

PHACE REGISTRY: ENROLLMENT QUESTIONNAIRE

**We welcome any additional information to this form, such as pertinent medical records and imaging reports.

1. Child's name : _____

Child's date of birth: _____

2. Please tell us about your child's hemangioma:

a. When was it first noticed (right at birth, a few days or weeks later)? _____

b. How did it look at first ? _____

c. Did it grow ? _____

d. If it has stopped growing, how old was your child when it stopped ?

e. Where is it ? (please describe in as much detail as possible) _____

f. Does your child have hemangiomas anywhere else? _____

If so, please describe where they are and how they were found.

g. Has the hemangioma caused any problems? (for example, blocked the eye, ulcerated or developed a wound on the surface, etc) _____

h. Has treatment been needed for the hemangioma? _____

If so, what treatment(s) were used and why? _____

i. Has the hemangioma been biopsied (a sample of tissue removed, processed, and examined under the microscope)? _____

If so, when was this done? _____

What type (specialty) of doctor did the biopsy? _____

Please provide this doctor's contact information:

1. Name _____

2. Address _____

3. Office phone# _____

4. Office fax# _____

**If possible, please include a picture(s) (print, disk or CD is fine) of your child's hemangioma(s). Please note that photos will not be returned.

3. Who made the diagnosis of PHACE syndrome and why? _____

4. Please tell us about your child:

- a. Name _____
- b. Gender _____
- c. Date of birth _____
- d. Birth weight (lbs or kgs) _____
- e. How many weeks was your child when he or she was born? _____
- f. How would you best describe your child's ethnicity? (please check one)

White/Non-Hispanic

Black, Hispanic

White/Hispanic:

Asian:

Black, African

Black, African America

Central American

Indian/Pakistani

Native America (USA)

South American

Filipino

Polynesian

Mexican

Chinese

West Indies/Caribbean

Puerto Rican

Hmong

First Nations (Canada)

Dominican/Dominican

Japanese

Aboriginal (Australia)

Republic

Korea

Middle-Eastern

Vietnamese

Other

Other Asia

5. Please tell us about you (the person filling out this form)

- g. Your name _____
- h. Are you this child's mother, father or another caregiver? _____

- i. Your home address: _____

- j. Your home phone number and/or cellular number(s): _____

- k. Your work phone number: _____
- f. Alternate contact number(s): _____
- l. Your email address: _____

6. Who is your child's pediatrician or primary care physician?

- m. Name _____
- n. Office address: _____
- o. Office phone number: _____
- p. Office fax number: _____

7. Please tell us about other problems or tests your child has had:

- q. Has your child had special pictures taken of his/her brain? _____
If yes, do you know what type(s)? (Ultrasound, CT, MRI) _____

- When was this done? _____
- Who ordered this test(s)? _____
- What type (specialty) of doctor is he/she? _____

Please provide this doctor's contact information:

1. Name _____
2. Office address: _____
3. Office phone number: _____
4. Office fax number: _____

r. Has your child had any problems with his/her brain? _____

If yes, please describe _____

s. Has your child had any neurologic problems? (for example, delays in normal development like crawling or talking; seizures, headaches, etc)? _____

If yes, please describe _____

Has your child seen a neurologist? _____

If so, please provide this doctor's contact information:

1. Name _____
2. Office address: _____
3. Office phone number: _____
4. Office fax number: _____

t. Has your child had heart problems? _____

If yes, please describe _____

Has your child had special pictures taken of his/her heart? _____ 5

If yes, do you know what type(s)? (Ultrasound, CT, MRI, echocardiogram)_____

When was this done?_____

Who ordered this test(s)?_____

What type (specialty) of doctor is he/she?_____

Please provide this doctor's contact information:

1. Name_____
2. Office address:_____
3. Office phone number:_____
4. Office fax number:_____

Has your child seen a cardiologist (heart specialist)? _____

If so, please provide this doctor's contact information:

1. Name_____
2. Office address:_____
3. Office phone number:_____
4. Office fax number:_____

d. Has your child had any problems with his or her eyesight/vision?

If yes, please describe_____

Has your child seen an ophthalmologist (eye specialist)?_____

If so, please provide this doctor's contact information:

1. Name _____
2. Office address: _____
3. Office phone number: _____
4. Office fax number: _____

e. At birth, did your child have any problems with the skin in the middle of his or her chest or stomach? (for example, a pit, hole or scar?) _____

If so, please describe _____

Was surgery needed for this? _____

If yes, Date of surgery: _____

1. Name of surgeon: _____
2. Office address: _____
3. Office phone number: _____
4. Office fax: _____

**If possible, please include a picture(s) (print, disk or CD is fine) of this skin problem. Please note that photos will not be returned.

f. Does your child have any other medical problems (including other birthmarks)? _____

g. If your child is now deceased, what was the cause of death? _____

Was an autopsy performed? _____

8. Has your child seen any other doctor(s) not listed above?

1. Name: _____

2. Type (specialty) of doctor: _____

3. Office address: _____

4. Office phone number: _____

5. Why did your child see this doctor? _____

1. Name: _____

2. Type (specialty) of doctor: _____

3. Office address: _____

4. Office phone number: _____

5. Why did your child see this doctor? _____

1. Name: _____

2. Type (specialty) of doctor: _____

3. Office address: _____

4. Office phone number: _____

5. Why did your child see this doctor? _____

1. Name: _____

2. Type (specialty) of doctor: _____

3. Office address: _____

4. Office phone number: _____

5. Why did your child see this doctor? _____

9. Is your child biological foster adopted

If biologic or foster, please answer the following questions about the biological mother of your child and any biological siblings:

a. How old was mother when your child was born? _____

b. Did she finish elementary school, high school, college or more? _____

c. How many times has she been pregnant? _____

d. Does she have any other children? _____

If yes, please list ages, gender, and whether they are full or half siblings of this child _____

e. Has she had any miscarriages? _____

If yes, how many and when? _____

Is the reason known? _____

f. Did she have any trouble becoming pregnant with this child? _____

- g. Did she need help to become pregnant with this child? (for example, use medication like Clomid, in vitro fertilization, artificial insemination, other?)_____
- h. Was this child a twin or triplet?_____
- i. Did she have an amniocentesis? This is a procedure done after the 14th week of pregnancy, when a needle is inserted through the abdomen into the uterus to obtain amniotic fluid._____
- If yes, were the results normal or abnormal?_____
- If abnormal, why?_____
- _____
- j. Did she have chorionic villus sampling or CVS? This is a procedure done during the first trimester to obtain a sample of the placenta. This is usually collected by inserting a thin flexible tube (catheter) through the vagina and cervix into the placenta. However, the sample can also be obtained by inserting a long, thin needle through the abdomen into the placenta._____
- If yes, were the results normal or abnormal?_____
- If abnormal, why?_____
- _____
- k. Did she have pre-eclampsia with this pregnancy? Pre-eclampsia is also known as toxemia of pregnancy, characterized by very high blood pressure often in association with persistent headaches, stomach pain, vision changes, and swelling of the face, hands and feet that does not go away during the day.
- _____

l. Did she have any problem(s) with her placenta during this pregnancy?_____

If yes, what type of problems and when during the pregnancy were

they seen?_____

m. Did she have any other problems during this pregnancy?_____

n. Does she have any other medical problems?_____

o. Does she have any other skin problems or birthmarks?_____

This form may be sent by email or regular mail to:

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THANK YOU SO MUCH FOR YOUR PARTICIPATION.