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www.boyneresearch.ie

INTRODUCING OUR NEW WEBSITE

For details on Boyne Research Institute activities, please visit our website

Study of Irish Families with Neural Tube Defects

What is the purpose of this project? We are looking for patterns of inheritance of neural tube defects within families. Ultimately, we hope that our studies will lead to development of a diagnostic test. The test would determine who is at risk for having a child with a neural tube defect, or another type of birth defect, and might also indicate who would benefit from taking supplemental folic acid, or food fortified with folic acid.

What have we done so far? Here's a synopsis of the last 11 years of this family studies project:

Phase I: Nuclear families: 1995-2002. Interviews with 79 nuclear families, either parents or probands (the person with the neural tube defect), about their own health, the health of their children and the health of the uncles and aunts.

Phase II: Uncles and aunts: 2000-2002. Interviews with 373 uncles and aunts of the proband, about their own health, including birth defects and the health of their children.

Phase III: First cousins: 2002-2004. Interviews with 431 first cousins of the proband, about their own health, including birth defects, their offspring's health, including birth defects.

Phase IV: Siblings, 2006. The study is complete with 150 siblings interviewed (see below), and the data is being prepared for analysis.

REPORT: Phase IV, Sibling Study. 150 siblings participated in a telephone interview from April to September, 2006. Siblings reported 143 pregnancies, consisting of 114 liveborn children and 22 miscarriages (15.4%). Among the pregnancies, eight had birth defects, including scoliosis and hole in the heart; none was reported with an NTD.

For further details please consult our new website www.boyneresearch.ie. Please take a look and send us your feedback.

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What do we plan for the future?

Proband Study: In early 2007, we plan to interview the probands, that is, the person in each family who is living with a neural tube defect.

Fortification Study: Later in 2007, the Irish Government intends to introduce a programme of fortification of flour with folic acid. BRI is preparing to take advantage of this unique opportunity to determine if relatives will achieve the same blood folate levels after fortification as the general population. If they do not, perhaps fortification does not work for everyone, and that some people, or groups of people, may require additional folate.

Clinical Studies: Future studies include physical examinations of relatives looking for the presence or absence of birth defects.

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THANK YOU

Without the active involvement and participation of our families and donors we would not have achieved the very interesting and provocative results that are showing the way to preventing birth defects.

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MISSION

The **Boyne Research Institute** is a community-based research facility that conducts research for the community and in the community directed towards a better understanding of the origins of birth defects, and methods of prevention.

<p>2006 Staff of the Boyne Research Institute</p> <p><i>Dorothy Collins</i>, our long-time administrator/researcher, continues part-time to share her duties at the Boyne Research Institute with her golf game.</p> <p><i>Ruth Campbell</i>, a licensed nurse, most recently worked in the breast unit of the Lourdes Hospital in Drogheda, and shares her duties as BRI researcher with her passion for set dancing.</p> <p><i>Julianne Byrne</i> directs the activities of the Boyne Research Institute and divides her time between Washington, DC and Drogheda.</p>	<p>Your donations to assist the work of the Boyne Research Institute are gratefully appreciated</p> <p>In Ireland: Boyne Research Institute Duke House, Duke Street Drogheda, IRELAND Tel: +353 (0)41-9836041 Email: admin@boyneresearch.ie An Irish-registered charity (no. 10275)</p> <p>In the USA: Boyne Research Foundation 1656 Newton Street, NW Washington, DC 20010, USA Tel: +1 202-234-8719 Email: boyne.research@verizon.net</p>
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