

Patient Engagement Annual Report 2021

48 Research Family Leaders



18 Research Family Leaders acting as advisors on projects, up by **125%** since 2020

520 hours of volunteering by Research Family Leaders

56 reviews completed

Research Family Leaders reviewed **11** Start Smart requests from early career researchers, allowing for meaningful patient engagement from day one



Provided 8 letters of support towards various research projects and grants.

"The CAN-PREPARE team came and consulted with the group, sharing both the study they were undertaking and methodology behind it. After explaining to us the challenges they were encountering and what they were hoping to accomplish; the group was able to share its feedback and brainstorm ideas on how we could help drawing from our experience. It was also great to hear that some of our feedback was incorporated into the study and hear how the study was going." - **Azam Ishmael, PFAC Patient/Family Representative**



"We would like to take a moment to extend our gratitude to the Research Patient and Family Advisory Committee, who provided advice and recommendations for the CAN-PREPARE Study on childhood anaphylaxis. These thoughtful comments play a significant role in continuously improving the conduct of studies like this." - **Cheryl Kreviazuk, Research Coordinator, CAN-PREPARE**

We will grow, it will show!



- 2** Research Family Leaders on Selection Committees for the hiring of new scientists.
- 2** Research Family Leaders on Research Ethics Board (REB).
- 2** Research Family Leaders on Equity, Diversity, Inclusion and Indigeneity, (EDII) Task Force.
- 3** Youth Advisors on National Research Advisory Committee

The Research Family Leader Program's opportunity to present during **Grand Rounds** spread awareness of the program and services. This led to increased collaborations between researchers and patients/family members



Research Patient and Family Advisory Committee (PFAC)

13 research consultations provided by the Research Patient & Family Advisory Committee (PFAC).

- PFAC's ongoing input was critical to the new RI Programmatic restructuring.
- Hosted 5 scientific presentations.