

"Our Experiences as Parent Partners in Research"

Parent-partners were asked the following questions with the goal of sharing their experiences and providing advice to other parents to overcome barriers and engage in research as collaborators.

*How does a parents lived experience benefit research?
How can parents give advice to overcome barriers?*



1 Duty to oneself and loved ones/society

"The more I know the better I can inform my son's medical team as well as myself."

"we have a moral obligation **to be conscious** of intended and unintended consequences of research."

"It's imperative to me to **be involved**"

Trust your voice

"If there's a point of the study that you're not comfortable or are concerned about- **speak up**"

"Let your voice **be heard** and the voice of your child/children to influence and inform in a research study."

"be **true** to yourself"

3 Communicate and Connect

"You're there **together as a team** and keeping the communication and connection will lead to empowering everyone."

"being **open and flexible** to the research team"

Be Reflective

"Be comfortable being vulnerable, not knowing, and **reflective of one's own privileges/lack of privilege**"

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