



**It takes all of us**  
to move retinoblastoma  
research forward!

## **Your guide** to the Canadian **Retinoblastoma Research Community**

Learn how your lived experience and skills  
can be used to influence retinoblastoma research.

# **RETINOBLASTOMA RESEARCH** *and you!*



Canadian Retinoblastoma  
Research Advisory Board

Created by Canadian retinoblastoma patients, health professionals, and researchers

# Introduction

## Patients Partnering in Research

The term “**patient**” is often used in the broad sense to refer to patients and informal caregivers including parents, family and friends<sup>1</sup>.

- Traditionally, patients have only been the subject of research.
- Researchers, funders and policy makers have started to recognize the importance and value of partnering with patients in all steps of the research process.

### Steps of the Research Process



\*Reading and learning about research results is also a part of the research process.

## Benefits of patient partnership in research:

- Align limited research funds with patient priorities
- Improve quality of research results
- Accelerate the uptake of research findings and, in turn, improve patient outcomes
- Match research outcomes with patient needs



<sup>1</sup>Canadian Institutes of Health Research. Canada's Strategy for Patient-Oriented Research. Ottawa, Canada: Canadian Institutes of Health Research; 2011

# Roles for Patient Partners in Research: A Case Study

Patients were instrumental in determining the **Top 10 Retinoblastoma Research Priorities** in Canada (Top 10 Priorities)<sup>2</sup>. A Steering Committee was set up to lead this research project, and included patients, health professionals and researchers.

The roles of patient partners in all steps of the research process are outlined below.

## Identify Problem

- Spoke up about the need for research studies that address patient priorities

## Set Research Question

- Contributed to study question development (i.e. “What are the Top 10 Retinoblastoma Research Priorities in Canada?”)

## Plan/Design Research Study

- Selected study method: (1) online survey to gather list of priorities (2) refine list of submitted priorities, (3) finalize Top 10 Priorities at an in-person workshop.
- Set inclusion/exclusion criteria for participation
- Developed participant recruitment tools and survey questions

## Seek Funding

- Wrote sections of grant proposal
- Provided letters of support to accompany grant application

## Collect, Analyze, and Interpret Data

- Reviewed, refined, and ranked the list of priorities gathered from online survey
- Participated in an in-person workshop to rank the Top 10 Priorities
- Attended online meetings to refine list of submitted priorities

## Collect, Analyze, and Interpret Data

- Wrote sections of scientific article<sup>2</sup>
- Gave oral and poster presentations at conferences
- Developed social media posts, videos and infographics
- Wrote and circulated policy brief

## Change Practice

- Learned about research results
- Created opportunities for patients to join research teams focused on solving Top 10 Priorities



<sup>2</sup>Kaitlyn Flegg, Maxwell J. Gelpopf, Sarah A. Johnson, and Helen Dimaras, for the Canadian Retinoblastoma Research Advisory Board Priority Setting Steering Committee The top 10 retinoblastoma research priorities in Canada as determined by patients, healthcare professionals and researchers: a patient-oriented priority-setting partnership CMAJ Open 8:E420-E428; published online June 9, 2020, doi:10.9778/cmajo.20190221.

# By Partnering in Research You Can:



✓ **Make a difference** for future retinoblastoma families

✓ **Build relationships** with Canadian retinoblastoma survivors, parents, health professionals and researchers



✓ **Influence the direction** of retinoblastoma research



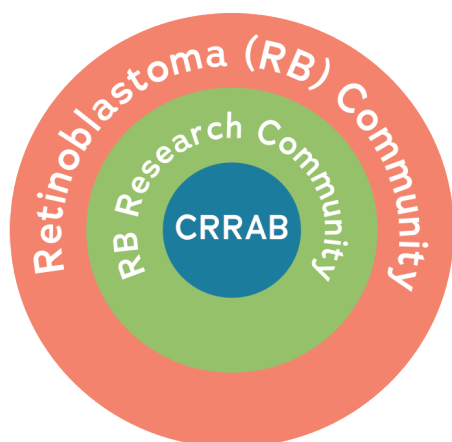
✓ **Improve your knowledge** of retinoblastoma and gain access to the latest research findings



✓ **Apply your lived experience** and skills to enhance retinoblastoma research

# Navigating the Canadian Retinoblastoma Research Landscape

## How to Become a Patient Partner



Decide on your **individual involvement in research** based on your availability and interests.

