

Estimated NTD rates in 2° and 3° relatives in selected studies, published 1965-1984

Area	Rate in	No. of	Rate in	Rate in	Rate	Rate in	Rate in	Rate in
	area's	index	maternal	paternal	in all	maternal	paternal	all first
	population	cases	uncles/	uncles/	uncles	first	first	cousins
			aunts	aunts	/aunts	cousins	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%
Southampto	0.6%	77	1.0%	0.0%	0.5%	2.3%	0.4%	1.5%
n								
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/	0.2%	377	1.0%	0.3%	0.6%	0.6%	0.2%	0.4%
Quebec								

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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° female relatives (ages 18-44) or partners of 2° 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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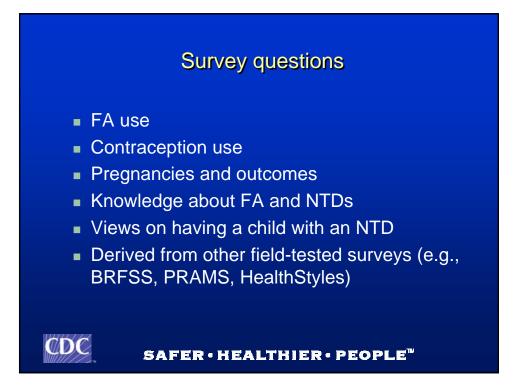


Key steps

- 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

- 1. Do you currently take any vitamin pills or supplements?
 - a. Yes
 - b. No (GO TO QUESTION 5)
 - Don't know/Not sure (GO TO QUESTION 5)
- 2. Do any of the vitamin pills or supplements you take contain folic acid? a. Yes
 - b. No (GO TO QUESTION 5)
 - c. Don't know/Not sure (GO TO QUESTION 5)
- How often do you take this vitamin pill or supplement? 3.
 - a. Less than once a week
 b. 1-3 times a week
 c. 4-6 times a week
 d. Every day of the week
- 4. I take a folic acid-containing vitamin because...



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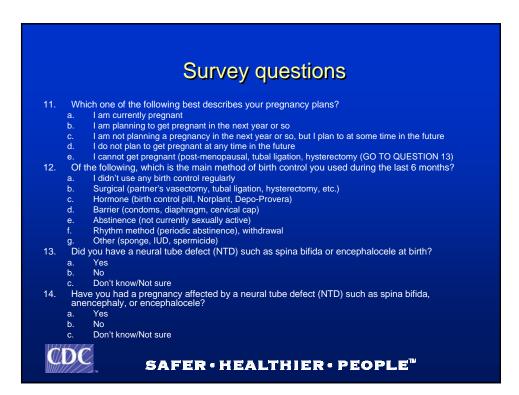
		Surve	ey questic	ons			
5.	l intend to	take a mult	ivitamin every o	lay:			
	Strongly agree			Strongly disagree			
	1	2	3	4	5		
6.	It is likely defect: Strongly a		have a pregnar	ncy affected by a Strongly			
	1	2	3	4	5		
7.	l am afrai	d of having a	a baby with seri	ous birth defects			
	Strongly agree			disagree			
	Strongly a	gree					

Survey questions

Stron	gly agree	imin every day:	Strongly	disagree
1	2	3	4	5
9. It is p defec		ould have a preg	nancy affected	by a birth
Stron	gly agree		Strongly	disagree
1	2	3	4	5
	possibility of ha	wing a baby with	serious birth de	fects
Stron	gly agree		Strongly	disagree



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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?
 - Yes No (GO TO QUESTION 17) b.
- 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? 16.
 - The parents of the infant told me
 - Another relative told me
 - Someone outside the family (such as a family friend or clergyperson) told me
 - Other (please tell us):
- 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? 17.

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- a.
- She is my sister She is the sister of my husband or partner
- She is my brother's wife or partner She is the wife or partner of my husband/partner's brother
- d. She is my aunt e.
- She is my daughter
- She is my son's wife or partner g.
- ň. She is my mother
 - She is the mother of my husband or partner



Demographics questions 18. What is your current age? 19. Which of these groups would you say best represents your race? White b. Black or African American Asian d. Native Hawaiian or Other Pacific Islander American Indian or Alaska Native Multiracial (parents of different background, please indicate) 20. Are you Hispanic or Latino? Yes b. No Don't know/Not sure 21. Are you Arabic or Chaldean? Yes No Don't know/Not sure **@DC** SAFER • HEALTHIER • PEOPLE[™]

