

Frequently Asked Questions

WHAT IS THE RESEARCH FAMILY LEADER PROGRAM?

The Family Leader Program (FLP) is the Research Institute's patient and family engagement program. It includes 50+ former patients, parents, caregivers, and community members with a keen interest in research and lived experiences with CHEO services. Hear more about how it started on our [podcast](#).

Q

A

HOW IS THAT DIFFERENT FROM THE RI PATIENT FAMILY ADVISORY COMMITTEE (PFAC)?

The PFAC is a smaller subset of the FLP. The [RI PFAC](#) provides live consults once a month for research teams. PFAC is made up of 7 family leaders from diverse backgrounds. It also includes 5 RI staff from various research positions. During the live consults, the research teams explain what they are working on and bring a few questions for the group. These range from ideas for a research question, specific questions about parts of the study, or knowledge translation questions. A rich discussion ensues.

WHAT ARE THE ADVANTAGES OF HAVING FAMILY ENGAGEMENT IN RESEARCH (FER)?

FER brings the patient and family voice to the research process and provides a perspective that would otherwise be missing. Having the viewpoint of someone with lived experience informs the research question, recruitment, design, and knowledge translation. Check out what we have been up to in our [annual report](#).



IF I WANT TO PRESENT MY PROJECT TO THE PFAC, WHAT IS THE PROCESS?

Plan your visit to the PFAC early. There are 10 meetings a year and consults are often planned at least 1 month in advance. Reach out to the program coordinator to see if your project is a good fit for PFAC. If you have questions that would benefit from feedback from researcher staff and family leaders, then PFAC would be a good match. Sometimes if the consult is very specific to one illness or disease the coordinator may recommend submitting a summary via Redcap. The coordinator will then seek out reviews from family leaders with that specific set of lived experiences related to the study area. These reviews can be done through Redcap or informally over a video call. Family leaders are given 2 weeks to complete their reviews.



HOW DO I ASK FOR A FAMILY LEADER TO REVIEW MY PROJECT?

If you are submitting your project through Smart Start, indicate that you are looking for family review. The coordinator will be alerted and reach out to see what your current or future need is and set up support accordingly to help you engage with patients and families. You can also just use the standardized Redcap links to request a family review:

- [Bio Med](#)
- [Clinical](#)

The survey tool allows you to provide an overview of your project, answer a set of questions and add any attachments you want to include.



WHAT DOES A FAMILY REVIEW CONSIST OF?

After submitting your project overview in Redcap, a family leader will read your completed overview template and fill in a corresponding survey. This allows standardized feedback to the researcher on the project. Reviews, once assigned are completed by family leaders within 2 weeks. If you would like an in-depth review and feedback throughout your project, consider asking the coordinator if this reviewer would like to become an advisor and join your team for the length of the project.

WHEN SHOULD I ASK FOR A LETTER OF SUPPORT?

Early. Asking for a letter of support is something to consider well in advance. Ideally, the letter can include specific ways you have already begun FER. This may consist of visiting the PFAC or adding a family advisor. This practice ensures that the letter of support is not purely tokenistic, and that rich engagement is happening or is planned shortly.



IF I HAVE A FAMILY ADVISOR ON MY PROJECT, HOW SHOULD I RECOGNIZE THEM?

Great question, and one we hear often. Compensation and recognition are topics to address early with a family advisor assisting with your project. In our experience, at the RI family leaders have individual and unique preferences when it comes to their contributions. Some family leaders do not want any form of compensation. Others welcome a determined hourly rate of payment in the form of gift cards. Offering hourly payments in the form of gift cards is a gesture that ensures family leaders are not limited in their engagement due to financial barriers. Recognition can take many forms. This could include co-presenting the project at a conference or a handwritten thank you card. The best bet, have this conversation before you get started.

Here are a few helpful guides:

- [Family Engagement Tools](#)
- [Should money come into it?](#)
- [RI guidance document](#)
- [Patient Partner Compensation Guidelines - CIHR](#)

HOW DO I ENSURE FAMILY ENGAGEMENT IS MEANINGFUL?

Family leaders tell us the most essential part of meaningful engagement for them is communication. Family leaders should be looped into meetings. Finding the time when they can meet with the group is an important consideration. Having a point person in your team that can reach out one-on-one after the meeting can be a great way to ensure your family advisor is feeling oriented and comfortable with sharing their feedback on the project. It is common to have starts and stops with a project. If you are waiting for results about a grant application or publication review, make it a practice to provide a short update to your family leader so they still feel engaged and have a good sense of the stage of the project.

WHERE CAN I FIND MORE RESOURCES ABOUT FER?

- McMaster has a [10-week FER course](#) for researchers and family leaders. This has been well attended by many RI staff and family leaders. There are readings, discussions, and a final project that foster best practices for partnering in research.
- During the FER course researchers and family members are partnered together to create a knowledge translation (KT) tools. These co-created tools are current and easy to read. They likely have just the resource you are looking for: [Student Projects | CanChild](#)
- Did you know you can connect with CHEO families and beyond in the Facebook Group, [Parents Partnering in Research](#)? It's a great page with regular updates about national projects and events.

