Appendix A

Glossary

Approach. A means by which to move toward meeting an objective or goal.

Central Location Intercept Interviews.

Interviews conducted with respondents stopped at a highly trafficked location frequented by individuals typical of the desired target audience.

Community. An interacting population of various kinds of individuals sharing some commonality together within a larger society.

Epidemiologist. A scientist who deals with the incidence, distribution, and control of disease in a population.

Focus Group Interviews. A type of qualitative research in which an experienced moderator leads about 8 to 10 respondents through a discussion of a selected topic, allowing them to talk freely and spontaneously.

Gatekeeper. Someone you must work with before you can reach a target audience (e.g., a schoolteacher) or accomplish a task (e.g., a television public service director).

Goal. The overall improvement the program will strive to create.

Human Subject Review Board.

A specially constituted review body established or designated by your agency for the purpose of protecting the rights and welfare of human subjects involved in research projects.

In-Depth Interviews. A form of qualitative research used to find out what people think and feel about a given topic.

Informed Consent. Persons who participate in research should have the opportunity to choose what will or will not happen to them. Three necessary elements of informed consent are full disclosure, adequate comprehension, and voluntary choice

Institutional Review Board (IRB).

A specially constituted review body established or designated by your agency for the purpose of protecting the rights and welfare of human subjects involved in research projects.

Objective. A quantifiable statement of a desired program achievement necessary to reach a program goal.

Outcome Evaluation. Evaluation conducted to identify a program's accomplishments and effectiveness; also called end-stage or impact evaluation.

Pretest. A type of formative research that involves systematically gathering target audiences reactions to messages and materials before they are produced in final form

Process Evaluation. Evaluation to study the functioning of components of program implementation; includes assessments of whether materials are being distributed to the right people and in what quantities, whether and to what extent program activities are occurring, and other measures of how the program is working.

PSA (Public Service Announcement).

A message for the public's good for which outlets do not charge.

Qualitative Research. Research that is subjective in that it involves obtaining information about feelings and impressions from small numbers of respondents. The information gathered usually should not be described in numerical terms, and generalizations about the target populations should not be made.

Quantitative Research. Research designed to gather objective information from representative, random samples of respondents; results are expressed in numerical terms (e.g., 35% are aware of X and 65% are not). Quantitative data are used to draw conclusions about the target audience.

Reach. Term refers to the number of different people or households exposed to a specific media message during a specific period of time.

Self-Administered Questionnaires.

Questionnaires that mailed directly to the respondents and are filled out by respondents themselves, or filled out by respondents gathered at a central location.

Target Audience. The desired or intended audience for program messages and materials (see segmentation). The primary target audience consists of those individuals the program is designed to affect. The secondary target audience is that group (or groups) that can help reach or influence the primary target audience.

Theater Tests. A large group of audience members reviews draft materials, which are embedded into other materials, and are asked to respond to brief written surveys.

Appendix B

Useful Literature and Information

Frequently Asked Questions and Answers

Can you describe NTDs (neural tube defects) in more detail?

There are several different types of NTDs. **Spina bifida** and **anencephaly** comprise 90% of all NTDs that occur. It is estimated that 4,000 pregnancies in the United States each year are affected by NTDs. Of that number, approximately 2,500 infants with NTDs are born.

- When the **upper** end of the neural tube fails to close properly, early in the first month of pregnancy, two different types of NTDs can result: **anencephaly** and **encephalocele**.
 - 1) The more common of the two, **anencephaly** is a defect in which the skull bones and brain are partially or totally absent. Babies born with anencephaly die before or shortly after birth.
 - 2) **Encephalocele**, the other type, is a defect in which parts of the brain protrude outside the skull in a sac of skin. This defect occurs in approximately 10 % of NTD affected pregnancies. Children who suffer from encephalocele usually live. Often, their mental capacities do not develop normally, but the degree of mental disability depends upon the size and extent of the brain involvement.
- C When the **lower** end of the neural tube fails to close properly, also during the first month of pregnancy, one of three forms of **spina bifida** result. **Spina bifida occulta**, **meningocele**, and **myelomeningocele**, in that order, vary from least to most severe.
 - 1) **Spina bifida occulta** consists of a small gap in the backbone or spine but no protrusion of the spinal cord or meninges (membranes that cover the spinal cord and the brain). Ordinarily, treatment is not needed because there are usually no symptoms or disability. In fact, most people are unaware that they have this minor defect of the spine.
 - 2) **Meningocele** is a sac made of spinal fluid and meninges that protrudes through the bony defect in the spine. The spinal cord and the spinal nerves are not in the protruding sac. This form of spina bifida is less common than myelomeningocele and results in less severe disabilities. The defect needs to be repaired surgically.
 - 3) **Myelomeningocele** is the most severe type of spina bifida. A sac composed of meninges, spinal fluid, spinal cord, and spinal nerves protrudes through the bony defect. Depending on the size and location of the meningomyelocele, varying degrees of paralysis, loss of bowel and bladder control, and learning disabilities occur. This defect also needs to be repaired surgically. Children with myelomeningocele frequently develop a condition called hydrocephalus or "water on the brain." If this condition is not treated quickly, severe brain damage can occur.

How can I find out if my baby is affected by an NTD when I am pregnant?

Women should be aware that there are ways to test whether a fetus has been affected by an NTD. When the neural tube fails to close, a fetal substance, AFP (alpha-fetaprotein), leaks into the blood and the amniotic fluid (fluid in the mother's uterus). Between the 16th and 18th week after a woman's last period, a test of a mother's blood revealing a high AFP level is an indicator that a pregnancy possibly is affected by an NTD. If the blood test reveals a high levels of AFP, the woman is encouraged to have an ultrasound and possibly an amniocentesis. The ultrasound can be effective in diagnosing encephalocele and myelomeningocele. Ultrasound is used before the amniocentesis to identify where the placenta is located in the mother's uterus. Locating the placenta reduces the risk of harm to the fetus during the amniocentesis. During an amniocentesis, amniotic fluid is taken from the mother's uterus with a long needle. This fluid is then tested for AFP levels. The results of this test along with an extensive ultrasound are used to confirm NTD-affected pregnancies. Women should be aware that these tests cannot detect all NTDs.

Why do NTD birth rates vary by geographic region?

Historically, in the United States, NTD rates have been higher in East, particularly in the Appalachian region, than in the West. Similar geographic-based NTD rate variations have also been observed in other countries. Why these variations occur is not known but may be due to socio-economic levels, race/ethnicity, or other factors.

Are there genetic causes of NTDs?

It is rare that NTDs result from chromosomal abnormalities or genetic traits. However, NTDs are more likely to recur in families that already have an affected child, and they are more likely to occur in some racial/ethnic groups than others. Studies looking at familial or genetic factors indicate that multiple variables influence the closure of the neural tube. For example, it has been speculated that even if a genetic disorder in folate metabolism were present, an additional amount of folic acid taken by the mother may increase folate levels in the body enough to compensate for the inborn error of folate metabolism. It is known that 50-70% of NTDs can be prevented through the consumption of 400 micrograms of folic acid per day.

What are CDC's recommendations and policies towards women at a higher risk for NTDs?

The CDC guideline published in August 1991 and the PHS guideline published in September 1992 recommend that *women who have had a previous NTD-affected pregnancy* consume 400 micrograms (0.4 milligram) of folic acid daily if they are not planning a pregnancy and 4,000 micrograms (4.0 milligrams) of folic acid daily <u>under the direction of their health care provider</u> if they are planning a pregnancy.

More studies of the prevention of NTDs among other higher risk women need to be done. Nevertheless, these women should follow the PHS recommendation of 400 micrograms (0.4 milligram) of folic acid daily throughout their childbearing years. If they are planning a pregnancy, it is advisable for them to discuss their potential risk for having an affected child with their physician. They should talk about the advantages and disadvantages of using 4,000 micrograms (4 milligrams) periconceptionally (that is, one month before conceiving a baby through the first three months of pregnancy). Other high-risk women include:

- C Women with a close relative (e.g., sibling, niece, nephew) who has an NTD.
- C Women or their partners who themselves have an NTD.
- C Women with insulin-dependent diabetes mellitus.
- C Women with seizure disorders being treated with valproic acid or carbamazepine.
- C Women with medically diagnosed obesity.

What are the costs associated with NTDs?

The average total lifetime cost to society for each infant born with spina bifida is approximately \$532,000 per child. This estimate is only an average. For many children, the total cost may be well above \$1,000,000. The money involved does not address the physical and emotional tolls upon the families affected.

Are there other health benefits with folic acid?

Although not conclusive, there is evidence that periconceptional use of folic acid may prevent other types of birth defects. These include cleft lip and cleft palate as well as some congenital heart defects, limb-reduction defects, and urinary tract defects.

High levels of the amino acid homocysteine are independently associated with an increased risk for heart disease and stroke. Studies have shown that taking folic acid lowers homocysteine levels in both men and women, but it has not yet been proven that folic acid supplementation also lowers the risk for heart disease and stroke.

Folic acid may play a role in prevention of cancers of the cervix and colon also.

If folic acid is destroyed by cooking, what will happen to enriched cereal-grain products like pasta and rice?

The FDA had allowed for additional amounts of folic acid (beyond the level of 140 milligrams per 100 grams) to be added to individual enriched cereal-grain products whose levels of folic acid may be lost due to factors such as food preparation and product shelf life. Thus, depending on the type of food and the estimated loss of folic acid due to many factors, different amounts of folic acid are added to enriched cereal-grain products to ensure that 140 micrograms of folic acid will be consumed per 100 grams of enriched cereal-grain product.

Sources of Folic Acid and Folate

The products listed below, among others, contain 400 micrograms of folic acid per serving, which is 100 percent of the recommended daily amount (RDA) of folic acid for a woman of childbearing age. Most other breakfast cereals contain 100 micrograms, 1/4 of the RDA per serving.

| С | Whole Grain Total, Total Corn Flakes, and Total Raisin Bran (General Mills Inc.) |
|---|--|
| С | Product 19 (Kellogg's) |
| С | Just Right with Crunchy Nuggets (Kellogg's) |
| С | Smart Start (Kellogg's) |
| С | Multi-Grain Cheerios Plus (General Mills Inc.) |
| С | Most multivitamin tablets and folic acid supplements |

The following is a list of sources of folate from foods to help you enhance your dietary choices. It is very important for a woman to eat a nutritionally healthy diet, including foods high in folate. There are so many factors affecting the bioavailability of naturally occurring food folates that we have not quantified food folate in the food items. In addition, although it is conceivable, it has not been demonstrated that food folate protects against NTDs as well as synthetic folic acid.¹

Beans and Lentils, Canned or Dry **Carbohydrates:**

Enriched Cereals Enriched Breads

Meats: Enriched Rice Eggs **Enriched Pastas** Liver

Juices: **Vegetables:**

Orange Juice from concentrate Artichokes Pineapple Juice, canned Asparagus Avocado

Collard Greens Lettuce, romaine Cantaloupe

Strawberries Okra

Kiwis Spinach, fresh or frozen

Legumes:

Fruits:

¹ Institute of Medicine. Dietary Reference Intakes: Folate, Other B Vitamins, and Choline: Prepublication Copy. In: Dietary Reference Intakes for Thiamin, Riboflavin, Vitamin B₆, Folate, Vitamin B₁₂, Pantothenic Acid, Biotin, and Choline. Washington, DC: National Academy Press, 1998. Chapter 8, page 32.

Sample Nutrition Label Highlighting Folic Acid

(.4 mg = 400 micrograms = 400 mcg = 100%RDI=Daily Value) (.1 mg = 100 micrograms = 100 mcg = 25%RDI=Daily Value)

The Nutrition Facts on food packages show how much of each nutrient's Recommended Daily Allowance (RDA) is included in one serving of the food product. This label tells you that with one serving, 1/2 cup, you will receive 25% of the folic acid you need in a day. Folic acid, like other vitamins and minerals, will not always be listed on all food packages. Seek out products that let you know they contain folic acid.

| Nutrition Facts Serving Size 1/2 cup (52 g) Servings Per Container 8 | | | | | |
|--|----------------------|-------------------------------|--|--|--|
| Amount per Serving Calories Calories from fat | Cereal 200 25 | with 1/2 cup Skim Milk 240 25 | | | |
| Total Fat 3g | % Daily Value | % Daily Value | | | |
| Saturated Fat 0.5g | 3% | 3% | | | |
| Cholesterol 0mg | 0% | 0% | | | |
| Sodium 240mg | 10% | 13% | | | |
| Potassium 200mg | 6% | 11% | | | |
| Total Carbohydrate 43g | 14% | 16% | | | |
| Dietary Fiber 5g | 20% | 20% | | | |
| Sugars 15g | | | | | |
| Other Carbohydrate 23g | | | | | |
| Protein 4g | | -1 | | | |
| Vitamin A | 25% | 30% | | | |
| Vitamin C | 0% | 2% | | | |
| Iron | 25% | 25% | | | |
| Vitamin D | 10% | 25% | | | |
| Thiamin | 25% | 25% | | | |
| Riboflavin | 25% | 35% | | | |
| Niacin | 25% | 25% | | | |
| Vitamin B6 | 25% | 25% | | | |
| Vitamin B12 | 25% | 35% | | | |
| Folate or Folic Acid | 25% | | | | |
| 25% | | | | | |
| Phosphorus | 15% | 25% | | | |
| Magnesium | 15% | 20% | | | |
| Zinc | 10% | 15% | | | |

References on Living with Spina Bifida

- C "For parents who have lost a pregnancy or had a child with spina bifida, anencephaly, or encephalocele--what you should know about folic acid," Genetic Center at Children's Hospital Center of Akron, Ohio. National Maternal and Child Health Clearinghouse, 2070 Chain Bridge Rd., Suite 450, Vienna, VA 22182. (703) 356-1964 FAX: (703) 821-2098 E-Mail: NMCHC@circsol.com
- C Havermans T, Eiser C. Mothers' perceptions of parenting a child with spina bifida. *Child: Care, Health and Development* 1991; 17(4): 259-273.
- C Lindstrom B. Quality of life for disabled children based on health as a resource concept. *Journal of Epidemiology and Community Health* 1994; 48: 529-530.
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- C Sandler A. *Living with spina bifida: a guide for families and professionals.* Chapel Hill, NC: University of North Carolina Press, 1997.
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- C Spina Bifida Association of America Brochure and Handbook. Spina Bifida Association of America: 4590 MacArthur Blvd., N.W., Suite 250, Washington, DC, 2007. (202) 944-3285. (800) 621-3141. E-Mail: spinabifida@aol.com.
- C Van Hasselt V, Ammerman R, Hersen M, Reigel D, Rowley F. Assessment of social skills and problem behaviors in young children with spina bifida. *Journal of Developmental and Physical Disabilities* 1991; 3(1): 69-80.

Mailing Lists, News Groups and Web Sites

Inclusion on this list is not an endorsement. Sites are not reviewed for the accuracy of the information they provide. Any information you find should be reviewed with your health care provider for accuracy.

- Anencephaly Support Foundation at http://www.asfhelp.com is dedicated to serving parents, families and the educational and medical communities. They provide information, personal stories, and medical articles regarding anencephaly, support and encouragement to parents who have chosen to carry an anencephalic pregnancy to term, and information regarding possible causes, prevention theories, and support group referrals.
- Association of Birth Defect Children, Inc. at *http://www.birthdefects.org* is a charitable organization started by parents in 1982. ABDC provides free phone information to parents and professionals about all kinds of birth defects, resources, support groups and environmental exposures that may cause birth defects.
- C BIFIDA-L is an electronic mailing list is for anyone interested in spina bifida. To subscribe send an e-mail message to: *listserv@mercury.dsu.edu*. In the body of the message type: BIFIDA-L Your First Name Your Last Name.
- C Birth Defects Prevention Legislation Committee at http://www.birthdefectsprevention.org writes about what is happening and what you can do in the area of birth defects and spina bifida at a policy level.
- SB-Parents is an electronic mailing list and a discussion forum for people interested in the care of children who have spina bifida. To subscribe, send an e-mail message to: listserv@waisman.wisc.edu. In the body of the message type: Subscribe SB-Parents Your First Name Your Last Name

References on Folic Acid and NTDs

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C British Medical Research Council Study, 1991

This randomized trial of women who previously had NTD-affected pregnancies showed that usual diet plus periconceptional supplementation with 4 mg folic acid per day decreased the risk of having a subsequent NTD-affected pregnancy. (MRC Vitamin Study Research Group. Prevention of neural tube defects: results of the Medical Research Council Vitamin Study. *The Lancet* 1991; 338:131-7.)

C Hungarian Study, 1992

This randomized trial of women who had <u>not</u> previously had NTD-affected pregnancies showed that usual diet plus daily periconceptional supplementation with a multivitamin containing 0.8 mg folic acid decreased the risk of having an NTD-affected pregnancy. (Czeizel AE, Dudas I. Prevention of the first occurrence of neural-tube defects by periconceptional vitamin supplementation. *The New England Journal of Medicine* 1992; 327:1832-5.)

C Observational Studies, 1983-1995

Five out of six of these studies corroborated the results of the randomized clinical trials with folic acid-containing multivitamins and further suggested that usual diet plus 0.4 mg (400 mcg) of folic acid per day could prevent about 50% of neural tube defects. (Smithells RW, Nevin NC, Seller MJ, et al. Further experience of vitamin supplemntation for the prevention of neural tube defect recurrences. *Lancet* 1983; 1:1027-31. Mulinare J, Cordero JF, Erickson JD, et al. Periconceptional use of multivitamins and the occurence of neural tube defects. *JAMA* 1988; 260: 3141-5. Mills J, Rhoads GG, Simpson JL, et al. The absence of a relation between the periconceptional use of vitamins and nueral tube defects. *N Engl J Med* 1989; 321: 430-5. Milunsky A, Jick H, Jick SS, et al. Multivitamin/folic acid supplementation in early pregnancy reduces the prevalence of neural tube defects. *JAMA* 1989; 262: 2847-52. Daly, L, Kirke P, Molloy A, et al. Folate levels and neural tube defects: implications for prevention. *JAMA* 1995; (27)21:1698-1702. Shaw GM, Schaffer D, Velie EM, et al. Periconceptional vitamin use, dietary folate, and the occurrence of neural tube defects in California. *Epidemiolgy* 1995; 6:219-226.)

2. There have also been recommendations for childbearing age women on the use of folic acid to prevent NTDs.

- C Centers for Disease Control and Prevention. Recommendations for the use of folic acid to reduce the number of cases of spina bifida and other neural tube defects. *Morbidity and Mortality Weekly Report: Recommendations and Reports* 1992; 41(RR-14): 1-7.
- C Institute of Medicine(IOM). (Dietary reference intakes: folate, other B vitamins, and choline: prepublication copy. In: *Dietary reference intakes for thiamin, riboflavin, vitamin B₆, folate, vitamin B₁₂, pantothenic acid, biotin, and choline.* Washington, DC: National Academy Press, 1998. To order: write the National Academy Press, 2101 Constitution Avenue, N.W., Box 285, Washington, DC 20055; call (800) 624-6442 or visit NAP's on-line bookstore at *http://www.nap.edu*. For more information about the Institute of Medicine or the Food and Nutrition Board, visit the IOM website at *http://www2.nas.edu/iom*

Articles on Folic Acid and NTDs

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Folic Acid Information for Health Care Professionals

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- Brown J, Romanczuk A. Folic acid will reduce risk of neural tube defects: periconceptional use of folic acid is now recommended for all women. Word must be spread with sensitivity and care. *American Journal of Maternal Child Nursing* 1994; 19: 331-4.
- Institute of Medicine (IOM). (Dietary reference intakes: folate, other B vitamins, and choline: prepublication copy. In: *Dietary reference intakes for thiamin, riboflavin, vitamin B₆, folate, vitamin B₁₂, pantothenic acid, biotin, and choline.*) Washington, DC: National Academy Press, 1998. To order: write the National Academy Press, 2101 Constitution Avenue, NW, Box 285, Washington, DC 20055, telephone (800) 624-6442 or visit NAP's on-line bookstore at http://www.nap.edu. For more information about the Institute of Medicine or the Food and Nutrition Board, visit the IOM website at http://www2.nas.edu/iom.

