

## Child Information Sheet

<b>Study Title</b>	<b>NeuroCONNECT: The SCHN Registry for Neurological Disorders</b>
<b>Principal Investigator/s</b>	<p>Prof. Russell Dale &amp; Dr Richard Webster            The Children's Hospital at Westmead            Ph: 02 9845 2006            E: <a href="mailto:Russell.dale@health.nsw.gov.au">Russell.dale@health.nsw.gov.au</a> ; <a href="mailto:Richard.webster@health.nsw.gov.au">Richard.webster@health.nsw.gov.au</a></p> <p>A/Prof Michelle Farrar &amp; Dr Hugo Sampaio            Sydney Children's Hospital            Ph: 02 9382 1549            E: <a href="mailto:m.farrar@unsw.edu.au">m.farrar@unsw.edu.au</a> ; <a href="mailto:Hugo.Sampaio@health.nsw.gov.au">Hugo.Sampaio@health.nsw.gov.au</a></p>
<b>NeuroCONNECT Team</b>	This registry was established on behalf of all neurologists of the Sydney Children's Hospital Network, who will be the part of the collaborative NeuroCONNECT Team.
<b>Main Study Contact Person</b>	<p>Kristine Concepcion            The Big Brain Project, Kid's Neuroscience Centre            Sydney Children's Hospital Network            E: <a href="mailto:Kristine.Concepcion@health.nsw.gov.au">Kristine.Concepcion@health.nsw.gov.au</a></p>



This information sheet has been put together to help you choose if you would like to take part in our research project. We are collecting information about children with conditions affecting the nervous system.

You can ask someone you know and trust, like your Mum or Dad, to help you understand the things written on this sheet.

## 1. What is this study about?

We are a team of doctors and researchers who work at the children's hospital called The Sydney Children's Hospitals Network. We take care of children who have different types of conditions affecting the nervous system. We want to collect medical information and organise them into scientific data. All of this will be kept in a computer program. This information will help us learn more about the nervous system and how we can help kids like you get better.



## 2. Do I have to be in this study?

No you don't. If you say no, that is ok. You and your parent or carer will decide if being in this study is the right thing for you.

You can also change your mind later if you **don't want to** be a part of the study anymore. That is not a problem at all. You just need to tell the researcher or your parents/carers that you don't want to take part anymore. We will still look after you in the best way we can.



### 3. What will happen to me in this study?



Once you have said it's okay to be in this study, we will ask your parent or carer to sign the consent form. This will allow us to get your medical record and include it in our research project.

### 4. Is there anything that could make me upset if I take part in the research?

We do not think this project will affect you in any way. The information we need are already from the clinic, blood tests and images your doctor requested. You don't have to do anything else!



## 5. What will happen to my information?



Your information will only be used by the doctors and researchers in this project team. Your name or any information that can help identify you will not be used in any report from this project.

Your information may also be shared with other doctors and researchers who want to know more about similar conditions you have. The same information may also be used for future projects outside our team.

## 6. Who can answer my questions?



If you have any questions, you can ask your doctor or talk to Kristine, she is helping the doctors with this project. You can also ask your parents/carers to talk to us.

Remember, even if you take part at the beginning and change your mind later and don't want to be a part of the study anymore; that is okay as well. All you need to do is tell the researcher or your parents/carers that you don't want to take part anymore. We will still look after you in the best way we can.



Please talk to your parents/carers if you are worried about being in this study, or you have a complaint. They can talk to Prof Russell Dale on (02) 9845 2006, or they can talk contact the Human Research Ethics Committee on (02) 9845 1253 or [SCHN-Ethics@health.nsw.gov.au](mailto:SCHN-Ethics@health.nsw.gov.au).

It is their job to listen to you and find out what happened. Tell them this number: 2020/ETH03064.