



June 6, 2013

To whom it may concern:

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. I am conducting this research with *Pamela Garcia-Filion, PhD, MPH*. 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) 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.

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 directly submitted to us over the Internet at www.onhsurvey.org. The survey can also be accessed at 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: ONH Research Program
Children's 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 Children's 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.