



CHILD'S ASSENT FOR RESEARCH STUDY
(Ages 7-13)

Study Title: Genetic Analysis of PHACE Syndrome

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Name: _____ **Medical Record Number:** _____

- **We are asking you to be in a research study.**
- **It is your choice. You do not have to be in the study.**
- **Feel free to ask questions.**

A. Why are we asking you to be in this research study?

You are being asked to take part in this study because you have PHACE syndrome or LUMBAR syndrome and we want to learn more about it.

B. Why are we doing this study and what do we hope to learn from it?

The reason we're doing this study is to learn why some people are born with this disease and how doctors can better help people who have it. By looking at your body and cells, we hope to find clues that will teach us more about what it is.

C. What will you have to do?

If you are going to be in this study, you will:

- Have 1 small tube of blood taken from your arm. This is a safe amount and we don't expect it to cause you any problems.
- Have a cheek cell sample taken. We will rub inside your cheeks with a brush. This will not hurt you.
- Sometimes, the doctor might ask you for a skin sample. This may be done when you already have a surgery happening. The doctor will put numbing cream on the spot to help with discomfort when the doctor injects medicine to make sure you don't feel anything. Then, the doctor will use a tool that looks like a pen to remove a pencil-eraser size part of your skin to study. You will get one or two stitches and medicine put on the area to help you heal. This medicine is only for you and should never be shared with anyone else.
- The researcher will ask you some questions about your syndrome and when you were little.



- The doctor may take a picture of the spots on your skin.

All of this will probably take a half hour to do. Your samples will be a part of the study until all tests are done on them. You may be asked to put your name on another of these sheets if the doctors find other important things about your syndrome and may need to ask you more questions or get another sample. If you turn 18 while the study is still going, then you will sign another of these forms if you still want to be part of the study.

D. Can anything bad happen to you because of this study?

Doctors may ask you to have a blood draw from your arm. This means that the doctors will use a needle which may feel uncomfortable or painful for a short time. They may also ask you for a small piece of your skin. They will use medicine to numb the spot first, but after the medicine wears off, you will feel some pain. Your parents will get medicine to take home to take care of the spot so that it doesn't get infected while it heals.

E. Are there any good things that could happen to you while you or others take part in this study?

Being in this study will not help you, but may help people with PHACE syndrome in the future.

F. Will you be paid for taking part in the study?

You will receive no payment for taking part in the basic parts of this study. However, if we ask you to give skin samples, you will get a Target Gift Card worth \$50.00.

G. Do you have to take part in this study? Can you quit the study any time you want?

You do not have to be in this study, and if you are in it you can stop at any time. If you have any questions please ask one of the people who are doing the study.

I. PERMISSION TO PROCEED

Writing my name on this form means that the form was read to me and that I agree to be in the study. I know what will happen to me. If I decide to quit the study, all I have to do is tell one of the people who are doing the study.

Your parents / guardian will receive a copy of this form. A copy of this form will also be kept in your medical record.

Childs Name

Child's Signature

Date

Assent Form administered and explained in person by:



Study Leader or Study Team Designee

Date

