctors and patients at Children’s Hospital Los Angeles.

Megan graduated in 1990 from the University of Notre Dame with a BA in psychology and second concentration in business. Upon graduation she moved to Chicago where she initially worked at the Intercontinental Hotel and later The Drake Hotel for the General Manager and public relations department. Megan initially coordinated events and activities across all departments of the hotel and expanded her role into functioning as a liaison between the office of the general manager, Public Relations, Rooms Division and Special Events. From there, she was recruited to run the Front Office, Reservations and Rooms Division for Chicago Athletic Association where she learned all areas of hotel operation.

From 1994-1996, Megan worked as Office Manager for The Hefner Agency, an insurance company specializing in estate planning. In 1996, she joined Whittman-Hart, an information technology consulting firm, working initially as the executive assistant to the CEO. While developing her career in the company, she was asked to assist with the lead team opening offices around the country and internationally for Whittman-Hart.

After moving with her husband to Los Angeles in 2000, Megan continued her career with Whittman-Hart until July of that year when she retired to start her family. Raising three children provided her the chance to pursue volunteer opportunities at school and in the community. Chairing membership for Pacific Palisades Junior Women’s Club and later becoming Vice President, President, and Past President of the PPJWC, she led the effort raising \$100,000 annually, which was then distributed to local community projects in Pacific Palisades.



Co-founder

Sandra Roderick is the Co-founder of Know the Glow, a global awareness campaign focused on eliminating preventable childhood blindness globally. Mrs. Roderick is also the Co-founder and Co-President of BrightEyes, a nonprofit organization to further promote and provide additional funding for the doctors of the Vision Center of Children’s Hospital Los Angeles. She is an Advisory Board Member for The Vision Center at Children’s Hospital Los Angeles, providing guidance to the doctors and leadership of the hospital to ensure that the needs of the children and families are met during their experience with The Vision Center at CHLA.

Mrs. Roderick offers successful experience in merchandising, electronic commerce, business development, and marketing with extensive background in the following areas: management/administration, sales, product development, vendor negotiations and operations.

From the years of 1994-1998, Mrs. Roderick was employed by MGM/UA® as the Director of Merchandising. Mrs. Roderick was responsible for and managed day-to-day operations of the MGM® Merchandising Division and oversaw retail rollout plans and strategies into key consumer markets.

From the years of 1998 – 2000, Mrs. Roderick joined E! Entertainment® as Director of Electronic Commerce. She developed, implemented and administered all online retail activities. Her responsibilities included assembling and managing a staff to administer all commerce aspects of the online stores, including product selection, supply, pricing, merchandising, order processing, distribution, customer service, vendor management and marketing. She was responsible in overseeing all new business development with key partners.

Mrs. Roderick earned her BS degree at UCLA and is an active member of other philanthropic organizations in the Greater Los Angeles Area.



Medical Advisor

As director of the Retina Institute in The Vision Center at Children’s Hospital Los Angeles, **Dr. Thomas C. Lee** is overseeing the growth of this highly respected program. He came to Children’s Hospital in 2006 from New York Presbyterian Hospital/Cornell University, where he was Director of the Pediatric Retina Service, and Associate Director of the Robert M. Ellsworth Ocular Oncology Center. Dr. Lee earned his bachelor’s at John Hopkins University and received his MD from Cornell University where he graduated with honors in research as a Howard Hughes Scholar. He completed his ophthalmology residency at Cornell and then went to Harvard Medical School as a Heed Fellow where he studied retinal stem cells and the role they play in cancer. He completed his retina fellowship at Massachusetts Eye and Ear Infirmary, Harvard Medical School before returning to Cornell where he was a Fred Gluck Scholar. He held the position of Associate Director of the Robert M. Ellsworth Ocular Oncology Center at Cornell until being recruited to Children’s Hospital Los Angeles.

Dr. Lee made significant advances in our understanding of pediatric retinal disorders. He has pioneered the use of cutting-edge imaging techniques such as Spectral Domain Optical Coherence

Tomography (SDOCT) to identify retinal detachments at the earliest possible stage. He is also the first to use an intraocular endoscope to perform complex surgery in pediatric retinal detachments resulting from retinopathy of prematurity, familial exudative vitreo-retinopathy, x-linked retinoschisis, and trauma. He has identified novel drugs that can induce blood vessel and tumor regression and is currently designing new ways to enhance delivery into the eye.

His work has been supported by a number of grants from research foundations and has numerous peer-reviewed publications in recognition of these accomplishments. Dr. Lee has an active research program that focuses on developing new therapies to treat Retinopathy of prematurity and Retinoblastoma. He has identified a novel class of drugs to accelerate cell death of both retinoblastoma cells and vascular endothelial cells. He also studies the role that retinal stem cells play both in the formation of Retinoblastoma tumors as well as replacement of damaged neurons resulting from degenerative retinal diseases.

OUR BOARD OF DIRECTORS



Secretary

Annie Barnes is an entrepreneur, philanthropist and mother of two. In 1999, Annie founded Narrowfeet.com that quickly became the largest online narrow shoe retailer. She grew the company into multi-million dollar revenues before selling the company three years later. Narrowfeet.com was the first niche market retailer on the Web and was at the forefront of the internet retailing boom. Annie has been featured in consumer and trade publications for her innovative brand strategies and unique approach to building a retail business online.

