



# One Retinoblastoma World

Virtual Conference  October 1-3, 2021

**HOSTED BY:**

World Eye Cancer Hope and Australian Retinoblastoma Supporters

# World Eye Cancer Hope

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## Life and Sight for Every Child

World Eye Cancer Hope was inspired by two little girls born worlds apart who were united through their experiences with retinoblastoma.

### Daisy's Story

In England, Daisy was 13 months old when cancer was found in both eyes. Sadly, her first eye was removed just two months into treatment. In a last attempt to save her second eye, her family took her to Canada. The Daisy Fund was set up to raise money to meet the costs of treatment and living in Canada for 15 months. Despite successful treatments, complications led to Daisy's second eye being removed in February 2004, a month before her fifth birthday.



### Rati's Story

In Botswana, Rati's cancer was initially missed, but later diagnosed in one eye, which led to its removal when she was 11 months old. Her doctors considered her cured, but 19 months later the cancer was back. Rati's parents connected online with Abby White, a retinoblastoma survivor living in Oxford, UK. A search for help led to The Daisy Fund providing funds for care. Rati responded well to treatment, but after a year in remission, the cancer returned, and no more treatment was possible. Rati passed away on August 21, 2006. She was four and a half years old.



**World Eye Cancer Hope** evolved from the generosity of Daisy's family and the agony of Rati's loss, creating light within the darkness cancer brought to their lives. Daisy, Rati and their families inspire us every day on our journey to develop high quality sustainable care that protects life and sight for every child fighting retinoblastoma, brings hope to their families and life-long care to all survivors.



## Welcome

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# One Retinoblastoma World

World Eye Cancer Hope is excited to welcome families, survivors, patients, and medical professionals to One Retinoblastoma World 2021! While we wish everyone was gathering in person on the sunny beaches of Hawaii, we are confident that you will enjoy, learn, and connect virtually with our international retinoblastoma community.

This year, World Eye Cancer Hope USA partnered with supporters, families, survivors, and clinicians in Australia to shine a light on our community in the Pacific Rim. We are delighted to showcase many of our Aussie Rb team and are excited to have a large contingent of participants in attendance. Continuing to engage a local co-host for these conferences is vital to connect with Rb communities around the world, and we are grateful to all of our Australian supporters who made this year's conference possible.

Between the two of us, we have attended all five One Retinoblastoma World conferences: London in 2012, Toronto in 2014, Dublin in 2016, Washington D.C. in 2017, and virtually in Ottawa in 2020. We witnessed first-hand the camaraderie that is built when parents and survivors are at the table with medical professionals. Bringing everyone together ignites conversations about the care and treatments for Rb patients, survivors, and the need for long-term survivorship care.

Working groups, support groups and friendships are built at these conferences, and it is a testament to the participants who have maintained these valuable relationships through the years. These partnerships will continue to flourish during our virtual meeting, and new attendees will be welcomed into this unique community. We encourage participants to use the networking sessions to meet new people and reconnect with those you have not seen in years. The global retinoblastoma community grows and is strengthened by these relationships.

Thank you for joining us for this year's One Retinoblastoma World. We look forward to spending the next three days with you and working alongside all of you to provide life, sight, and hope for all who live with retinoblastoma.

**Follow the conference on social media using  
#OneRbWorld2021.**

**Marissa D. Gonzalez**

Bilateral Retinoblastoma Survivor  
President and Founding Board Member,  
World Eye Cancer Hope USA  
Event Chair, One Retinoblastoma World  
2017 and 2021

**Dr. Sandra Staffieri, BAppSc(orth), Ph.D.**

Retinoblastoma Care Co-Ordinator, Royal  
Children's Hospital, Victoria, Australia  
Research Fellow, Centre for Eye Research  
Australia, Victoria, Australia  
Event Chair and Scientific Program Co-  
Ordinator, One Retinoblastoma World 2021

# Program

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**Friday, October 1, 2021**

**Schedule provided in Pacific Daylight Time (UTC-7).**

## **3:00 – 3:10 pm: Welcome Remarks**

**Session Leaders:**

- Marissa D. Gonzalez, President and Founding Board Member, World Eye Cancer Hope USA; Retinoblastoma Survivor, Los Angeles, California, USA.
- Dr. Sandra E. Staffieri, BAppSc(orth), PhD, Retinoblastoma Care Coordinator, Royal Children’s Hospital, Victoria, Australia; Research Fellow/Clinical Orthoptist, Centre for Eye Research Australia, University of Melbourne, Melbourne, Australia.