### Canadian Retinoblastoma Community ..... pg. 5

People personally or professionally connected to retinoblastoma in Canada, including (but not limited to) patients, health professionals, and researchers.

### Canadian Retinoblastoma Research Community ..... pg. 6

People in the Canadian Retinoblastoma Community who are interested in research. To formally join the community, individuals are encouraged to sign up online (see back cover). The Canadian Retinoblastoma Research Community was formerly known as the Canadian Retinoblastoma Research Registry.

### Canadian Retinoblastoma Research Advisory Board (CRRAB)..... pg. 7

Members of the Canadian Retinoblastoma Research Community who participate in patient partnered research and related activities and events. CRRAB is led by a Steering Committee which is responsible for ensuring annual goals are set and progress is tracked towards patient partnership in research. The Steering Committee also manages CRRAB tools, such as the website, social media accounts, and the online sign-ups for the Canadian Retinoblastoma Research Community.



Members of CRRAB who draw from personal experience to promote patient partnership in research and encourage sign-up to the Canadian Retinoblastoma Research Community are designated **Retinoblastoma (RB) Champions** - read their stories on page 11.

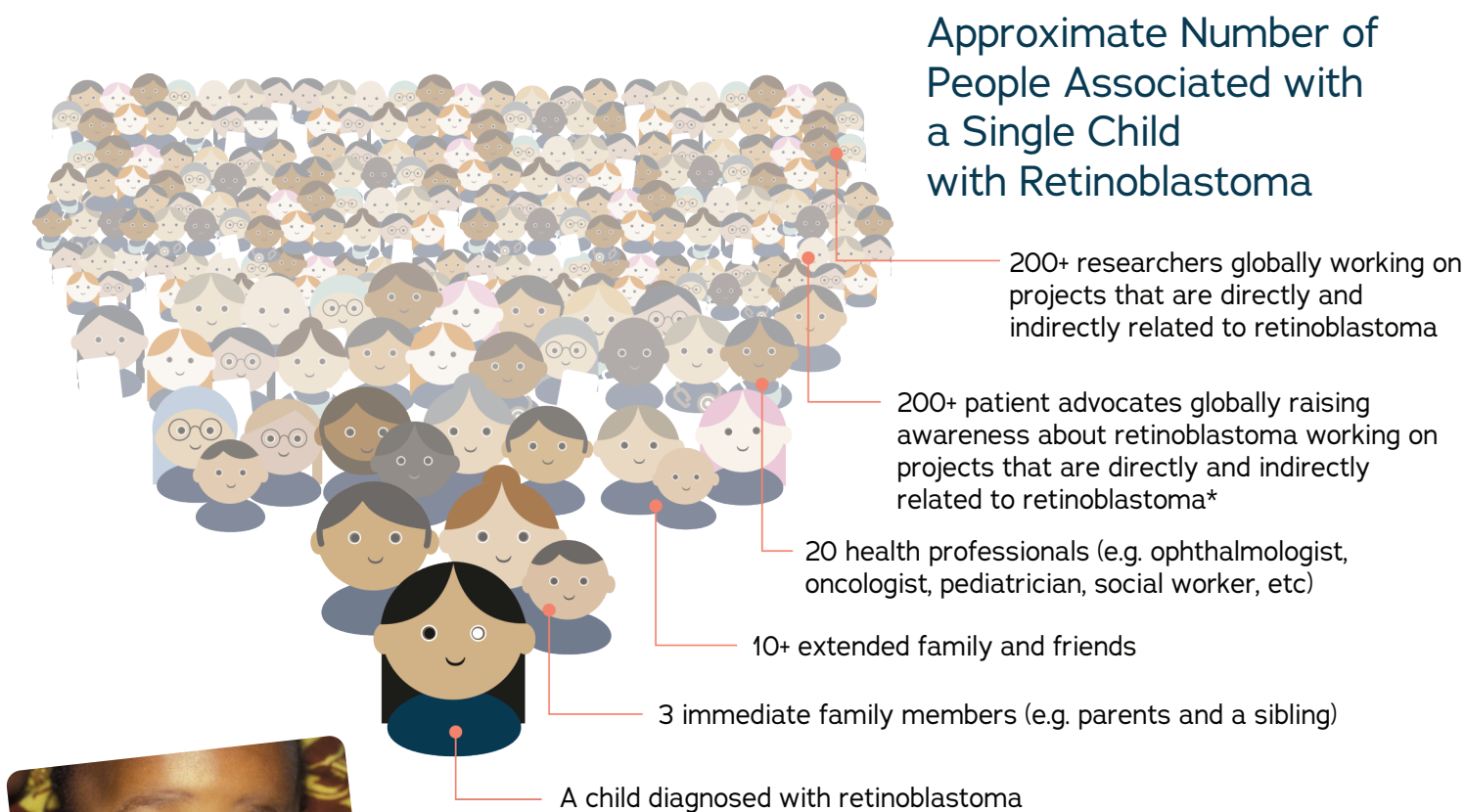
## Canadian Retinoblastoma Community

# A Large Community Standing Behind You

Retinoblastoma affects 1 child in every 15,000 live births, with about 23 children being diagnosed in Canada each year.

- Retinoblastoma is a highly curable cancer with more than 95% patient survival in high-income countries.
- We estimate that there are nearly 2,000 survivors in Canada.
- Although retinoblastoma is a rare disease, when touched by retinoblastoma considered, the retinoblastoma community is large.

The care of each patient incorporates a large team (depicted below)



\*The main retinoblastoma advocacy group in Canada is the Canadian Retinoblastoma Society

