ANNUAL REPORT

2023

The eye is the jewel of the body.-Henry David Thoreau



KNOW THE GLOW* PREVENT CHILDHOOD BLINDNESS

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

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KNOW THE GLOW

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.







Message From our Co-Founder



2023 has been an extraordinary year for KTG. Not only have we expanded our reach into multiple continents and

added amazing new Country ambassadors but we have begun to see our collaborative advocacy flourish in ways we had not even dreamed of a year ago. Attending the ISOO Conference in Mombasa, Kenya, was a pivotal turning point for KTG. Meeting in person the ocular oncologists and ophthalmologists we've worked with for years was an amazing experience. Being asked to close the conference alongside partner We C Hope was a special honor and it was a gift to be able to see how the KTG message of awareness was one also of hope for many of the conference attendees who face unique challenges in each of their home countries. At KTG we are more determined and more optimistic than ever about the future of pediatric vision globally. The KTG vision of eliminating glow-related preventable childhood blindness suddenly seems nearly within reach. Working alongside our incredible KTG volunteers, our patient family ambassadors, our doctors and researchers, students and global partners there is a future brimming with opportunity and we can't wait to be part of it. For now, though, we are beyond grateful for the gifts of this year all made possible by the generous support of our KTG donors and families. We can't wait to see what 2024 might bring but we know it will be another year full of breathtaking surprises and global inspiration!

Meet our new Country Ambassadors!



We are excited to welcome our six new Country Ambassadors (clockwise starting top left), Larry Wagh, India; Grace Mbugua, Kenya; Diane Zizzadoro, United States; Judith Mollel, Tanzania, Rhoda Mboga, Kenya; and Stacy Brown, United Kingdom. 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 have partnerships with Jack McGovern Coats' Disease Foundation,

Prevent Blindness, Arclight Project, Sight For All, We C Hope, Canadian Retinoblastoma Society, Specs for Little Heroes, Iksha Foundation, Half Helen, Sankara Eye Foundation, La Nineta Dels Uls, University of Notre Dame/BolerParseghian Center foe Rare and Neglected Diseases, Cradle , The Ocular Octopus, Seva, Santa Clara University, Lemon Aid Apparel, and KAKS. This year we formed new partnerships with Eyehesive, 1iCollective, The Center for **Ocular Prosthesis, TanzanEye, Lighthouse for** Christ, Childhood Eye Cancer Trust (CHECT), Canadian Retiniblastoma Research Advisory Board (CRRAB), World Society of Pediatric **Opthalmology and Strabismus (WSPOS)**, Retinostop and the RB-NET.



Updates on Medical Advisory Board



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.

Children's Hospital Los Angeles (CHLA) has developed a new method to diagnose retinoblastoma by sampling the fluid at the front of the eye. The National Cancer Institute of the National Institutes of Health (NIH) has awarded Dr. Jesse Berry \$2.8 million to lead the first prospective international retinoblastoma liquid biopsy study to date. The first of its kind, the international liquid biopsy retinoblastoma study, will lead by CHLA's Dr. Berry, MD. Berry's research aims to find a better way to diagnose retinoblastoma, which affects the light-sensing layer at the back of the eye and can result in loss of one or both eves if not treated guickly. Berry's team will lead an international research study, which will include samples from 18 centers, including the largest retinoblastoma center in Canada. The study will be conducted at CHLA, under the direction of Dr. Berry, who is the sole principal investigator named on the grant. The results of the study will help shape the next phase of her research, and the team plans to develop a clinical trial to evolve the standard of care for diagnosing and treating retinoblastoma and link specific treatments to the information identified in the liquid biopsy. Dr. Berry was also in attendance

where she address the ISOO conference and spoke about the liquid aqueous biopsy.

Three other Medical Advisory Board members were also prominently featured at this year'



s ISOO Conference in Mombasa, Kenya. **Dr. Ashwin Mallipatna** (UK) moderated the session on Scientific Collaboration for Improving RB Outcomes along with Helen Dimaras (Canada). **Dr. Francis Munier** (Switzerland) delivered a presentation on



"New Techniques and Technologies in RB," with a particular emphasis on "Intracameral chemotherapy." Additionally, Dr. Munier addressed the paradigm shift in the management of retinoblastoma,

moving from traditional systemic treatments to more targeted and segmented ocular drug delivery methods. **Dr. Carol L. Shields** (USA) discussed "Ocular Surface Squamous Neoplasia," covering surgical approaches and potential treatment options, including "Magic Potions." This session likely offered significant

insights and advancements in the field of retinoblastoma management and ocular surface neoplasia.



