

# 2021/2022 Patient & Family Engagement

## In the Numbers

This infographic provides a summary of how patients & families were engaged through the Alberta Children's Hospital's (ACH) Patient & Family Centered Care (PFCC) team. Due to continued COVID-19 health concerns and on-site restrictions, all patient & family engagement was conducted virtually.



**1972** Total Patient & Family Engagement Volunteer Hours

**191**

**PFCC Network Advisors**

**42**

**Requests sent for input/feedback**

**32**

**Child and Youth Advisory Council (CAYAC) Members**

**9**

**Consults**

**27**

**Family Advisory Council (FAC)**

**10**

**Consults**

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“In consulting with CAYAC and FAC, we were able to have a full and rich conversation about values-based decisions and the role of Clinical Ethics at the Alberta Children’s Hospital. They were able to provide considered and useful feedback around the accessibility of the Clinical Ethics Service.”

Virginia McLaughlin, Clinical Ethicist  
Alberta Children’s Hospital

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## FAMILY TO FAMILY Connections

**91 Peer Mentor Volunteers**

**554 Total Peer Mentor Volunteer Hours**

- One to One Connections
- After ASD Diagnosis Sessions
- Teen Talk Transition Workshop
- Parents Talk Transition Workshop
- Peer Mentor Training

**953**

**PFCC e-Newsletter Subscribers**

### One to One Connections

**44**

**New Connections**

**29**

**Virtual NICU Bedside Connections**

*“It was nice not to feel so alone and the peer support group leaders were so lovely.” – Family Participant (Building Connections Peer Support Group for NICU families)*

*“I chose to become a mentor because I do not want families to feel alone. I feel that I have an opportunity, maybe even an obligation, to ensure families facing a new diagnosis have a smoother journey than ours.” Peer Mentor*

# ACH Patient & Family Advisors Placed on Committees/Projects or Working Groups

## Alberta Children's Hospital

- 100 Year Celebration Committee
- Complex Care Clinic Advisory Committee
- Cumulative Risk Clinic QI Project
- NICU Enhanced Recovery after Surgery Research Project
- NICU Parents in Partnership Committee
- Pain Committee
- Patient Engagement in Safety Project
- PFCC Week Working Group
- PIV/PIVIE Working Group
- Rehabilitation Planning Working Group
- Stroke Therapy Research Project
- Transition Social Media Working Group

## Other

- Transition Research Advisory Council (youth)

## Alberta Health Services

- Provincial Eating and Swallowing (PEAS) Working Groups
- Communication Intervention Standardization Working Group
- Primary Health Care Alberta Surgical Initiative
- MNCY Strategic Clinical Network
- Provincial Patient and Family Advisory Group
- Youth Addictions and Mental Health Provincial Advisory Council

## Calgary Zone

- South Health Campus Citizen Advisory Team
- Women's Health Quality Assurance Committee

“*Having an advisor on our research team has been invaluable. Her lived experience has enhanced our understanding of the study feasibility and value. Her input has been key for the development of the research study design and the creation of materials for study participants. We look forward to continuing our partnership throughout study stages!*”

Alicia Hilderley, Researcher, ACH

## Focus Groups

(planned or hosted with the ACH PFCC team and attended by PFCC Network members)

- Advisor Education
- COVID Immunization for Children
- IV Experience
- Neurology Transition Project
- Neurosciences Strength Training Program
- PEAS Family Journey Mapping
- PEAS Ordering Portal
- Pediatric Nutrition Screening
- Youth Proxy Access to MyAHSCConnect

“*Patient and family focus groups are priceless. Capturing key stakeholder perspectives is essential and undoubtedly uncovers important information that clinicians have not considered. It is one of the best ways to mine for gold!*”

Candice Natrasony, Physiotherapist  
Neuromotor Clinic, Alberta Children's Hospital