Children's Hospital Los Angeles

Optic Nerve Hypoplasia

Disease Distribution Survey

This survey is being conducted by Mark Borchert, MD and Pamela Garcia-Filion, PhD, MPH. If you have any questions regarding this survey, you can contact us at (323) 361-6219 during the hours of 8 A.M. and 4 P.M. Monday through Friday. This study is approved by the Committee on Clinical Investigations [(323) 361-2265].

Purpose: The following survey is being used to gather information on how cases of optic nerve hypoplasia (ONH) are spread across the United States and to determine if there are unique distributions of this disease. Participation is available to families with a child diagnosed with ONH and is completely VOLUNTARY. This survey does not require that you identify yourself.

Survey Directions: Please complete this survey if you are a parent to a child with ONH. If you are an adoptive parent, please only complete if you have accurate knowledge of the birth mother's residence during pregnancy. Please do not complete the survey if you lived outside of the United States 3 months before your pregnancy or during your 1st and 2nd trimesters. Completing this survey is an indication of your consent to participate in this survey research.

To submit this survey on-line, click on the 'SUBMIT' button on the bottom of the last page. If you prefer, you can print this survey, complete it and then mail to us at:

Attn: ONH Research Program
Children's Hospital Los Angeles
4650 Sunset Blvd. MS #88
Los Angeles, CA, 90027

********** Please DO NOT complete more than one survey. **********

Section 1: If you have one child with ONH, please only answer the questions in Section 1.
Section 2: If you have more than one child with ONH, please also answer the questions in Section 2 for your second child.

Section 3 (Optional) Contact Information: The results from this survey will be used to evaluate trends in the distribution of ONH cases in the United States. It is possible that additional research studies into possible causes of ONH. If you would like to be contacted to participate in future research about ONH, provide your contact information in Section 3.

You will only be contacted if your information is relevant to the study. This information will be available only to study directors. Providing such information is completely VOLUNTARY and is not necessary for participation in this survey. If you provide this information, it is an indication of your consent to be contacted in the future.

To help us protect your privacy, we have obtained a Certificate of Confidentiality from the National Institutes of Health. With this, the researchers cannot be forced to disclose information that may identify you, even by a court subpoena, in any federal,state, or local civil, criminal, administrative, legislative, or other proceedings. The researchers will use the Certificate to resist any demands for information that would identify you, except as explained below.

You should understand that a Certificate of Confidentiality does not prevent you or a member of your family from voluntarily releasing information about yourself or your involvement in this research. If an insurer, employer, or other person obtains your written consent to receive research information, then this Certificate can not withhold that information.

This information will be kept private, however there is the potential for unintentional disclosure of confidential information. To withdraw at any time, please contact us at (323) 361-2267.

Your participation in this research is VOLUNTARY. Your choice about whether or not to participate will have no affect on any future access for you or your child to care, services, or benefits at Children's Hospital Los Angeles.

SECTION 1

When was your child born? (Please only use season and year.)
Fall = September, October, November Spring = March, April, May
Winter = December, January, February Summer = June, July, August

Season

Year

What is the race/ethnicity of your child?

Select One

Where did you live 3 months before you became pregnant with your child that was diagnosed with ONH?

House number & Street name

City

State

Zipcode

Example: 1826 Anywhere Street
1826 = house number
Anywhere St = street name

Where did you live during the first 3 months of your pregnancy?

House Number & Street Name

City

State

Zipcode

Example: 1826 Anywhere Street
1826 = house number
Anywhere St = street name

Where did you live between the 3rd and 6th months of your pregnancy?

House Number & Street Name

City

State

Zipcode

Example: 1826 Anywhere Street
1826 = house number
Anywhere St = street name

**** If you have more than one child with optic nerve hypoplasia, please answer the questions in this section for your second pregnancy. Please ONLY complete this section if you more than one child with optic nerve hypoplasia. If you only have one child with ONH, complete ONLY Section 1.

SECTION 2

When was your child born? ((Please only use season and year.)
Fall= September, October, November *Spring*= March, April, May
Winter= December, January, February *Summer*= June, July, August

Season

Year

What is the race/ethnicity of your child?

Select One

Where did you live 3 months before you became pregnant with your child that was diagnosed with ONH?

House Number & Street Name

City

State

Zipcode

Example: 1826 Anywhere Street
1826 = house number
Anywhere St = street name

Where did you live during the first 3 months of your pregnancy?

House Number & Street Name

City

State

Zipcode

Example: 1826 Anywhere Street
1826 = house number
Anywhere St = street name

Where did you live during the 3rd and 6th month of your pregnancy?

House Number & Street Name

City

State

Zipcode

Example: 1826 Anywhere Street
1826 = house number
Anywhere St = street name

Section 3

Contact Information

The results of this survey will help provide a picture of how ONH is distributed. It is possible that new surveys or research studies will develop from these results. If you would be interested in participating in future research and would like to be contacted, please provide your current contact information in the space provided below.

You will only be contacted if your survey information collected in this study is relevant to the new study.

You are not required to provide this information for participation in this survey. This is completely VOLUNTARY. Your name and contact information will be kept in a private file and only be used to contact you if it is determined that your information will be useful for future research. To withdraw your information at any time, please contact us at (323) 361-2267.

Full Name of Parent:

Current Contact Information:

Street Address	
City	
State	
Zipcode	
Phone Number	
Email address	

This information will be kept private, however there is the potential for unintentional disclosure of confidential information. To withdraw at any time, please contact us at (323) 361-2267.

Your participation in this research is VOLUNTARY. Your choice about whether or not to participate will have no affect on any future access for you or your child to care, services, or benefits at Children's Hospital Los Angeles.

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