



June 6, 2013

Dear Parent(s):

At Children's 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. The study investigators for this research are *Mark Borchert, M.D.* and *Pamela Garcia-Filion, PhD, MPH.*

The survey takes less than 15 minutes to complete and participation is voluntary. Our Institutional Review Board has approved us to collect information from parents about the pregnancy of their child that was diagnosed with ONH/SOD, including:

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

The survey can be directly submitted to us over the Internet at www.onhsurvey.org. The survey can also be accessed at any one of the following websites.

www.onesmallvoicefoundation.org
www.focusfamilies.org

www.magicfoundation.org
www.onhconsulting.org

If you do not wish to complete the survey over the Internet, then you can complete the paper version of the survey attached to this letter and return it to us by mail. Our address is:

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

The person that is providing this information to you is not part of this research survey. All questions about this survey must be directed to us at Children's Hospital Los Angeles. Please feel free to reach us at the following phone number - (323) 361-6219.

Thank you so much for your help,

Mark Borchert, M.D.

Pamela Garcia-Filion, PhD, MPH

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.