Canadian Retinoblastoma Society



# Canadian Retinoblastoma Research Community Connecting Those Interested in Research

The **Canadian Retinoblastoma Research Community** was created to connect members of the Canadian Retinoblastoma Community who are interested in research.

By **signing up on our website you can join** retinoblastoma patients, health professionals, and researchers who participate in the Canadian Retinoblastoma Research Community (this was formerly known as the Canadian Retinoblastoma Research Registry).

## Join us!

As a member of the Canadian Retinoblastoma Research Community you can choose to receive:

### ✓ Quarterly Newsletters

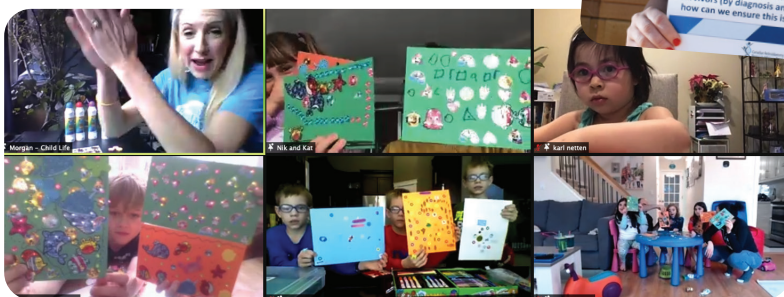
updates about  
**retinoblastoma  
treatment** and  
management in  
Canada

plain language  
**summaries**  
of research  
articles

education and  
**training**  
opportunities

information  
about **meetings  
and events**

### ✓ Information about Opportunities to Partner in Research



# Canadian Retinoblastoma Research Advisory Board Patients, Health Professionals and Researchers Partnering Together

The Canadian Retinoblastoma Research Advisory Board (CRRAB) is composed of patients, health professionals, and researchers from across Canada who participate in patient-partnered research and related activities and events.

## CRRAB leads a Patient Engagement Strategy with 3 aims:

1. share research results with patients;
2. identify and include a large and diverse group of patients in research; and
3. promote research that is created and led by patients.

Ultimately, CRRAB aims to have patients work alongside researchers and health professionals to create meaningful retinoblastoma research that is relevant to patients and improves outcomes.

CRRAB was designed to be led by volunteer patients, health professionals, and researchers, with administrative support provided by the retinoblastoma research team based at The Hospital for Sick Children (Toronto, Canada).