Folic Acid Information for Childbearing-Age Women

C Doheny K. More on folic acid: why you need this crucial vitamin now. *Fit Pregnancy* 1998; (5):46-7.

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- C Glanz K, Rimer BK, Lewis FM, (Eds). *Health behavior & health education: theory, research, & practice.* (2nd ed). San Francisco: Jossey Bass, 1997.
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Journals, Websites, and Listservs for Making Health Campaigns Effective

- C *Health Communication*. To subscribe: write Lawrence Erlbaum Associates, Inc. 365 Broadway, Hillsdale, NJ 07642.
- C *Health Education Quarterly*. To subscribe: write John Wiley & Sons, Inc., 605 3rd Ave., New York, New York 10158 or telephone (212) 850-6645.
- C *Health Education Research*. To subscribe: write Oxford University Press, 2001 Evans Rd., Cary, NC 27513.
- C *Journal of Health Communication*. To subscribe: write Taylor & Francis Ltd., 1 Gunpowder Square, London ECA 3DE, U.K.
- C Social Marketing Quarterly. To subscribe: write Best Start Social Marketing, 3500 E. Fletcher Ave. #519, Tampa, Fla. 33613, telephone (813) 971-2119, fax (813) 971-2280, or e-mail: bestart@mindspring.com.
- C *The American Journal of Health Communications*. To subscribe: write Turning Point Communications, P.O. Box 7070 Loudon, NH 03301or telephone (603) 798-5180.

More Information on...

Step 1: "Mobilizing Your Community"

- C Bracht N, Gleason J. Strategies and structures for citizen partnerships. In: [Bracht N] (ed). *Health promotion at the community level.* 1990; Newbury Park, CA: Sage Publications, 109-24.
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- C Durazzo R. *Building a media resource inventory*. Palo Alto, CA: Stanford Center for Research in Disease Prevention, 1989. Telephone (415) 723-1000.
- C Feighery E, Rogers T. *Building and maintaining effective coalitions*. Palo Alto, CA: Stanford Center for Research in Disease Prevention, 1990. Telephone (415) 723-1000.
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Where To Get Information About Your Audience

Data available to you

- C Demographic data is available at local and state health departments and on the U.S. Census Bureau's Internet web site at http://www.census.gov/.
- C Review national data. State-specific information may be found by contacting your state's surveillance supervisor listed in Appendix C on page 6-14.
- Information about a target audience's psychographic profile, media habits, and other lifestyle factors that influence their knowledge, attitudes, beliefs, and behaviors (KABBs) can be found in many databases like Arbitron, The Roper Center/Institute for Social Inquiry, Mediamark Research Inc., Simmons Market Research Bureau, PRIZM, Yankelovich Partners Inc., and Porter-Novelli's Healthstyles.
- Public and private university research libraries, university marketing departments, state or local governments, education, and social service departments, the US Census Bureau and Government Printing Office, newspapers, radios stations, television stations, and ad agencies are also potential sources of information on women in your community.

Data you have to collect

- Add questions about vitamin usage and/or knowledge about folic acid and neural tube defects, provided in Appendix G to an existing health survey. Call your state's Department of Health and ask them to add some of these questions to its Behavioral Risk Factor State Surveillance Survey (BRFSS).
- C Conduct surveys and/or focus groups to better assess the KABBs of your target audience. Information on focus groups is provided on page 20 of this Appendix B.
- Ask local market research firms for data on women in your community. You may get pro bono or reduced-cost help from a local market research firm, the research department of a large company, the advertising departments of local media (newspapers, radio, and TV), local advertising and public relations firms, and communications or public health departments at nearby universities and colleges.

Selecting Your Audience

- C Albrecht TL, Bryant C. Advances in segmentation modeling for health communications and social marketing campaigns. *Journal of Health Communication* 1996; (1) 65-80.
- C Andreason AR. *Cheap but good marketing research*. Homewood, Illinois: Dow Jones-Irwin, 1988.
- C Center for Substance Abuse Prevention. *Technical assistance bulletin: identifying strategy development.* 1994. On-line at http://www.health.org/pubs/makepub/tab13.htm.
- C Slater MD. Theory and method in health audience segmentation. *Journal of Health Communication* 1996; (1): 267-283.

Women's Health Beliefs and Practices

The following are sources of national, regional, and community level information. Use these sources to help set your goals, objectives, and activities.

- C Block G, Cox C, Madans J, Schreiber GB, Licitra L, Melia N. Vitamin supplement use, by demographic characteristics. *American Journal of Epidemiology* 1988; 127:297-309.
- C Center for Disease Control and Prevention. 4770 Buford Highway NE, Mailstop F-34. Atlanta, GA 30341. Conducted focus group testing on different populations of women to create a consistent national campaign message that can be adapted to meet the needs of specific communities on a local level.
- C Greenwood Genetics Center. 1995. 1 Gregor Mendel Circle. Greenwood, SC 29646. Conducted four focus groups of women age 18 28 years old, not actively trying to get pregnant, black and white, and married and single.
- C Healthstyles. National survey of women's knowledge, attitudes, beliefs, and behaviors about health. This data can be broken down on a regional level, by race/ethnicity, age, and other factors. CDC can provide you with basic summaries of the information provided about women of reproductive age. If you need more information, CDC can also direct you to the marketing research firm that collects the data.
- C Lebow M, Arkin EB. Women's health and the mass media: the reporting of risk. *Women's Health Issues*, 1993; 3(4): 181-190.
- C *Michigan Department of Community Health*. 1995. Bureau of Child and Family Services, 3423 N. M.L.K. Jr. Blvd., PO Box 30195, Lansing, MI 48909. Conducted three focus groups, one each of high school girls, teachers, and college students.

- C New Mexico Birth Defect Prevention and Surveillance System. 1994. Beradilla County Health Office, 1111 Stanford Drive, NE, PO Box 25846, Albuquerque, NM 87125-0846. Conducted eight focus groups throughout the state of 10 15 women aged 15 44 and not currently pregnant. Participants were representative of New Mexico's population of women in terms of ethnicity, income/education level, and geographic location.
- C Ohio Department of Health. *Ideas on educating Ohioans about the importance of folic acid: a brochure for health clinics, schools, hospitals, and family organizations.* 1996. A summary of Ohio's statewide folic acid education focus group recommendations. For more information, contact Help Me Grow at 1-800-755-GROW.
- C Preparing for Pregnancy II: Second National Survey of Women's Behavior and Knowledge Relative to Consumption of Folic Acid and Other Vitamins and Pre-pregnancy Care. March of Dimes Birth Defects Foundation. Conducted by the Gallup Organization. CDC has some results they can share. Detailed results can be bought.
- C The Combined Health Information Database (CHID) at http://chid.nih.gov. This is a source of other programs that are successfully reaching a similar target audience.
- C *The U.S. Census Bureau at http://www.census.gov/*. Search statistics you would like to see through the letters of the alphabet. For example, if you would like to see the breakdown of women in your community by age, search "A" to finding Age statistics.
- C Virginia Department of Health. 1997. Commonwealth of Virginia. 1500 E. Main Street, Suite 131, P.O. Box 2448, Richmond, Virginia, 23218. Contact Linda Foster at (804) 786-5420 or fax (804) 371-6162. Conducted focus groups of women (stratified by rural versus urban locations, adult versus adolescent ages, low versus moderate income, and minority versus nonminority status) to determine what motivates women to change their dietary habits and obtain information to guide the content of radio and television public service announcements. Also, conducted a telephone survey to assess nutritional awareness and dietary practices among women of childbearing age in the state.

Women's Consumer Habits

- C Kerr DL, Gascoigne JL. Getting to know generation X: health education for the thirteenth generation. *Journal of Health Education* 1996; 27(5), 268-273.
- C Leeming EJ, Tripp CF. Segmenting the women's market: using niche marketing to understand and meet the diverse needs of today's most dynamic consumer market. Burr Ridge, Illinois: Irwin Professional Publishing, 1994. Segments the U.S. women's consumer market by age, race/ethnicity, class, marriage status, and profession.

Women's Media Habits

The following information about women in the United States may help your program identify what women's media habits may be in your community.

C Claritas' PRIZM database. Information about U.S. women's media habits can be broken down on a regional level, by race/ethnicity, age, and other factors. CDC can provide you with basic summaries of the information provided about women of reproductive age. If you need more information, CDC can direct you to the marketing research firm.

Special Populations of Women

These sources will help you plan culturally sensitive and appropriate programs.

- C Center for Substance Abuse and Prevention. *Technical assistance bulletin: developing effective materials for Hispanic/Latino audiences*. 1997. [On-line at http://www.health.org/pubs/makepub/tab15.htm].
- C Center for Substance Abuse and Prevention. *Technical assistance bulletin: you can use communications principles to create culturally sensitive and effective prevention materials.* 1994. [On-line at http://www.health.org/pubs/makepub/tab12.htm].
- C Gonzalez V, Gonzalez J, Freeman V, Howard-Pitney B. *Health promotion in diverse cultural communities*. Palo Alto, CA: Stanford Center for Research in Disease Prevention, 1991. Telephone (415) 723-1000.
- C Health promotion for low-income groups: programming strategies. Chicago, IL: American Hospital Association, 1989.
- C National Coalition of Hispanic Health and Human Services Organizations (COSSMHO). Write 1030 15th Street, NW, Room 1053, Washington, DC 20001or telephone (202) 628-9600.
- C Randall-David E. *Strategies for working with culturally diverse communities and clients*. Bethesda, MD: Association for the Care of Children's Health, 1989. Telephone (301) 654-6549.
- C Search *http://www.ag.ohio-state.edu/~ohioline/hyg-fact/5000/5250.html* to find out about different cultural groups eating habits and preferences in America.

Creating Messages and Materials

- C Adler E. Everyone's guide to successful publications: how to produce powerful brochures, newsletter, flyers and business communications, start to finish. PeachPit Publishers, 1993 (ISBN No.:156609027X).
- C Beyond the brochure: alternative approaches to effective health communication. AMC Cancer Research Center, 1993. 1600 Pierce Street, Denver, CO, 80214.
- C Center for Substance Abuse Prevention. *Technical assistance bulletin: a key step in developing prevention methods is to obtain expert and gatekeeper reviews.* (1994). [Online at http://www.health.org/pubs/makepub/tab6.htm].
- C Center for Substance Abuse Prevention. *Technical assistance bulletin: careful concept development paves the way to effective prevention materials.* 1994. [On-line at http://www.health.org/pubs/makepub/tab4.htm].
- Center for Substance Abuse Prevention. *Technical assistance bulletin: you can avoid common errors as you develop prevention materials.* 1994. [On-line at http://www.health.org/pubs/makepub/tab8.htm].
- C Center for Substance Abuse Prevention. *Technical assistance bulletin: you can prepare easy-to-read materials.* 1994. [On-line at http://www.health.org/pubs/makepub/tab10.htm].
- Condit C, Parrott R. *Evaluating women's health messages: a resource book.* Thousand Oaks: Sage Publications, 1996.
- C Maibach E, Parrott RL. *Designing health messages--approaches from communication theory and public health practice.* Thousand Oaks, CA: Sage Publications, 1995.
- C National Cancer Institute. Clear and simple: developing effective print materials for low-literate readers. Washington, DC: National Cancer Institute, 1994. [Online at http://rex.nci.nih.gov/NCI_Pub_Interface/Clear_and_Simple/HOME.html].
- C Search http://osu.orst.edu//dept/ehe/communic.html for information on how to use language that recognizes the diversity of people in the United States.
- C Search http://osu.orst.edu//dept/ehe/10keys.html for 10 tips that work well with hard-to-reach audiences.

Tips to Write Easy-to-Read

- 1. Choose the right reading level for the audience you want to reach.
- 2. Use simple, clear writing style; good organization of key points; and consistent format.
- 3. Let your research guide the style and tone of your publication.
- 4. Use familiar examples, personal experiences, and/or characters with whom the audience can relate. Personalize the information.
- 5. Make the headlines tell the story without the supporting text.
- 6. Keep sentences short (8-10 words). Never use more than five bullets in a list.
- 7. Summarize frequently and repeat your main points.
- 8. Use the active voice.
- 9. Use large easily readable type and type size (14 point, serif typeface).
- 10. Show pictures only of what you want readers to do.
- 11. Consider non-print or multimedia presentations such as audiotapes, posters, or videotapes to replace or accompany complex materials.

Testing Messages and Materials

- C Trotter RT. Excerpt, Section 3: Setting up focus group research. *Handbook for excellence in focus group research*. Washinton, DC: Academy for Educational Development/HEALTHCOM, 1986. 1875 Connecticut Avenue, NW Washington, DC 20009-1202. Telephone: (202) 884-800. E-mail: adminc@aed.org. Discusses how to set up focus groups, recruit participation, and develop a moderator's guide.
- C Bertrand JT. Techniques for analyzing focus group data. *Evaluation Review* 1992; 16(2), 198 209. Discusses strategies for analysis.
- C Centers for Substance Abuse Prevention. *Technical assistance bulletin: pretesting is essential: you can choose from various methods.* 1994. [On-line at http://www.health.org/pubs/makepub/tab4.htm].
- C Centers for Substance Abuse Prevention. *Technical assistance bulletin: you can manage focus groups effectively for maximum impact.* 1994. [On-line at http://www.health.org/pubs/makepub/tab2.htm].
- C HealtCOM and USAID. Excerpts, information and exercises for improving moderators' skills. In: *A guide book on how to be a focus group moderator*. Washington, DC: Academy for Educational Development, . E-mail: adminc@aed.org. Telephone: (703) 312-6800.
- C Krueger RA. *Developing questions for focus groups*. Thousand Oaks, CA: Sage Publications, 1997.
- C Krueger RA. *Involving community members in focus groups*. Thousand Oaks, CA: Sage Publications, 1997.
- C Krueger RA. *Moderating focus groups*. Thousand Oaks, CA: Sage Publications, 1997.
- C Krueger RA. *Focus groups: a practical guide for applied research*. Thousand Oaks, CA: Sage Publications, 1997.
- C Making health communications programs work: a planner's guide. Wasington, DC: U.S.

Department of Health and Human Services, Public Health Service, National Institute of Health, Office of Cancer Communications, National Cancer Institute, 1992; 87-123. NIH Publication No. 92-1492, is available from OCC, Bethesda MD 20892, (800) 422-6237 or on-line at http://rex.nci.nih.gov/NCI_PUB_INDEX/PUB_INDEX_DOC.html. (Pre-Post Booklet Testing Form, Central Location Intercept Questionnaire, How to Develop a Moderator's Guide, Gatekeeper/Professional Review Questionnaire, Standard PSA Pretest Questions, How to Design a "Theater" Style Test for PSAs, Producing the Rough PSA, Planning, Conducting, and Analyzing the PSA Pretest Results, Pretest Budget and Time Table, Sample Planning Form, Sample Pretest Questionnaire, and Sample Theater Script)

- C Patton. *How to use qualitative methods in evaluation*. Newbury Park, CA: Sage Publications, 1987.
- C The AIDS Control and Prevention (AIDSCAP) Project. *How to conduct effective pretests:* ensuring meaningful behavior change communication messages and materials. Arlington, VA: Family Health International, 1996.

Focus Group Cost Breakdown

| 1 | | |
|---|----------------------|----------|
| ĺ | Salaries | \$1745 |
| I | Fringe Benefit | \$218.88 |
| l | Stipends | \$296 |
| ĺ | Contractual Services | \$145 |
| į | Equipment | \$113 |
| į | Supplies | \$1024 |
| | Phone | \$55.14 |
| ı | Total Direct Costs | \$3597 |
| ĺ | Indirect Costs | \$1537 |
| l | TOTAL COSTS | \$5234 |
| ı | | |

As a rule of thumb, focus groups can range between \$1,000-4,000 per group depending on how much you have to pay participants and how many groups you do in however many locations.

This is the cost breakdown for one campaign's focus groups. South Carolina produced brochures and billboards. They employed a contractor to run four focus groups to test the slogan and the graphics. Remember that you can request a donation of services as well as receive assistance from local students or professors.

Testing for Readability

SMOG Readability Test

To calculate the SMOG reading grade level, begin with the entire written work that is being assessed, and follow these four steps:

- 1. Count off 10 consecutive sentences near the beginning, in the middle, and near the end of the text.
- 2. From this sample of 30 sentences, circle all of the words containing three or more syllables (polysyllabic), including repetitions of the same word, and total the number of words circled
- 3. Estimate the square root of the total number of polysyllabic words counted.
- 4. Finally, add a constant of three to the square root. This number gives the SMOG grade, or the reading grade level that a person must have reached if he or she is to fully understand the text being assessed.

A few additional guidelines will help clarify these directions:

- A sentence is defined as a string of words punctuated with a period(.), an exclamation point (!), or a question mark (?).
- Hyphenated words are considered as one word.
- Numbers which are written out should also be considered, and if in numeric form in the text, they should be pronounced to determine if they are polysyllabic.
- Proper nouns, if polysyllabic, should be counted, too.
- Abbreviations should be read as unabbreviated to determine if they are polysyllabic.

Not all pamphlets, fact sheets, or other printed materials contain 30 sentences. To test a text that has fewer than 30 sentences:

- 1. Count all of the polysyllabic words in a text.
- 2. Count the number of sentences.
- 3. Find the average number of polysyllabic words per sentence as follows:

 Average = Total # of polysyllabic words / Total # of sentences
- 4. Multiply that average by the number of sentences short of thirty.

- 5. Add that figure onto the total number of polysyllabic words.
- 6. Find the square root and then add the constant of 3.

The quickest way to administer the SMOG grading test is by using the SMOG conversion table. Simply count the number of polysyllabic words in your chain of 30 sentences and look up the approximate grade level on the chart.

| SMOG Conversion Chart | | | | | | |
|----------------------------|---|----------------------------|-------------|--|--|--|
| Polysyllabic Word Count | Grade Level | Polysyllabic Word Count | Grade Level | | | |
| 0 - 2 | 4 | 57 - 72 | 11 | | | |
| 3 - 6 | 5 | 73 - 90 | 12 | | | |
| 7 - 12 | 6 | 91 - 110 | 13 | | | |
| 13 - 20 | 7 | 111 - 132 | 14 | | | |
| 21 - 30 | 8 | 133 - 156 | 15 | | | |
| 31 - 42 | 9 | 157 - 182 | 16 | | | |
| 43 - 56 | 10 | 183 - 210 | 17 | | | |
| * Predicts the gr | * Predicts the grade-level difficulty within 1.5 grades, plus or minus. | | | | | |

Delivering Your Program

The following information will help you to *deliver* messages and materials.

- C Breitrose P. *Writing and sending press releases*. Palo Alto, CA: Stanford Center for Research in Disease Prevention, 1988. Telephone (415) 723-1000.
- C Hartman NS. *The media and you: a basic survival guide*. Atlanta, GA: National Public Health Information Coalition, 1993. Telephone 770-458-2872 or fax: 770-458-8516.
- C Klamen D, Binder LS. Visual aids for communicating information to patients: an excellent second step. *Acad. Emerg Med* 1996; 3(3):200-201.
- C Roter DL, Hall JA. *Doctors talking with patients, patients talking with doctors: Improving communication in medical visits.* Westport, CT: Auburn House, 1992.
- C Ryan C. *Prime time activism: media strategies for grassroots organizing.* Boston: South End Press, 1991.
- C Stewart M, Roster D, (Eds.). *Communicating with medical patients*. Newbury Park, CA: Sage Publications, 1989.
- C Wicke DM, Lorge RE, Coppin RJ, Jones KP. The effectiveness of waiting room notice-boards as a vehicle for health education. *Family Practice* 1994; 11(3), 292-295.

Tracking And Evaluating Your Program

The following references will help you to *track and evaluate* your program.

- C Fitz-Gibbon, Herman, Morris. *Evaluator's handbook*. Newbury Park, CA: Sage Publications, 1987.
- C Fitz-Gibbon, King, Morris. *How to assess program implementation*. Newbury Park, CA: Sage Publications, 1987.
- C Muraskin LD. *Understanding evaluation: the way to better prevention programs.* Washington DC: U.S. Department of Education, 1993.
- C Peetz-Schou M. How to measure consumer awareness of mass media campaigns for public health purposes. *Patient Education Counseling* 1997; 30(1):53-59.