## **3:10 – 3:25 pm: Keynote: Cheryl Newman**

**Session Leader:**

- Cheryl Newman, Retinoblastoma Survivor and Parent, Victoria, Australia.

**Session Description:**

“**Thriving as a Survivor.**” I have been fortunate to live a full and blessedly ordinary life. How does being a retinoblastoma survivor impact me, and what has helped me thrive as I have lived with a diagnosis with lifelong implications for myself and others whom I hold dear?

## **3:25 – 3:30 pm: Child Life Overview: “Child Life for Retinoblastoma: Commitment to Coping”**

**Session Leader:**

- Morgan Livingstone, MA CCLS CIMI-2/CIIT, Child Life Therapist, Sick Kids Hospital, Toronto, Ontario, Canada.

## **3:30 – 4:00 pm: Concurrent Child Life Activity: Eye Dropper Art**

**Session Leaders:**

- Morgan Livingstone, MA CCLS CIMI-2/CIIT, Child Life Therapist, Sick Kids Hospital, Toronto, Ontario, Canada.
- Olivia Larkens, Certified Child Life Therapist, Royal Children’s Hospital, Melbourne, Victoria, Australia.

**Session Description:**

During this interactive session, children will create eye dropper (pipette) art creations, read a new social narrative story book about eye drops. Why we need to get eye drops, positions that help us feel more comfortable when receiving eye drops, and building up our

independence in administering eye drops on our own when we are ready. We will write a song to help us focus, stay calm and cope better when we need to have eye drops.

**Art Supplies:**

- Eye droppers/pipettes/syringes
- Food colouring or liquid paints
- Paper or paper towels (absorbent paper helps)

**3:30 – 4:20 pm: Survivor Panel Discussion**

**Session Leader:**

- Marissa D. Gonzalez, President and Founding Board Member, World Eye Cancer Hope USA; Retinoblastoma Survivor, Los Angeles, California, USA.

**Session Panelists:**

- Cheryl Newman, Retinoblastoma Survivor, Wodonga, Victoria, Australia.
- Kieran Donovan, Retinoblastoma Survivor, Edinburgh, Scotland, UK.
- Genevieve Savoie, Retinoblastoma Survivor, Toronto, Ontario, Canada.

**Session Description:**

Hear from three survivors from three continents and learn about their experiences with retinoblastoma through adolescence and adulthood.

**4:20 – 4:30 pm: Break**

**4:30 – 5:20 pm: Survivorship and Second Cancer Risk**

**Session Leader:**

- Marissa D. Gonzalez, President and Founding Board Member, World Eye Cancer Hope USA; Retinoblastoma Survivor, Los Angeles, California, USA.

**Session Presenter:**

- David R. Freyer, DO, MS, Director, Survivorship and Supportive Care Program, Children's Hospital Los Angeles, Los Angeles, California, USA; Director, Cancer Survivorship Program and Co-Director, Adolescent and Young Adult Cancer Program, University of Southern California Norris Comprehensive Cancer Center, Los Angeles, California, USA; Professor of Clinical Pediatrics and Medicine, Keck School of Medicine, University of Southern California, Los Angeles, California, USA.
- Yasmeen Khan, PA, USC Norris Comprehensive Cancer Center, Los Angeles, California, USA.

**Session Description:**

Learn about second cancer risks and the importance of finding a survivorship clinic for life-long care.