## The continued success of CRRAB rests on your involvement!



CRRAB members at the 2020 Retinoblastoma Research Symposium





# Canadian Retinoblastoma Research Advisory Board Member Activities



**Organize and host**  
the annual  
Retinoblastoma  
Research  
Symposium



**Facilitate project-specific  
patient partnerships**  
to develop and advance solutions to the  
Top 10 Priorities

**Share opportunities to  
participate in research**  
through the Canadian Retinoblastoma  
Research Community



**Promote and increase  
participation**  
in the Canadian Retinoblastoma  
Research Community



**Build  
connections**  
between patients,  
health professionals,  
and researchers

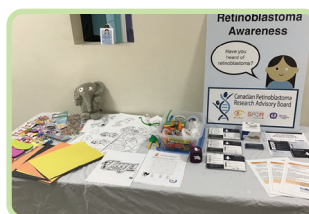


**Promote education,  
advocacy, and support**  
for retinoblastoma research

**Host an awareness table**  
during retinoblastoma follow-up clinics to  
showcase the Canadian Retinoblastoma  
Research Community



**Offer tools  
and  
platforms**  
for patient  
partnership in  
research



# Canadian Retinoblastoma Research Advisory Board

## Ways to Participate

### Attend the Retinoblastoma Research Symposium

Once a year, CRRAB members meet for a weekend-long event.

This includes:

- CRRAB Annual Meeting (review progress, set new goals towards achieving aims of Patient Engagement Strategy)
- A family gathering
- A Child Life-directed children's program
- Research workshops
- A marketplace
- Networking opportunities and social time

### Attend a CRRAB Quarterly Meeting

Once every quarter, CRRAB members meet virtually to review progress toward the goals set at the CRRAB Annual Meeting.

### Join a CRRAB Regional Working Group

A subset of CRRAB members meet monthly for virtual working meetings to actualize goals.

### Participate in Project-Specific Patient Partnerships

These are patient-partnered research teams that are focused on solving a specific Top 10 Priority.

Teams include patients, health professionals, and researchers. Meetings are held on an ad hoc basis, and activities involve the full spectrum of the research process.



# Canadian Milestones in Patient Research Partnership

towards the future...

## 2020

- Second project-specific patient partnership developed, aimed at solving Priority #9
- Third project-specific patient partnership developed, aimed at solving Priority #1
- Plain language summaries of published research articles published

## 2021

- "Retinoblastoma research and you!" booklet developed and distributed
- Virtual "Cup of Tea" (informal journal club discussions) initiated to share important research results with the Canadian Retinoblastoma Community

## 2019

- Awareness campaign launched, using materials co-developed with patients, to share the Top10 Priorities and inspire action towards solving them

## 2017

- First Retinoblastoma Research Symposium held
- The Top 10 Retinoblastoma Research Priorities in Canada jointly determined by patients, health professionals and researchers

## 2018

- 'Parent in Research' role established in the Retinoblastoma Program at The Hospital for Sick Children
- First project-specific patient partnership developed, aimed at solving Priority #3

## 2016

- Founding of CRRAB
- Launch of the Canadian Retinoblastoma Patient Engagement Strategy
- Creation of the Canadian Retinoblastoma Research Community

## 2009

- Publication of the National Retinoblastoma Strategy Clinical Guidelines for Care, developed by patients, health professionals and researchers

The journey so far ...



# Canadian Retinoblastoma Research Advisory Board

## RB Champion Stories

RB Champions are members of CRRAB who draw from personal experience to promote patient partnership in research and encourage sign-up to the Canadian Retinoblastoma Research Community.

## RB Champion Stories

In the following pages, RB Champions share stories of ways they have partnered and promoted patient partnership in research.

<b>Ivana:</b> Setting the Top 10 Priorities.....	pg. 12
<b>Jay:</b> Learning more about Retinoblastoma through CRRAB.....	pg. 13
<b>Jill:</b> Attending the Retinoblastoma Research Symposium .....	pg. 13
<b>Leslie:</b> Building a Research Project .....	pg. 14
<b>Taline:</b> Partnering in Research .....	pg. 15
<b>Tara:</b> Connecting with Other Parents.....	pg. 16



# Canadian Retinoblastoma Research Advisory Board

## RB Champion Stories



### Ivana: Setting the Top 10 Priorities

**“I have created professional and personal connections with researchers, health professionals, and other families which I will always carry with me.”**

My son is my motivation to be involved in research. I learn as much as I can about retinoblastoma so I can not only teach him, but also introduce him to the people and organizations who support the retinoblastoma community.