The following references provide some insight to *survey design*.

- C Davis and Stecher. *How to focus an evaluation*. Newbury Park, CA: Sage Publications, 1987.
- C Fitz-Gibbon, Henerson, and Morris. *How to measure attitudes*. Newbury Park, CA: Sage Publications, 1987.
- C Fitz-Gibbon and Morris. *How to design a program evaluation*. Newbury Park, CA: Sage Publications, 1987.
- C Gregg, M. Field epidemiology. New York, NY: Oxford University Press, 1996.
- C Lavrakas, P. *Telephone survey methods: sampling, selection and supervision.* Newbury Park, CA: Sage Publications, 1993.

The following references provide some insight to *data analysis*.

- C Fitz-Gibbon and Morris. *How to analyze data*. Newbury Park, CA: Sage Publications, 1987.
- C Fitz-Gibbon, Freeman, and Morris. *How to communicate evaluation findings*. Newbury Park, CA: Sage Publications, 1987.

Appendix C

Contacts

Professionals Who Serve Families Affected by NTDs

A variety of medical specialists treat children with NTDs. The treatment for a child with spina bifida usually requires a multi-disciplinary approach, including surgeons, physicians, and therapists. One individual, often a pediatrician, will coordinate a child's treatment program. In addition, support staff will be needed to offer time, information, and comfort to parents learning that their child will suffer from a condition like an NTD. This experience and adjustment can cause an enormous amount of stress and grief for the family involved. Following is a list of medical specialists who treat children with NTDs and who can help parents make appropriate choices for themselves and their children. In this day of managed health care, most patients must be referred by their primary care provider to any of these specialists.

Dieticians and Nutritionists are trained to provide nutrition assessments and counseling to ensure adequate nutrition and promote the development of self-feeding skills.

Education specialists are available in schools and private practices to guide families whose children have learning disabilities and other special education needs.

Family physicians have a broad range of training that includes general medicine, surgery, gynecology, and pediatrics. They are <u>primary care physicians</u> who provide medical diagnosis, treatment, and guidance for an individual or a family on a long-term, continuing basis.

Genetic counselors are health professionals who use the information from genetic studies and geneticists to answer questions for and to give guidance to families about inherited disorders and diseases.

Geneticists deal with heredity and its variations. They look at genes from the body's cells to identify certain inherited disorders and diseases.

Internists are physicians who are trained in the general medical care of adults. They diagnose and treat nonsurgical diseases of the body. Providing long-term, comprehensive care for adults in the hospital as well as the office, they are considered <u>primary care physicians</u>. Internists may also receive additional training to specialize in certain areas of medical care. Some examples are cardiologists who treat heart disease; pulmonologists who treat lung disease; and endocrinologists who treat diseases of the endocrine system, such as thyroid problems and diabetes.

Mental health professionals include psychiatrists (MDs), psychologists, psychiatric clinical nurse specialists, psychiatric social workers, and other mental health counselors who help individuals and families deal with the emotional stress that frequently accompanies long-term medical problems and disabilities.

Neurologists are physicians trained to diagnose and treat with medicine diseases and problems with the nervous system, which includes the brain, the spinal cord, and the nerves in the body. They deal with conditions such as seizure disorders and migraine headaches.

Neurosurgeons are physicians who perform surgery on people having problems with the brain, the spinal cord, or the nerves in the body. They often operate on spinal defects to "repair" or "close" them and put in shunts to relieve pressure on the brain in children with hydrocephalus.

Nurse practitioners are nurses who have received additional education and training to provide <u>primary health care</u> to individuals or families. They usually work with one physician or a group of physicians and provide treatment and guidance for a variety of conditions and diseases. Nurse practitioners can also be specialized to provide health care for certain patients, such as children, or certain medical problems, such as neurological diseases and disorders.

Obstetricians and Gynecologists are physicians who have expertise in the normal and abnormal functions of the female reproductive system and may provide information on family planning, pregnancy, and birthing options.

Occupational therapists help people with physical and mental challenges to achieve their maximum level of performance. They help people with physical, developmental, social, or emotional problems to learn new ways of coping with those problems so that they can be more independent, productive, and happy with their lives.

Orthopedists are specialized physicians who are trained in the care of patients with musculoskeletal problems. They may treat, with or without surgery, conditions involving the bones and the muscles of the body. Congenital deformities of the bone and muscle, injuries to the bone and muscle, and infections of the bone and muscle are some of the conditions with which they deal.

Orthotists are skilled in the straightening or correction of a deformity. They develop splints, braces, and other physical devices to help patients retain or attain as much structure and function of the body as possible.

Pediatricians are physicians who specialize in children's health issues.

Pharmacists are responsible for monitoring medication therapy and helping patients to manage that therapy. They work closely with other health care professionals to ensure the best outcome of medication therapy.

Physical therapists are health care professionals who have been trained to assess and improve movement and function of the body and to relieve pain. They work with people who have injuries or disabilities and use a variety of therapeutic physical agents, including heat, light, water, electrical stimulation, massage, and exercise.

Physician assistants are similar to nurse practitioners. They work with one physician or a group of physicians to provide <u>primary health care</u> to individuals or families. They can also be specialized to provide care for certain patients and /or diseases or conditions.

Social workers are professionals who help patients and their families deal with the social, emotional, and some financial aspects of their medical problems.

Organizations That Serve Families Affected by NTDs

If an e-mail address is not listed below, then the web site listed will provide access to e-mail addresses.

American Academy of Pediatrics

141 Northwest Point Boulevard Elk Grove Village, IL 60009-0927 (847) 434-4000 (847) 434-8000 - Fax

Web site: http://www.aap.org/

American Academy of Family Physicians

11400 Tomahawk Creek Parkway Leawood, KS 66211-2672 1-800-274-2237

Web site: http://www.aafp.org

American College of Obstetrics and Gynecology

409 12th Street SW, P.O. Box 96920 Washington, DC 20090-6920 (202) 638-5577 Fax: (202) 484-5107

Web site: http://www.acog.org

American College of Physicians

190 N Independence Mall West Philadelphia, PA 19106-1572 (215) 351-2400

Web site: http://www.acponline.org

American Dietetic Association

120 South Riverside Plaza, Suite 2000 Chicago, IL 60606-6995 800/877-1600

Web site: http://www.eatright.org

American Nurses Association

600 Maryland Avenue, SW Suite 100 West Washington, DC 20024-2571 (202) 651-7000 (202) 651-7001- Fax

Web site: http://www.nursingworld.org

American Pharmaceutical Association

2215 Constitution Avenue, NW Washington, DC 20037-2985 (202) 628-4410 (202) 783-2351 - Fax

Web site: http://www.aphanet.org

American Society for Nutritional Sciences

9650 Rockville Pike, Suite 4500 Bethesda, Maryland 20814-3998 (301) 634-7050 (301) 634-7892 - Fax

Web site: http://www.asns.org

Association of State and Territorial Public Health Nutrition Directors

1015 15th Street NW, Suite 601 Washington, DC 20005 (202) 659-2230 (202) 659-2339 – Fax

Web site: http://www.astdhpphe.org

Association of Women's Health, Obstetric, and Neonatal Nurses

2000 L Street NW, Suite 740 Washington, DC 20036 (800) 673-8499 (202) 728-0575 - Fax

Web site: http://www.awhonn.org

Centers for Disease Control and Prevention

National Center on Birth Defects and Developmental Disabilities 1600 Clifton Road Mailstop E-86 Atlanta, GA 30333 (404) 498-3800

Web site: http://www.cdc.gov/ncbddd

Healthy Mothers Healthy Babies

121 North Washington St., Suite 300 Alexandria, VA 22314 (703) 836-6110 (703) 836-3470

Web site: http://www.hmhb.org

March of Dimes Birth Defects Foundation

1275 Mamaroneck Avenue White Plains, NY 10605 (914) 428-7100

Web site: http://www.modimes.org

National Coalition of Hispanic Health and Human Services (COSSMHO)

1501 16th Street, NW Washington, DC 20036-1401 (202) 387-5000 Fax (202) 797-4353

Web site: http://www.hispanichealth.org

National Rehabilitation Information Center (NARIC)

4200 Forbes Boulevard, Suite 202 Lanham, MD 20706 (301) 588-9284 1-800-346-2742

Web site: http://www.naric.com

Shriners Hospitals for Children

2900Rocky Point Drive Tampa, FL 33607-1460 (813) 281-0300

Web site: http://www.shrinershq.org

Spina Bifida Association of America

4590 MacArthur Boulevard, NW, Suite 250 Washington, DC 20007-4226 (202) 944-3285 (202) 944-3295 - Fax Information and Referral: (800) 621-3141

Web site: http://www.sbaa.org
E-mail: spinabifida@aol.com

State Birth Defects Surveillance Systems

STATE BIRTH DEFECTS SURVEILLANCE PROGRAMS CONTACTS September 2003

Alabama

Alabama Birth Defects Surveillance and Prevention Program (ABDSPP) Wladimir Wertelecki, MD Director

AL Birth Defects Surv. & Prev. Prog. CCCB room 214

307 University Boulevard Mobile, AL 36688

Phone: 251-460-7505; Fax: 251-461-1591

E-mail: <u>bdprevention@usouthal.edu</u>

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E-mail: philliard@usouthal.edu

Alaska

Alaska Birth Defects Registry (ABDR)
Janine Schoellhorn, MS, MPH
MCH Epidemiology Unit Manager
MCH Epidemiology
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Arizona

Arizona Birth Defects Monitoring Program (ABDMP)

Timothy J. Flood, M.D.

Medical Director

Bureau of Public Health Statistics
150 North 18th Avenue, 5th Floor

Phoenix, AZ 85007

Phone: 602-542-7331; Fax: 602-542-1289

E-mail: tflood@hs.state.az.us

Hoa Lien Tran, M.D., M.P.H. Program Manager, ABDMP 150 North 18th Avenue, 5th Floor Phoenix, AZ 85007

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E-mail: avarga@hs.state.az.us

Arkansas

Arkansas Reproductive Health Monitoring
System (ARHMS)
Bridget S. Mosley, MPH
Epidemiologist
Arkansas Center for Birth Defects Research
and Prevention
11219 Financial Center Parkway
Financial Park Place, Suite 250
Little Rock, AR 72211
Phone: 501-320-5000; Fax: 501-320-5107

Phone: 501-320-5000; Fax: 501-320-510' E-mail: MosleyBridgetS@uams.edu

Charlotte A. Hobbs, M.D., Ph.D. Co-Director

Arkansas Center for Birth Defects Research and Prevention

11219 Financial Center Parkway Financial Park Place, Suite 250 Little Rock, AR 72211

Phone: (501) 320-5000; Fax: (501) 320-5107

E-mail: HobbsCharlotte@uams.edu

California

California Birth Defects Monitoring Program (CBDMP)

Barbara Warmerdam
Data Operations Manager

California Birth Defects Monitoring Program

1919 Fifth Street

Berkeley, CA 94710-1916

Phone: 510-549-4155; Fax: 510-549-4175

E-mail: <u>bwa@cbdmp.org</u>

Gary M. Shaw, Dr. Ph, MPH Research Director/Senior Epidemiologist California Birth Defects Monitoring Program 1919 Fifth Street

Berkeley, CA 94710-1916

Phone: 510-549-4155; Fax: 510-549-4175

E-mail: gsh@cbdmp.org

Colorado

Colorado Responds To Children With Special

Needs: Colorado (CRCSN) Margaret Schonbeck Program Manager, CRCSN 4300 Cherry Creek Dr Denver, CO 80246-1530

Phone: 303-692-2636; Fax: 303-782-0904 E-mail: margaret.schonbeck@state.co.us

Lisa Ann Miller, MD, MSPH Medical Director, CRCSN 4300 Cherry Creek Dr Denver, CO 80246-1530

Phone: 303-692-2663; Fax: 303-782-0904

E-mail: lisa.miller@state.co.us

Connecticut

Children with Special Health Care Needs Registry (CSHCN REGISTRY) Martha Okafor Division Director Family Health Division

410 Capitol Avenue, MS#11FHD Hartford, CT 06134-0308

Phone: 860-509-8066 Fax: 860-509-7720 E-mail: martha.okafor@po.state.ct.us

Delaware

Delaware Birth Defects Surveillance Project JoAnn Baker, MSN, FNP Director, Family Planning Program DE Division of Public Health PO Box 637

Dover, DE 19903

Phone: (302) 744-4554; Fax: (302) 739-6653

E-mail: JoAnnM.Baker@state.de.us

Betsy Voss

Newborn Screening/Birth Defects Coordinator PO Box 637

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Potential Partners in Your Community

<u>Note:</u> This is not an exhaustive list of possibilities. Each community has its own unique set of resources. Customize a database of interested parties for your own community. Begin now and add to it throughout the campaign.

Partners Already Involved in the Folic Acid Issue

C National Task Force Members

American Academy of Family Physicians

American Academy of Pediatrics

American College of Physicians

American College of Obstetricians and Gynecologists

American Dietetic Association

American Nurses Association

American Pharmaceutical Association

American Society for Nutritional Sciences

Association of Maternal and Child Health Programs

Association of State and Territorial Public Health Nutrition Directors

Centers for Disease Control and Prevention

Healthy Mothers Healthy Babies

March of Dimes Birth Defects Foundation

National Coalition of Hispanic Health and Human Services Organizations

Shriners Hospitals for Children

Spina Bifida Association of America

Partners Who Have Women as Customers, Members, Clients, or Employees

C Health Care Links

Community clinics (e.g., teen health, maternal support)

Family planning service providers

Genetic counselors

Home visitors & other community workers (e.g., Meals on Wheels/AFDC/Social

Workers)

Hospitals

Infertility clinics

Lay midwives

Managed care providers (HMOs)

Nurses

Parish nurses

Pharmacists

Physician assistants

Physicians (pediatricians, OB/GYNS, internists, family practitioners, children's special health care services)

Prenatal clinics

Registered dietitians/ public health nutritionists (e.g., WIC)

Specialized health/nutrition services (e.g., Indian Health Services health educators,

Migrant Health Program)

C Community Business Links

Beauty salons

Billing agencies (utility bill inserts)

Bookstores

Bridal fairs/ bridal registries

Fitness clubs

Food distributors

Groceries/corner stores/farmer's markets

Insurance companies

Laundromats

Mass merchandise retail stores

Nonprescription drug manufacturers

Nutrition stores

Printing/copying companies

Restaurants

Retail and distribution outlets

Video stores

Weight loss centers

C Other Community Links

Children's Miracle Network

City Hall/Marriage License Bureau

Day care centers

Girl Scouts

Head Start Programs

Libraries

Local public and private schools

Local or regional broadcaster's association

Local or regional public relations clubs

Parent Teacher Associations

Preschools

Red Cross

Religious associations

School boards

Trade schools

Unions

United Way Universities

C Public Forums

Health fairs

Outdoor advertising venues (billboards, mass transit, malls) Media:

Television stations (networks and local cable access)

Radio stations

Newspapers

Special-interest journals (e.g., Hispanic community newsletters)

C Government Agencies

Governor's Office
Maternal and Child Health Bureau
Public assistance programs (e.g., AFDC, Food Stamps, Medicaid)
Public health departments/ state prevention programs
USDA, Food and Nutrition Service
U.S. Food and Drug Administration

Appendix D

Involving Others

Sample Cover Letters

We have provided a variety of cover letters for your use. They all have different tones and are addressed to different types of professionals or organizations. If you find you like the style of one, but the purpose of another, you can combine elements of different letters to suit your needs.

Nurse Manager

YOUR AGENCY
YOUR ADDRESS
YOUR PHONE AND FAX NUMBERS
YOUR E-MAIL ADDRESS

Date

Dear Nurse Manager (Use Name):

I want to share with you a project of great importance, and one that is close to my heart as a (e.g., parent of a child with spina bifida or a health care provider who treats children with spina bifida). As you may know, 400 micrograms (0.4 milligram) of folic acid per day taken preconceptionally and through the first three months of pregnancy can prevent 50-75% of new cases of neural tube defects (NTDs). Timing is the critical factor in prevention; folic acid must be in a woman's body **before** she conceives to prevent NTDs. Because over 50% of all pregnancies are not planned, **all** women of childbearing age should consume 400 micrograms of folic acid daily.

We have sent your office an information kit, poster and brochures about folic acid. We would appreciate your giving out these brochures to your clients who are women of childbearing age. We would appreciate your help in getting the word out and hope that you are able to place these materials in a prominent location in your waiting room, and talk to your patients about how important folic acid is for their health and for the health of their future children.

| 1 | | |
|--|------|---|
| If you find you need more materials please call you play a vital role in preventing neural tube defects. support you in that role. | atat | Please know that for the opportunity to |
| Sincerely, | | |
| Your name Your title | | |

Health Care Provider

YOUR AGENCY YOUR ADDRESS YOUR PHONE AND FAX NUMBERS YOUR E-MAIL ADDRESS

Date

Dear Health Care Professional (Use Name):

You have a vital role in preventing some serious birth defects: spina bifida, anencephaly, and encephalocele. It is time to spread the word about folic acid's role in preventing these serious and common birth defects. We would like to send you some free educational materials for you to give your female patients of childbearing age. Enclosed you will find a sample pamphlet.

In 1992, the US Public Health Service (PHS) recommended that all women of childbearing age consume 400 micrograms (0.4 milligram) of folic acid each day. If taken preconceptionally and through the first three months of pregnancy, 400 micrograms (0.4 milligram) of synthetic folic acid in addition to a women's regular diet can prevent 50-75% of neural tube defects (NTDs). This timing is important because the neural tube forms 2-4 weeks into development, often before a woman realizes she is pregnant.

Women can attain the PHS recommendation of 400 micrograms of folic acid per day by taking a multivitamin containing folic acid daily, eating a breakfast cereal fortified with 100 percent of the daily value of folic acid (e.g., Total, Product 19), or eating plenty of foods fortified with folic acid and rich in folate. PHS recommends that women with a previous NTD-affected pregnancy, who are at increased risk, take 4 mg of folic acid per day. These women should consult their health care professional about taking this amount of folic acid daily.

I/We encourage you to evaluate **all** women's diets for adequate folic acid consumption, beginning with early adolescence in order to establish good nutritional habits. It is critical to counsel women who are planning to become pregnant to ensure that they have adjusted their diets and are consuming daily the recommended 400 micrograms of folic acid.

| Should you wish to obtain additional information, please contactaddress, phone number. | , title, |
|--|----------|
| Sincerely, | |
| Your name Your title | |

Pharmacist

YOUR AGENCY YOUR ADDRESS YOUR PHONE AND FAX NUMBERS YOUR E-MAIL ADDRESS

Date

Dear Pharmacist (Use name):

YOUR GROUP is very excited to collaborate with THE PHARMACISTS ORGANIZATION/STORE to prevent neural tube defects (NTDs). Your support in promoting folic acid to women of childbearing age shows your concern for the health of your customers. We thank you very much and hope that the message will have a particular impact for women around the celebration of MOTHER'S DAY [or other appropriate date] in a few weeks.

Enclosed are the following items: one poster to display at your pharmacy, Mother's Day cards for distribution to your customers, and a master copy of the educational information contained inside this card. Please feel free to make additional copies of the educational information to use for flyers to educate your customers. Because Mother's Day is in a few weeks, you can display the poster and begin distributing the educational material immediately and through the week of Mother's Day.

| I/We appreciate your willingness to disseminate this important public health message to your |
|--|
| childbearing-age customers. It is collaborative efforts such as this that will help ensure the |
| health of future generations of your city/county/state. Should you have any questions concerning |
| the activity, please contact , title, address, phone number. |
| |

Sincerely,

Your name Your title

Newsletter or Newspaper Publisher

YOUR AGENCY YOUR ADDRESS YOUR PHONE AND FAX NUMBERS YOUR E-MAIL ADDRESS

Dear Use Contact Name:

YOUR GROUP would like to introduce "The Title of Your Program," with the support of LIST OF YOUR PARTNERS. This campaign is designed to YOUR GOAL.

