



GloBE-Reg

Information For Children

TITLE: GloBE-Reg Management Protocol

PROTOCOL NO.: None
WCG IRB Protocol #20231657

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STUDY-RELATED

PHONE NUMBER(S): 720-420-3636 (24 hours)

Taking part in this research is voluntary. You may decide not to participate, or you may leave the study at any time. Your decision will not result in any penalty or loss of benefits to which you are otherwise entitled.

If you have any questions, concerns, or complaints or think this research has hurt you, talk to the research team at the phone number(s) listed in this document.

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 GloBE-Reg?

- GloBE-Reg is a project which collects information on people with conditions like yours who are starting on new treatments.
- The information that is collected about you will be shared with other doctors and scientists.
- This information allows doctors and research scientists to learn more about how the body grows and develops.
- This information also allows doctors and research scientists to improve the treatments that they use.
- 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 Information Does The Registry Collect?

- The Registry collects some very simple information on how you developed the condition and how it's treated.
- If you want to find out what information is entered into the Registry then just ask your doctor or visit the website, <https://globe-reg.net/>.

- 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. Although we will try our best to keep your data safe, there is always a risk that your data can be shared without our permission.

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 18 years old your hospital doctor will send you a more detailed leaflet to read and sign. If you want to look at this leaflet now, just ask for it. You can also find out more from the doctor whose details are on the first page of this document.

Name of Child: _____

Signature of Child: _____

Date: _____

Name of Parent or Guardian: _____

Signature of Parent or Guardian: _____

Date: _____

<https://globe-reg.net>