## **5:20 – 5:30 pm: Break**

## **5:30 – 6:20 pm: Genetics and Retinoblastoma**

### **Session Leader:**

- Dr. Hilary Racher, PhD, Scientific and Laboratory Operations Director, Genetics, Toronto, Ontario, Canada.

### **Session Description:**

This session will discuss a brief history of *RB1* genetics, heritable vs. non-heritable retinoblastoma, and a day-in-the-life of a sample at a genetics laboratory.

## **6:20 – 6:30 pm: Break**

## **6:30 – 7:20 pm: All About Prosthetic Eyes!**

### **Session Leader:**

- Marissa D. Gonzalez, President and Founding Board Member, World Eye Cancer Hope USA; Retinoblastoma Survivor, Los Angeles, California, USA.

### **Session Presenters:**

- Matthew Milne, Ocularist, Toronto, Ontario, Canada. **“The Role of the Ocularist in the Retinoblastoma Patient Journey.”**
- Marissa Gonzalez, Retinoblastoma Survivor, Los Angeles, California, USA. **“My Implant Story.”**
- Camille Loyer, Ocularist, Loyer Artificial Eyes, Melbourne, Victoria, Australia. **“Pets, Play and Prosthetic Eyes.”**

### **Session Description:**

Ocular prosthetics are familiar to many retinoblastoma survivors. An overview of ocular prosthetics and strategies to support visits to the ocularist for young children.

## **7:20 – 7:55 pm: Networking**

### **Topic for Discussion:**

- Sharing thoughts and experiences on survivorship.

## **7:55 – 8:00 pm: Closing Remarks**

### **Session Leader:**

- Mark Billings, Treasurer and Board Member, World Eye Cancer Hope USA; Retinoblastoma Parent, Philadelphia, Pennsylvania, USA.

# Program

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**Saturday, October 2, 2021**

**Schedule provided in Pacific Daylight Time (UTC-7).**

## **2:00 – 2:05 pm: Welcome Remarks**

**Session Leader:**

- Dr. Sandra E. Staffieri, BAppSc(orth), PhD, Retinoblastoma Care Coordinator, Royal Children’s Hospital, Victoria, Australia; Research Fellow/Clinical Orthoptist, Centre for Eye Research Australia, University of Melbourne, Melbourne, Australia.

## **2:05 – 2:15 pm: Keynote: Sarah Yang**

**Session Leader:**

- Sarah Yang, Retinoblastoma Survivor, Melbourne, Victoria, Australia.

**Session Description:**

“**Shaped, but not defined by RB.**” In between studying and university classes, you can catch Sarah scaling walls, building cars, playing piano, and drawing. Get to know Sarah and hear about her hobbies, studies, future plans, and how her experience with RB has shaped who she is, but not defined her.

## **2:15 – 2:30 pm: Photo Collage Presentation: “Life Without Limits”**

**Session Leader:**

- Sarah Yang, Retinoblastoma survivor, Melbourne, Victoria, Australia.

**Session Description:**

Narrated by Sarah Yang. Check out what survivors around the world love to do!

## **2:30 – 3:20 pm: Taking Care of Our Mental Health**

**Session Leader:**

- Dr. Pernille Gregersen, Senior Consultant, Clinical Geneticist, Department of Clinical Genetics, Aarhus University Hospital, Aarhus, Denmark.

**Session Presenters:**

- Dr. Pernille Gregersen, Aarhus, Denmark. “**Preserving positive mental health.**”
- Olivia Larkens, Certified Child Life Therapist, Royal Children’s Hospital, Melbourne, Victoria, Australia. “**Mental health strategies – A family affair.**”
- Grace Dillon, Retinoblastoma Survivor, Student, Brisbane, Queensland, Australia. “**It’s the little things....**”

### Session Description:

Why is preserving positive mental health from diagnosis through to adult survivorship in patients, parents, and families important and how can we support it? How and why do we as clinicians need to look after ourselves too?