YOUR GROUP would like to request that NEWSLETTER PUBLISHER join in spreading this important information by including some or all of the following information in your newsletter.

YOUR GROUP is proud to introduce "The Title of your Program." This project is a city/county/state wide health program to encourage childbearing age women to consume 400 micrograms of folic acid daily to reduce their risk of having a pregnancy affected by severe birth defects called neural tube defects (NTDs) or anencephaly and spina bifida. Women who take 400 micrograms of folic acid on a daily basis before they become pregnant can reduce their chances of having a child with an NTD by up to 75%. Women can get enough folic acid daily by taking a multivitamin containing folic acid, eating a breakfast cereal fortified with 100 percent of the daily value of folic acid (e.g., Total, Product 19), or eating plenty of foods fortified with folic acid and rich in folate (e.g., dark, green leafy vegetables). In YOUR CITY/COUNTY/STATE the rate of NTD-affected pregnancies is ____ the national rate. If you have any questions, please call YOUR GROUP at YOUR PHONE NUMBER."

Enclosed is more information regarding NTDs (spina bifida and anencephaly), and any printing of this material would be greatly appreciated. I will check back with you in a few months to see if you were able to use the information provided and if I can be of further assistance.

Thank you in advance for helping us spread the folic acid message.

Sincerely,

Your name Your title

Radio or Television Station Public Service Announcement Director

YOUR AGENCY
YOUR ADDRESS
YOUR PHONE AND FAX NUMBERS
YOUR E-MAIL ADDRESS

Date

Dear Public Service Announcement Director (Use name):

You can play a vital role in preventing birth defects in your community. "Not since the rubella vaccine became available 30 years ago have we had a comparable opportunity to effectively, safely and inexpensively prevent such common and serious birth defects (Oakley, Godfrey, MD, JAMA, March 10, 1993)." Each year about_____ of babies in your CITY/COUNTY/STATE and approximately 2500 babies nationwide are born with serious birth defects of the spine and brain, called neural tube defects (NTDs). A woman can reduce her risk of having a child born with an NTD by 50-75% by just consuming daily 400 micrograms of a B-vitamin called folic acid before becoming pregnant.

Women can get enough folic acid daily by taking a multivitamin containing folic acid, eating a breakfast cereal fortified with 100 percent of the daily value of folic acid (e.g., Total, Product 19), or eating plenty of foods fortified with folic acid and rich in folate (e.g., dark, green leafy vegetables). Even though folic acid is easy to obtain, it is estimated that two-thirds of women in the U.S. do not get enough. We are writing to ask that you help inform women in CITY/COUNTY/STATE about the benefits of folic acid by airing the enclosed ??-second public service announcement. Also enclosed is an "announcer copy" spot for use by your DJs and other on-air personalities. (*If you are familiar with the radio station*-- add text which indicates that you are a listener and that you would be thrilled if "DJ's name" would make the announcement and talk about the importance of preparing to have a healthy baby.

Please use both spots as often as possible, especially during Folic Acid Awareness Week/Month in your CITY/COUNTY/STATE, DATES.

And be sure to let us know of your support by returning the enclosed "bounce-back" card.

Thank you for your assistance in spreading the word to women in CITY/COUNTY/STATE with this important health message.

Sincerely,

Your name Your title

Advertising Agency

YOUR AGENCY
YOUR ADDRESS
YOUR PHONE AND FAX NUMBERS
YOUR E-MAIL ADDRESS

Date

Contact Name, Agency Name & Address

Dear Mr./Mrs./Ms. Contact Name:

You can play a vital role in helping to prevent serious birth defects by promoting folic acid in your community. "Not since the rubella vaccine became available 30 years ago have we had a comparable opportunity to effectively, safely and inexpensively prevent such common and serious birth defects (Oakley, Godfrey, MD, JAMA, March 10, 1993)."

YOUR AGENCY along with YOUR PARTNERS would like to introduce to you TITLE OF YOUR PROGRAM. We are a nonprofit group dedicated to get the word out about the benefits of folic acid. However, none of our partners can provide the unique skills of AD AGENCY NAME. We hope you will seriously consider joining us and improve the health of our community's mothers and babies. Following is some background information to further acquaint you with our hopes for a folic acid promotional program.

The program's goal is to increase the number of women who know that folic acid can prevent some birth defects and consumes enough folic acid daily to reduce the risk for these serious birth defects. Nationally, approximately 4,000 pregnancies are affected by spina bifida every year. Annually, in YOUR COMMUNITY, XX babies are born with spina bifida. Women who take enough folic acid on a daily basis, before and after they become pregnant, can reduce their chances for having a baby with spina bifida by up to 75 percent. Even though there are several easy and inexpensive ways to get enough folic acid daily, two-thirds of women in the United States still do not consume enough to prevent these serious birth defects. We would greatly appreciate any help you may be able to provide with any aspects of our campaign including: logo, billboards, television/radio PSAs, transit advertising, magazine/newspaper ad slicks, and mall advertising. More information about the important discovery of folic acid reducing the risk for spina bifida and our association is attached.

I understand that you have a large number of non-profits requesting your assistance on other valuable efforts. "YOUR PROGRAM'S NAME" is one of the most important health issues for women of childbearing age today and needs the creative expertise of ADVERTISING AGENCY to get the message out effectively. I will be grateful for any services you may be able to provide.

Very Truly Yours, Your Name, Your Title

Community Partnership Activity Lists

| Groo | ocery Stores | |
|-----------|---|---|
| Store | e name: Contac | et name: |
| Addre. | ress: Phone | |
| Please (| e check all activities that you are able to participate in a | uring |
| | Develop and post labels to signify foods that naturall | y contain, or are fortified with, folic acid. |
| | Design a seasonal produce section display to highligh sources of folate. | nt fresh fruits and vegetables that are good |
| | Include "folic acid facts" in your store's printed, radi | o, or television advertisements. |
| | Include folic acid brochures and posters in the literat and on store bulletin boards. | ure display of the customer service area |
| | Organize shopper's clubs discounts for the purchase grown produce that contain folate, for example, gree and breads. Track the number of folic acid-rich food | n leafy vegetables, orange juice, cereals, |
| | Conduct food preparation or cooking demonstrations | using folic acid-rich foods. |
| | Include folic acid messages on recipes given out to c | ustomers at in-store demonstrations. |
| | Print folic acid messages on flyers, grocery bags, bar | ners, and so forth. |
| | Include a folic acid brochure with each grocery order pharmacy. Track the number of brochures distribute purchased. | |
| | Print a folic acid message on store-brand orange juic | e cartons. |
| | Donate or underwrite the cost of discount coupons for | or purchase of store-brand multivitamins. |
| | Wear folic acid buttons while at work. | |
| Fill in t | n the blank with your own suggestions. | |
| | | |
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| Name: Address: | Contact name: Phone: |
|-------------------|--|
| Address: | Phone: |
| | |
| Please che | eck all activities that you are able to participate in during |
| Se | nd letters to other MDs, family practices, OB/GYNs. |
| Dis | scuss and distribute folic acid on grand rounds. |
| | rite an article highlighting the benefits of folic acid for childbearing age women a professional organization newsletter. (e.g., medical or pharmaceutical society) |
| Dis | stribute informational packets to MDs, RNs, and staff. |
| Pai | rticipate in a folic acid advisory board. |
| | andout folic acid Rx pads to my female patients of childbearing age and encourage peers to do the same. |
| Dis | splay flyers, posters and fact sheets in waiting or exam rooms. |
| Pla | ace folic acid materials in various waiting rooms. |
| Pro | ovide sample vitamins to female patients. |
| Pro | ovide "Lunch and Learn" in-services on folic acid to MDs and staff. |
| Ru | n a video on folic acid on the television in the waiting room. |
| Please tell | us your own suggestions below. |

| Pharmacies | |
|--|---------------------|
| Store Name: Contact name: | |
| Address: Phone: | |
| Please check all activities that you are able to participate in during | · |
| Include a folic acid brochure with each prescription dispensed. | |
| Donate or underwrite the cost of discount coupons for purchase of s vitamins. | tore brand multi- |
| Incorporate a folic acid message in print, television, and/or radio ad | vertisements. |
| Include folic acid brochures in the literature display at your custome | er service area. |
| Print a folic acid message on prescription bags for one month. | |
| Donate or underwrite the cost of printing promotional materials (e.g and so forth). | g., banners, flyers |
| Distribute promotional and educational materials, such as magnets, flyers, and stickers. | brochures, |
| Print an article on folic acid in professional and customer newsletter | rs. |
| Provide a folic acid message on pharmacy display boards. | |
| Incorporate folic acid information and education during Pharmacy V | Week. |
| Distribute folic acid information at health fairs. | |
| Please tell us your own suggestions below. | |
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| School | ls |
|----------|---|
| Name: | Contact name: |
| Address: | Phone: |
| Please c | heck all activities that you are able to participate in during |
| | Plan a strategy for spreading the word about the benefits of folic acid with dministrators, nurses, and health, family and consumer science teachers. |
| | Conduct a "Train the Trainer" activity in-service for health, family, consumer cience teachers and school nurses. |
| | ncorporate a folic acid video tape or other activities into the lesson plans of health lasses for middle and high school students. |
| | Provide information at non-traditional educational programs (e.g., adult Graduation Equivalent Degree (GED) programs or refugee programs). |
| I | ncorporate a folic acid lesson plan into Teen Mother and other after-school programs. |
| H | Have orange juice served in classes receiving the folic acid lesson. |
| D | Display posters and provide information for school health bulletin boards and centers. |
| E | Broadcast messages on college campus radio and TV stations. |
| F | Hold poster contests. |
| V | Work with the school lunch staff to highlight foods high in folic acid. |
| U | Jse folic acid tray liners in the cafeteria. |
| P | Publish articles about folic acid in newsletters for both staff and parents. |
| | |

| Managed Care Providers | | |
|------------------------|---|--|
| Name: | Contact name: | |
| Addre | ss: Phone: | |
| Please | e check all activities that you are able to participate in during | |
| | Write informational articles to medical directors, providers, staff, and members in newsletters. | |
| | Medical director a. provide information packet to medical staff. b. provide packet to network provider. c. provide information to clients/members. | |
| | Distribute educational Rx pads to practitioners. | |
| | Provide information on folic acid for managed care providers and staff. | |
| Please | tell us your own suggestions below. | |
| | | |

| Women, Infants, and | d Children (WIC) Clinics |
|--|---|
| Name: | Contact name: |
| Address: | Phone: |
| Please check all activities t | that you are able to participate in during |
| | Folic Acid and It's Role in Prevention of Neural Tube Defects" and an imunity effort" for your newsletter or local newspaper. |
| | from Rds in the community. Encourage RDs (registered dieticians) to become omoting the community folic acid promotion effort in their work environments. |
| | e acid in WIC Newsletter. Encouraging consumption of food sources of folic using seasonal foods high in folic acid. |
| Adapt WIC Dietary Scr already included on scr | reening Form to highlight foods high in folic acid (may be some overlap to foods eening form.) |
| | ion buttons. Message ideas include: Ask a Nutritionist About Folic Acid, Did Acid, or Cereal, Broccoli, and Orange Juice Help Your Baby to a Healthy Start- |
| Wear T-shirts that say A | Ask Me About Preventing Birth Defects and give a folic acid message. |
| Place table tents on table | le with folic acid information in WIC clinic. |
| Give out materials to cl | ients on folic acid and/or list of foods that are good sources of folic acid. |
| Display posters or play | videotapes for clients in WIC Clinic waiting rooms on the benefits of folic acid. |
| Conduct classes on foli | c acid for prenatal orientation groups. |
| Display posters in restro | ooms and over changing table about folic acid. |
| | t One Free" farmers market coupon for foods high in folate (provided a WIC ate with the Farmer's Market Nutrition Program.) |
| Design and print WIC e | envelopes with a message about food high in folic acid. |
| Give away water bottle | s, magnets, pens, and so forth with folic acid slogan on them. |
| Please tell us your own suggestion | ons below. |

Appendix E

Planning for Action

Program Planning Worksheet

You may find this **Program Plan Worksheet** useful as a tool for brainstorming objectives, approaches, activities, and tasks to develop your program plan.

| Title of Program: |
|---|
| Program Goal: (to increase the number of women who have healthy babies or to reduce the number of women with pregnancies affected by an NTD) |
| Objective: |
| Approach: |

Activity:

Task:

Evaluation:

Evaluations (including audience research, message and material testing, program monitoring and outcome assessment):

| Partners: |
|--|
| |
| |
| |
| |
| Resources Available (e.g., spokes people, technology, time, money, staff): |
| |
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| |
| Primary Target Audiences (in priority order include age, gender, ethnic group, and other pertinent lifestyle and behavioral characteristics): |
| pertinent inestyte and behavioral enaracteristics). |
| |
| |
| Secondary Target Audiences (in priority order): |
| |
| |
| |
| Strategies For Each Target Audience: |
| |

| Messages/Materials/Channels: |
|--|
| Key Dates (e.g., March of Dimes Walk America Day): |
| Potential Problems (e.g., scheduling conflicts, clearances, policies and approvals you and other staff must address): |
| Resources Required: (e.g., staff, art shop, computer time): |
| Estimated costs (refer to budget examples following in this section of the appendices): |

Blank Charts to Outline Activities/Tasks

|--|

Approach:

Activity/Task:

Activity/Task Preparation Efforts

| Preparation Efforts | Person Responsible | Estimated Staff and Time Required | Funds Required | Date Completed |
|---------------------|--------------------|--------------------------------------|----------------|----------------|
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Activity/Task Implementation Efforts

| Implementation Efforts | Person Responsible | Estimated Staff and Time Required | Funds Required | Date Completed |
|------------------------|--------------------|--------------------------------------|----------------|----------------|
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Activity/Task Evaluation Efforts

| Evaluation Efforts | Person Responsible | Estimated Staff and Time Required | Funds Required | Date Completed |
|--------------------|--------------------|--------------------------------------|----------------|----------------|
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Camera-Ready Materials

Camera-ready materials are produced to make good quality photocopies. You can also adapt camera-ready materials for printing or photocopying with the help of someone with graphic art skills. The CDC will soon have tested camera-ready materials for you to order, use and adapt. Call (404) 498-3550 for more information.

- Add your own organization's name, contact information, and logo.
- Combine the best parts of existing materials to make new materials. Cut and paste graphics from one source to accompany text from another.

All materials produced by the federal government are available for public use. That means that they are not copyrighted, so you can reproduce them without obtaining special permission. However, many other organizations do copyright their materials. You should be sure to check with them about any materials you would like to use. Some nonprofit organizations may permit you to reproduce materials they have already developed.

The following is information to help you with printing your own materials. Materials can be duplicated in two simple ways: photocopying and printing. Variables that affect the cost of printing:

- Quantity. Unlike photocopying when the price stays the same per item, printing costs per unit go down as quantities go up. The more you print the more you save. For example, a black and white one-sided flyer might cost \$40 for 1000 copies (\$.04 per copy), \$53 for 2000 copies (\$.026 per copy), and \$85 for 4000 copies (\$.021 per copy).
- Printer. Every printer charges differently. Printing quality can also vary. Get several cost estimates and discuss any special requirements you may have. Ask your co-workers or partners for their recommendations. When you're getting cost estimates from the printers, look at samples of their work and ask for references.
- Paper quality. Once you've chosen a printer, ask to see paper samples in different weights, colors and finishes. If you can be flexible about the paper color, ask for paper at the end of a ream; paper left over from other printing jobs should cost you less money.
- , **Ink color**. Materials that require only one ink color will be the least expensive. For quantities under 10,000 copies, black ink will be the cheapest choice. Prices increase with each different color you add.
- Art work. Printers charge more for materials with drawings or photographs than they do for materials with words alone.

Finding Appropriate Methods for Your Budget

You can plan and carry out a successful folic acid campaign with either a small or large budget. Below are examples of two such programs:

The **Oklahoma State Department of Health** ran its campaign with a small budget of \$9,104.22. With limited funds, campaign workers produced a large number of communication materials—pamphlets, posters, and buttons. They also distributed grocery bags displaying folic acid information for no cost. They sought in-kind services and partnered with a private corporation which donated labor and materials at no cost.

| Mother's Day posters | 3000 posters | \$768.00 |
|---|--------------------|---|
| Mother's Day cards | 30,000 cards | \$1731.00 |
| Printing art work for buttons | 1000 buttons | \$126.24 |
| Button covers, backs, and assembly | 1000 buttons | \$300.00 |
| Pamphlets | 50,000 pamphlets | \$1750.00 |
| Neural tube defect fact sheet | 50,000 fact sheets | \$1690.00 |
| Grocery bag: Art work Printing and distribution | | Produced in-kine Donated by food company |
| Two-part billboard art printing | 6 posters | \$748.98 |
| Posting of billboards (usage fee) Lawton Oklahoma City Tulsa | | \$160.00 \$150.00 \$130.00 |
| Pharmacy mailings | approx. 1000 | \$1250.00 |

The **Onondaga County Health Department** (OCHD) in New York had a much larger budget. Including in-kind support and financial donations, the OCHD spent \$112,038. With such a large amount of money and dedicated employees, Onondaga County was able carry out a wide variety of activities and target many different women. The varied nature of their campaign should give you many ideas for activities and their approximate expenses. Do remember to factor in local cost differences.

| Personnel | % Project | % Fringe | Funds Source | Total In-kind |
|----------------------------|-----------|----------|-----------------|---------------|
| Commissioner | 5% | \$1870 | OCHD | \$7370 |
| Deputy Commissioner | 5% | \$1074 | OCHD | \$4234 |
| Family Planning, Dir. | 5% | \$887 | OCHD | \$3497 |
| Health Promotion, Dir. | 5% | \$887 | OCHD | \$3497 |
| Assistant to Commissioner | 75% | \$9129 | OCHD | \$35,979 |
| Health Educator | 10% | \$1050 | OCHD | \$4140 |
| Nutritionist | 5% | \$646 | OCHD | \$2546 |
| Health Ed. Supervisor | 20% | \$2434 | OCHD | \$9594 |
| Health Educator | 5% | \$525 | OCHD | \$2070 |
| Health Educator | 5% | \$525 | OCHD | \$2070 |
| Surveillance & Stats, Dir. | 10% | \$1536 | OCHD | \$6056 |
| Research Tech. | 5% | \$610 | OCHD | \$2405 |
| | | | Total = approx. | \$72,000 |

| Communications | Source of Funds | Total |
|----------------|---|-------|
| Postage | Pharmaceutical Society, Onondaga County & OCHD | \$395 |
| Telephone | OCHD | \$300 |
| Fax | OCHD | \$200 |
| | Total = | \$895 |

| Supplies | Source of Funds | Total |
|-------------------------|---|--------|
| Paper | OCHD | \$150 |
| Folders | Community General Hospital (CGH) Donation | \$50 |
| Brochure Holders (80) | CGH Donation | \$100 |
| Campaign Buttons (1000) | CGH Donation | \$800 |
| Posters (1000) | CGH Donation | \$500 |
| Fliers (100,000) | CGH Donation | \$4000 |
| | Total = | \$5600 |

| Media | Source of Funds | Total |
|---|-----------------|----------|
| Warner/McKenna "Media Buyer" & total media campaign | CGH Donation | \$15,000 |

| Surveys | Source of Funds | Total |
|--------------------------------------|-----------------|--------|
| Lunch for volunteers | OCHD | \$500 |
| Parking for volunteers | OCHD | \$50 |
| Phones | OCHD | \$800 |
| Compensatory time for OCHD employees | OCHD | \$4000 |
| | Total = | \$5350 |

TOTAL COST \$112,038

Foundations For Grant Seekers

Where can you read about grant-making foundations?

The Foundation Center at 79 5th Avenue, New York, New York, 10003-3766 (tel: (212) 620-4230; fax: (212) 691-1828; and e-mail: http://fdncenter.org) publishes and houses a library of sources listing grant-making foundations.

