



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

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## Estimated NTD rates in 2<sup>o</sup> and 3<sup>o</sup> relatives in selected studies, published 1965-1984

Area	Rate in area's population	No. of index cases	Rate in maternal uncles/aunts	Rate in paternal uncles/aunts	Rate in all uncles/aunts	Rate in maternal first cousins	Rate in paternal first cousins	Rate in all first cousins
Belfast	0.9%	226	0.5%	0.6%	0.5%	0.8%	0.5%	0.7%
South Wales	0.8%	784	—	—	—	0.9%	0.4%	0.6%
Southampton	0.6%	77	1.0%	0.0%	0.5%	2.3%	0.4%	1.5%
London	0.3%	870	—	—	—	0.5%	0.3%	0.4%
Hungary	0.3%	400	0.2%	0.1%	0.2%	0.5%	0.2%	0.3%
Quebec	0.3%	146	0.0%	0.7%	0.3%	0.9%	0.5%	0.7%
Atlanta	0.2%	360	0.7%	0.0%	0.3%	—	—	—
Ontario/Quebec	0.2%	377	1.0%	0.3%	0.6%	0.6%	0.2%	0.4%



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## Use of family history information for NTD prevention

- Use family history information to identify women at increased risk of having a child with an NTD
- Integrated into existing state-based recurrence prevention programs
- Target 2<sup>o</sup> female relatives (ages 18-44) or partners of 2<sup>o</sup> male relatives of an affected proband
- Retrospective: determine whether more likely to take folic acid supplements than the general population
- Prospective: intervention to promote FA use
- Evaluation: measured both by whether or not relatives take folic acid and by rates of NTD recurrence within the family



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## Public health need

- Only about 30% of women of childbearing age report consuming the recommended daily level of FA
- Even among those women with an affected child, a sizeable fraction do not take FA
- Familial cases account for 3.7-18% of all NTD cases
- Recurrence prevention programs have been shown to be effective in increasing FA intake and reducing recurrence



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## Key steps

- Protocol development and Institutional Review Board approval
- Identify 2006-2007 probands with NTDs
- Pre-contact letter sent to proband mothers
- Proband mothers contacted by telephone to obtain consent to participate in study and to determine number of eligible relatives
- Surveys sent to proband mother for distribution to relatives
- Relatives counseled about the importance of FA for prevention of NTDs and provided with standard information about FA
- Relatives re-contacted after six months to assess differences in FA use since the first contact
- Look for differences between maternal and paternal relatives, by demographics



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## Survey questions

- FA use
- Contraception use
- Pregnancies and outcomes
- Knowledge about FA and NTDs
- Views on having a child with an NTD
- Derived from other field-tested surveys (e.g., BRFSS, PRAMS, HealthStyles)



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## Survey questions

*You have been contacted because you have a relative with a pregnancy or child affected by a neural tube defect (NTD) such as spina bifida, anencephaly, or encephalocele.*

15. Did you know that you had a relative with a pregnancy or child affected by a neural tube defect (NTD) such as spina bifida, anencephaly, or encephalocele?
  - a. Yes
  - b. No (GO TO QUESTION 17)
16. How were you told about your relative with a pregnancy or child affected by a neural tube defect (NTD) such as spina bifida, anencephaly, or encephalocele?
  - a. The parents of the infant told me
  - b. Another relative told me
  - c. Someone outside the family (such as a family friend or clergyperson) told me
  - d. Other (please tell us):
17. What is your relationship to the relative with a pregnancy or child affected by a neural tube defect (NTD) such as spina bifida, anencephaly, or encephalocele?
  - a. She is my sister
  - b. She is the sister of my husband or partner
  - c. She is my brother's wife or partner
  - d. She is the wife or partner of my husband/partner's brother
  - e. She is my aunt
  - f. She is my daughter
  - g. She is my son's wife or partner
  - h. She is my mother
  - i. She is the mother of my husband or partner



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## Demographics questions

18. What is your current age? \_\_\_\_\_
19. Which of these groups would you say best represents your race?
  - a. White
  - b. Black or African American
  - c. Asian
  - d. Native Hawaiian or Other Pacific Islander
  - e. American Indian or Alaska Native
  - f. Multiracial (parents of different background, please indicate)
20. Are you Hispanic or Latino?
  - a. Yes
  - b. No
  - c. Don't know/Not sure
21. Are you Arabic or Chaldean?
  - a. Yes
  - b. No
  - c. Don't know/Not sure



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## Demographics questions

22. What is the highest grade or year of school you completed?
  - a. Never attended school or only attended kindergarten
  - b. Grades 1 through 8 (Elementary)
  - c. Grades 9 through 11 (Some high school)
  - d. Grade 12 or GED (High school graduate)
  - e. College 1 year to 3 years (Some college or technical school)
  - f. College 4 years or more (College graduate)
23. Are you...?
  - a. Married
  - b. Divorced
  - c. Widowed
  - d. Separated
  - e. Never married
  - f. A member of an unmarried couple
24. What state do live in?
  - a. Colorado
  - b. Michigan
  - c. Other (please specify):



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## Folic Acid Education Materials



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