Current Activities

SAVING SIGHT WORLDWIDE

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 **Spain**, the United Kingdom, Kenya and Tanzania. Going forward in 2024, KTG hopes to launch campaigns in Brazil, Nigeria, Israel and Switzerland. As we progress internationally, we will be particularly attentive to enlisting international NGO partners with a global or regional presence, but also mindful of the



success that grassroot campaigns can be in remote and far reaching areas. 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 worked 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.





PERFORMANCE BREAKDOWN:

INDIVIDUAL CAMPAIGN PERFORMANCE

| CAMPAIGN | CLICKS | REACH | IMPR. |
|-------------------|---------|-----------|------------|
| TANZANIA CAMPAIGN | 182,731 | 1,519,491 | 8,225,294 |
| KENYA CAMPAIGN | 172,655 | 1,644,410 | 8,839,613 |
| SPAIN CAMPAIGN | 34,168 | 607,620 | 1,384,675 |
| UK CAMPAIGN | 24,268 | 305,914 | 752,830 |
| | 413,822 | 4,075,666 | 19,202,412 |

KTG New Developments



Megan Webber,

Co-Founder of KnowTheGlow, attended the 2023 International Society of Ocular Oncology (ISOO) Conference in Mombasa, Kenya, where she

highlighted the alarming 50% of global Retinoblastoma-related fatalities being concentrated in Africa. Dr. Kahaki **Kimani**, the event's co-coordinator and esteemed Kenyan Ocular Oncologist, crystallized the essence perfectly: "We are at war with this disease, and our response must be relentless and encompassing. We need to bring together all possible weapons from land and sky!"The conference highlighted the dedication and compassion of remarkable physicians, who shared a strong connection despite the challenges faced by Sub-Saharan nations. The conference aimed to create a future where collaborative efforts and a global focus on Africa could serve as the foundation to curb Retinoblastoma's devastation on the continent and transcend it worldwide. The conference also highlighted the need for innovative tools and programs to reduce Retinoblastoma mortality in Africa, paving a swift pathway to diagnosis and referral, eradicating treatment delays, and enveloping patient families in unwavering support. The event represented a turning

point for Megan Webber, who has been forging connections with doctors, researchers, and healthcare professionals worldwide to promote early



detection and treatment of debilitating conditions like Retinoblastoma. Meeting many of these individuals in person, such as **Dr. Laurence Desjardins, Dr. Didi Fabian, Dr. Andrew Blaikie, and Dr. Richard Bowman**, provided a unique opportunity to witness how they are all interconnected and passionately dedicated to the common objective of early detection and treatment of debilitating conditions like RB.





Working Together to Spread Awareness

In October, our friends at TanZanEye, led by founder Karsten Paust and project manager Ryner Linuma in Kasulu, Kigoma Region, Tanzania, dedicated their efforts to providing crucial vision-related healthcare. Dr. Andrew Blaikie and The Arclight Project supported their endeavors, collaborating with KnowTheGlow to raise awareness about eye health in Tanzania. Their tireless work resulted in the examination of almost 600 patients and the completion of nearly 500 eye surgeries. Additionally, around 10 children were referred to specialized centers. The use of The Arclight ophthalmoscope played a vital role in training eye care workers and in examining patients. This

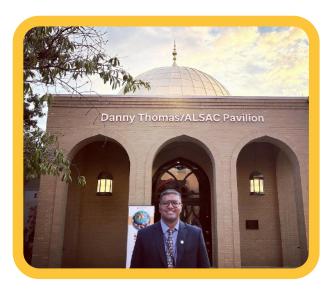


collaborative effort extended further: at this year's ISOO, **WeCHope's President, Marissa Gonzalez,** committed \$5,000 to ensure the device's availability in LMICs like Kenya, Nepal, Nigeria, Ghana, and Tanzania. We take immense pride in the impactful work achieved in Tanzania and extend heartfelt gratitude to everyone involved.!





Our Champions



Larry Wagh, an RN, MSN, and PhD Scholar from St. Andrews College of Nursing in Pune, participated in the 5th St Jude Global Academy in Palliative Care Pediatric Training in Memphis, Tennessee, USA. The training brought together 39 healthcare professionals from 30 institutions across 24 countries, fostering international collaboration. Wagh, the sole Indian nurse selected from 200+ applicants, gained insights into St. Jude's focus on improving patient dignity and comfort for enhanced quality of life. In October 2023, Dr. Larry Wagh organized an International Webinar on World Sight Day, addressing Diagnosis, Treatment, Nursing Care, and Prevention Practices for Good Eye Health and offered eCertificates to attendees. Wagh found his U.S. experience enriching, appreciating the openness, friendliness, and helpfulness of the people. He emphasizes the importance of impactful actions that leave a lasting resonance in our lives.



