

## Why should I do it as a researcher or as a parent?

Robyn:

From what I can tell talking to other parents of children with cerebral palsy around the world (whether they are in Hong Kong as I am, or South Africa where I grew up, or in Canada...) there seems to be a consistent theme of struggling to find information – the right information at the right time. Whether it's about diagnoses, or rehabilitation programmes, or recommended equipment and diagnostics, I have felt quite passionately as I have been going through this process that I would like to be able to share my experience with other parents. Because if you can't get it through formal channels, then maybe the best way to do it is via other parents somehow? Possibly one way of doing this could be through family engagement in research. I think it has the potential to be quite transformational for families and children with neurodisabilities. That is, if it was done very intentionally - by which I mean, that family research partners are equal partners to academic researchers, and that what we bring to the table is given equal weight; it is not simply a token or a tick-box exercise - then I think family engagement in research could really help to steer research towards things that matter to us and our children. It could also be a way to channel information to families – so that information finds them at the right time and in an easily accessible way.