

## **Our Mission**

Know the Glow (KTG) is a US based non-profit organization that seeks as its mission, to achieve the global elimination of preventable Glow-related childhood blindness through public awareness of the Glow, leukocoria. Through its website, social media and other channels, KTG has been forming global collaborations with health professionals, NGOs, service workers and families all structured around building awareness regarding the prevalence and outcomes of leukocoria-related eye disease/blindness. Know the Glow works under the fiscal sponsorship of Los Angeles-based Community Partners, IRS # 95-4302067

## Meet our new Country Ambassadors!



We are excited to welcome our four new Country Ambassadors (clockwise starting top left), Ana Sebrek of Croatia, Dhiman Halder of Bangladesh, Lauren Selvik of Texas, USA and Kellie Perrin of Australia. Together they are finding and connecting families, doctors and NGO's to our KTG community. Encouraging families to share their stories with our audience and helping connect other families with doctors, ocularists, and other health care professionals in their area is vital to the health and growth of our community. We applaud their dedication and hope that we continue to grow our family of ambassadors across the globe! We are thrilled to report that we are adding new ambassadors monthly!



## **Collaborative Advocacy in Action**

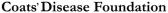
KTG is proud to announce that no single nonprofit or foundation can do the work of spreading awareness of preventable childhood blindness alone. KTG strives to promote collaborative advocacy working together to highlight newsworthy and important information about early detection of blinding childhood conditions. We are partnering with nonprofits and agencies around the world to better serve the children of today and the parents of tomorrow who will be better educated about the Glow and who will know what to look for in their own children's eyes one day. We are proud to be members of the International Agency for the Prevention of Blindness (IAPB) and to announce our 20 international partners.















































# Our Medical Advisory Board welcomes 3 New Members

KTG has been fortunate to engage with top doctors around the world. In the last year we have added in realm of ocular oncology and pediatric ophthalmology, three new members to our Medical Advisory Board. KTG is committed to having the top medical professionals connecting our families around the world and to helping us spread awareness of preventable childhood blindness.

**Dr. Ashwin Mallipatna** is a Pediatric Ophthalmologist and the Head of the Retinoblastoma Program at the Hospital for Sick Kids in Toronto Canada. Dr. Mallipatna has significant academic achievements, including leading the work involved in staging retinoblastoma for the American Joint Committee on Cancer (8th Edition of the AJCC Cancer Staging Manual), which impacts retinoblastoma management worldwide. With the support of a Thrashers Research Early Career Grant Award, he led work that would promote the early detection of leukocoria using a camera flash. He collaborated with researchers from Université de Montréal, the University of Toronto and the University of Adelaide. This work attracted recognition from the Massachusetts Institute of Technology's Young Innovators Award in India (INDIA TR35 Young Innovators Award).





**Dr. Francis L. Munier** joins us from Lausanne, Switzerland where he is presently the head of the Retinoblastoma Unit and the Oculogenetic Unit at Jules Gonin Eye Hospital. After medical studies and residency in Lausanne, he obtained board certification in both Ophthalmology and Medical Genetics. From 1991 to 1993, he received additional training in Molecular Genetics and Pediatric Oculo-Oncology at Children's Hospital Los-Angeles under the guidance of A. Linn Murphree. Back in Lausanne he joined the Retinoblastoma Clinic at Jules-Gonin Eye Hospital and founded the first Swiss Oculo-Genetics Unit. Dr. Munier delivered more than 250 invited lectures and is the author or co-author of some 300 peer-reviewed papers and 34 book chapters.

Dr. Carol Shields completed her residency in ophthalmology at Wills Eye Hospital in Philadelphia in

1987 and subsequently did fellowship training in ocular oncology, oculoplastic surgery, and ophthalmic pathology. She is currently Director of the Oncology Service, Wills Eye Hospital, and Professor of Ophthalmology at Thomas Jefferson University in Philadelphia. She has authored or coauthored 11 textbooks, 323 chapters in edited textbooks, over 1700 articles in major peer-reviewed journals, given over 850 lectureships, and has received numerous professional awards. Dr. Shields is a member of numerous ocular oncology, pathology, and retina societies and has delivered 57 named lectures in America and abroad. She has been active in the American Academy of Ophthalmology. She serves on the editorial/advisory board of 31 journals including JAMA Ophthalmology, Retina, Ophthalmic Plastic and Reconstructive Surgery, and International Journal of Clinical Oncology.

