



## A letter from the Chair of OICR's Patient and Family Advisory Council



What an incredible year the OICR Patient and Family Advisory Council (PFAC) has had!

I wanted to start off by thanking Diana Lemaire for her year of service as PFAC Chair. It was an honour to take over the Chair role in April. Diana left the Council well positioned to continue its important work, and thankfully has stayed on as a Council member.

We were very pleased to recently welcome Michelle Audoin and Carla Bossart to PFAC. Their expertise and enthusiasm are a huge asset to our team.

PFAC is an independent group of patient partners who act as advisors to OICR on many facets of the business. Patient partnership allows the patient (and/or caregiver) experience to inform how the research is done. By giving patients a seat at the table, and embedding the patient voice in everything OICR does, it allows for greater alignment of priorities, better governance and more effective knowledge translation.

We have accomplished so much over our second year. Here are some of the highlights:

- Continued to review funding requests for Adaptive Oncology, PanCuRx, and CATA/pre-CATA.
- Grew our Patient Community to 60 members.
- Convened two working groups to design training programs for patient partners and for researchers.
- Established a newsletter for the Patient Community, distributed on a weekly basis.
- Developed a Patient Partner Payment Policy to formalize how we recognize patient partner contributions.
- Established a Patient Partner Privacy document that allows patient partners to understand how their data is collected, used, and shared.
- Patient Partnership Evaluation Plan was developed and implemented.
- Patients reviewed applications for the Innovation to Implementation (I2I) funding

- request, the first time Patient Community members were added to this process.
- OICR-supported research Programs/projects have recruited patient partners, including OHCRN, OHS and Imaging. We continue to help match projects and patient partners.
  - Patient partners were included at OICR events and meetings, including the Slight Forum, two Imaging program events on breast and prostate cancer, the Clinical Translation meeting, the RNA Nanomedicine event, the OHCRN Spring Reconnect event, and FACIT's Falcon's Fortunes.
  - A new series of "Ask a Cancer Researcher" explainer videos began development, with questions posed by patients and the public.
  - Adaptive Oncology storytelling project translated each AO team's work into a story for lay readers.
  - Patient partners had a decisive role in charting the way forward for OCTANE 2.0 after a partnership dissolved.

As you have read, we have much to celebrate. I am immensely proud of this group. The professionalism and leadership are unmatched. I would be remiss not to thank OICR for its unwavering support of our work. There is a strong mutual respect that allows us all to maximize the patient voice. I also want to thank Justin Noble and Rebecca Tamarchak, who continue to show up for the Council in every way. Thank you for helping to create an inclusive space for patients to amplify their knowledge.

I could not end this letter to you all without remembering our dear friend and Council member, Jill Hamer-Wilson, who we lost last year. Her patient partner expertise and advocacy in the research community will have an everlasting effect on us all. I feel blessed to have worked alongside her and learned from her.

**Beth Ciavaglia**

Chair of OICR's Patient and Family Advisory Council