

Summary of 2024 CRRAB Annual General Meeting

GOALS

The goals of CRRAB are designed to be aligned with the 3 main aims of the Canadian Patient Engagement Strategy. Each year, “SMART” goals are set to help move the Strategy Aims forward.

Strategy Aim 1: Include a large and diverse group in retinoblastoma research.

2024 SMART Goals:

- Update the infographic quarterly and share at Quarterly Meetings
- Add 10 patient members and 10 non-patient members to RB Research Community

How does this goal help support Strategy Aim 1? The infographic will be updated with the current RB Research Community data and shared at the Quarterly Meetings to show progress in adding new members and provide insights on missing groups.

Strategy Aim 2: Share research results.

2024 SMART Goals:

- 4 Cup of Tea events and recordings
- Enhance website design as per AGM co-design session
- Create 4 blog posts covering research results to coincide with the Cup of Tea
- Engage 2 patient partners to support the development of CRRAB tools (1 partner to support 1 blog creation and 1 partner to support 1 Cup of Tea development)

How does this goal help support Strategy Aim 2? In addition to sustaining the Cup of Tea as a method of sharing research results, we will also plan events in advance with themes selected at the AGM (see list below) which will align with the quarterly blog posts. An enhanced website design will make navigation and information access easier. This will align our tools and offer additional ways for the RB Community to access research results. Involving partners by aligning with their skills and interest will support the development of CRRAB tools to ensure sustainability and open the opportunity to create more content and programs.

Strategy Aim 3: Promote patient-partnered research.

2024 SMART Goals:

- Host 3 research workshops to facilitate patient and non-patient engagement
- Identifying and share 4 patient partner opportunities with the RB Research Community

How does this goal help support Strategy Aim 3? By hosting research workshops, we introduce patients to the research process and show how they can be involved. Similarly with non-patient partners, we will expand their experience in partnering with patients and

offer collaboration opportunities where they can build relationships with patients outside the clinic. These workshops will be held at the RB Research Symposium where we have the experience in creating an inclusive and engaging environment. Additional opportunities to build partnerships and grow patient engagement in research will be well-defined and clearly communicated to the RB Research Community.

SCHEDULE OF EVENTS

Date	Time	Event Name
March 19	8:00PM ET	Cup of Tea
April 20 & 21	All Day	RB Research Symposium
June 18	8:00PM ET	Cup of Tea
July 24	12:00PM ET	CRRAB Quarterly General Meeting
September 17	8:00PM ET	Cup of Tea
October 26	12:00PM ET	CRRAB Quarterly General Meeting
December 17	8:00PM ET	Cup of Tea

QUARTERLY THEMES

2024

Quarter	Theme
Quarter 1: January to March	Second Cancer
Quarter 2: April to June	3D Printing for Ophthalmology
Quarter 3: July to September	Impact of RB on Daily Living
Quarter 4: October to December	Coping after Enucleation

2025

Quarter	Theme
Quarter 1: January to March	DEPICT Health: eHealth communication tool that facilitates communication across the circle of care
Quarter 2: April to June	Long-term Treatment Side Effects
Quarter 3: July to September	Biobank: collection of biospecimen and associated data for the purpose of research into vision and eye health
Quarter 4: October to December	New Treatments