### **3:20 – 3:30 pm: Break**

### **3:30 – 4:30 pm: The Dreaded Drops!**

#### Session Leader:

- Paula Dillon, BN, PostGradDip Mid, MMid, Retinoblastoma Parent, Brisbane, Queensland, Australia.

#### Session Presenters:

- Dr. Sandra Staffieri, Retinoblastoma Care Co-Ordinator, Royal Children's Hospital, Melbourne, Victoria, Australia. **"Do I have to have drops today?"**
- Belinda Faure, Retinoblastoma Parent, Melbourne, Victoria, Australia. **"The challenge of eye drops – A parent's perspective."**
- Olivia Larkens, Certified Child Life Therapist, Royal Children's Hospital, Melbourne, Victoria, Australia. **"Helping children with eye drops."**

#### Session Description:

This session is dedicated to the dilating eye drops that are used to fully examine the eyes. They remain the primary cause of great angst and distress for the child having the drops, the caregiver who supports the child, and the health professional who instils them. This repeated, invasive, but very necessary part of any eye exam can set the infant or child up for a lifetime of distress related to medical procedures. We will examine eye drops from the perspective of the clinician, the child, the parent, and the Child Life Therapist who works to mitigate the distress.

### **4:30 – 5:00 pm: Concurrent Child Life Activity: Milk Rainbows**

#### Session Leader:

- Olivia Larkens, Certified Child Life Therapist, Royal Children's Hospital, Melbourne, Victoria, Australia.

#### Session Description:

During this interactive session, children will read a story about feelings and colours and then experiment with some of these colours using an eyedropper, food colouring and some other common items found around the house. We will be making some mesmerising patterns and we might even be able to make some new colours!

#### Art Supplies:

- A shallow bowl or plate with a lip on it
- A cup of milk

- Liquid food colouring
- A small dish with a little bit of dishwashing liquid
- Eye droppers (if the food colouring isn't in droppers)
- A cotton bud (q tip)

### **4:30 – 5:00 pm: Networking**

#### Topic for Discussion:

- Normalizing discussions around preserving mental health.

### **5:00 – 5:10 pm: Break**

### **5:10 – 6:55 pm: Raising Awareness of Retinoblastoma – Thinking Outside the Box**

#### Session Leader:

- Dr. Sandra E. Staffieri, BAppSc(orth), PhD, Retinoblastoma Care Coordinator, Royal Children's Hospital, Victoria, Australia; Research Fellow/Clinical Orthoptist, Centre for Eye Research Australia, University of Melbourne, Melbourne, Australia.

#### Session Presenters:

- Jo Croft, Eye Health Educator, Optometrist - Sight for All. Adelaide, South Australia, Australia. **“Teaching the world to see – Sight for All’s work raising awareness of retinoblastoma.”**
- Petra Maxwell, Information and Research Manager, Childhood Eye Cancer Trust (CHECT), London, UK. **“Retinoblastoma Awareness on a Shoestring.”**
- Paula Dillon Brisbane, Queensland, Australia. **“All roads lead to Retinoblastoma awareness.”**
- Dr. Sandra Staffieri, Retinoblastoma Care Co-Ordinator, Royal Children's Hospital, Melbourne, Victoria, Australia. **“From inspiration to implementation – the never-ending story.”**
- Dr. Ligia Fu MD. Tegucigalpa, Honduras. Pediatric Hematologist & Oncologist, Hospital Escuela Universitario, Tegucigalpa, Honduras. **“Raising Healthcare Provider Awareness in the Virtual World.”**

#### Session Description:

We all seek the same goal – earlier diagnosis and better outcomes – saving lives, eyes and sight. This session will showcase organizations and strategies that are being used around the world to improve awareness and early diagnosis of retinoblastoma.

### **6:55 – 7:00 pm: Closing Remarks**

#### Session Leader:

- Lisa Hester, Board Member, World Eye Cancer Hope USA; Retinoblastoma Parent, Southern California, USA.