- The Foundation Directory (and Supplement). Includes data on funders who hold assets of at least \$2 million or give \$200,000 or more in grants each year. Features grant descriptions, which should help guide your foundation search.
- , The Foundation Directory Part 2 (and Supplement). Features information on mid-size foundations, those with assets between \$1 million and \$2 million or that give \$50,000 to \$200,000 in grants annually. Includes grant descriptions.
- *The Foundation 1000.* Profiles the 1000 wealthiest foundations, with details about geographic regions and subject areas.
- National Directory of Corporate Giving. Provides information on more than 2700 grant-making corporations to help you determine their giving interests.
- The Foundation Grants Index. Includes grants of more than \$10,000. Details grant makers by field and geographic area.
- Numerous **Web Sites** that assist foundation and grant searches. Many of these web sites also teach necessary skills (such as proposal writing), offer training (both on-line and on-site registration), and furnish examples of common application forms, budget forms, and requirements for proposals.
- , **Office of Minority Health Resource Center** (http://www.omhrc.gov/welcome.htm). Includes a database of funding and grant resources to help support minority health projects.
- , **MedWeb** (http://www.gen.emory.edu/medweb/medweb.grants.html). Lists links to funding opportunities and grant-seeking and grant-writing resources.
- , Grantsmanship Center (http://www.tgci.com).
- , The Foundation Center (http://fdncenter.org/).
- , **Philanthropy Journal Online** (http://philanthropy-journal.org/).
- , **Internet Nonprofit Center** (http://nonprofits.org/).

How should you approach grant-making foundations?

Many resources exist to guide this process, a number of which can be found on the Internet at some of the addresses listed previously. The Foundation Center Web Site details on-line training classes, as well as on-site training. The following is a brief reference list:

- Carlson, Mim. Winning Grants Step by Step: Support Centers of America's Complete Workbook for Planning, Developing, and Writing Successful Proposals. San Francisco, CA: Jossey-Bass Publishers.
- Fey, Don. *The Complete Book of Fund-Raising Writing*. Garden City, NY: Hoke Communications.
- Hall, Mary. *Getting Funded: A Complete Guide to Proposal Writing*. 3rd ed. Portland, OR: Continuing Education Publications.
- Lansdowne, David. *The Relentlessly Practical Guide to Raising Serious Money*. Medfield, MA: Emerson & Church, 1997.
- Locating Funds for Health Promotion Projects. Washington, DC: Office of Disease Prevention and Health Promotion, U. S. Department of Health and Human Services, 1984.
- Miner, Lynn E; Griffith, Terry. Proposal Planning and Writing. Phoenix, AZ: Oryx Press.
- Robinson, Andy. *Grassroots Grants: An Activist's Guide to Proposal Writing*. Berkeley, CA: Chardon Press, 1996.

What are some basic strategies and tips to guide your grant search?

- 1. DO YOUR RESEARCH to determine whether the foundations' and corporations' goals and objectives for grant making are consistent with your type of grant request.
- 2. After you do your research, contact the grant maker to verify its specific grant-making guidelines.
- 3. Include a cover letter with each proposal that introduces your organization and your proposal, as well as makes a strategic link between your proposal and the funder's mission and grant-making interests.
- 4. Type and single-space all proposals.
- 5. Answer all the questions in the order listed.
- 6. Submit the number of copies each grant maker requests according to its guidelines.
- 7. Do not include any materials other than those specifically requested.
- 8. Do not exceed any set page limits.

If you are sending a direct-mail fund-raising appeal, you should know that according to some people, 25% of all mail is never read. What can you do to ensure that *your* envelope is opened? You can make your envelope stand out from junk-mail by hand writing the address and using a real postage stamp. As an alternative, you can use laser-personalized envelopes that look typed, with a meter-postage impression.

Appendix F

Delivering Your Program

Activity Packets provided by Spina Bifida Association of Kentucky

The following pages provide helpful tips for collaborating with new partners and volunteers. Keeping these tips in mind, design packets to orient new partners to your folic acid promotion program. Preparing these packets before you program kicks off will allow you to involve other interested partners at any time in the promotion effort.

Advertising Agency

TIPS:

- C Network with other not-for-profit agencies to acquire lists of ad agencies and contact names that do pro bono work for not-for-profit agencies.
- C Communicate your expectations. The agency can only do what you ask of them.
- C The agency may suggest a different approach to the campaign. Have an open mind and approachable attitude.
- C The campaign is your responsibility; they are only assisting you.
- C The agency may serve as an advisory committee by helping to formulate the goal of the campaign, offering connections with other clients or corporations that may assist your folic acid campaign, and so forth.
- C This is a free service: always say "please" and "thank you."
- C Because it is a free service, deadlines may be hard to keep. Remember your ad agency partners are doing their best.
- C Always proof any work ad agencies do for you. You may proof a concept design, but the actual design needs to be proofed as well.
- C Be sure to let other partners review drafts of the agency's work so that everyone can approve of the work done.

ATTACHMENTS:

Letter to agency Follow-up letter Creative Brief for outdoor advertising

Outdoor Advertising

TIPS:

- C Locate all outdoor advertising agencies in the area the association serves, such as billboard companies, transit advertising, and mall advertisers.
- C Send letter of interest, and explain a follow-up will occur when funding is received.
- C Phone every other month to maintain the relationship.
- C Get full details on the cost of posting, printing, shipping, handling, etc. before making a commitment. (Most companies may have a special rate for nonprofit organizations).
- C Ask the ad agency you work with to recommend a printer and a funding source.
- C Inquire about pro-bono opportunities (e.g., do they have time slots not booked which they will donate for use to promote folic acid?).

Publications/newsletters

TIPS:

- C Locate lists for newsletter connections through the local Chamber of Commerce, the state business director, the phone book, the state Gold Book, etc.
- C Compile lists with a contact name for each group or company.
- C Network with friends, educational institutions, etc. for contacts. The sky is the limit.

ATTACHMENTS:

Electric company letter
Electric company insert (In Appendix I on pp. I-18.)
Church bulletin insert
Sample Louisville Magazine insert
Direct mail letter
Direct mail insert for Pac Mail reaching 250,000 homes in the Louisville area.
"Project Healthy Babies" direct mail insert (In Appendix I on pp. I-19.)

Presentations

TIPS:

- C Know the material.
- C Ask a doctor who is associated with your association to lend slides of babies with spina bifida to be copied for presentations. Showing the impact of spina bifida will make the disability a reality to people who see the presentation.
- C Get your audience's attention and tell them how they can help in the prevention effort.
- C Following the presentation, encourage questions.
- C Hand out information on your association (e.g., brochures, flyers).
- C You are the expert on the topic, don't be nervous!

ATTACHMENTS:

Presentation (In Appendix I on pp. I-20.) Speaking tips (In Appendix I on pp. I-21.) Sample flyer

Health Fairs

TIPS:

- C Contact health agencies, chiropractors, hospitals, educational agencies, etc. and explain your interest in health fairs. They will point you in the right direction. Once you have attended one or two fairs, they in turn will come looking for you to participate.
- C Have a slide or picture of a baby with spina bifida.
- C Either ensure that the people staffing your booth know the basic information you are trying to convey or have them take the names of people who are interested in learning more so that you can follow up with a phone call or letter after the health fair.

ATTACHMENTS:

Health Fair
Health fair letter
Fact Sheet for volunteers available at the table (In Appendix I on pp. I-24-I-26.)
Volunteer sign-up for staff board, and volunteers

"Help Needed" response card/Fair brochure

Folic acid flyer distributed at table

Ready-made Materials for Volunteers from Onondaga County, New York

This Folic Acid Awareness Week packet is provided as a do-it-yourself guide to conducting your organization's health promotion activities during Folic Acid Awareness Week, October 26 - November 2, 1996. The materials are designed to increase community awareness and involvement. This packet contains:

- C <u>Media Materials</u>. A fill-in-the-blank news release and a broadcast public service announcement on folic acid. (In Appendix I on pp. 1-10.)
- C <u>Fill-in-the-Blank Proclamation</u>. To be used by a local official in recognizing Folic Acid Awareness Week in your community. (In Appendix I on p. 1.)
- C <u>Community Suggestions</u>. Activities your organization can do during Folic Acid Awareness Week. (Look to "Real World Examples" throughout the guide.)
- C <u>FYI Materials</u>. The Department's folic acid brochure, fact sheet, a resource listing and publications request form. Also included are a March of Dimes reproduction slick for tray place mats and a poster provided by the March of Dimes. A list of March of Dimes chapter offices from which additional posters can be ordered is provided as well.

For more information, or assistance is mounting your organization's activities, please contact:

Bureau of Community Relations New York State Health Department Corning Tower, Room 1084 Empire State Plaza Albany, NY 12237

(518) 474-5370

Sample Checklist from a folic acid promotion program in Onondaga County, NY for one of their partners: family planning service programs.

- / Inform all Family Planning Staff of Folic Acid Campaign in Onondaga County at family planning staff meeting (Aug. 1996)
- Provide information to clinical staff regarding folic acid and prevention of neural tube defects (NTDs) at clinical meeting (Aug. 1996)
- Provide clinical staff with articles regarding the risk and prevention of NTD (Aug. 1996) [Shaw, et al, JAMA, 275:1093-1096; Literature Monitor, Clinician Reviews, June. 1996, 57-59; Hine, J, JADA, 96:451-452]
- Provide in-service to all staff regarding folic acid, prevention of NTDs, and the Campaign in Onondaga County. (Sept. 1996)
- Have all clinical staff wear "Ask Me About Point 4 The Future" buttons on Lab Coats (Oct. 1996 Dec. 1997)
- Hang posters on "Point 4 The Future" in all family planning clinics (Oct. 1996 Dec. 1997).
- / Display pamphlet in all family planning waiting rooms regarding "Point 4 The Future" Campaign. (Oct. 1996 Dec. 1997)
- Revise family planning education to include a statement on the need for folic acid in the diet of all women 15-44 years (Nov. 1996)
- / Encourage all family planning clinicians will discuss the importance of folic acid in the diet and to distribute "prescriptions" encouraging the daily intake of 400 micrograms (Oct. 1996 Dec. 1997)
- Revise the exit interview at family planning to re-enforce the daily intake of 400 micrograms of folic acid. (Nov. 1996)
- / Distribute materials about folic acid at the exit interview. (Oct. 1996 Dec. 1997)

Appendix G

Sample Survey Questions

Before and After Survey Questions-

The following questions come from the **1998 Behavioral Risk Factor Surveillance Survey (BRFSS)**. You are free to use the questions along with the coding system. The questions are divided into two sections: one for demographics and one for knowledge and use of folic acid. The demographics section asks information about the respondent's age, annual household income level, race/ethnicity, education level and occupation. The other section asks about the respondent's use and knowledge of folic acid.

1998 BRFSS: Demographics

| 01. | What is your age? | | |
|-------------------|--|---------------------------------|------------------|
| | Code age in years Don't know/Not sure Refused | 0 7 09 | |
| 02. | What is your race? | | |
| | Would you say: Please Read | | |
| | a. Whiteb. Blackc. Asian, Pacific Islanderd. American Indian, Alaska Native | | 1 2 3 4 |
| | e. Other: (specify) | - | 5 |
| Do not read these | Don't know/Not sure | | 7 |
| responses | Refused | | 9 |
| 03. | Are you of Spanish or Hispanic origin? | | |
| | a. Yesb. NoDon't know/Not sureRefused | 1 2 7 9 | |

| 04. | What is the highest grade or year of school you completed? | | |
|------------------------|--|--|--|
| Read Only if Necessary | | | |
| | | | |

| Never attended school or only kindergarten | 1 |
|--|---|
| Grades 1 through 8 (Elementary) | 2 |
| Grades 9 through 11 (Some high school) | 3 |
| Grade 12 or GED (High school graduate) | ۷ |
| College 1 year to 3 years (some college or | |
| technical school) | 4 |
| College 4 years or more (College graduate) | 6 |
| | |
| Refused | g |
| | Grades 1 through 8 (Elementary) Grades 9 through 11 (Some high school) Grade 12 or GED (High school graduate) College 1 year to 3 years (some college or technical school) College 4 years or more (College graduate) |

05. Are you currently:

Please Read

| a. | Employed for wages | 1 |
|----|----------------------------------|---|
| b. | Self-employed | 2 |
| c. | Out of work for more than 1 year | 3 |
| d. | Out of work for less than 1 year | 4 |
| | | _ |
| e. | Homemaker | 5 |
| f. | Student | 6 |
| g. | Retired | 7 |
| | or | |
| h. | Unable to work | 8 |
| | Refused | g |

06. Is your annual household income from all sources:

Read as Appropriate

| | a. Less than \$25,000 If "no," ask e; if "yes," ask b | |
|---------|--|-----|
| If res- | (\$20,000 to less than \$25,000) | 0 4 |
| pondent | | |
| refuses | b. Less than \$20,000 If "no," code a; if "yes," ask c | |
| at any | (\$15,000 to less than \$20,000) | 0.3 |
| income | | |
| level, | c. Less than \$15,000 If "no," code b; if "yes," ask d | |
| code | (\$10,000 to less than \$15,000) | 0.2 |
| refused | | |
| | d. Less than \$10,000 If "no," code c | 0 1 |

| | e. Less than \$35,000 If "no," ask f (\$25, 000 to less than \$35,000) | 0 5 |
|----------------------------------|--|------------------------|
| | f. Less than \$50,000 If "no," ask g (\$35,000 to less than \$50,000) | 0 6 |
| | g. Less than \$75,000 If "no," code h (\$50,000 to \$75,000) | 0 7 |
| | h. \$75,000 or more | 0 8 |
| Do not | Don't know/Not sure | 77 |
| read these responses | Refused | 99 |
| 1998 BRF | SS: Knowledge and Use of Folic Acid | |
| 1. | Do you currently take any vitamin pills or suppler | ment? |
| Include liquid supplements | a. Yes b. No Go to Q5 Don't know/Not sure Go to Q5 Refused Go to Q5 | 1 2 7 9 |
| 2. | Are any of these a multivitamin? | |
| | a. Yes Go to Q4b. No | 1 2 7 9 |
| 3. | Do any of the vitamin pills or supplements you ta | ke contain folic acid? |
| | a. Yes b. No Go to Q5 Don't know/Not sure Go to Q5 Refused Go to Q5 | 1 2 7 9 |

4. How often do you take this vitamin pill or supplement?

| a. | Times per day | 1 |
|----|---------------------|-----|
| b. | Times per week | 2 |
| c. | Times per month | 3 |
| | Don't know/not sure | 777 |
| | Refused | 999 |

If respondent is 45 years or older, go to the next module.

5. Some health experts recommend that women take 400 micrograms of the B-vitamin folic acid, for which one of the following reasons...

Please Read

| | a. To make strong bonesb. To prevent birth defectsc. To prevent high blood pressure | 1 2 3 |
|------------|---|-------------|
| | or d. Some other reason | 4 |
| _ | | 4 |
| Do not | Don't know/Not sure | 7 |
| read these | | |
| responses | Refused | 9 |

The following questions were created by the CDC and have been asked along with many other questions on **Porter-Novelli's Healthstyles survey**. You are free to use the questions along with the coding system. The questions in this survey are designed to determine respondents' beliefs, knowledge, attitudes and behavior toward multivitamin usage, folic acid and pregnancy.

| | etimes MISS taking a multivitamin OR DON'T TAKE multivitamins because: |
|------|--|
| (CHE | ECK AS MANY AS APPLY) |
| | Lagratimas forgat |
| | I sometimes forget |
| | Vitamins cost too much |
| | I don't think vitamins are important for my health |
| | I can't always find the time to take a vitamin |
| | I get all the vitamins I need from my diet |
| | Vitamins upset my stomach |
| | I don't like taking pill |
| | I am afraid vitamins will make me gain weight |
| | I don't think I need to worry about vitamins preventing birth defects |
| | My health care provider has not recommended vitamins |
| | |
| | Does not applyI take a multivitamin every day |
| | |
| [TA] | KE multi-vitamins or TRY TO take multivitamins because: |
| | CCK AS MANY AS APPLY) |
| | , |
| | I've made taking a vitamin part of my daily routine |
| | The cost of vitamins is small compared to the benefits |
| | Taking vitamins is important for my health |
| | I feel vitamins give me more energy |
| | I don't always eat a balanced diet |
| | i don t dividys out a samiloud dist |
| | |
| | I take vitamins to reduce the chance of birth defects in future pregnancies |
| | I take vitamins to reduce the chance of birth defects in future pregnancies I can take my vitamins with meals or before bed and avoid an upset stomach |
| | I take vitamins to reduce the chance of birth defects in future pregnancies I can take my vitamins with meals or before bed and avoid an upset stomach My health care provider recommends vitamins |
| | I take vitamins to reduce the chance of birth defects in future pregnancies I can take my vitamins with meals or before bed and avoid an upset stomach |

The following questions have been included for you to use. The questions are designed to determine respondents' beliefs, knowledge, attitudes and behavior toward multivitamin usage, folic acid and pregnancy. They have been tested and are used in the PRAMS (Pregnancy Risk Assessment Monitoring System), a survey conducted by mail and telephone to assess maternal behaviors that affect pregnancy outcomes.

| Thinking back to <i>just before</i> you got pregnant, how did you feel about becoming pregnant? Check the best answer. | I wanted to be pregnant sooner I wanted to be pregnant later I wanted to be pregnant then I didn't want to be pregnant then or at any time in the future I don't know |
|---|---|
| Have you ever heard or read that taking the vitamin called folic acid can help prevent some birth defects? | ^ No ^ Yes |
| Were you taking a multivitamin <i>daily</i> for one month <i>before</i> you got pregnant? | ^ No ^ Yes |

The following is a list of additional ideas that you may like to find out about. To develop good questions however, you will need qualified assistance. Field testing is important because a question can be interpreted in so many different ways. We have survey questions that may address some of these concepts. Some have been designed but not field tested. If you would be interested in learning more about these questions, please call us.

- , Respondent's consumption of fortified foods
- , Respondent's pregnancy intentions
- , Respondent's health and pregnancy information channels
- , Respondent's past vitamin usage
- Respondent's barriers and incentives to increasing consumption of folic acid

Appendix H

More About the Media

Characteristics of Mass Media Channels

| | Television | Radio | Magazines | Newspapers |
|---------------------|--|--|--|--|
| Reach | Potentially largest/wide range of audiences, but not always at times when PSAs are most likely to be broadcast. | Formats offer more potential to target an audience than television (e.g. teenagers via rock stations). May reach fewer people than TV. | Can more specifically target to segments of public (young women, people with an interest in health). | Can reach broad audiences rapidly. |
| Content | Opportunity to include health messages via news broadcasts, public affairs/interview shows, dramatic programming. | Opportunity for direct involvement via call-in shows. | Can explain more complex health issues, behaviors. | Can convey health news/breakthroughs more thoroughly than TV or radio and faster than magazines. Feature placement possible. |
| Presentation | Visual as well as audio portrayal of message to make emotional appeals possible. Easier to demonstrate a behavior. | Audio alone may make messages less intrusive. | Print may lend itself to more factual, detailed, rational message delivery. | |
| Special Benefits | Can reach low income and other audiences not as likely to turn to health sources for help. | Can reach audiences who do not use the health care system. | Audience has chance to clip, read, contemplate material. | Easy audience access to indepth issue coverage is possible. |
| Impact | Passive consumption by viewer; viewers must be present when message is aired; less than full attention likely. Message may be diluted by commercial "clutter." | Generally passive consumption; exchange with audience possible, but target audience must be there when aired. | Permits active consultation. May pass on. Read at reader's convenience. | Short life of newspaper limits rereading, sharing with others. |
| Dead- lines | Deadlines are 3 to 8 weeks in advance for public announcements, usually by 10 a.m. to make the 6 p.m. news and "day before" for breaking news. | Allow several days notice for public eventswith other news, the same day is adequate. | Deadlines are 6 to 8 weeks before publication goes to the press. | Deadlines for daily issues are a.m. to 2 to 3 p.m. the afternoon before or p.m. to early a.m. the day of the issue. Weekly issues need notice 3 to 5 days ahead. |
| Requir- ements | Deregulation ended government oversight of station broadcast of PSAs, public affairs and programming. | Deregulation ended government oversight of station broadcast of PSAs, public affairs and programming. | No requirement for PSA use; PSAs more difficult to place. | PSAs virtually non- existent. |
| Costs | PSAs can be expensive to produce and distribute. Feature placement requires contacts and may be time consuming. | Live copy is very flexible and inexpensive; PSAs must fit station format. Feature placement requires contacts and may be time consuming. | Public service ads are inexpensive to produce; ad or article placement may be time consuming. | Small papers may take public service ads; coverage demands a newsworthy item. |

Media Costs

Following are the media costs for the campaign of the Onondaga County Health Department. Onondaga County used money wisely by strategically purchasing the placement of its PSAs during times when their target audience was likely to be watching. This is a good example of knowing your target audience well and purchasing advertising when you know they will most likely be watching television, listening to the radio or reading the newspaper. These spots were placed during a variety of programs: "What Every Baby Knows" (Lifetime), "Parenting Today" and "Your Health" (CNN Saturdays), and prime time movies. The time table below shows that they were able to leverage some free spots by purchasing others. In addition, these costs may vary by community.