, Dr. Kanwal "Ken" Nischal a pioneer in pediatric ophthalmology, leads transformative change through the World Society of Pediatric Ophthalmology and Strabismus (WSPOS). His inclusive and innovative initiatives foster global collaboration, revolutionizing children's eye care. WSPOS, under his guidance, adopts a multidisciplinary approach, welcoming professionals from diverse backgrounds, including optometrists and ophthalmologists. Their annual conferences emphasize the interconnected nature of pediatric and adult ophthalmology, promoting holistic eye health. Dr. Nischal advocates for campaigns to disseminate consistent information, address eye care awareness discrepancies, and encourage early detection. WSPOS democratizes education by partnering with local pediatric communities. The COVID-19 pandemic has boosted WSPOS's digital presence, with webinars and YouTube channels gaining thousands of viewers. Dr. Nischal pushes for a robust digital platform, with support from organizations like the World Bank, to overcome barriers like data limitations and unreliable electricity.

Victor Mugadiri, a clinical officer from Kenya, has become a local hero through his collaboration with Megan Webber and Helene Dameris of KnowTheGlow. Mugadiri, a clinical officer with a degree in clinical medicine and community health, has honed his skills through a rigorous degree program and internship at Mombasa Coast General Hospital. He also takes on a part-time lecturer role at the Kenya Medical Training College. Victor's passion for community health is evident in his dedication to raising awareness about preventable and manageable health conditions. He emphasizes the importance of early detection and treatment, particularly in rural areas. The unique structure of Kenya's healthcare system, consisting of six levels, often lacks doctors, making clinical officers and nurses crucial in delivering healthcare services to rural areas. Victor has collaborated with religious organizations to address common health conditions in communities, tapping



into existing networks and working towards a shared goal of raising awareness about preventable health issues before they escalate. He envisions incorporating KnowTheGlow's message into medical camps, church meetings, and community gatherings to provide a space for people to access information and educate today's parents and save sight for the children of tomorrow.



Christian, a retinoblastoma survivor, carries himself with confidence and grace. When asked about his eye, he proudly shares a bible quote assuring people that

he is "fearfully and wonderfully

made." His story, like that of his mother

Grace, is a testament to the power of love, resilience, and unwavering determination in the face of adversity.



KnowTheGlow recently collaborated with **Marcia Zondervan**, leader of the VISION 2020 LINKS & Networks Programme at the International Centre for Eye Health, London School of Hygiene & Tropical Medicine, and her colleague Claire Walker at the ISOO conference in Mombasa, Kenya. They discussed the **Retinoblastoma Network (Rb-NET)**, a

global collaboration diagnosing and treating children with retinoblastoma. The meeting revealed a potential partnership

between KnowTheGlow and Rb-NET to address retinoblastoma challenges in lowand middle-income countries (LMIC). Rb-NET, originating from the urgent need to treat retinoblastoma in low-income countries, strengthens capacities in these nations and conducts multi-country research to address global inequities in survival rates. They've established a Multi-Disciplinary Team (MDT) approach for expert panels to discuss cases and provide support, improving treatment outcomes. Rb-NET's collaborative spirit extends to partnerships with organizations like ISOO and COECSA, with the goal of fostering knowledge exchange and sustainable solutions. The meeting underscored the importance of collaboration in improving children's eye care, aligning with KnowTheGlow's mission to provide brighter futures for children with sight-threatening eye conditions worldwide.

Beyond the Glow is a heartfelt initiative founded in 2023 by **Christina Gill.** Driven by her personal journey navigating a child's rare eye disease, Christina envisioned this platform as a guiding light for families facing similar challenges. With firsthand experience in the struggle to find resources on enucleation for her young son, Christina aims to foster a supportive community and provide invaluable information.



Beyond the Glow aspires to expand, spotlighting exceptional organizations and offering vital insights for families transitioning 'beyond the glow' of initial diagnosis, ensuring a brighter future for all.

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

Student Chapters and Internships



We are so proud and inspired by our **Notre Dame University** chapter of KTG!! Working with KTG and the **Rare ND Club** in advance of the **IAPB's World Sight Day** on October 12th, students at the University of Notre Dame hope to raise widespread awareness of ways to focus on vision health as we encourage people worldwide to Love Your Eyes!





Dr. Jen Viñola, the Chapter Advisor for the **Manila Central University** chapter in the Philippines, was delighted to announce the success of their inaugural in-person seminar held in May, titled "Eye Care Awareness: New Eye Knowledge the Glow." Their audience consisted of students ranging from 4th to 6th grade, affectionately referred to as their 'Glow Detectives.' The children were accompanied by their parents via the Zoom Meeting platform.

The seminar delved into the organization's advocacy and mission, with Chapter members providing insights into the concept of the Glow. The discussion covered how to detect it, its underlying causes, and the profound impact early detection and treatment can have on a child's life trajectory.







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



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