He was diagnosed with bilateral retinoblastoma and had an enucleation at 4 months old. I didn't know what the future would hold so my husband and I sought out ways we could learn more and get to know other families. We learned more about research and the importance of participating during the One Retinoblastoma World conference in Washington in 2017. When the research team at SickKids described the project to determine the Top 10 Retinoblastoma Research Priorities, I thought this was a great opportunity for me to voice the priorities that were important to my family as well as other families I knew. I participated in all 3 steps of the project, which were

based on an established method. First, I submitted my question to an online survey. Second, I joined the Steering Committee with other parents, survivors, researchers, and health professionals where we narrowed down the list of submitted questions. We determined whether the questions were already answered by research, grouped similar questions together and removed questions that were not feasible. Third, I attended an in-person workshop in which the shortlist of questions was ranked to identify the Top 10 Priorities. During the workshop, we discussed which priorities were important. I saw that all the participants shared their thoughts and in turn listened attentively to the others as we discussed which priorities are important to us, and why. If it wasn't for the passion of parents and survivors sharing our stories and persuading the researchers and health professionals that the priorities we were passionate about need to be in the Top 10, the list would have looked a little different. This is not because researchers and health professionals do not find our priorities important, but because they don't have the lived experience and are sometimes not aware of the problems we faced (and continue to face). By including our voices, we were able to enrich this experience and collaborate together to decide on a list of Top 10 Priorities that are important to all who are impacted by retinoblastoma, both personally and professionally. This experience motivated me to become a member of CRRAB and apply to be a member of the research team. I have definitely achieved my goal in learning more about retinoblastoma and I continue to learn more every day! I have also created professional and personal connections with researchers, health professionals, and other families which I will always carry with me.



# Canadian Retinoblastoma Research Advisory Board

## RB Champion Stories



**Jay: Learning more about retinoblastoma by joining CRRAB**

**“I’ve definitely shifted from being reactive to proactive in taking ownership of my own health.”**

Despite being a 31-year-old bilateral retinoblastoma survivor, I've lived most of my life without visibility (hah!) to any retinoblastoma research or support communities. After all, I've gone 3 decades in remission and there was no need! As my wife and I recently began family planning; it struck us how little we knew about the chances of passing my cancer on – and it terrified us. Since then, we've plugged into the retinoblastoma community – and it was quite the eye-opener (hah again). There is so much support here in Canada, both in terms of available information, latest progressions in research and honestly, just an astounding number of people who were related to retinoblastoma across research, survivorship, or family. I've definitely shifted from being reactive to proactive in taking ownership of my own health – and hopefully our children's health – moving forward! I'm tremendously grateful for the opportunity to be part of this community! After my ophthalmologist directed me to the retinoblastoma community, I have been plugged into the regional working group calls and contributing to a resource where families

can better understand how they can be involved in retinoblastoma research. It's quite fulfilling being part of something larger than myself - especially in enabling families to know that they're not alone in learning more about retinoblastoma and continue to learn more every day!



**Jill: Attending the Retinoblastoma Research Symposium**

**“What we hadn't anticipated is the profound impact the annual symposium would have on Sylvie.”**

I am the mother of a bilateral retinoblastoma survivor. Sylvie was diagnosed at 9 months, required the enucleation of her left eye, and thus began our journey with cancer and the amazing team at The Hospital for Sick Children in Toronto. She's now grown into a vibrant, brave and brilliant 10 year old. As a health care leader in Alberta, part of my own work is to facilitate patients' and families' involvement with health professionals, researchers, and administrators for the purpose of improving care and outcomes across the health care system. I first got involved in CRRAB through the development and prioritization of the Top 10 Priorities. I was intrigued to see patient engagement truly in action and participate not as a health care provider but as a retinoblastoma family. Since 2017, we've attended the annual Retinoblastoma Research Symposium to connect with other retinoblastoma families, to share our story, to learn the latest in retinoblastoma care and survivorship, and to participate in the annual strategy and planning discussions on how to advance retinoblastoma research and patient



# Canadian Retinoblastoma Research Advisory Board

## RB Champion Stories

engagement. What we hadn't anticipated is the profound impact the annual symposium would have on Sylvie. Participating in the child life program, learning more about her cancer journey, feeling safe to talk about her special eye, and meeting other children affected by retinoblastoma has been life changing for her.