## **Current Activities**



more than ten years sharing information about the Glow and courses of action with parents, advocates and medical Glow professionals, Know the continued its Global Strategic Plan to systematically, on a country-by-country basis, inform individuals worldwide about the dangers associated with finding the Glow in photos of children and steps to be taken when it occurs. In this past year, KTG launched successful awareness has campaigns in the USA, Croatia, Bangladesh, Canada, Australia and the surrounding

countries of Oceania, a second campaign in India and the Philippines. Going forward in 2023, KTG hopes to launch campaigns in Spain, Germany, Tanzania and Kenya. As we progress internationally, we will be particularly attentive to enlisting international NGO partners with a global or regional presence. Such organizations may work to collaborate on extended campaigns, or work with us to build Glow awareness, highlighting the foundational work they have already done in regions where they have an established presence or established network of local professionals and advocates.







## Progress to Date - KTG Reach

KTG has strived to increase our social media footprint globally across our multiple platforms. Below are the breakdowns of each of our awareness campaigns by country. Every chance we have to find a child with a vision threatening condition furthers our mission to prevent avoidable blindness and also increase early detection of life-threatening eye diseases.



#### **Overall KPIs**

**▼** LINK CLICKS KNOW THE GLOW ADVERTISING

703,201

**▼** REACH KNOW THE GLOW ADVERTISING

10,632,580

**™IMPRESSIONS KNOW THE GLOW ADVERTISING** 

25,514,422

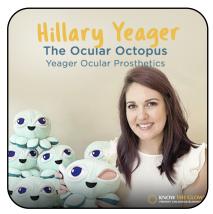
### **Performance Breakdown**

#### INDIVIDUAL CAMPAIGN PERFORMANCE

KNOW THE GLOW ADVERTISING

Campaign	Clicks	Reach	Impr.
Philippines Campaign	342,845	4,341,518	10,996,195
Bangladesh Campaign	226,543	2,318,867	4,616,977
Hindi Campaign	51,710	2,705,460	4,575,616
Oceania Campaign	38,043	663,677	3,625,620
Canada Campaign	18,541	190,048	467,188
USA Campaign	13,978	229,759	422,280
Croatia Campaign	11,541	212,607	810,546
	703,201	10,632,580	25,514,422

## KTG New Developments



The Ocular Octopus, an educational, stuffed octopus with removable eyes, is the wonderful creation of **Hillary Yeager**. Children featured in the KTG
Glow Gallery who have lost an eye to a glow-related eye

disease will be sent this fun yellow octopus and its accompanying book in the name of another KTG highlighted child. The son of **KTG newest Board Member, Christina Gill** will launch the project. Eli was diagnosed when he was not even a year old by Dr. Shields with Stage Five Coats' Disease. Stage five is the most advanced level of this condition. Eli is thriving and doing well and

This past year KTG launched a second campaign throughout India. With the help of Notre Dame Intern, **Adviti Bali** and **IKSHA Foundation**Co-Founder, **Thanmaya Bekkalele** and his team of translators, KTG has been able to share our Awareness campaign and various languages throughout India. KTG is dedicated to making our messaging in multiple language with images reflective of the country so that our message can be easy to understand and enduring.

Christina is eager to spread awareness of the Glow. Looking back the family realized that the very first photo of Eli with the Glow was posted on Facebook by his Christina on Christmas 2020. The cycle will continue when children featured in future KTG stories receive their own octopus in the name of a child previously highlighted – connecting and bringing joy to children dealing with eye disease all over the

world. This gift program provides a physical reminder of how one person's story can lead the way for an infinite number of future Glow families. The Ocular Octopus is a perfect example of children helping

children...one child (and oneoctopus) at a time.





KTG 's 7th Fundraising Event was hosted again by Jimmy Choo in October of 2022. After a 3-year hiatus due to the COVID pandemic, it was wonderful to bring together a community committed to raising awareness among parents around the world. In attendance were members of our KTG Board, our Medical Advisory Board, ocular oncologists, retina surgeons, RB and Coats' Disease survivors, as well as their friends and families. Marissa Gonzalez (an adult survivor of RB), the President and

Founding Board Member of one of KTG's newest partners, WeCHope, gave a moving and inspirational speech. Board member, **Cindy Mays**, and her daughter, **Sullivan Mays**, shared their journey and about growing up with retinoblastoma. With nearly 100 in attendance, the event was our most successful to date and 100% of the proceeds raised will go towards KTG's continued efforts in providing critical sight-saving support and education to parents of children at risk of blindness around the world.

## Our Champions

**Dr. Enayet Hussain** is the current Directorate General of Medical Education (DGME), under the Ministry of Health & Family Welfare. Surprisingly, much of what Dr. Husain promotes today can be traced back to his experience working as the Director of Non-communicable Diseases in the public health sector. "Eyecare should be a multisector area." He explained to KTG that he found many of his ideas for policy-making issues and advocacy ideas while he was working in this sector. The Ministry of Child Affairs, the Ministry of Local Government, and the Ministry of Education should all be integrated and work together to increase awareness. Even school teachers should be involved at the community level. Ideally, there should be a pilot program created and implemented in a given area engaging all of

these health and non-health sectors. Following a review of the outcomes, the program could be scaled up once successfuly implemented.





