How Can You Be Involved in Cerebral Palsy Research?

How can I be involved?

As a parent or person with cerebral palsy you might be asked to be a research participant. But this is only one way that you can be involved. Parents and people living with cerebral palsy can also partner with researchers to plan and carry out research projects. You can help researchers decide what topics are important to study, how to run the study, and what questions to ask participants.

What are the benefits of partnering with researchers?

Everyone benefits when people with real life experience partner with researchers. Partnerships help make sure that research is relevant, meaningful, and addresses people’s needs and concerns. Everyone can learn new skills (like writing or presenting at conferences) or use their existing skills in a new way to help other families who are on the same journey.

But what if I don’t have any research training?

No Problem! Parents and people living with cerebral palsy bring something to the table researchers don’t have: real life experience. Because of this parents, and people living with cerebral palsy, can advise researchers on things like what is important for them and/or how to best engage parents to participate in research.

What will I be asked to do as a research partner?

It depends on the project, your own interests and skills! You can join a reference group, review information forms, communicate results, co-author a publication, interview other members, review draft questionnaires, represent the views of the CP community, participate in focus groups, answer a survey... Be sure to discuss roles and expectations with the research team ahead of time. Some research projects have a small budget to cover expenses of partnering.

Where can I learn more?


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*This resource was adapted with permission from Kinga Pozniak & Perri Tuttleman 2019, How can parents be involved in child health research? Kids Brain Network, McMaster University Canada.