



One Retinoblastoma World
Virtual Conference  October 3-4, 2020

CONFERENCE REPORT

HOSTED BY:

World Eye Cancer Hope, International Retinoblastoma Consortium,
Canadian Retinoblastoma Research Advisory Board, Canadian Retinoblastoma Society

Conference Report

Attendees from 6 Continents

12 American States

5 Canadian Provinces

37 Countries

(Argentina, Australia, Belgium, Botswana, Brazil, Bulgaria, Canada, Chile, Colombia, Congo (Democratic Republic), Denmark, Ethiopia, Finland, France, Gambia, Germany, Ghana, Honduras, India, Ireland, Kenya, Malaysia, Mexico, Morocco, Nigeria, Pakistan, Philippines, Portugal, Russian Federation, Scotland, South Africa, Spain, Turkey, Ukraine, United Kingdom, USA, Vietnam)

199 Attendees Overall

117 Patients, Survivors, Family Members

82 Medical Professionals & Researchers

What is One Retinoblastoma World?

One Retinoblastoma World is a global network with the bold idea that all children with retinoblastoma can have equal access to optimal care. This conference gathers together eye and cancer specialists, researchers, parent and survivor advocates from around the world to pursue best possible care for all affected children and survivors.

The One Retinoblastoma World Conference is held every 2-3 years in conjunction with the International Society of Paediatric Oncology congress. Previously held in London (2012), Toronto (2014), Dublin (2016), and Washington, D.C. (2017), the Conference is co-directed by World Eye Cancer Hope, a global patient-driven advocacy organization, and a local host.

The 2020 Society of Paediatric Oncology congress was originally planned to be held in Ottawa, Canada. Three Canadian organizations were selected as co-hosts for the 2020 One Retinoblastoma World Conference: the International Retinoblastoma Consortium, the Canadian Retinoblastoma Research Advisory Board, and the Canadian Retinoblastoma Society.

While this conference was planned to occur in Ottawa, due to the uncertainty created by the COVID-19 pandemic, the co-hosts decided to hold the 2020 conference virtually. This novel structure allowed for global collaboration and networking while prioritizing attendee health and safety.

The One Retinoblastoma World 2020 Virtual Conference was held in October and encouraged collaboration and networking while focusing on understanding the needs of the child and family. In order to improve survival, vision outcomes and psychosocial care for all children, families and survivors there must be a solid foundation to support multi-centre global research in order to develop greater knowledge and scientific evidence. The collaboration and partnership of this conference helped build some of this foundation.

The conference programming was based on community feedback and covered a wide variety of topics related to

retinoblastoma, including awareness, early diagnosis, treatment guidelines, vision, child life, genetics, psychosocial impacts, second cancer screening, survivorship and research. Important aspects of retinoblastoma care were explored through a combination of presentations, question-and-answer periods, and networking sessions to facilitate small group discussions.

Drawing inspiration from the Canadian Retinoblastoma Patient Engagement Strategy, a guiding principle for the conference was patient partnership. Each panel of the conference was co-led by an individual with lived experience with retinoblastoma and a healthcare professional or researcher.

As with all four previous meetings attendees included a broad mix of oncologists, ophthalmologists, nurses, allied health professionals, research scientists, parents, family members and survivors. Collaborative research, clinical care and family support benefitting the majority of children and survivors can only be developed through these inclusive meetings with a real-world focus. Thanks to the completely virtual format, the 2020 conference was able to reach a wider range of people around the world.

When diagnosed early and treated effectively, retinoblastoma is highly curable. No child should die, or suffer avoidable blindness, from this cancer. Working together we can provide life, sight and hope for all affected by retinoblastoma.



Pictured above: Some of the conference attendees signing off after closing remarks.