Maria Arce Moreira, the Executive Director for VOSH/International (Volunteer Optometric Services to Humanity) is neither an optometrist nor a health care specialist, but she has always worked with global networks. Maria gravitates towards collaboration because she knows that if you connect people, you inevitably have more success. With more than 20 years in the nonprofit and international NGO realm, she has enjoyed

working with VOSH because it is a group of highly motivated, committed and knowledgeable people who are selfless and have clear and common goals. Maria was introduced to Megan by **Dr. Jenn Viñola**, an optometrist and professor at Manilla Central University who has a very active student chapter SVOSH-MCU. Maria explained to Megan that VOSH works as a network so each of the 98 affiliated chapters are autonomous but abide by the same vision, values and code of conduct. While VOSH/International provides policy and clinical recommendations to its chapters, they are autonomous in their operations and decision-making. Student chapters (SVOSH) are a vibrant piece of the structure because these young future professionals are fertile ground to plant the interest and motivation to embrace the full scope of optometry as a key eye health profession with significant impact in people's lives.

KTG became acquainted with **Dr. Jaume** through the Català-Mora equally inspirational mother one of his patient's, Carme Juliá Ferré. Carmé is also a computer scientist and is also collaborating with mathematician Dr. Català-Mora on the development of a vision screening tool. Dr. Català-Mora is currently on staff at the St. Joan de Déu hospital in Barcelona, but as KTG discovered, he is in constant communication with hospitals treating children with retinal diseases in Madrid and Seville, and his work often extends far beyond the borders of his homeland Globally, of Spain. Dr. Català-Mora worked with has two organizations that focus on vision issues worldwide and in Francophone countries in The International Council Ophthalmology and the Alliance Mondiale Centre le Cancer (led by Dr. Laurence **Designation** of the Madame Curie Institute in France). As part of the AMCLC, Dr. Català has monthly meetings where programs and patients are discussed. In cases where warranted, bringing patients to Paris or Barcelona to be treated if needed. The ultimate goal, though, is to train local



ophthalmologists so that treatment can be accomplished in a sustained way locally in their own countries. For example, in Mali as well as in Senegal, the local ophthalmologists have been outfitted with proper equipment and necessary to treat even their most difficult including retinoblastoma. cases, Català-Mora is currently working with **Dr.** Mariamo Abdallah, pediatric а ophthalmologist from the Central Maputo Hospital in Mozambique, spearheading a campaign aimed at promoting the need to address leukocoria education there.



## In Loving Memory of Dr. A. Linn Murphree

"Know About The Glow" was the phrase given by **Dr. A. Linn Murphree** to the Co-Founders of KnowTheGlow when we first began in 2010 to assist us in our efforts to find children at risk of retinoblastoma and other leukocoria related blinding diseases through finding glows in flash photographs of the eyes of children. All of us at KnowTheGlow take very seriously our mission of carrying forward his legacy, his words, and his commitment to finding and caring for all children at risk of glow-related blindness wherever they may be.

## Student Chapters and Internships

Know the Glow continues its relationship with students from the University of Notre Dame through the Boler- Parseghian Center for Rare and Neglected Diseases. Under the direction of their faculty advisor, Professor Barbara Calhoun, RN, these six dedicated students provide valuable services such as gathering research on the countries to which they have been assigned, schedule and join zoom meetings with country representatives enabling Know the Glow to keep track of progress and extend our reach. This past year, three of our interns, Camey Calzolano, ND '22, Adviti Bali, ND '23, and Bailey Perczak, ND'22 were names joint winners of the 2022 Megan K. Crowley Award for Patient Advocacy and the John M. and Mary lo Boler Rare Disease Research Award. The





award recognizes their outstanding combined contributions in patient advocacy as well as their translational work in rare diseases. On the other side of the country at Santa Clara University (SCU), three interns were selected to work with KTG through SCU REAL Program (Real Experience, Applied Learning). These interns were assigned translations for future campaigns, project developing, social media strategies and targeted research projects for current and future projects.

Under the guidance of **Dr. Jenn Vińola**, the optometry students at Manilla Central University in the Philippines have officially chartered a student chapter of KnowTheGlow.

The goal is to spread awareness of leukocoria within the school as well as through the country as they conduct vision screenings and connect families in need of proper medical care. They hope ito also collaborate with KnowTheGlow on webinars to encourage further understanding of the more than 20 eye conditions that can be detected by the Glow.



## KNOW THE GLOW BOARD OF DIRECTORS



Megan Webber, Co-Founder, President

Sandra Roderick, Co-Founder, Vice President/Treasurer





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Kara Ciocca, Member, Communications Liaison





Janette Flintoff, Member. Los Angeles City
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Ali Reilly, Member, Fundraising Coordinator

**Christina Gill, Global Family Coordinator** 



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