

Colorado Responds to Children with Special Needs



Families Informed: 2006-2007 NTD Family History Survey

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Results: Family HX

- 73 letters sent to Index Families (2006-07)
- 15 returned, 8 not eligible
- 50 families contacted re: Participation
- 10 families did not want to be contacted again- ever
- 16/40 families agreed to participate
- Survey completed: n=17; outstanding n=11
- Follow-up: 13 respondents wanted to be/ were contacted by email. 1 individual responded to email thankful for the opportunity to participate.

Survey Findings: Supplement Intake

- **What we know about our supplements:**
 - 3/17 did not take supplements
 - 8 knew supplement contained Folic Acid
 - 4 did not know if supplement contained Folic Acid
 - 2 knew supplement did not contain folic acid
 - 3 did not respond to the question
- **How frequently were supplements taken:**
 - 5 took supplements everyday
 - 3 took supplements 4-6 x/week
 - 4 took supplements 1-3 x/week
 - 1 took supplements <1 x/week
 - 4 did not respond to the question

I take a folic acid-containing vitamin because...

- "I heard it was a benefit to my health."
- "I know it helps prevent NTDs."
- "Preparing for pregnancy."
- "Previous NTD pregnancy."
- "Planning an IVF transfer."
- "It is already included in my multivitamin."

I intend vs. I will take a multivitamin!

- 11 strongly agree to intend to take a multivitamin
- 5 moderately agree to intend
- 1 strongly disagrees to intend
- 11 strongly agree they will take a multivitamin
- 3 moderately will take
- 3 strongly will not take

It is likely vs. possible I will have a pregnancy affected by a birth defect

- 7 strongly agree it is likely they will have a pregnancy affected by a birth defect
- 6 moderately agree it is likely
- 4 strongly disagree it is likely
- 8 strongly agree it is possible they will have a pregnancy affected by a birth defect
- 7 moderately agree it is possible
- 2 strongly disagree it is possible

I am afraid vs. scared of having a baby with a serious birth defect

- 9 strongly agree they are afraid of a serious birth defect occurring
- 5 are moderately afraid
- 3 strongly disagree that they are afraid
- 8 strongly agree they are scared of a serious birth defect occurring
- 4 are moderately scared
- 2 strongly disagree they are scared
- *3 did not respond

***** There did not appear to be a strong connection between taking folic acid and concern about having a baby with a birth defect in either group**

Respondent Demographics

- **Average age of respondent:** 34 years of age
- **Race/Ethnicity:** 16 white; 1 Native Hawaiian/other Pacific Islander
- **Resident State :** 13 Colorado; 1 each NY,OH,NH TX
- **Education:** 11 $4 \geq$ years of college; 6 1-3 years of college
- **Marital Status:** 13 married; 3 divorced; 1 never married

Colorado vs. Michigan Differences in Protocol

- Colorado collects data for: Spina bifida, encephaloceles, anencephaly (fetal demise included) .
- No incentive
- Access to birth defects data (registry)
- Anonymous surveys
- Michigan provided an incentive
- Did not include fetal demise cases
- Surveys not anonymous
- Follow –back mailed survey
- Expedited IRB Review



Lessons Learned

- Emma's story is not a message that index families need to see. In an effort to be transparent, we included the pamphlet so the proband's family could review the information being sent to their family members.
- CRCSN needs to reinstate the maternal interview. Every family contacted had been sent a letter within 3 months of having had a NTD affected pregnancy-- not one had contacted CRCSN with questions.