

Agenda
Retinoblastoma Research Symposium
Peter Gilgan Centre for Research and Learning

Retinoblastoma Family Gathering
Saturday January 25, 2020

8:00 AM – 8:30 AM	Registration, 3rd Floor Lobby		Children's Program, Event Room 3a
8:30 AM – 8:45 AM	Welcome and Introductions, Auditorium		
8:45 AM – 9:30 AM	Panel 1: Research and Treatment Updates, Auditorium		
9:30 AM – 10:15 AM	Panel 2: Patient Stories, Auditorium		
10:15 AM – 10:30 AM	Break, 3rd Floor Lobby		
10:30 AM – 11:15 AM	Panel 3: Patient Involvement in Retinoblastoma Research and Care, Auditorium		
11:15 AM – 12:00 PM	Panel 4: Ask the Experts, Auditorium		
12:00 PM – 12:15 PM	Closing Remarks, Auditorium		
12:15 PM – 1:30 PM	Lunch, 3rd Floor Lobby & Marketplace 2nd Floor Lobby	Adolescent and Young Adult Q&A and Networking, Event Room 2a <ul style="list-style-type: none"> • Discuss questions anonymously submitted prior to meeting • Discuss experiences related to popular topics including: accommodations in post-secondary education and work force, family planning, second cancer screening 	

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4th Annual CRRAB Meeting
Saturday January 25, 2020

1:30 PM – 1:45 PM	Welcome and Introductions, Auditorium <ul style="list-style-type: none"> • Agree upon meeting objectives 	Children's Program, Event Room 3a
1:45 PM – 2:30 PM	CRRAB Overview, Auditorium <ul style="list-style-type: none"> • Review mission and Terms of Reference • Discuss 2019 accomplishments • Discuss Steering Committee and Working Group composition and roles • Elect leadership roles • Discuss sustainability and funding 	
2:30 PM – 2:45 PM	Break, 3rd Floor Lobby	
2:45 PM – 3:15 PM	Working Group Break Out Sessions, Multimedia Room, Event Rooms 2a and 2b <ul style="list-style-type: none"> • Discuss objectives for 2020 	
3:15 PM – 4:00 PM	Set 2020 Work Plan, Auditorium <ul style="list-style-type: none"> • Establish collective goals for 2020, determine timelines and assign to working groups 	
4:00 PM – 4:30 PM	Closing Remarks, Auditorium	

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Retinoblastoma Research Workshop
Sunday January 26, 2020

8:30 AM – 9:00 AM	Registration, 3rd Floor Lobby	
9:00 AM – 10:00 AM	Morning Yoga, Event Rooms 2a and 2b	
10:00 AM – 10:30 AM	Welcome and Overview, Auditorium	Children's Program, Event Room 3a
10:30 AM – 1:00 PM	Breakout Sessions: 1. Priority # 1: Early Diagnosis, Event Room 2a 2. Priority # 9: Pathway of Care, Event Room 2b 3. Foundations in Patient-Oriented Research, Multimedia Room	
1:00 PM – 2:00 PM	Lunch, 3rd Floor Lobby	
2:00 AM – 3:00 PM	Presentations, Auditorium <ul style="list-style-type: none">• Groups share their work and next steps	
3:00 PM – 4:00 PM	Family Activity, Auditorium <ul style="list-style-type: none">• Kids presenting what they did in Children's Program	
4:00 PM – 4:30 PM	Closing Remarks and Group Picture, Auditorium and Amphitheatre	

Priority # 1: Early Diagnosis

- In 2017 patients, researchers and health professionals jointly agreed that the top retinoblastoma research priority was, "How to increase early diagnosis of retinoblastoma (i.e., decrease age or stage at diagnosis)?" In order to conduct research that will address this important question, funding application and a research protocol are required. The main goal of this session will be to establish a process for developing funding application and a research protocol in 2020. We will also participate in discussion and brainstorming activities about the study design.

Priority # 9: Pathway of Care

- Retinoblastoma research priority # 9 is, "How to provide a detailed pathway of care or plan, outlining treatment and follow-up, to retinoblastoma patients and families?". The main goal of this session will be to develop a prototype of a patient-centered pathway of care. The prototype will be an illustrative treatment map, based on the 'Get Well Maps' concept, a form of child-centered medical communication. Children may participate in this session with their parents.

Foundations in Patient Oriented Research

- The main goal of this session is for participants (including researchers and health professionals) to learn the basic skills and knowledge needed for patients to partner in research.