



*Knowledge is love and light  
and vision.-Helen Keller*

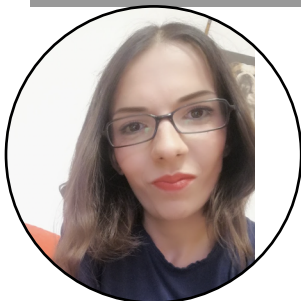


**KNOW THE GLOW®**  
PREVENT CHILDHOOD BLINDNESS

## 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

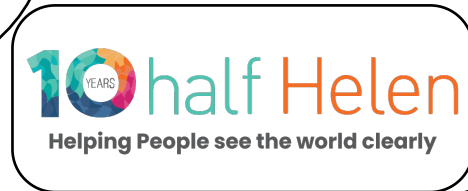
## Meet our new Country Ambassadors!



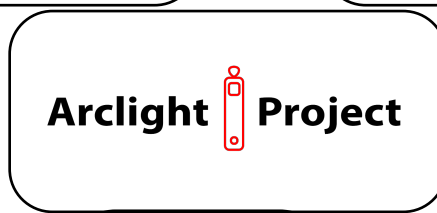
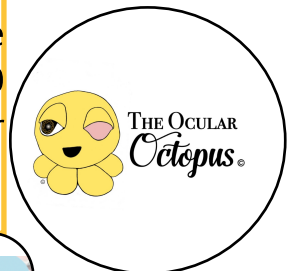
We are excited to welcome our four new Country Ambassadors (clockwise starting top left), Ana Sebrek of Croatia, Dhiman Halder of Bangladesh, Lauren Selvik of Texas, USA and Kellie Perrin of Australia. Together they are finding and connecting family to our KTG community. Encouraging families to share 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!



# Collaborative Advocacy in Action



KTG is proud to announce that no one nonprofit or entity can do the work of spreading awareness of preventable childhood blindness alone. KTG strives to promote collaborative advocacy so that we work 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 new members of the International Agency for the Prevention of Blindness (IAPB) along with 150 organizations in over 100 countries working together for a world where everyone has access to eye care.



# Our Medical Advisory Board welcomes 3 New Members

Since last year, KTG has been fortunate to engage with the top doctors around the world. In the realm of ocular oncology and pediatric ophthalmology, our three new members on our Medical Advisory Board are no exception. KTG is committed to having the top medical professionals helping connect our families around the world to the best care 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).



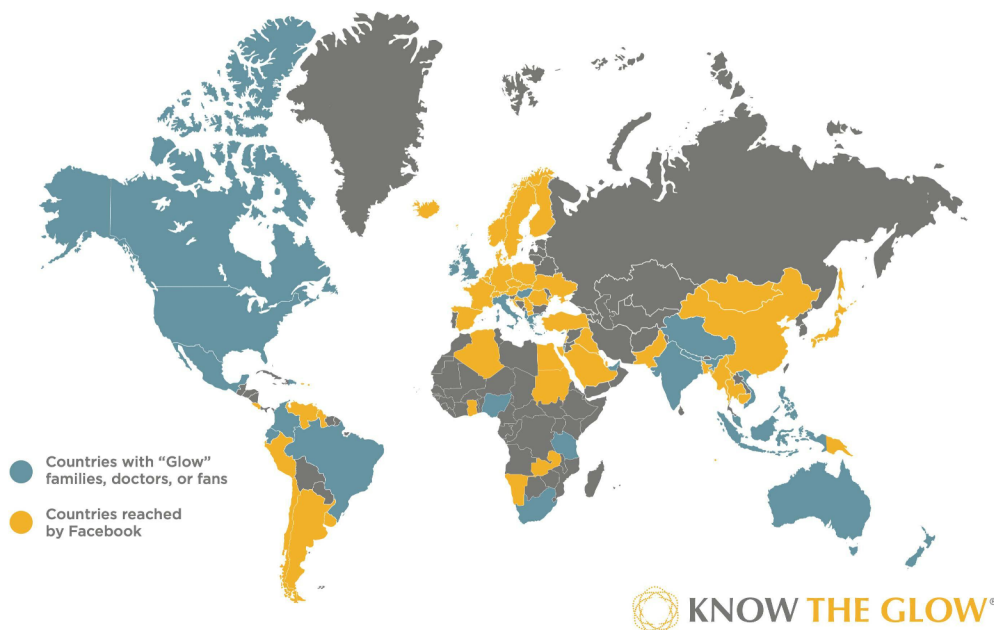
Dr. Francis L. Munier joins us from Lausanne, Switzerland where he is presently the head of the Retinoblastoma Unit and the Oculogenetic Unit at Jules Gonin Eye Hospital. After medical studies and residency in Lausanne, he obtained board certification in both Ophthalmology and Medical Genetics. From 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.



