



June 12, 2007

To whom it may concern:

At Childrens Hospital Los Angeles (CHLA), a national survey is being performed to examine the distribution of optic nerve hypoplasia/septo-optic dysplasia (ONH/SOD) cases across the United States. I am conducting this research with *Pamela Garcia-Filion, MPH*, who is a Ph.D. student in Epidemiology at the University of Southern California.

I am asking for your assistance in providing this survey to families that have a child with ONH/SOD. The survey takes less than 15 minutes to complete and participation is voluntary. The Institutional Review Board at CHLA has approved us to collect information from the parents about the:

- 1) season and year their child with ONH was born,
- 2) zipcode for where the mother lived 3 months before conception,
- 3) zipcode for where the mother lived during the 1st trimester and
- 4) zipcode for where the mother lived during the 2nd trimester of the pregnancy.

I have enclosed copies of the survey packet for you to please distribute. The packet includes information about the survey and how to participate if they are interested. The survey can be submitted to us by mail or it can be completed over the Internet at any one of the following websites.

www.onesmallvoicefoundation.org
www.focusfamilies.org

www.magicfoundation.org
www.onhconsulting.org

If they do not want to complete the survey over the Internet, then they can complete the paper version of the survey provided and return it to us by mail. Our address is:

Attn: Pamela Garcia-Filion, MPH
Childrens Hospital Los Angeles
4650 Sunset Blvd., MS #88
Los Angeles, CA 90027

Please emphasize that you are not conducting this research and that all questions about this survey must be directed to us at Childrens Hospital Los Angeles. Please feel free to contact me if you have any questions or comments, we can be reached at the following phone number – **(323) 361-4510**.

In gratitude,

Mark Borchert, M.D.

Information collected from parents is protected under a Certificate of Confidentiality issued by the National Institute for Health and the data will be entered into a confidential database at CHLA.

Optic Nerve Hypoplasia

Disease Distribution Survey

Childrens Hospital Los Angeles

This survey is being conducted by Mark Borchert, M.D. and Pamela Garcia-Filion, M.P.H.. If you have any questions regarding this survey, you can contact us at (323) 361-2267 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 (or SOD) 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, complete the survey and click on the 'SUMBIT' 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: Pamela Garcia-Filion
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 distribution trends may develop from this survey. If you would like to be contacted to participate in future research about the distribution of 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.

******For on-line submission of survey: If your computer has a virus, trojan horse, or other malicious program, your responses may be vulnerable to viewing by unauthorized persons up until you click the 'SUBMIT' button.******

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

When was your child born? (Please only use season and year.)

Season

Fall = September, October, November

Spring = March, April, May

Winter = December, January, February

Summer = June, July, August

Year

<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
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What is the ethnicity of your child?

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

A.

Zipcode

OR

B.

Block Number
& Street Name

Block number example:

1826 Street Name

1800 is the block number

City or County

State

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

A.

Zipcode

OR

B.

Block Number
& Street Name

Block number example:

1826 Street Name

1800 is the block number

City or County

State

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

A.

Zipcode

OR

B.

Block Number
& Street Name

Block number example:

1826 Street Name

1800 is the block number

City or County

State

SECTION 2

** 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.

When was your child born? (Please only use season and year.)

Season

Fall = September, October, November Spring = March, April, May
Winter = December, January, February Summer = June, July, August

Year

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What is the ethnicity of your child?

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

A.

Zipcode

OR

B.

Block Number
& Street Name

Block number example:

1826 Street Name

1800 is the block number

City or County

State

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

A.

Zipcode

OR

B.

Block Number
& Street Name

Block number example:

1826 Street Name

1800 is the block number

City or County

State

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

A.

Zipcode

OR

B.

Block Number
& Street Name

Block number example:

1826 Street Name

1800 is the block number

City or County

State

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 are not required to provide this information for participation in this survey. This is completely VOLUNTARY.

State and federal privacy laws protect the use and release of your information. The contact information that you provide is considered protected health information. Under these laws, the study directors cannot use your contact information unless you give permission. If you decide to give your contact information, this will indicate that you give permission for Dr. Mark Borchert and/or Pamela Garcia-Filion to use your information to contact you in the future for the purpose of research. 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 Childrens Hospital Los Angeles.

Your name and contact information will be kept in a private database and only be used to contact you if it is determined that your information will be useful for future research. It will not be provided to other researchers, put into a research report or used to receive compensation.

This information will only be used by Dr. Mark Borchert and Pamela Garcia-Filion for this research study. However, your information may also be seen by the CHLA Institutional Review Board and U.S. government agencies that are required by law to review and monitor research activities.

This permission to release your contact information to the research investigators will expire when the research study ends. At that time, all contact information will be destroyed. You can print a copy of this survey and privacy protection statement for your records. You can cancel your permission at any time by writing to Dr. Mark Borchert and request that your information be removed. If you cancel your permission, information that was already collected and disclosed about you may continue to be used. Please feel free to call the CHLA Institutional Review Board [(323) 361-2265] or Dr. Mark Borchert [(323) 361-4510] with any questions about the privacy of your contact information.

Full Name of Parent:

Current Contact Information:

Street Address

City

State

Zipcode

Phone Number