Day One

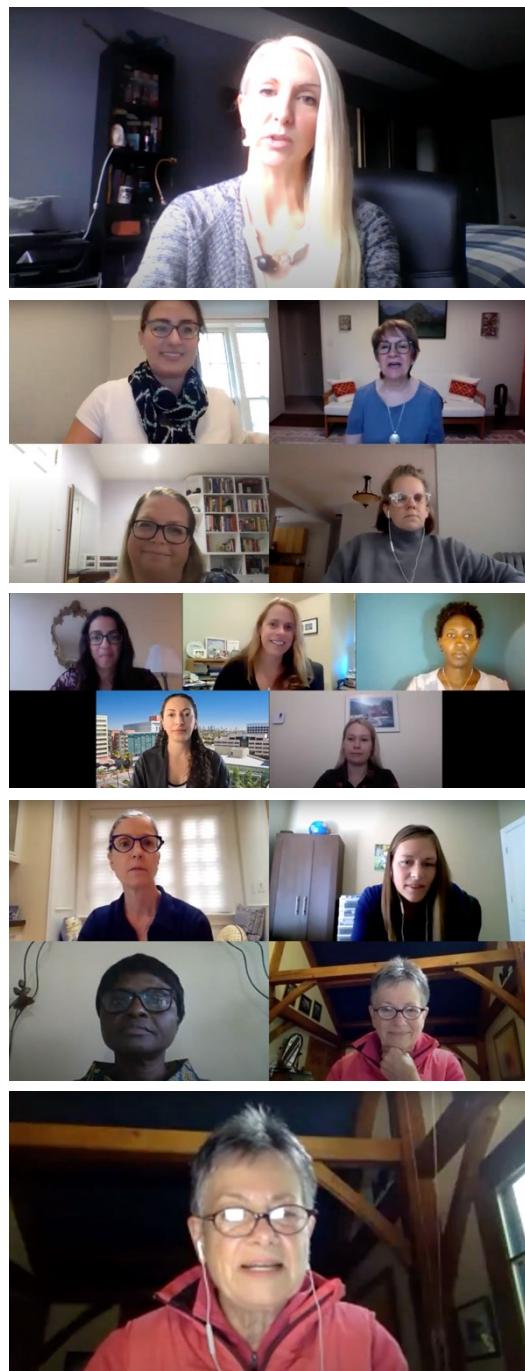
We kicked off the conference with an engaging keynote on retinoblastoma patient engagement and how two of the conference's co-hosts, the Canadian Retinoblastoma Research Advisory Board and the Canadian Retinoblastoma Society, engage the retinoblastoma community in research, education and advocacy. The first panel of the day discussed the psychosocial impacts of retinoblastoma diagnosis, treatment and survivorship on retinoblastoma patients, survivors, and families. Here we learned about programs available in North America and Africa and heard perspectives of a survivor and family member. Following this session was the conference's first Child Life activity. Children were able to interact with a Child Life Specialist to create Feelings Tubes. This fun activity showed children the importance of opening up and talking about their feelings. After this fun session and a short break all attendees were randomly put into small groups for an informal networking session to share retinoblastoma stories, passions and experiences. The next session of day one discussed survivorship and second cancer screening. Here we learned about survivorship clinics, the role of the ocularist, and the importance of self-advocacy as an adult retinoblastoma survivor. The final session of Day One focused on retinoblastoma awareness and early diagnosis. Speakers discussed the importance of awareness for early detection and highlighted past campaigns in Brazil and Australia. Also presented were tools available to help diagnose retinoblastoma and parent perspectives on how awareness of retinoblastoma influenced their child's retinoblastoma journey.



Pictured above: Morgan Livingstone reads a story to begin the Child Life activity.

Day Two

Day Two began with an engaging keynote on the importance of Child Life in a young patient's retinoblastoma journey and empowered parents of children affected by retinoblastoma to offer support to their children. The first session of the day covered the topic of retinoblastoma and vision, in which speakers discussed the effect of treatment on vision and how vision and hearing develops in those with only one eye. We heard from patients on how visual impairment from retinoblastoma treatment affected their lives as children and how it affects them today. The next session covered the topic of retinoblastoma genetics. Speakers discussed the genetic causes of retinoblastoma, genetic counselling services in relation to family planning, and new genetic research studies. We heard from a patient who shared her family's history to show how retinoblastoma diagnosis, treatment and outcomes have changed with each generation. In the following panel on retinoblastoma treatment guidelines and new treatments, speakers discussed the importance of evidence-based clinical guidelines and presented the current progress on the Canadian and Ghanaian retinoblastoma treatment guidelines. We also learned about a new eHealth communication tool and advancements in intra-arterial chemotherapy and testing of the sustained-release chemotherapy plaque. Following these sessions was the conference's second Child Life activity. Children interacted with a Child Life Specialist to create Calming Jars. This activity showed children the importance of coping strategies to focus and relax when feeling make you upset. To close out the conference, we held one final networking session – a great opportunity to meet people with personal and professional experience of retinoblastoma, and to share our thoughts on the topics presented throughout the day.