# SAVING SIGHT WORLDWIDE



## Current Activities

After more than ten years sharing information about the Glow and courses of action with parents, advocates and medical professionals, Know the Glow has 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 has launched successful awareness 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 wish to collaborate on extended campaigns, or be interested in working with us to build Glow awareness, highlighting the foundational work they have already done in regions where they have an established presence or an established network of local professionals and/or advocates.



# Progress to Date

# Our Champions

Dr. Hussain is the current Directorate General of Medical Education (DGME), under the Ministry of Health & Family Welfare. Surprisingly, much of what Dr. Hussain 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 Megan 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



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 Català-Mora through the equally inspirational mother one of his patient's, Carme Juliá Ferré. Carmé is also a computer scientist and is also a mathematician collaborating with 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 of Spain. Globally, Dr. Català-Mora has worked with two organizations that focus on vision issues worldwide and in Francophone countries in Africa, The International Council of Ophthalmology and the Alliance Mondiale Centre le Cancer (led by Dr. Laurence Desjardins 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 the proper equipment and training necessary to treat even their most difficult cases, including retinoblastoma. Dr. Català-Mora is currently working with Dr. Mariamo Abdallah, a pediatric ophthalmologist from the Central Maputo Hospital in Mozambique, spearheading a campaign aimed at promoting the need to address leukocoria education there.

***For more 'Champion' stories, visit <https://knowtheglow.org/category/news/>***

# 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, these five 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 their reach. This past year, three of our interns, Camey Calzolano, ND '22, Adviti Bali, ND '23, and Bailey Perczak, ND'22 as the three joint winners of the 2022 Megan K. Crowley Award for Patient Advocacy and the John M. and Mary Jo Boler Rare Disease



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

Under the guidance of Dr. Jenn Viñola, the optometry students at Manila Central university in the Philippines have official chartered a student chapter of KnowTheGlow. The goal is the spread awareness of leukocoria within the school as well as through the country side as they conduct vision screenings and connect families in need the proper medical care. They hope is to also collaborate with KnowTheGlow on webinars to encourage further understanding of the more many eye conditions that can be detected with the Glow.



# KNOW THE GLOW BOARD OF DIRECTORS



**Megan Webber, Co-Founder, President**

**Sandra Roderick, Co-Founder, Vice President/Treasurer**



**Helene Dameris, Member, Global Outreach Director**

**Kara Ciocca, Member, Communications Liaison**



**Janette Flintoff, Member. Los Angeles City  
Attorney's Office, Grant Director**

**Cindy Mays, Member, Corporate Liaison**



**Ali Reilly, Member, Fundraising Coordinator**

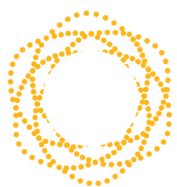
**Christina Gill, Global Family Coordinator**



**528 Palisades Drive, #199, Pacific Palisades, CA 90272**

**[info@knowtheglow.org](mailto:info@knowtheglow.org) \* [www.knowtheglow.org](http://www.knowtheglow.org)**

# ORGANIZATION BUDGET: July 2022 – June, 2022



**KNOW THE GLOW®**