### Leslie: Building a Research Project

**“Having an opportunity to actively participate in the leg-work that goes into a research project was very eye opening for me.”**

In 2013, we were blessed with triplet boys! When they were 3 months old, my husband (who was in residency training to become a family doctor) noticed that one of our triplet's pupils appeared to be shaped abnormally. We traveled from Alberta to The Hospital for Sick Children for treatment over the next few years. Each of the triplets lost one of their eyes but have very healthy remaining eyes. Because we spent so much time in the hospital and received numerous treatments, I became genuinely interested in retinoblastoma and wanted to continue to stay informed about treatments. I wanted to learn about developing potential treatments for future children diagnosed with retinoblastoma and I wanted to know more about my boys' risks for second

cancers. I attended and participated in One Retinoblastoma World in Dublin, Ireland in 2016 and met some of the research team from The Hospital for Sick Children. I learned about some of their initiatives and I have continued to stay active in CRRAB ever since by attending events either virtually or in person. In 2019 I attended the Retinoblastoma Research Symposium in person and began to take a more active role. In one of the working groups, we began to tackle one of the Top 10 Research Priorities: How to provide culturally competent social, emotional, and psychological support to retinoblastoma patients, survivors, parents and families (at diagnosis and beyond)?

The group consisted of retinoblastoma researchers, health professionals and patients. The majority of the work was completed by the The Hospital for Sick Children research team who would lead the meetings and delegate assignments. In about a year's time we were able to develop a plan for how to execute the research in order to provide more psychosocial support to patients and their families. We discussed the best ways to gather the information (i.e., survey), how and when to collect this information from patients, and which grants we could apply for. Having an opportunity to actively participate in the leg work that goes into a research project was very eye opening for me. It helped me understand why research takes so long - everything from understanding the ethics behind research, to precise wording of survey questions, to applying for funding for the project takes time. Applying for the grants and receiving funding has not been easy, but we have learned a lot along the way and have gotten great feedback! We are hopeful that the grant will soon be accepted so that we can



# Canadian Retinoblastoma Research Advisory Board

## RB Champion Stories

continue this initiative and get to work helping the future Canadian families impacted by retinoblastoma!



### Taline: Partnering in Research

**“By being involved with CRRAB, I feel I’m able to gain a better understanding of the cancer my son had...”**

My name is Taline, and I’m the parent of a retinoblastoma survivor and hero. Our retinoblastoma story started in July of 2017. Our son, Logan, was only 5 and a half months old. For a couple of months, my husband and I had noticed that our son had an odd glow in his left eye. We mostly saw this glow when we took a picture of our son using the flash on our phone cameras. We dismissed it thinking it was likely the flash or bad lighting. After some time, we noticed the glow under dim lighting, depending on the angle the light was hitting his eye. This became concerning, and so we decided to take him to our pediatrician for a checkup. Our pediatrician had never seen anything like this before and was perplexed herself. She didn’t think it was anything malignant as our son would be presenting symptoms of vomiting etc. I wanted answers now. With our persistence, we were able to get our pediatrician to book an appointment with an ophthalmologist. Luckily, we got in the very next day. The ophthalmologist dilated our son’s

