

Extending Folic Acid Education to Families Affected by Neural Tube Defects

Interventions to increase intake of folic acid in families

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Use of family history information for neural tube defect prevention: integration into state-based recurrence prevention programs

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Families Informed: 2006-2007 NTD Family History Survey

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Reaching Beyond NTD Follow-up

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The risk of having a child with a neural tube defect (NTD) is higher in certain individuals with a family history of NTDs, with a 2-5% recurrence risk for parents with a single affected child and a risk in other relatives that is increased above that of the general population. It is especially important for relatives in families affected by a neural tube defect to be aware of their excess risk of recurrence. However, despite knowledge of the benefits of folic acid, supplemental folic acid intake by relatives of an affected child, both close and distant, falls short of optimal. Previous studies in the United States and Ireland showed that short-term interventions with limited follow-up could help individuals increase their intake of supplemental folic acid. However, sustained support for families is probably needed to ensure that all female relatives in their reproductive years are reached and encouraged to do all that they can to promote their own health and that of their unborn children.

This session will focus on a study that utilized NTD family history information to identify and enroll women at increased risk. This study was integrated into existing state-based recurrence prevention programs in Colorado and Michigan. The study targeted second degree female relatives and female partners of second degree male relatives of an affected child: paternal and maternal grandmothers and aunts, as well as sisters, of childbearing age. The study included a survey to determine folic acid supplementation use, reproductive planning, and views on having an affected child. Participants who provided contact information were sent standard folic acid education materials.

The experiences of both state programs will be discussed, including results, lessons learned, and future plans. Margaret Ruttenber, from Colorado Responds to Children with Special Needs (CRCSN), will describe the cohort studied (case definition, sample size, etc.), methods used for notification and follow-up of study participants, and future contact methods for the CRCSN recurrence prevention program for families who have had an affected pregnancy. Joan Ehrhardt, from the Birth Defects Program of the Michigan Department of Community Health, will present a brief overview of Michigan Birth Defects Registry (MBDR) reporting, the Michigan Birth Defects Program, NTD reporting, and NTD follow-up, as well as reviewing the purpose, protocol, and implementation of the Michigan *Family History of NTD and Folic Acid Study*.