Television

| Vendor | Job Description | Total |
|-------------|---|--------|
| Cable Sales | Nineteen paid spots and 19 no-charge spots on Lifetime, CNN, and USA (January 17- February 34) Adelphia and Time/Warner | \$1000 |
| WIXT | Ten 30-second spots (January 13-23) | \$1530 |
| WSTM | Seven 30-second spots January 14-31) | \$900 |
| WSYT | Four 30-second spots (January 14-30) | \$600 |
| Production | Tag 30-second spot. Includes studio time, dubs for all stations, and revision of end tag. | \$300 |

Total \$4330

Radio

| Vendor | Job Description | Total |
|------------------|---|--------|
| WLTI Lite 105.9 | Sixty-second "Folic Acid" (Eighteen days with 4 spots per day) Thirty-six paid and 36 bonus | \$720 |
| WNTQ (93 Q) | Sixty-second "Folic Acid" (Four days with 4 spots per day run between 6am-8pm) Reduced rate for week after Christmas | \$800 |
| WNTQ (93 Q) | Sixty-second "Folic Acid" (January 7-9 with 6 spots per day, run between 6ammidnight) Nine paid and 9 bonus | \$540 |
| WNTQ (93 Q) | Sixty-second "Folic Acid" (Six days in February with 3 spots per day, run between 6am-midnight) Nine paid and 9 bonus | \$540 |
| HOT 108 | Sixty-second "Folic Acid" (Twelve days with 4 spots per day, run between 6ammidnight) Twenty-four spots paid and 24 bonus | \$960 |
| COOL 102 | Eighteen 60-second "Folic Acid" (4 days) | \$576 |
| B104.7 | Sixty-second "Folic Acid" (Eight days with 3 spots per day) | \$1560 |
| Production Costs | Write and produce 60-second spot. Include talent and studio time and dubs. | \$300 |

Total \$5996

Newspaper

| Vendor | Job Description | Total |
|---------------------|---|-----------|
| New Times | Two col. x 4" display ad "Folic Acid" (January 15, 22) Reduced rate | \$340 |
| New Times | Two col. x 4" display ad "Folic Acid" (February 12) | \$170 |
| Scotsman | Onondaga County Editions Two co. x 4" display ad "Folic Acid" (January 20, 27) | \$642.56 |
| Scotsman | Onondaga County Editions Two col. x 4" display ad "Folic Acid" (February 10) | \$321.28 |
| Syracuse Newspapers | Two col. x 4" display ad "Folic Acid" (January 23, 30 & February 6, 20 with 4th insertion) CNY Sections (Chose Thursday issues because they contained the weekend calendar of activities and drew a lot of interest.) | \$1827.20 |
| Syracuse Parent | One-fourth page ad "Folic Acid" (February, March, June issues) | \$405 |
| Warren/McKenna | Fifteen percent Agency commission on net print space costs (Newspaper totaled \$3881.18 net) | \$685.03 |
| Warren/McKenna | Revise design provided and prepare mechanicals to size for all print publications. | \$100 |

Total \$4666.07

Working with the Media

- C Look for a local angle to your story. Some suggestions include
 - --A profile of an active community member or health care provider on what they have done and why.
 - --Fund-raisers and projects local groups organize in support of women's health.
 - --Personal stories of children with spina bifida or families with spina bifida children.
 - -- Targeted prevention programs for those at high risk for an NTD-affected pregnancy.
 - --An exceptional folic acid educational program at a local business, house of worship, or school.
- C **Deliver your message with a "twist."** For example, an environmental group sent a news release glued to a plastic container. Releases and advisories are usually distributed by mail. For small community media, hand delivering works best.
- C **Telephone actively.** Call the assignment editor a week before the event, the day before the event, and then follow up after the event has taken place.
- Develop and maintain media lists. You can create your own lists by using your local library's reference books on local and national media, as well as media lists from local celebrities, public relations agencies, public relations professional organizations, and your own media contacts. Keep your detailed media list in a loose leaf binder, using one page per media list. The following references will provide you with names of media contacts in your community. However, purchased media lists often overlook small, new, and transient publications and programs. You want to keep your list current because you never want to use the wrong name.

Gebbie Press New Paltz, NY 12561 914/255-7560 (About \$100)

Daily/weekly papers, radio/TV stations, Black and Hispanic press, all by city and state, plus consumer magazines by subject, business, trade press, and wire services.

News Media Yellow Book Leadership Directories, Inc.

New York, NY 10011

Do not send blanket mailings with the same press release to several reporters at the same media outlet.

- Contact your state health information officer. They have established relationships with key media contacts in your state and they can help you make these connections. To find who this person is in your state go to the national organization's web site at http://www.nphic.org.
- Check with reporters to see how they wish to receive press releases (mail, fax, or e-mail). Be sure to get a reporter's permission the first time you send materials via e-mail.
- C **Assume that everything you say is "on the record"** even if you say something is "off the record." Don't assume that anything you say before or after the interview won't be included in the story.
- Monitor and measure your media coverage to correct misstatements and errors, to identify persons in the media who are attuned to prevention issues, and to replicate successful media strategies. You can measure your media coverage by tracking how much space the story got, where it was placed, and whether the content was positive, negative, or neutral.

For further references on working with the media look to

- C Center for Substance Abuse and Prevention. *Technical assistance bulletin: you can increase your media coverage*. 1994. [On-line]. Available: http://www.health.org/pubs/makepub/tab3.htm.
- C Convissor RB, et al. Using national news events to stimulate local awareness of public policy issues. *Public Health Reports* 1990; 105(3):257-260.
- C Evans CA Jr., et al. Public health week: marketing the concept of public health. *Public Health Reports* 1992; 107(1): 110-112.
- C Friede A, et al. Public health informatics: how information-age technology can strengthen public health. *Annual Review of Public Health* 1995; 16: 239-252. (Review)
- C Harris, L.M. (ed.). *Health and the new media: Technologies transforming personal and public health.* Hillsdale, NJ: Lawrence Erlbaum Associates, 1995.
- C Holder HD, et al. Media advocacy in community prevention: news as a means to advance policy change. *Addiction* 1997; 92 Suppl 2:S189-S199.

- C Holmes P. Health and media. How health hits the headlines. *Nurs Times* 1985; 81(15):18-19.
- C Jernigan DH, et al. Media advocacy: lessons from community experiences. *Journal of Public Health Policy* 1996; 17(3):306-330. (Review)
- C Korn R, et al. Computerization of standards and patient education material. *J Nurs Staff Dev* 1995; 11(6): 307-312.
- C Skinner, CS, Siegfried, JC, Kegler, MC, and Strecher, VJ. The potential of computers in patient education. *Patient Education and Counseling* 1993; 22, 27-34.
- C Wallack, L., Dorftman, L., Jernigan, D., & Themba, M. *Media advocacy and public health: power for prevention*. Newbury Park: Sage Publications, 1993.
- C Wallack L. Media advocacy: a strategy for empowering people and communities. *Journal of Public Health Policy* 1994; 15(4):420-436.
- C Woodruff, K. Media strategies for community health advocacy. *Primary Care* 1995 22(4):805-815.

Creating Your Own Media Materials

1. News Release

You can write a news release in advance of an event (to encourage media coverage and public awareness), concurrent with an event (to make sure that key points are highlighted), or following an event (to inform the public of what happened). Write your own or adapt the two examples of news releases provided in Appendix I on pp. 2-5. Here are the key elements of a news release.

- Name, phone, and e-mail address of contact person for media to call.
- Just the facts--who, what, where, why, when, how. Include the most important point in the first paragraph-- preferably the first sentence. Quote experts. Disclose funding sources. Write it at a ninth grade reading level or less. Don't use jargon.
- Double-space the text and use no more than two pages.
- Include an "embargo" date and time on press materials if your information is to be used after a specific time. Write "Embargo until DATE and TIME." Otherwise, say "for immediate release."
- Always include a statement at the end which gives a brief description of your organization and information about how the public can contact you (e.g., phone number or web site address).

2. Media Advisory

You can use a media advisory instead of a news release to alert the media to an event worthy of coverage. The media advisory should be a page in length and should state the answers to who, what, why, when, and where. When you use a media advisory, always distribute a more detailed news release or press kit to the media just before the event. You can use the example of a media advisory given in Appendix I on p. I-6 as a model for your own campaign.

3. Public Service Announcement (PSA)

PSAs are either general messages or specific announcements for radio and television. Sometimes, you can add the telephone number of your organization to a national PSA and announce a community event. PSAs are more likely to be aired if the station's program director is asked in-person by someone in his or her community to play them. Find examples of various PSAs in Appendix I on pp. 7-10.

When writing:

- Provide a contact name, phone number and e-mail address.
- Include word-for-word written text, 8 to 15 lines, with prerecorded PSAs timed to 10 seconds, 15 seconds, and 30 seconds, and one slide for each second of air time if possible.
- Triple space your text and use all caps.
- Include a beginning date and an ending date. A maximum of three months is a good idea.
- Hand-deliver PSAs for radio and television at least three to four weeks ahead of time.

When calling:

- The best time is Tuesday, Wednesday, or Thursday morning. Do not call on a Friday or just before or after a holiday.
- Ask for the person who schedules PSAs--not the general manager, sales manager, or news director.
- In two minutes, give the your name and the name of your organization and specify if it is a non-profit; mention 501(c)3 status if this applies, describe your event in one sentence, and sell your PSA knowing that it is competing with other announcements. Emphasize your goal: to prevent birth defects in your community.
- Offer to deliver the tapes or scripts to the station's reception desk.
- Send a thank you note whether or not your PSA is accepted. If you are not successful, try again in a few weeks.

When visiting:

Keep your visit brief and to the point. Introduce yourself and your "cause." Ask for his/her help in preventing NTDs in the community. State who you are trying to reach and ask him/her to air the PSA when more women are likely to be watching.

4. Letters to the Editor and Op-Ed Articles

Most newspapers devote at least one page to opinions, presenting them in editorials, letters to the editor, regular columns (local and nationally syndicated), political cartoons, and contributed articles. Different letters on a single topic will strengthen your case; form letters or any indication of an organized letter-writing campaign will weaken your effort. In Appendix I on pp. 11-14 you can find an example of an article.

- Call the newspaper editorial department and ask for any specific rules you should follow (usually 800 words for Op-ed articles and less than 400 for editorials).
- Type the letter and include the full name of the author and a telephone number the newspaper can use to check authenticity.

5. Calendar Listing of Events

This one-page listing is a short and sweet way to introduce a program of many events and to pave the way for upcoming news releases and PSAs.

Remember to provide full street addresses after locations and a contact phone number the public may call for information.

6. Photos with Long Captions

You can use a photo with a long caption to highlight an event, presentation, or health screening.

7. Press Kit

A press kit packages lots of information for the media to use and have on hand during your campaign. Press kits can be made up with the following:

- , Nice folder w/business card holder.
- , News brief.
- List of story ideas.
- Organization overview and biographies, CVs, or resumes with photo.
- Fact sheets, past newspaper/magazine clippings, and medical illustrations.
- , Charts, graphs, statistics (on diskette if possible).
- , Maps to events and your organization's headquarters.

8. Press Conferences

Plan a press conference if you have breaking news. Find an example on in Appendix I on pp.

15-16. Otherwise, invite a reporter to do one or more of the following:

- , Interview family member of a child or an adult with spine bifida.
- Attend a cooking demonstration with a gourmet chef.
- Cover a panel of local celebrities discussing the benefits of folic acid.

Appendix I

Materials to Use and Adapt

The following section of the appendices provides materials such as newsletter inserts, folic acid presentations, pre- and posttests, PSAs, and news releases to help you expedite your folic acid promotion plans. Please use and adapt these materials for your own program.

Sample Proclamation

(<u>TITLE AND NAME</u>) OF (<u>COUNTY HEALTH UNIT NAME</u>) PROCLAMATION IN SUPPORT OF FOLIC ACID AWARENESS WEEK, OCTOBER 26-NOVEMBER 2, 1996

WHEREAS, each year, about 130 babies in New York State and nearly 3,000 babies nationwide are born with serious birth defects of the brain and spine called neural tube defects (NTDs); and WHEREAS, folic acid, a B vitamin, can reduce a woman's risk of having a child born with NTDs by up to 50 percent if taken BEFORE she becomes pregnant; and WHEREAS, folic acid can be found in most multi-vitamin supplements and in certain foods, such as dark, leafy vegetables, and

WHEREAS, folic acid may also decrease a woman's risks of developing heart diseases, stroke, colon cancer and precancerous legions of the cervix; and

WHEREAS, it is imperative that women in their child-bearing years eat foods high in folic acid and take multi-vitamins containing adequate amounts of the vitamin;

NOW, THEREFORE, I (official and title) do hereby proclaim the week of October 26-November 2, 1996, as Folic Acid Awareness Week in (locality). **News Release**--Change these materials to suit your needs. For Immediate Release or Embargo for Release Until Date and Time

CATCHY TITLE: "FOLIC ACID HELPS PREVENT CERTAIN BIRTH DEFECTS"

Media Contact: Name And Phone Number Of Media Contact

COMMUNITY, STATE--A woman may reduce her risk of having a child born with certain serious defects by at least 50 percent just by taking a B vitamin called folic acid, said (title and name) of the (agency name).

The U.S. Public Health Service recommends that all women of childbearing age (15-44 years old) consume 400 micrograms (0.4 milligrams) of folic acid each day. Folic acid is crucial for a woman and her baby at *least* one month before the women becomes pregnant and through the first month of her pregnancy, a time period when most women do not know yet that they are pregnant. Since half of the pregnancies in the United States are unplanned, all women of childbearing age should take 400 micrograms of folic acid daily..

How much folic acid does that mean to a typical woman? On average, a woman consumes half to two-thirds of the recommended amount of folic acid from her diet alone. To get 400 micrograms of folic acid daily, a woman can take a vitamin supplement containing folic acid, eat a breakfast cereal containing 100 percent of the daily value of folic acid, or increase her consumption of foods fortified with folic acid and foods rich in folate.

The following are examples of foods with folic acid: Orange juices from concentrate, cantaloupe, kiwi, strawberries, romaine lettuce, spinach, broccoli, all enriched cereals and grains, including some breakfast cereals, breads, pasta, and rice.

FOR IMMEDIATE RELEASE POINT 4 THE FUTURE: FOLIC ACID PREVENTS BIRTH DEFECTS

County of Onondaga Department of Health

Media Contacts: Name, Phone Number And E-mail

Onondaga County, New York--Onondaga County Executive Nicholas J. Pirro announced today that the Onondaga County Health Department has launched Point 4 the Future, a community-wide folic acid education campaign to prevent spina bifida and other neural tube defects in children born in Onondaga County. "Onondaga County is setting a precedent in New York State by leading the way with this innovative and aggressive public health campaign to help reduce infant mortality and help ensure the birth of healthy babies," Pirro said.

According to Health Commissioner Lloyd F. Novick, M.D., M.P.H., this Health Department's health promotion campaign is a bold, community-wide approach to raise awareness about the critical role folic acid (also called folate) plays in the prevention of births defects of the brain and spinal cord.

The campaign's major objective is to encourage women of childbearing age (15 years to 44 years) to take 400 micrograms of folic acid everyday through a vitamin supplement containing folic acid, breakfast cereals containing 100% of the daily value of folic acid, or foods fortified with folic acid and foods naturally rich in folate. "If a woman is planning to have children some day, we want her to start folic acid today, "Novick said. The Health Department will spread this message through the participation of businesses, health care providers and community organizations in Onondaga County.

Point 4 the Future---222

Consumers will see a variety of campaign activities to assist them with the identification, selection and purchase of foods and vitamin supplements containing folic acid. Point-of-purchase displays will be set up in local pharmacies and grocery stores, patient education packets will be available in physician offices, and folic acid fact sheets will be distributed at WIC and Family Planning clinics, community health fairs, and with medications dispensed at participating pharmacies. Food preparation and cooking demonstrations will be conducted in participating Wegmans and Hometown Markets.

The medical terms used to describe the two major birth defects reduced by adequate folic acid intake are anencephaly and spina bifida also known as neural tube defects (NTDs). Babies with anencephaly do not develop a brain and die shortly after birth. Babies with spina bifida do not properly develop their spinal cord and back bones. These babies may require a series of operations and other treatments throughout their lives. Some children may require leg braces, crutches, and other devices to help them walk, and many have learning disabilities.

An estimated 2,500 infants are born with neural tube defects in the U.S. each year. Approximately five cases occur in Onondaga County annually. The average total lifetime cost to society for each infant born with spina bifida is approximately \$532,000. This estimate is only an average, and for many children the total cost may be well above \$1,000,000.

Approximately 50 percent to 70 percent of neural tube defects could be prevented if women of childbearing age were to consume 400 micrograms of folic acid daily at *least* one month before conception through the first three months of pregnancy. The Public Health

Point 4 the Future---333

service recommends that women get 400 micrograms (0.4 milligrams) of folic acid daily *throughout their reproductive years* because half of all pregnancies in the United States are unplanned.

Point 4 the Future campaign has a folic acid information telephone line to answer public questions and refer callers to appropriate community resources. The number is (315) 435-8218.

###

Media Advisory

Date

GEORGIA FOLIC ACID TASK FORCE PLANS A SPRING HEALTH CAMPAIGN

Media Contacts: Name, Number and E-Mail

WHAT:

The Georgia Folic Acid Task Force desires participation of the media in the spring folic acid promotional campaign. The vitamin folic acid has been proven to prevent the serious birth defects of spina bifida and anencephaly. We need your support to get the folic acid message out to all women.

Reporters are invited to participate in campaign activities--to wear a folic acid t-shirt and walk with at Walk America Day, or pick up a brochure and product sample at a mall information table. We also have experts available for interviews to be broadcast during the two week campaign.

WHY:

To reduce birth defects in Georgia by promoting the daily use of 400 micrograms of the vitamin folic acid by women capable of becoming pregnant.

WHEN

The George Folic Acid Task Force plans to launch a two week folic acid promotional campaign to run from **April 25**, 1998 through **May 10**, 1998.

WHERE:

April 25th, March of Dimes Walk America Day, will kick off the campaign.

May 2nd and 3rd Task Force members and volunteers will set up information tables with brochures and folic acid-rich product samples at metro Atlanta shopping malls. Throughout these two weeks, the Task Force plans to provide information at youth sporting events and at any coinciding health fairs. On May 10th, Mother's Day, all teleflora flowers will be delivered with a folic acid message. A theme for the campaign will relate to Mother's day and Motherhood.