eyes and discovered that he had a lesion. We were immediately sent to the The Hospital for Sick Children’s Eye Clinic for investigation. The retinoblastoma team performed a series of tests and determined that our son had unilateral retinoblastoma. We were devastated and didn’t know what this meant for our son. A couple days later, my son had an MRI to determine the severity of the issue. Just 5 days later, he had an examination under anesthesia and it was decided that he was going to have his left eye enucleated. Logan’s pathology came back about 4 weeks post-surgery, and we got the all clear. We were fortunate to have taken care of this in the early stages. Our son did not receive further treatment, as he did not present with high risk features. He lives a full life with a prosthetic eye. We are seen by the ophthalmologist at the Eye Clinic at The Hospital for Sick Children every 6 months, as well as for regular maintenance of Logan’s prosthetic eye. Logan has been cancer free since July 13th, 2017. I joined CRRAB in the fall of 2017. I attended my first Retinoblastoma Research Symposium with my husband, Serge and our 3 wonderful kids; Sydney, Kaylee and Logan, in January of 2018. CRRAB is a great way to get involved with research and provide input by contributing ideas. Joining CRRAB has given me opportunities to meet other families affected by retinoblastoma, keep current with new research, and participate in research projects. One of the most memorable things I was involved in was the creation and implementation of the Retinoblastoma Journey Maps. I attended the Retinoblastoma Journey Maps workshop in January 2020 at the Retinoblastoma Research Symposium. I assisted in developing sticker designs and implemented some great visuals to coincide with the maps. As an educator, I was able to contribute my expertise and skills and apply it





# Canadian Retinoblastoma Research Advisory Board

## RB Champion Stories

to something that will be an instrumental piece in the lives of other retinoblastoma patients and survivors. I'm currently in the midst of publishing my first children's book that talks about a boy with retinoblastoma who loses his ordinary eye and gets an extraordinary eye! I wanted to do something to honour my son's name and help other children with retinoblastoma feel good about themselves while raising awareness. By being involved with CRRAB, I feel I'm able to gain a better understanding of the cancer my son had and what I can do to apply my skills to help raise awareness. Join CRRAB today to make a difference!



### Tara: Connecting with Other Parents

**“As a first time mom, with a four month old, the last thing I expected to face was cancer; however, I am now the proud mom of an eight year old survivor and thriver.”**

The loss of his right eye to a giant tumour at such a young age has not slowed this kid down for a second. My goal through those next 3 & 1/2 years of active treatment was to make his life as normal as possible. He absolutely loves his visits to The Hospital for Sick Children. This is a devastating diagnosis in children who've barely just arrived into the world. Blake is a proud

survivor who happily shows his prosthetic eye to anyone who cares to see. Most people are amazed at how they can't tell the difference at all. Support for parents is critical in raising healthy, normal, thriving children. I found this support through connecting with other parents who have children diagnosed with retinoblastoma and through participating in CRRAB activities such as the annual Retinoblastoma Research Symposium, monthly working group calls, and helping to host the Retinoblastoma Awareness Table at the Eye Clinic at The Hospital for Sick Children. The monthly meeting dates and times are set once a year and availability is gathered from the participants to ensure a date and time is picked that is favourable to most attendees. I was able to attend most calls and really enjoyed participating in the discussions on how we can reach more retinoblastoma families and spread awareness of CRRAB. During the calls I interacted with other parents, adult survivors, and health professionals. One of the activities we discussed during these calls was volunteering at the Retinoblastoma Awareness Table where a Child Life specialist provided activities for the kids in the waiting room and the CRRAB team talked with the parents about research opportunities and CRRAB. I had signed up to volunteer when I had time and when the table lined up with my son's clinic appointment. I enjoyed talking with the other families at the Eye Clinic and telling them about CRRAB. I feel like I made a difference by connecting them to the research community!

I'm fortunate to also be a co-founder of the 'Parents of Children with Retinoblastoma treated at SickKids Toronto' Facebook group. This group has helped us build a community where parents and survivors can connect and share stories. I also share updates from CRRAB so that new members can be aware of CRRAB and how they can be involved in research.





## My Story

My retinoblastoma story began \_\_\_\_\_

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The reason I would like to get involved in research is \_\_\_\_\_

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I want to learn more about \_\_\_\_\_

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I am going to start by \_\_\_\_\_

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# Get involved! You can make a difference.

Join the  
Retinoblastoma  
Research  
Community!

[rbcanadaresearch.com](http://rbcanadaresearch.com)

Visit our website  
and sign up!

Email us



[retinoblastoma.research@sickkids.ca](mailto:retinoblastoma.research@sickkids.ca)


Scan our QR code on your  
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## RETINOBLASTOMA RESEARCH *and you!*



Created by Canadian Retinoblastoma patients, health professionals, and researchers