In addition to her successful business, Annie serves on a number of philanthropic and civic boards. She has served as President of the Board for City Hearts, an arts enrichment program for

inner-city youths. City Hearts serves more than 1500 at-risk children in Southern California, introducing them to vital programs that prepare them for college and beyond. Annie currently serves as Graduate Scholar Advisor on the National Fraternity Board of Delta Delta Delta, Advisory Board of her local YMCA®, VP of Community Outreach for her children’s school, and CEO of her family’s foundation which helps support and educates orphans in Tijuana, Mexico.

She was born and raised in Louisiana, and has a Bachelor of Arts in Political Science. An active and dedicated philanthropist, Annie will use her business skills, passion for advocating for children’s health and rights, and boundless energy and enthusiasm to promote the mission of Know the Glow.



Vice President

Lannette Turicchi is a mother of three and the wife of Scott Turicchi, the President of J2 Global Communications.

Lannette started her career at The Walt Disney Company as the assistant to the Head of Casting for Hollywood Pictures, a division of Walt Disney Studios. She held various other jobs at Disney including assistant to the Vice President of New Business Development for The Walt Disney Gallery, and sales assistant for Discover Magazine, a subsidiary of Walt Disney Publishing.

Lannette later became the head of Non Theatrical Distribution for DreamWorks® SKG. In this roll, Lannette started the division and was responsible for sales, marketing and distribution of all Non Theatrical elements for DreamWorks Television and Film product.

Lannette then started Captive Entertainment with Paul Poste and Karima Taylor. Captive Entertainment specializes in representing independent film producers in the Non Theatrical environment. Captive Entertainment remains a multi-million dollar company.

Lannette currently is the President of Falling Upwards Productions LLC, an independent production company, specializing in helping nonprofit companies to tell their story. Lannette directed and produced The Prophet of our Time, a documentary on the life and death of Blessed John Paul II. She is currently in development on a contemporary romantic comedy titled, “The Village Bride of Beverly Hills”.



Medical Advisor

Dr. Jesse L. Berry, MD, is Assistant Professor of Clinical Ophthalmology and the Assistant Director of Ocular Oncology at the USC Eye Institute at the University of Southern California and Children’s Hospital Los Angeles. In addition, Dr. Berry is Associate Residency Program Director for the Los Angeles County + University of Southern California (LAC+USC) ophthalmology residency program.

She specializes in ocular oncology, and has both surgical and clinical expertise in anterior segment/intraocular/external and orbital tumors. Furthermore, Dr. Berry has surgical expertise in cataract and comprehensive ophthalmology. Her research endeavors focus on clinical outcomes of Retinoblastoma and Choroidal Melanoma.

Dr. Berry is the founder of WOO, Women in Ocular Oncology, and she is a member of the Society of Heed Fellows and received the University of Southern California Excellence in Resident Teaching Award in 2013 and 2014.

She received her undergraduate and medical degrees from Harvard University in Massachusetts. Following her ophthalmology residency at the University of Southern California, she was the Assistant Chief of Service at the Los Angeles County LAC+USC Medical Center. She then completed a fellowship in Occular Oncology at Children’s Hospital Los Angeles under the mentorship of Drs. Jonathan Kim and Linn Murphree.



Research Leader

Gina Vincent graduated with a degree in communications with an emphasis in public relations. She worked at the Xerox® Corporation for 13 years. Her career with Xerox started with the position of customer support representative where she trained customers on newly purchased equipment to ensure complete customer satisfaction. She was soon promoted to the position of marketing representative and was responsible for cultivating and bringing new business to Xerox. She was awarded the STAR award for top sales in the region and was also the number one marketing representative in the nation in sales revenue. She was soon offered the position of account representative, responsible for sales to existing accounts and was the President’s Club winner for seven years.

After developing an interest in finance, she spent her final three years as a finance manager and was responsible for approximately 200 sales representatives in the Southern California area. Her responsibilities included supporting the sales staff in developing sales strategies to encourage customers to finance new equipment. She worked with various CFO’s and other decision makers in negotiating corporate pricing and negotiated the terms for these large contracts.

After retiring from Xerox to spend more time with her family, Mrs. Vincent has volunteered with her local community as President of the Library Association, which raises money for books and supplies to supplement what the County of Los Angeles budgets for this branch. She has also served as president of the Pacific Palisades Junior Women’s Club to raise money for nonprofit organizations.



Grants & Corporate Sponsorship Chair

Janette Schatteles Flintoft is the Grant Director for the Los Angeles City Attorney’s Office, which administers \$3-\$5 million annually in grant awards. In this role Ms. Flintoft focuses on grant making policies, procedures, procurement and compliance. An author and conference presenter, Ms. Flintoft also serves on the Scientific Justice Review Panel for the National Institute of Justice and is a peer reviewer for the Bureau of Justice Assistance.

Through her work in the area of drugged driving, Ms. Flintoft has secured nearly \$2 million in state and federal funding and built relationships across stakeholders to advance drugged driving enforcement. Ms. Flintoft earned her BA degree from UCLA and her JD from Southwestern University. Prior to her current role, Ms. Flintoft worked as a prosecutor for the Los Angeles City Attorney’s Criminal Division.



For more information about “The Glow,” go to www.knowtheglow.org.

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