WHO: Georgia Folic Acid Task Force

Association of Women's Health, Obstetric, and Neonatal Nurses

Department of Human Resources, Division of Public Health, Office of Child Health, Family
Planning, Nutrition, Women's Health, Perinatal Epidemiology and Pharmacy

Georgia Chapter of American Academy of Pediatrics

Georgia Chapter of March of Dimes

Georgia Perinatal Association

Georgia Pharmacy Association

Spina Bifida Association of Georgia

USDA, Food and Nutrition Services (WIC)

###

Broadcast Public Service Announcements

For Use Month to Month/Year

Contact Name Your Agency Telephone Number

Title--Folic Acid & Birth Defects

30 SEC: A LARGE GLASS OF ORANGE JUICE. A BOWL OF FORTIFIED CEREAL.

THIS IS AN EASY BREAKFAST TO FIX. IT'S ALSO A HEALTHY WAY

FOR WOMEN TO START THEIR DAY. THAT'S BECAUSE THIS BREAKFAST HAS

LOTS OF A B-VITAMIN CALLED FOLIC ACID. WOMEN WHO TAKE FOLIC BEFORE

THEY BECOME PREGNANT MAY REDUCE THE CHANCES THEIR BABIES WILL BE

BORN WITH SERIOUS BIRTH DEFECTS. TO LEARN MORE ABOUT FOLIC ACID AND

HOW IT MAY PREVENT BIRTH DEFECTS, CONTACT THE (AGENCY NAME) AND

(PHONE NUMBER). THIS MESSAGE IS BROUGHT TO YOU BY THE (AGENCY NAME)

AND (STATION CALL LETTERS)

...more

folic acid and birth defects--222

20 SEC:

A VITAMIN CALLED FOLIC ACID TAKEN BEFORE A WOMAN

BECOMES PREGNANT CAN PROTECT BABIES FROM SERIOUS BIRTH

DEFECTS. MOST MULTI-VITAMINS AND FOODS SUCH AS ORANGE

JUICE, SPINACH, AND FORTIFIED BREADS AND CEREALS CONTAIN

FOLIC ACID. FOR MORE INFORMATION, CONTACT THE (COUNTY

HEALTH AGENCY NAME) AT (PHONE NUMBER). THIS MESSAGE

COMES FROM THE (COUNTY HEALTH AGENCY NAME) AND (STATION

CALL LETTERS).

10 SEC:

A VITAMIN CALLED FOLIC ACID TAKEN BEFORE A WOMEN BECOMES

PREGNANT CAN PROTECT BABIES FROM SERIOUS BIRTH DEFECTS.

FOR MORE INFORMATION, CONTACT THE (AGENCY NAME) AT

(PHONE NUMBER). THIS MESSAGE COMES FROM THE (AGENCY NAME) AND (STATION CALL LETTERS).

###

For use month-month/year

Contact: Amanda Nestor

Onondaga County Health Department

(315) 435-3252

Title--Folic Acid

30 SEC. FOLIC ACID IS A B-VITAMIN THAT CAN PREVENT 50 TO 75% OF

BRAIN AND SPINAL CORD BIRTH DEFECTS. THESE BIRTH DEFECTS,

KNOWN AS NEURAL TUBE DEFECTS, OCCUR BETWEEN 18 AND 30

DAYS AFTER CONCEPTION, LONG BEFORE MOST WOMEN KNOW

THEY ARE PREGNANT. THE U.S. PUBLIC HEALTH SERVICE

RECOMMENDS THAT ALL WOMEN OF CHILD BEARING AGE SHOULD

CONSUME 400 MICROGRAMS OF FOLIC ACID, FOUND IN VITAMINS,

BREAKFAST CEREALS AND SOME FOODS, EVERYDAY. FOR MORE

INFORMATION ABOUT FOLIC ACID CALL THE ONONDAGA COUNTY

HEALTH DEPARTMENT AT 435-8218.

20 SEC. FOLIC ACID IS A B VITAMIN THAT CAN PREVENT 50 TO 75% OF

BRAIN AND SPINAL CORD BIRTH DEFECTS. THE U.S. PUBLIC

HEALTH SERVICE RECOMMENDS THAT ALL WOMEN OF CHILD

BEARING AGE SHOULD CONSUME 400 MICROGRAMS OF FOLIC ACID,

FOUND IN MULTI-VITAMINS, BREAKFAST CEREALS AND SOME

FOODS, EVERYDAY. FOR MORE INFORMATION ABOUT FOLIC ACID

CALL THE AGENCY AT 435-8218.

10 SEC. THE U.S. PUBLIC HEALTH SERVICE RECOMMENDS THAT ALL

WOMEN OF CHILD BEARING AGE SHOULD CONSUME 400

MICROGRAMS OF FOLIC ACID, FOUND IN VITAMIN SUPPLEMENTS

AND FOODS, EVERYDAY TO PREVENT BIRTH DEFECTS. FOR MORE

INFORMATION ABOUT FOLIC ACID CALL THE AGENCY AT 435-8218.

Newspaper Article

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October 28, 1997, Tuesday 08:28 Eastern Time

SECTION: Domestic, non-Washington, general news item

HEADLINE: Parents Of Child With Spina Bifida Hope To Spread Word About Preventive Effects Of Folic Acid

Eds: With Folic Acid-box-cox. By Kevin Lamb

Dayton, Ohio--Justin Skinner took his first steps last week. He had just turned 2, and he needed the help of a walker, but his parents wouldn't have been any more excited if their first child had cartwheeled out of his crib at six months.

"We're not sure he'll ever walk independently," Janice Skinner says. But she also knows a lot of people with spina bifida as severe as Justin's never take steps at all. Her son was born with part of his spinal cord sticking out of his back, covered only by a mucous membrane.

"This is a really big step for him," says Justin's father, David. "Much more than we expected at one time."

The Skinners focus on the ordinary things Justin does, from putting puzzles together and using words in phrases to whipping a tennis ball across the room and smiling proudly. They know he'll never feel anything below his knees and he'll always need leg braces and a shunt to drain his brain of excess fluid and probably a catheter to empty his bowel and bladder, but they've learned to accept those as inconveniences rather than catastrophes.

What's harder to swallow is that Justin might have been born with a normal spine if someone had told his parents all women of childbearing age should take 400 micrograms a day of folic acid, a B vitamin. The U.S. Public Health Service issued that advisory in September 1992 as soon as research came out of that extra folic acid could prevent neural tube defects, including spina bifida but the warning resonated little more than a whisper into a windstorm.

"As far as we knew, we were doing everything right," David says. Janice saw her doctor regularly, ate a healthy diet and started taking prenatal vitamins as soon as her doctor said she was pregnant.

"But once you find out you're pregnant, it's too late," Janice says.

The embryonic spine develops in the first six weeks after conception, before many women know they are pregnant. The crucial time for folic acid supplements is from at least a month before conception to two months after.

"All women of childbearing age" should take the extra folic acid, stresses the public health advisory, because half of all U.S. pregnancies are unplanned and hardly anyone's diet includes 400 micrograms (0.4 milligrams) of folic acid. The Skinners first remember hearing that when Justin was 2 months old.

Justin's misfortune illustrates one of the biggest problems in American health care. Researchers produce valuable medical information every week, but it's not filtering down from the labs and the journals to the lives it is meant to help. Public health experts say most people aren't hearing, understanding or acting on basic information that can save lives, whether it's the beneficial effect of regular aspirin or exercise on heart disease or of pap smears and prostate exams on cancer.

"We really have failed as an industry to address the prevention side," interim CEO Duane Erwin of Franciscan Medical Center says of health education.

"We've got to be better communicators," says president Bob Thimmes of the Miami Valley Health Improvement Council. "We've got to put it in language that John Q. Public on the street can understand"

In the case of Justin and 4,000 American babies every year, the neural tube defect rate of one for every 1,000 births goes beyond frustration to "melancholia," says Gail Noel, Dayton Division director of the March of Dimes Birth Defects Foundation. Half to three-quarters of those cases were preventable with folic acid, according to the U.S. Centers for Disease Control and Prevention.

"It's one thing when people won't do what you want them to do," Noel said. "But this is a case of babies actually suffering because people don't hear the word or don't understand the word."

The United States still has relatively high infant mortality rates for a developed country in spite of "better technology and better knowledge," Noel said. "What we don't have is a hearing or listening public."

Spina bifida is the most common "complex birth defect," says Dr. Adrian Sandler of the University of North Carolina, author of Living with Spina Bifida: A Guide for Families and Professionals. It happens when the neural tube doesn't close properly and encase the spinal cord, which then pokes through the gap. The condition usually is accompanied by excess fluid in the brain, or hydrocephalus.

The Skinners had only vaguely heard of spina bifida or neural tube defects that Thursday morning of the routine ultrasound appointment three weeks before Janice's due date. They

didn't even stay at the obstetrician's office for the doctor's report. But the phone call came to say they had an appointment that afternoon with an ultrasound specialist.

David remembers leaving the specialist's office, scared and stunned, with the words "neural tube defect" written on a card.

When Justin was born 10 days later, David said the bulge in his back "looked like the yolk of a sunny-side-up egg, but it way gray." Janice was not allowed to hold her baby, for fear of infecting him. She didn't get a good look at him until that night, when David showed her the tape from a friend's video camera.

Justin had a busy day. His first car ride was in the ambulance that took him from Miami Valley Hospital to The Children's Medical Center. Five hours after birth, he underwent surgery to put his spinal cord where it belonged. No one knew how much his nerves or brain had been damaged.

Two days later, more surgery left a shunt in his head to pipe the excess fluid to his abdomen, where it can be absorbed. He had five operations in his first six months, nine in his first two years.

The last two surgeries, in May and June, moved muscles from his groin, buttocks and abdomen to each thigh, where Justin's damaged nerves had been unable to generate muscles strong enough for him to walk. No one could promise the operation would allow Justin to walk, but it was his only chance.

The doctors would detach a muscle at one end and reattach it in the thigh area, keeping the nerves intact. They also cut his upper leg bones to better fit them into his abnormally shallow hip sockets.

He spent three months in a cast from his nipples to his toes, with his legs at about a 90-degree angle to keep them in his hip sockets. Justin could barely move. He couldn't fit in a car seat or a stroller. His parents don't know what they'd have done without that tip from someone in the local Spina Bifida Association about the kiddie car Justin could ride like a wheelchair.

In the past couple of months, Janice says, she has heard through the association of five or six families in the area giving birth to babies with spina bifida.

"You'd think it would be decreasing because we're trying to get the message out," she says.

"Trying," says David, "but not succeeding."

Their goal is for every gynecological practice in the Dayton area to encourage folic acid supplements for all their patients of childbearing age. Doctors' words carry more clout than those of friends and acquaintances, they say. But doctors are slow to change, they've learned

from seminars and literature on spina bifida.

The March of Dimes sends pamphlets to doctors, nurses, midwives, health clinics, even corporations, says director Noel. It holds health fairs for colleges, high schools and junior highs.

But the biggest breakthrough has been television commercials for orange juice, a leading dietary source of folic acid along with liver, beans, nuts, some dark green vegetables and fortified foods such as cereal and beginning Jan. 1, bread and pasta. The juice commercials mention folic acid and healthy babies.

"People figure if it's on TV, it must be right," Noel says.

Last summer, the CDC reported only 23 percent of women who'd been pregnant in the previous two years took daily supplements with enough folic acid. Only 30 percent of non-pregnant women were taking them when questioned. Two out of three women had heard of folic acid, but only 9 percent of them, 6 percent of the total, had heard about taking it before pregnancy.

"It's just hard to get healthy people in their 20s to take supplements every day," Janice Skinner says.

The Skinners hope the message doesn't have to stress fear too heavily. They don't want anyone telling Justin he's a tragedy. When he thinks of how gloomy words and attitudes might discourage his son, he says he no longer thinks it's too hokey to hear terms like "sight-challenged" or "special needs."

Justin's different, he says. Aren't we all? "I know the people I work with don't have to take their kids to physical therapy every week or neurological and orthopedic specialists every few months," David says, "but when I look at Justin, I see a normal little boy.

(Kevin Lamb writes for the Dayton Daily News, Dayton, Ohio.)

Press Conference Announcement

September 24, 1996

ATTENTION: ALL MEDIA POINT 4 THE FUTURE

PRESS CONFERENCE ANNOUNCEMENT

WHAT: Onondaga County Health Department Launches Major

Folic Acid Public Health Education Campaign

WHEN: Thursday, October 3, 1996

10:00 a.m.

WHERE: John H. Mulroy Civic Center

County Executive Suite Conference Room

14th Floor

WHO: * Nicholas J. Pirro, County Executive

* Lloyd F. Novick, MD, MPH, Commissioner of Health

* Onondaga County Medical Society, Representative

* Donna Parks, MS, Spina Bifida Clinic, Crouse Irving Memorial Hospital

* Beth Trunfio, Executive Director, March of Dimes Foundation

* Jim McLaughlin, Rph, President, Onondaga County Pharmaceutical Society

* Community General Hospital Representative

This press conference will announce the Onondaga County Health Department's Point 4 The Future folic acid educational campaign to prevent spina bifida and other neural tube defects. Point 4 The Future campaign includes a variety of activities that will be conducted in partnership with several local businesses and health care agencies during the next two years. Its major objectives is to educate women of the need to consume 0.4 mg (milligrams) of folic acid in their diet to reduce the risk of neural tube defects.

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Point 4 the Future

Folic Acid Prevents Birth Defects

Onondaga County Health Department

Press Conference

October 3, 1996 10:00 a.m.

County Executive's Suite Conference Room 14th Floor - John H. Mulroy Civic Center

Speakers

- 1. Nicholas J. Pirro County Executive
- 2. Lloyd F. Novick, M.D., M.P.H. Commissioner of Health
- 3. Mary T. Wisner, MS, RN
 Director of Nursing
 Community General Hospital
- 4. Beth Trunfio, Executive Director March of Dimes
- 5. Onondaga County Medical Society (Representative)

Following formal comments, the speakers and representatives from other organizations participating in Point 4 the Future campaign will be available for media interviews and photo opportunities in the back of the conference room.

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Newsletter Inserts

Pharmacy Newsletter

K-mart, Issue No. 5, Fall 1996

Protect The Health Of Your Unborn Child

Today and everyday seven children in the United States will be born with a devastating neural tube defect. The neural tube forms within the first month of pregnancy and develops into the baby's spine. The most common neural tube defect is spina bifida. This occurs when part of the baby's spinal cord and backbone does not develop properly. As a result, the baby may have paralyzed legs and develop bladder and bowel problems. Another more severe neural tube defect is anencephaly. In these cases, part of a baby's skull and brain are missing. These babies die shortly after birth.

Folic acid is a B-vitamin that can help to prevent neural tube defects. Because half of the pregnancies in the United States are unplanned and because the neural tube has already formed by the time most women realize that they are pregnant, all women of child bearing age (ages 15 to 45) should take 400 micrograms of folic acid on a daily basis even if they are not planning a family now.

To get enough folic acid daily, a woman can take a vitamin pill containing folic acid, eat a breakfast cereal fortified with 100 percent of the daily value or eat foods fortified with folic acid and rich in folate. Folic acid is found in enriched breads, breakfast cereals, grains, and beans. Foods that contain folic acid are leafy, dark green vegetables such as spinach and broccoli and orange juice from concentrate.

The Onondaga County Health Department, working with the county Pharmaceutical and Medical Societies is starting a local campaign to prevent neural tube defects from happening to unborn children. For any further information please contact your local pharmacy or the County Health Department at (315) 435-3252. Simple preventive steps can prevent devastating consequences later.

Electric Company Insert

The Pennyrile News

Volume 25, February 15, 1994, Number 08

The Spina Bifida Association of Kentucky (SBAK) has asked Pennyrile Rural Electric to share this important information with its employees.

"The Spina Bifida Association of Kentucky is proud to introduce "Project Healthy Babies." This project is a statewide public health service campaign encouraging childbearing age women to take folic acid, a B-vitamin that reduces the chance of spina bifida, a common and serious birth defect. Recent studies confirm that women who take 400 micrograms (0.4 milligrams) of folic acid, on a daily basis before they become pregnant, can reduce their chances of having a child with spina bifida by up to 75%. Folic acid can be found in vitamin supplements containing folic acid and a variety of foods".

In Kentucky, the number of newborns with spina bifida is double the national amount. Since almost half of all pregnancies are unplanned, and because spina bifida occurs within the first 26 days after conception, all women of childbearing age should take a daily multi-vitamin or supplements containing folic acid to be sure they get the necessary amount each day. If you have any questions, please call the Spina Bifida Association of Kentucky at (502) 637-7363.

Newspaper Insert Project Healthy Babies

Folic Acid Cuts Risk of Spina Bifida

Spina bifida is a disabling birth defect that results when the baby's spine cord and backbone cannot form properly during the first month of pregnancy. In many cases, a thin balloon-shaped sac develops outside the back that exposed the spinal cord and nerves. Today, more than 90 percent of spina bifida babies survive; but of those surviving, many have a range of physical challenges, from paralysis and severe bowel and bladder disorders to learning disabilities.

In Kentucky, the occurrences of babies with this defect is double the national average--2 per 1,000. With the support of Kosair Charities, the Spinal Bifida Association of Kentucky (SBAK) has launched "Project Healthy Babies" (PHB) to educate Kentucky on the prevention of spina bifida.

Since nearly 50 percent of pregnancies in the United States are not planned, it is vital that all women of childbearing age consume the recommended 400 micrograms (0.4 milligrams) of folic acid daily to reduce their chance of having a baby with spina bifida by up to 75%. Folic acid is a B-vitamin which can be found in vitamin supplements containing folic acid and a variety of foods such as green leafy vegetables, liver, beans and orange juice. To prevent these birth defects women must get enough folic acid daily one to two months before conception and through the first three months of pregnancy.

The SBAK is committed to promoting the prevention of spina bifida and to enhancing the quality of life of all those affected.

For more information on the SBAK, spina bifida, or folic acid, call (502) 637-7363.

Folic Acid Curricula

Letter to the Educators

In southwest Virginia, the folic acid promotion program partnered with the school board to incorporate lessons about folic acid in health, biology or nutrition classes. In addition, they designed a small pre-and posttest for the school children to evaluate the lessons effectiveness.

DATE

Dear Educator,

Your class has been chosen by the school board to teach, by the **end of NOVEMBER**, a very critical lesson on **Folic Acid**. It is the goal of the Perinatal Coordinating Council for Region I to reduce the number of babies born with birth defects. The B-vitamin, folic acid, can prevent some birth defects. Not in the last 30 years have we had a more significant opportunity **to prevent 50 to 70 percent of birth defects of the spine and brain.**

Since southwest Virginia has extremely high rates of these types of birth defects (up to 6 times the state and national rates), you play an integral part by teaching this important message. By teaching this lesson, we will be given the opportunity to so something about this terrible incidence of birth defects.

If you could incorporate this lesson into your nutrition, health or biology class **before the end of NOVEMBER**, **1997**, when the follow up survey is completed in December, 1997, more than 24% (as reported in January, 1997, survey) of women of childbearing age should know about the benefits of folic acid. Please help...

"Spread the word: Folic Acid prevents birth defects."
Thanks for your assistance. For more information contact:

Contact Name
Address
Phone Number
E-mail

Address outline for Folic Acid Education Speech

This could be adapted for a variety of audiences.

I. Introduction (This will be based on the age, education, and background of the group. Some of this information can be excluded and some can be spoken about in more detail.) A series of questions may be asked to emphasize the fact that they could help prevent this birth defect not only by educating themselves but educating someone else as well.

Do you know someone with spina bifida?

Do you know someone with special needs?

Do you know of someone who is planning to get pregnant?

Do you know someone who could get pregnant?

II. About Neural Tube Defects

- A. Three kinds
 - 1. Anencephaly 35% of NTDs
 - 2. Encephalocele 5% of NTDs
 - 3. Spina Bifida 60% of NTDs
- B. Living with NTDs--30 years ago babies died--now most survive

III. Spina Bifida

- A. Three kinds of varying disabilities--spina bifida occulta, meningocele, and myelomeningocele
- B. Range of problems-- learning disabilities, bowel and bladder problems, and hydrocephalus
- C. CDC estimates 3-400,000 cases worldwide; nationally 1 case per 1,000 births
- D. Causes--environmental and genetic; all women at risk; 50% pregnancies unplanned

IV. Folic Acid

- A. B-Vitamin needed at least one month before pregnancy through the first three months
- B. 400 micrograms (0.4 milligrams) daily for all childbearing age women
- C. How can women get enough
 - 1. Vitamin supplements containing folic acid
 - 2. Foods fortified with 100% of the daily value
 - 3. Fortified foods and food s rich in folate

V. Your Folic Acid Promotion Program

VI. Your organization

- A. Mission and history of organization
- B. Uses and resources of organization
- C. Funding basis of your organization and folic acid promotion program: bingo; grants; donations; fund-raisers

Delivering A Speech

1. **Preparation**

- a) Know your material
- b) Be rested
- c) Don't eat much prior to the presentation
- d) Get psyched up.