# Program

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**Sunday, October 3, 2021**

**Schedule provided in Pacific Daylight Time (UTC-7).**

## **9:00 – 9:05 am: Welcome Remarks**

**Session Leader:**

- Marissa D. Gonzalez, President and Founding Board Member, World Eye Cancer Hope USA; Retinoblastoma Survivor, Los Angeles, California, USA.

## **9:05 – 9:20 am: Keynote: Clayonia Colbert-Dorsey**

**Session Leader:**

- Clayonia Colbert-Dorsey, Retinoblastoma Survivor, Washington, USA.

**Session Description:**

**“More than Conquerors: We Are Legacy, We Are Hope, We Are Resilient – Rise Up!”**

When one faces life’s trials and tribulations, when there appears to be trouble on every side, how do we rise above those circumstances? Make no mistake, it is within these deep valleys that we must develop resilience that is reflective of hope, determination, promise, and victory. This session will explore harnessing this characteristic, especially in times of uncertainty.

## **9:20 – 9:50 am: Concurrent Child Life Activity: Learn with Bubbles!**

**Session Leader:**

- Morgan Livingstone, MA CCLS CIMI-2/CIIT, Child Life Therapist, Sick Kids Hospital, Toronto, Ontario, Canada.

**Session Description:**

In this interactive child life activity session, we will be blowing bubbles to create beautiful paintings. This activity helps teach children about breathing and blowing, and we explore how we can use deep breathing to stay calm. We will read a story about “My Magic Breath: finding calm through mindful breathing” and practice some fun animal-style breaths we can use when we need to relax our minds and bodies.

**Art Supplies:**

- A cup
- A straw
- Dish soap (to make good bubbles)
- Liquid children’s paint (Tempra paint is a water-based children’s paint that is non-toxic)
- Paper
- Tray, towel or mess tablecloth for possible paint spills

## 9:20 – 10:10 am: Retinoblastoma Around the World

### Session Leader:

- Marissa D. Gonzalez, President and Founding Board Member, World Eye Cancer Hope USA; Retinoblastoma Survivor, Los Angeles, California, USA.

### Session Presenters:

- Dr. Minh Chau MD, Hanoi, Vietnam. Paediatric Ophthalmologist, Retinoblastoma Specialist. **“Retinoblastoma in VietNam – On the way!”**
- Dr. Swathi Kaliki MD, Ocular Oncologist, Hyderabad, India. Head, The Operation Eye Sight Universal Institute for Eye Cancer, LV Prasad Eye Institute, Hyderabad, India. **“Retinoblastoma in India.”**
- Dr. Viviane Lanzelotte MD, Rio de Janeiro, Brazil. Pediatric Ophthalmologist, Master's Degree in Maternal and Child Health from Federal Fluminense University; Ophthalmologist at the Rio de Janeiro Municipal Health Secretariat; President of the Ophthalmology Working Group of the Pediatric Society of Rio de Janeiro (SOPERJ)  
  
Dr. Clarissa Mattosinho MD, PhD., Rio de Janeiro, Brazil. Ophthalmologist, Department of Ocular Oncology, National Institute of Cancer, Brazil.  
**“COVID-19 Pandemic in Brazil – Effect on diagnosis.”**
- Dr. Sandra Staffieri, Retinoblastoma Care Co-Ordinator, Royal Children's Hospital, Melbourne, Victoria, Australia. **“Retinoblastoma in Australia and New Zealand – The whole is greater than the sum of its parts.”**

### Session Description:

Retinoblastoma affects children in every corner of the world – albeit experiences and outcomes vary between high-income and low-middle income countries. This session will highlight retinoblastoma diagnosis, treatment, and overcoming challenges around the world.

## 10:10 – 10:15 am: Break

## 10:15 – 11:05 am: Global Glow Detection and RB Awareness

### Session Leader:

- Cindy Mays, Retinoblastoma Parent, Los Angeles, California, USA.

