

Institute of Genetics

Patient Partner Committee



Patients and caregivers from across Canada with diverse lived experience and representing multiple genetic conditions.

What does the committee do?

We give advice, focusing on how to integrate patient partnerships into health research.



We help develop guidance, influence the objectives of funding opportunities, and speak at conferences.

What do members value about the committee?



We learn about research and funding, and the value we bring as patient partners.

We develop knowledge and confidence to feel capable of contributing to research.

We receive additional opportunities in patient partnership.

We appreciate learning from each others' perspectives.

What has been important for the committee's success?

We follow best practices in patient partnership.

The committee is professional. We can be ourselves while being kind and sharing power.

It's okay to be quiet, to learn, and to contribute in whatever way is comfortable.

We took time to build relationships.

Our contributions "go somewhere." Our advice is shared with leadership and the impacts are fed back.

We are compensated to recognize our time and effort.

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