

Child Information Sheet

Study Title	APEG Patient Registry (APR)
Principal Investigator/s	Associate Professor Andrew Biggin Sydney Children's Hospital Network
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This information sheet has been put together to help you choose if you would like to give the APEG Registry your information for research.

1. What is this study about?

We are a big group of doctors and researchers from all over Australia and New Zealand called APEG. We are collecting information from kids like you, to understand what treatments work the best for endocrine conditions. Endocrine conditions can affect your growth, your energy, or chemicals in your body called hormones.

2. What is a registry?



A **registry** is a big collection of information on lots of different people. We also call this a **database**. For this study, your doctor will put information about how you are growing into the database.

3. Will my information be private?

Yes, your information will be private. Nobody will know where you live, and we will never give out your name.

4. Do I have to be part of the registry?

No, you don't. You or your parents/carers might feel that putting information about your health into the registry is not the right thing for you. If you are not sure, you can ask your parents/carers to help you decide.

It is also OK if you change your mind later. Just tell your parents/carers or your doctor if you want to change your decision. You will still be treated the same by your doctor even if you don't take part.

5. Who can answer my questions?

If you have any questions, you can talk to **Joan on 4985 5634 (ask for Doctor Komal Vora)**, or email komal.vora@health.nsw.gov.au. You can also ask your parents/carers to talk to us.

Thank you for reading!

Keep this information sheet so you can read it again later.