



The I-CAH Registry

Information For Children

Your doctors are looking for your help and this leaflet will explain why in more detail. If you have any further questions after reading this leaflet, you can ask your parents, or ask your doctor who will be happy to explain further.

What Is A Registry?

- A Registry is a place, like a database, where we keep information such as data or medical records.
- This information allows doctors and research scientists to learn more about how the body grows and develops.
- Sharing of information through a Registry is particularly important when people are affected by rare conditions.
- By studying this information and by talking to other doctors and scientists from across the world we all get better at looking after children who have a rare condition.

What Is The I-CAH Registry?

- The I-CAH Registry has been especially designed to collect information on rare conditions like yours.
- That is why we want to ask whether you will let us put some of your medical information into this Registry.

What Information Does The Registry Collect?

- The Registry collects some very simple information on how you developed the condition and how its treated.
- If you want to find out what information is entered into the Registry then just ask your doctor or visit the website, www.i-cah.org
- You can also ask your doctor to show you the information that has been entered on you.
- The Registry can also give you and your parents an option to access the Registry from your own home and enter information yourself.

Is It Safe?

- The data that are entered into the Registry are very safe. No one will know your name or where you live.

Do I Have To Take Part?

- No, you don't need to take part.
- If you can think of any reason you don't want the information put into the Registry, please let your parents know about it. Let your doctor know, too.
- If you change your mind about taking part, just let your doctor or your parents know and the information can be changed or removed.
- If you decide not to take part, don't worry, the doctors will still treat you the same way.

When you turn 16 years old your hospital doctor will send you a more detailed leaflet to read. If you want to look at this leaflet now, just ask for it. You can also find out more from the doctor whose details have been entered below:-

Name of doctor:

Hospital:

www.i-cah.org