Pictured above from top to bottom:
Keynote, Retinoblastoma and Vision
Panel, Retinoblastoma Genetics Panel,
Retinoblastoma Treatment Guidelines
and New Treatments Panel, Closing
Remarks.

Conference Feedback

"I think what resonated with me most is hearing other people's stories.... But then the other platforms are interesting as well. For example, the family member's experiences. And what is new in terms of future developments. I'm sure it took months to put that event together. I'm glad I joined."

— Adult Retinoblastoma Survivor

"Overall I liked the event and was glad to hear from the various people's different points of view. I've almost never spoken about this subject so it was a treat to listen to even a single person's words on any issue around RB."

— Adult Retinoblastoma Survivor

"I continue to be blown away by the compassion present in the RB community. It has been a wonderful experience to hear from medical professionals and other survivors, the world feels a little smaller for a few days."

— Adult Retinoblastoma Survivor

"I think it was overall a great experience and there was some valuable information gleaned. One could feel the community spirit, and there were parts that felt like a family picnic of sorts. My daughter really enjoyed the Child Life session and it was fantastic that she was able to jump in and out and see people like her. I think it also helped to provide an international perspective which was great."

— Parent of Retinoblastoma Survivor

My child was just diagnosed in recently, so seeing the people who have not only survived their RB diagnosis, but THRIVED brought tears to my eyes. So much goes through your mind with an RB diagnosis and seeing these extremely smart and thoughtful individuals move ahead in life was so amazing."

— Parent of Retinoblastoma Survivor

Thank You to Our Sponsors

One Retinoblastoma World 2020 was made possible through the generosity of our sponsors.

Thank you for supporting life, sight, and hope for every child.



KENDRA SCOTT



Plans for 2021 and Beyond

Retinoblastoma is an aggressive eye cancer affecting babies and young children. It is highly curable, and 90% of children survive in Canada and the USA. However, globally up to 80% of children die – 7,000 children every year – most of whom are in developing countries. Many precious young lives and sight can be saved by increasing awareness, access to existing treatments, evidence-based care, and compassionate family support. Together, we can create a bright future for all affected by childhood eye cancer.

World Eye Cancer Hope

Increasing access to specialist care will bring the promise of life and sight to every child, and improved life-long health to survivors. This is our mission. We:

- Educate the public and medical community about retinoblastoma to achieve early diagnosis and rapid referral to specialist care
- Empower medical teams to deliver sustainable high-quality, evidence-based care for affected children and adult survivors.
- Enable family support programs that reduce practical and emotional burdens and improve access to essential care.

For details on how to help, visit our website: wechope.org.

International Retinoblastoma Consortium

The International Retinoblastoma Consortium (IRBC) is a charitable organization committed to enhancing retinoblastoma patient care and research.

IRBC will continue to promote health by:

- Providing evidence based clinical practice guidelines for retinoblastoma
- Providing DEPICT HEALTH – an eHealth communication tool that facilitates effective, timely communication across the circle of care – to retinoblastoma treatment centers
- Funding and advancing retinoblastoma research

For details on how to help, visit our website: retinoblastomaconsortium.org.

Canadian Retinoblastoma Research Advisory Board

The Canadian Retinoblastoma Research Advisory Board (CRRAB) was created in response to the need for inclusive, high-quality, and translatable research. CRRAB works to ensure people affected by retinoblastoma (e.g., patients, survivors, the immediate family of someone diagnosed with retinoblastoma, etc.), clinicians, allied healthcare providers, researchers, patient engagement experts, and policymakers

collaborate to create meaningful, co-directed retinoblastoma research that is relevant to patients and improve outcomes.

To get involved visit our website: rbcanadaresearch.com.

Canadian Retinoblastoma Society

The Canadian Retinoblastoma Society (CRBS) is committed to helping Canadians affected by retinoblastoma. CRBS will continue in its dedication to education, advocacy, and support for Canadian retinoblastoma families.

For details on how to help, visit our website: rbsociety.ca.

One Retinoblastoma World 2020 Hosts:

