



Protocol Title: Genetic Analysis of PHACE Syndrome **IRB#** 10/202, GC# 1215

Principal Investigator Name: Dr. Dawn H. Siegel

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**Parent or Guardian
HIPAA Release of Information for Research
Authorization Form**

Researchers are required to get written permission from a child's parent or guardian to use the child's health information in a research study, data registry bank, and/or a tissue bank. This permission is called an "Authorization." In order for your child to take part in this research study and data registry you must sign this Authorization form.

A. How will my child's health information be used?

Your child's health information will be used to provide information needed for the research study. For example, visit notes from other specialists who have treated your child's syndrome, results from tests and procedures, and other general medical information can help the research team learn about PHACE syndrome and the various features and issues that occur along with it. Researchers will use the information collected from all of the subjects to better understand what the syndrome is, why it occurs, and how it can be more effectively treated.

B. What information will be used?

The following information about your child's health will be used for this research study and data registry: medical history, MRI/A reports, information from clinic visits, blood, tissue, and cheek cell samples, genetic reports, treatment records, history and diagnosis notes, laboratory, radiology, and pathology test results, and when applicable, information from other institutions your child has visited in the treatment of their syndrome

C. Who will use my child's health information?

The hospital or clinic that holds your child's medical records will share medical information with the researchers. The researchers may also share it with other people outside CHW (if your child's health information will be shared outside CHW, those outside institutions and researchers receiving your child's health information will be listed below).

The following are the researchers, groups, institutions your child's medical information will be shared with: Members of the research team as listed on the consent form, Children's Hospital and Health System, and the Medical College of Wisconsin.

D. How long will the permission last?

This authorization will last during the entire course of the study, and will extend until 20 years after we finish enrolling subjects. This is so that the researchers can go back to verify information during the analysis and publication of study results.

You can end this Authorization at any time by withdrawing your permission in writing. Beginning on the date your permission ends, no new health information from your child will be used. Any health information that was shared before you withdrew your permission will continue to be used. After this Authorization ends, your child can no longer actively take part in this research study and data registry.

Withdrawal of your permission should be made in writing to the person whose name is listed here: Dawn Siegel
9000 West Wisconsin Avenue
Milwaukee, WI 53226
Phone: (414) 955-2817
E-Mail: dsiegel@mcw.edu

E. Is the permission voluntary?

Your permission is voluntary. You do not have to sign this Authorization form. Your child's health care providers must continue to provide your child with health care services even if you refuse to sign this Authorization form. If you refuse to sign this form, your child cannot take part in this research study and data registry.

F. How will my child's health information be protected?

Whenever possible your child's health information will be kept confidential. Federal privacy laws, however, may not apply to some people outside of CHW who can share your child's health information without your permission. If you signed a consent form for your child to take part in this research, more information about confidentiality protections may be found there.

G. Additional information.

You should take as much time as you need to make your decision about giving permission for the use of your child's health information for this research study and data registry. Please ask any questions you may have about this Authorization form.

I have read this Authorization form describing how my child's health information will be used. I have had a chance to ask questions about the use of my child's health information and I have received answers to my questions. I agree to the use of my child's health information for this research study and data registry.

Child's Name: (Please print) _____

Parent/Guardian Name who is signing Authorization:

(Please print) _____

Signature of Parent/Guardian:

_____ **Date:** _____

Relationship to child: (Please print) _____