### Session Presenters:

- Megan Weber, Los Angeles, California, USA. **“Know the Glow.”**
- Dr. Andrew Blaikie, University of St Andrews, Scotland, UK. **“ArcLight Scope.”**
- Larry Wagh, Retinoblastoma Parent, Pune, India. **“Patient experience in India.”**

### Session Description:

The “white glow” in the pupil, described by parents at presentation, is the most common presenting sign for retinoblastoma. This session will focus on how this characteristic sign can be harnessed to enhance early detection of Rb.

### 11:05 – 11:30 am: Networking

#### Topic for Discussion:

- What? When? How? And Who? Brainstorming awareness strategies.

### 11:30 am – 12:20 pm: Ethnography in Retinoblastoma

#### Session Leaders:

- Dr. Helen Dimaras, PhD, Scientist. Child Health Evaluative Sciences and Centre for Global Child Health, SickKids Research Institute, Toronto Ontario, Canada.
- Clayonia Colbert-Dorsey, Retinoblastoma Survivor. Manager, Continuing Education Provider Services, The American Speech-Language-Hearing Association Gaithersburg, MD, USA

#### Session Description:

It’s been said that it takes a village to raise a child. Traditionally, African-American families have long embraced multi-generational familial engagement. Together, we will explore: the role family plays in navigating the childhood cancer journey; perspectives in which this may differ culturally; and, how extended relational bonds can improve psychosocial outcomes for children with retinoblastoma.

### 12:20 – 1:55 pm: Looking to the Future! What’s New and on the Horizon

#### Session Leader:

- Dr. Ashwin Mallipatna, Pediatric Ophthalmologist. Retinoblastoma Program, SickKids Hospital, Toronto Ontario, Canada. Assistant Professor, University of Toronto.

#### Session Presenters:

- Dr. Brenda Gallie SickKids Hospital Toronto, Ontario, Canada. **“Phase I Clinical Trial of Chemoplaque Sustained-release Chemotherapy for Retinoblastoma.”**
- Dr. Pernille Gregersen, MD, Senior Consultant, Clinical Geneticist, Department of Clinical Genetics, Aarhus University Hospital, Aarhus, Denmark. **“The role of regular follow-up at the Danish Retinoblastoma Survivorship Clinic.”**
- Dr. I. Didi Fabian, MD, Associate Professor, Sheba Medical Center, Israel, and the International Centre for Eye Health, the London School of Hygiene & Tropical Medicine, UK. **“Retinoblastoma management during the COVID-19 pandemic.”**

- Genevieve Savoie, Retinoblastoma Survivor, President, Canadian Retinoblastoma Society, Toronto, Ontario, Canada. **“Canadian Retinoblastoma Society – An Overview.”**
- Ivana Ristevski, Retinoblastoma Parent. **“Canadian Retinoblastoma Research Advisory Board (CRRAB) Strategies and Updates.”**
- Ana Janic, Medical Student, Toronto, Ontario, Canada. **“The Red Reflex: Past, Present and Future.”**
- Dr. Sandra Staffieri, Retinoblastoma Care Co-Ordinator, Royal Children’s Hospital, Melbourne, Victoria, Australia. **“Investigating pathways to diagnosis: Can the answer hold the key to awareness programs?”**

**Session Description:**

Research is the bedrock of new discovery and the way forward. In this session, we highlight recently published works and exciting projects that are on the horizon.

**2:20 – 2:30 pm: Closing Remarks**

**Session Leader:**

- Marissa D. Gonzalez, President and Founding Board Member, World Eye Cancer Hope USA; Retinoblastoma Survivor, Los Angeles, California, USA.

# Thank You

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**A special thank you to members of the organizing committee for making this meeting possible:**

**Sandra Staffieri, Marissa D. Gonzalez, Jennifer Franco, Emily Rainbolt, Kristen Small, and Abby White**

World Eye Cancer Hope and Australian Retinoblastoma Supporters would like to thank everyone who donated their time and expertise to this year's One Retinoblastoma World Conference. To all of our presenters, your insight and expertise are invaluable and very much appreciated. Thank you.



*One Retinoblastoma World 2017 attendees in Washington, D.C.*