

The Family Liaison

- an integral part of our research team

PRESENTER - Anne-Mette Hermansen

Introduction :

Today, care for children with serious illness is guided by a **family centred philosophy** that recognizes the family's priorities. Likewise, our research within this population is centred in the clinical as well as psychosocial and practical realities of the families we work with. We have developed the role of a Family Liaison within our team to build up Patient Oriented Research strategies in our overall research program.



Taking family engagement to the next level :

Patient Oriented Research seeks to **engage patients** (or in our case their parents) **as partners** in the research process. The difference across time and concrete strategies to do so lies in the level of engagement.

In our research program families have traditionally contributed to research in a number of ways:

Research ideas & questions arise from clinicians' relationship with patients & parents

Research objectives & designs are evaluated by parent advisory groups

Feedback is gathered from study participants & research processes are adjusted accordingly

Adding a Family Liaison to our team has **taken participant engagement to a new level**. Establishing the role of Family Liaison as **an embedded team member** is different from engaging participants in advisory roles. Firstly, the Family Liaison is a part of the research process from idea conception through data analysis. More importantly, the Family Liaison's role goes beyond that of advisory, as a paid team member participating in the research process **on equal footing with the rest of the team**.



The power of Patient Oriented Research

We believe that there is power and specific gains to be had from investing in Patient Oriented Research and in the case of our research program:

Embedding a Family Liaison role in every project.

The power is one of ensuring the relevance of our research questions and engaging with our participants from a place of understanding and connection with their lived realities. The gains are overarching: we know that the research projects we propose and the questions we ask are relevant to our target population and that the answers we may find will make a difference in their lives and the health care they receive. But the gains are also specific: In employing our Family Liaison we are able to connect with, recruit and engage families effectively, **ensuring that the work we do is for and with the families that form the cornerstone of our research.**

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Who is Laesa Kim?

It takes the right person to be successful in the role of Family Liaison. Our 2020 hire Laesa **shares in the lived experience** of our participants as the mother of a medically complex child, with years of learning to understand and navigate health care systems. It is these credentials, coupled with a gift of communication and connection with health care providers and fellow parents alike, that positions her perfectly to fill the role.

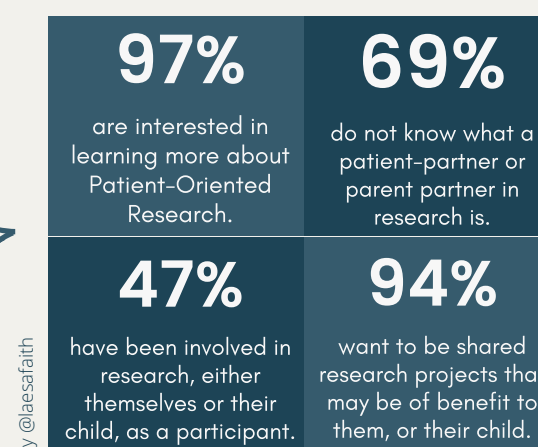


Fun Fact :

We found Laesa on Instagram, @laesafaith, where her writing on "motherhood and medical musings" offered evidence of her fit for the role as Family Liaison.

What does the Family Liaison do (differently)?

- Recruitment from a small pool of prospective participants has always been a hurdle in our program. Laesa's **aid in recruitment efforts** has paid off greatly because of the ability to create connections with fellow parents in safe spaces, often online.
- Laesa **leads her own study** of what motivates parents to participate in research with their children, which provides rich answers to our research questions and will inspire future project planning.
- Utilizing an already established social media presence and practice in advocacy for "medical" families, Laesa is able to **engage our target population** in novel ways, such as via online polling on aspects related to our research.



by @laesafaith

An informal questionnaire, with more than 200 respondents, gave these insights around Patient-Oriented Research and research participation.