2. Check the Arrangements

- a) Where you are sitting
- b) The sound system
- c) The lights
- d) Your equipment including visual aids.

3. Giving the Speech

- a) Be introduced briefly
- b) Move quickly into the speech; take charge
- c) Lose yourself in your talk
- d) Keep good eye contact with your audience
- e) Use your whole body to communicate
- f) Read your audience--don't leave them.
- g) Use variety in pace and timing.
- h) Feel what you are saying (and so will the audience).
- 4. <u>Notes</u> -- If you choose to use them, use big print: one-sided note cards or paper sheets. Number them in order. Don't study or look at them before the speech or until after introductions. You want to talk to your audience -- not your notes!

Speaking Tips

- 1. COMMIT YOURSELF. Practice. Preparation eliminates fear and embarrassment.
- 2. ANALYZE YOUR AUDIENCE. What would you want to hear?
- 3. ORGANIZE YOUR THOUGHTS. Talk with your audience--not at them.
- 4. THINK SIGHT. Dress appropriately. Eye contact and posture are important.
- 5. PRACTICE! PRACTICE! Rehearse before a mirror with a tape recorder.
- 6. *RELAX*. Use visualization techniques to see, hear, and feel a dynamic speaking experience.
- 7. HAVE FUN. Visualize yourself being congratulated. Know you have made a difference.

NTD Quiz for Audience from the Spina Bifida Association of Kentucky

| α . 1 | 1 41 | | 1 4 | | |
|--------------|------|----|------|-------|----|
| -1rc | е п | ne | nest | answe | r. |

| 1. | What is | spina | bifida? |
|----|---------|-------|---------|
| | | | |

- a. A birth defect
- b. A food
- c. An opening in the spine
- d. Both a and c
- 2. Can a B-vitamin reduce the risk of spina bifida?
 - a. Yes
 - b. No
 - c. A B-vitamin reduces the risk of having a baby with spina bifida by up to 75%.
- 3. Can you catch spina bifida?
 - a. Yes, by germs in the air
 - b. No
 - c. Yes, by not washing your hands
- 4. Children with spina bifida may be:
 - a. In a wheelchair
 - b. Have braces for their legs
 - c. Just like ME
 - d. All of the above
- 5. Do you know someone that could have a baby?
 - a. My mother
 - b. An aunt
 - c. A neighbor/a teacher
 - d. All of the above
- 6. Would you help *your program's name* by teaching the women you know to take a multivitamin regardless of whether they are planning to have a baby?
 - a. Yes
 - b. No

Draw a line to the best answer

- 1. Spina bifida
- 2. Neural tube defect
- 3. Folic acid
- 4. Cereals
- 5. Orange juice

- a. a source of folic acid
- b. a B vitamin that is found in fortified foods and vitamins
- c. a birth defect of the spine
- d. birth defects of the brain and spine

Fact Sheet

This fact sheet can be adapted and used as a reference for volunteers at health fairs or at folic acid tables in malls. It may also be adapted and used to pass out to those persons who are interested in learning more about your campaign.

Thank you for volunteering!

The purpose of this educational table is to educate women of childbearing age on the importance of consuming 400 micrograms of folic acid everyday. This, in turn, will reduce the risk of their unborn children developing spina bifida by 50%-75%.

POSSIBLE QUESTIONS:

What is spina bifida and anencephaly?

Spina bifida and anencephaly are birth defects that occur in the first four weeks of pregnancy, before most females know that they are pregnant. Since 50% of pregnancies are unplanned, it is important to include 400 micrograms of folic acid in every childbearing age women's diet.

Spina Bifida occurs when the lower end of the neural tube fails to close. Thus, the spinal cord and back bones do not develop properly. Sometimes, a sac of fluid protrudes through an opening in the back, and a portion of the spinal cord is often contained in this sac. Paralysis of the infant's legs, loss of bowel and bladder control, water on the brain (hydrocephalus), and learning disabilities are among the disabilities associated with spina bifida. Eighty to ninety percent of infants born with spina bifida live. Despite varying degrees of disability, many lead successful and productive lives.

Anencephaly is a fatal condition in which the upper end of the neural tube fails to close. In these cases, the brain either never completely develops or is totally absent. Pregnancies affected by anencephaly often result in miscarriages. Infants who are born alive die very soon after birth.

What is folic acid and where can I get it?

Folic acid is a B-vitamin. The recommended amount to prevent spina bifida and other neural tube defects is 400 micrograms (0.4 milligrams) of synthetic folic acid daily. This can be consumed in three ways:

1) Most multivitamins contain 400 micrograms (0.4 mg) of folic acid. Vitamin supplements containing folic acid can be bought at grocery, pharmacy, or discount stores that sell vitamins

- 2) Breakfast cereals fortified at 100% of the daily value of folic acid per serving. Total, Product 19, Cheerios Plus and Smart Start are some of these types of cereal products.
- 3) Foods fortified with folic acid (all enriched cereal grain products such as enriched pasta, rice, bread and cereal) in addition to a healthy diet. Foods rich in folate are green leafy vegetables, orange juice from concentrate, fortified cereals, liver and other foods.

Who Can Have A Baby With An NTD In The United States?

60 million women are of childbearing age in the United States; all those who are capable of becoming pregnant are at risk for having an NTD-affected pregnancy. It is not possible to predict which women will have a pregnancy affected by an NTD. 95 percent of NTDs occur in women with no personal or family history of NTDs. However, some risks factors are known:

- C An NTD-affected pregnancy increases a woman's chance to have another NTD-affected pregnancy approximately twenty times
- C Maternal diabetes
- C Anti-seizure medication use
- C Obesity
- C High temperatures in early pregnancy, fevers and hot tub use for example
- C Race/ethnicity (NTDs are more common among white women than black women and more common among Hispanic women that non-Hispanic women)
- C Lower socio-economic status.

Can Women Get Too Much Folic Acid?

Folic acid has no known toxic level. If you were to eat a bowl of fully fortified cereal (100 - 400 micrograms), take 400 micrograms (0.4 milligram) folic acid supplement, and eat foods rich in folate, women of reproductive age would not have a problem with too much folic acid. Even in very high amounts folic acid is non-toxic. Nevertheless, it is recommended that women consume no more than 1,000 micrograms of synthetic folic acid a day. Very large amounts of folic acid have been found to hide the ability to quickly diagnose a vitamin B-12 deficiency, a sign of pernicious anemia. This disease primarily affects the elderly population and in some cases can lead to neurological damage. Today, doctors can use a simple definitive test to check for a B-12 deficiency.

Are Women Getting Enough Folic Acid?

Even though there are several ways to get 400 micrograms (0.4 milligram) of folic acid every day, two thirds of women in the United States do not consume adequate amounts of folic acid.

What are the costs associated with NTDs?

The average total lifetime cost to society for each infant born with spina bifida is approximately \$532,000 per child. This estimate is only an average, and for many children the total cost may be well above \$1,000,000.

Are there other health benefits with folic acid?

High levels of the amino acid homocysteine are independently associated with an increased risk of heart disease and stroke. It has been shown that taking folic acid lowers homocysteine levels in both men and women, but it is not yet known whether folic acid supplementation also lowers the risk of heart disease and stroke.

What is the Georgia National Task Force? (Adapt this for your program)

A statewide educational campaign designed to educate women on the importance of folic acid for preventing spina bifida. We do need help, so influence people to fill out the little "HELP" sheet.

Some things you can mention to interested parties:

- * All Tel-A-Flora flowers will be delivered with a folic acid message on Mother's Day
- * Information booths will be set up in Atlanta area shopping malls, sporting events, and schools

TABLE CONTENTS:

framed posters; brochures
HELP wanted & folic acid volunteer and information fact sheet
sources of folic acid fact sheet
folic acid supplement bottle
pictures of children with spina bifida and agency brochure

Training Kit

Your title

Letter for Health Care Providers Receiving a Training Kit

YOUR AGENCY YOUR ADDRESS YOUR PHONE AND FAX NUMBERS YOUR E-MAIL ADDRESS

| Date |
|--|
| Dear Health Care Professional: |
| In <i>your city/county/state</i> , healthy mothers and babies are our highest priority. By educating all women about the necessity of folic acid for a healthy pregnancy, we can help improve the health of your <i>city's/county's/state's</i> children. |
| With this in mind, we are pleased to present you with "The Complete Trainer's Guide on the Role of Folic Acid in Preconceptional Nutrition." This comprehensive kit focuses on the importance of increasing the intake of folic acid (a B-vitamin) by all women who can become pregnant. The risk of birth defects of the spine and brain, called neural tube defects (NTDs-spina bifida and anencephaly) is greatly reduced when 400 micrograms (0.4 mg) of folic acid is included daily in every woman's diet. |
| Produced by, this kit contains all the necessary elements you will need to educate your clients, your peers, or the public about folic acid. With input and guidance from <i>your partners</i> , <i>your group</i> has worked very hard to ensure that you will feel confident educating <i>your city's/county's/state's</i> citizens about the importance of folic acid. |
| Included in the kit is a Registration and Feedback card. Please take the time to complete this short response card and return it promptly. We welcome any additional comments you have to offer. |
| We hope that you will use this tool to its full capacity. The health of our future children rests in your efforts today. Should you need additional information, please contact, title, address, phone number. |
| Sincerely, Your name |

Slide Show for Health Care Providers

Texas Department of Health Texas NTD Project 1100 W. 49th Street Austin, Texas 78756

This slide show was developed to inform clinic staff and other health-care professionals about neural tube defects and the use of folic acid to reduce the risk of these birth defects. It is not intended as an educational/informational program for clients or school programs.

Reducing the Risk of Neural Tube Defects

(Slide Show Script)

| #1 The spinal cord and brain develop in a fetus from the neural tube during the first month of pregnancy. Neural tube defects, or NTDs, are major birth defects of the brain and/or spinal cord which usually lead to death or disability. | What are neural tube defects (NTDs)? |
|--|--------------------------------------|
| #2 The spinal cord and brain develop from a strip of cells running along the back of the embryo. Two to three weeks after conception, a groove appears in the center of what will be the baby's back. | Graphic of neural tube closing |
| The groove deepens, and the edges of this strip gradually curl toward each other and fuse to form the neural tube. The neural tube later becomes the spinal cord and brain. | |
| The neural tube develops and closes in the fetus sometime between the 16th and 28th day after conception. In other words, as soon as a woman's period is a few days late, the neural tube is beginning to form. | |

| #2A Normally, the brain and spinal cord are surrounded by cerebrospinal fluid, which is contained between membranous layers called the meninges. In NTD cases, the neural tube fails to close properly and an opening or lesion occurs. Often, the meninges or cerebrospinal fluid protrude through this opening. Prenatal screening and diagnostic testing can usually determine if a pregnant woman is carrying a baby with an NTD. | Graphic of the cerebrospinal fluid and meninges |
|---|--|
| #3 The most common neural tube defects are spina bifida, anencephaly and encephalocele. Spina bifida accounts for over half of all NTDs. | Neural tube defects (NTDs) * Spina bifida *Anencephaly *Encephalocele |
| Spina bifida results when the neural tube remains open at the neck or back. In spina bifida, the meninges, the spinal cord and cerebral spinal fluid may be exposed or protrude through an open lesion of the spine. Spina bifida is treated by surgical closure of the defect at birth. Abnormalities of the spinal cord may result in motor paralysis, skeletal deformities, sensory loss, and bowel and bladder incontinence. | photo - spina bifida |
| #5 Anencephaly accounts for about 35% of all NTDs. Anencephaly occurs when the neural tube remains open at the level of the cranium, resulting in the partial or complete absence of the brain and incomplete development of the skull. Babies born with anencephaly are either stillborn or die shortly after birth. | photo - anencephaly |

| #6 Encephalocele accounts for less than 5% of all NTDs. In encephalocele, part of the brain or meninges protrudes through the skull. This birth defect is usually fatal, but survival is possible with small lesions and early surgery. Cognitive, motor, and sensory impairments can result from this malformation. | photo - encephalocele |
|--|-----------------------|
| #7 The definite cause or causes of NTDs are unknown. They are thought to occur through an interaction of genetic and environmental factors. | |
| Some factors associated with an increased risk of NTDs include: * A previous NTD-affected pregnancy; * Women with a close relative who had had an NTD; * Women or their partners who themselves have an NTD; * Race or ethnicity (In the U. S., NTDs are more common among white women than black women and more common among Hispanic women); * Maternal insulin-dependent diabetes; * Use of anti-seizure medication such as valproic acid or carbamazepine; * Lower socio-economic status; * Lower educational level; * Obesity; * Exposure to high temperatures in early pregnancy. Women with a low family income and a low educational level may eat less nutritious foods and their lifestyle may expose them to environmental hazards. Although some people suspect exposure to chemicals may be a risk | |
| factor, scientific data are lacking. This is an area that needs further investigation. | |

| #8 The Texas Department of Health became very alarmed about the rate of NTDs when three babies with anencephaly were born in a 36-hour period in Cameron County. A 1992 investigation of this NTD cluster found that the average NTD rate for Cameron County for the years 1986 to 1989 was 14.6 per 10,000 live births. For the years 1990 and 1991, it was 26.8 per 10,000. During the 80's, the average U.S. rate was approximately 8 per 10,000 live births. This is only an estimation, however, because many states do not have formal birth defects monitoring systems. | Bar chart |
|--|---|
| #9 Studies suggest that women who consume 400 to 800 micrograms of folic acid both before conception and during early pregnancy can reduce their risk of having a child with an NTD. | photo of woman and child |
| #10 In the September 11, 1992, issue of the Mortality and Morbidity Weekly Report, the Centers for Disease Control and Prevention (known as CDC) published a recommendation that all women capable of becoming pregnant should consume 400 micrograms of folic acid each day. | CDC Recommendation All women of childbearing age in the United States who are capable of becoming pregnant should consume 400 micrograms (0.4 mg) of folic acid per day for the purpose of reducing their risk of having a pregnancy affected with spina bifida or other NTDs. |
| #11 Daily consumption of 400 micrograms (0.4 milligrams) of folic acid prior to conception is important because NTDs occur in the first month of pregnancy, before most women know they are pregnant. Since over 50% of pregnancies in the United States are unplanned, it is important that all women capable of becoming pregnant consume enough folic acid. | photo of women seated at table outside |

#12

Total folic acid consumption should be less than 1 milligram per day, except under the supervision of a physician. The effects of high intake may include the masking of a vitamin B_{12} deficiency.

CDC Recommendation (continued)

Because the effects of high intakes do include complicating the diagnosis of vitamin B12 deficiency, care should be taken to keep total folate consumption under 1 mg per day, except under the supervision of a physician.

#13

Women who have had a prior NTD-affected pregnancy have a 2 to 4% risk of having a subsequent affected pregnancy. Their risk is about 25 times higher than a woman who has not had a prior NTD-affected pregnancy. The U.S. Public Health Service Recommends consulting with a doctor about taking a much larger amount of folic acid everyday, 4000 micrograms (4 milligrams), one month before conception and throughout the first three months.

CDC Recommendation (continued)

Women who have had a prior NTD affected pregnancy are at risk of having a subsequent affected pregnancy.

#14

If all women follow these recommendations, each year the incidence of NTDs in the United States would be reduced by about half to two-thirds, from 4,000 to 2,000 or 1,500.

photo of woman and man with physician

#15

Women who have not had a prior NTD-affected pregnancy can meet the recommendation in various ways. The first way is to take a daily vitamin supplement that contains 400 micrograms (0.4 milligrams) of folic acid. Another way is to eat breakfast cereals containing 100% of the daily value of folic acid. A third way is to eat foods fortified with folic acid and rich in folate.

Ways to get folic acid

- * Vitamin supplements with folic acid
- * Breakfast Cereals containing 100% of the daily value of folic acid
- * Foods fortified with folic acid and rich in folate

| #16 Vitamin Supplements containing folic acid can be purchased in supermarkets, drug stores, and discount stores. The least expensive multivitamins are generally the store brand for example, HEB One Daily, Target Multiple Vitamins, Albertson's Multivitamins, Walgreen Multiple Vitamins, Eckerd Vitamin-a-Day, and Walmart's Spring Valley One Daily Multiple Vitamins. Women should be cautioned to take only one vitamin pill each day and to store the supplements out of the reach of children. | photo of woman buying vitamins. |
|--|--------------------------------------|
| #17 Some foods that are high in folate include dried beans and peas, liver, spinach and other leafy greens, oranges, grapefruit, peanuts and sunflower seeds. Since the average American woman's diet includes only about 200 micrograms (0.2 milligrams) of folic acid, women who want to get an adequate amount of folic acid from food alone will need to plan their meals carefully. | photo of foods high in folic acid |
| #18 This TDH client pamphlet was developed for clients with a low reading level. It suggests simple ways that women can include more foods with folic acid in their diet. | photo of pamphlet cover |
| #19 The tips offered include: Eat five or more servings of fruits and vegetables everyday. When you cook vegetables, steam them or cook them in a small amount of water. Do not overcook them. | photo of inside of pamphlet |
| #20 Drink orange juice every day or several times a week. | photo of woman drinking orange juice |

| #21 Choose enriched cereal grain products. | photo of whole grain bread, pasta, rice |
|---|---|
| #22 Choose cereals that have folic acid added to them. Total, Product 19, and Just Right contain 100% of the U.S. RDA for folic acid in one serving. Many cereals contain 25% of the U.S. RDA for folic acid in one serving. | photo of enriched cereal |
| #23 Eat dried beans several times a week. Serve them as a main dish instead of meat or add them to soups, salads and casseroles. | photo of prepared bean dish |
| #24 Eat fruits and vegetables raw. Add fresh vegetables such as spinach, broccoli or romaine lettuce to tossed salads. | photo of fruit and vegetable platters |
| #25 Women should be encouraged to follow the "Food Guide Pyramid" which includes the recommendation to eat two to four servings of fruits and three to five servings of vegetable every day. | photo of food pyramid |
| #26 A woman is more likely to follow the suggestions if they are tailored to her usual dietary customs and lifestyle. When suggesting behavior or dietary changes, consider ethnic preferences, afford ability, and lifestyle factors such as eating out, packing lunches for work, and amount of time available for cooking. Also consider cooking skills and availability of meal preparation equipment like a stove, microwave and refrigerator. | photo of family eating |
| #27 If the client is on WIC, ask her if she is eating the fortified breakfast cereals and check to see if they contain 25% or more of the RDA for folic acid. Ask her if she drinks orange or grapefruit juice and eats dried beans and peas or peanut butter. | photo of family eating |

| Wear the end of the counseling session, it is helpful to ask the client what changes she plans to make to her diet in the upcoming weeks. Goal setting and reinforcement are key elements in behavior change. A client is going to be more successful if the initial behavior changes are limited to one or two, somewhat easy-to-achieve steps. Further desired changes can be discussed in future counseling sessions once the client has demonstrated success in achieving initial goals. | photo of woman being counseled. |
|--|------------------------------------|
| #29 This second TDH brochure is written at a fairly high reading level. It was designed for use by health professionals in their counseling. This is for highly motivated women who want to get the right amount of folic acid from their foods. It includes tables of foods with the amount of folic acid per specified serving. A nutritionist or other health professional doing diet counseling may want to use these lists to do a quick check on how much folic acid a woman consumed in a 24-hour period. | photo of yellow pamphlet cover |
| #30 A highly motivated woman may want to use these lists when planning her meals. The food table is perforated so she can tear this section off and take it to the grocery store to help her find foods high in folic acid. | photo of inside of yellow pamphlet |
| #31 The folic acid that occurs naturally in food is not as well absorbed by the body as the folic acid from vitamin supplements and fortified cereals. No guidelines are available to tell us how much folic acid is absorbed from individual foods - overall absorption from food is estimated to be 50%. Scientific agreement on this issue will not occur until there are more research trials using dietary intervention. | photo of both sides of food table |

#32

The Food and Drug Administration has fortified enriched flour, bread, and other grain products with folic acid. While this level of fortification offers some protection, it will not maximize it. On average, women will increase their total folate consumption to about 300 micrograms per day, an amount still short of the recommended dosage.

photo of staple foods

#33

In addition to promoting the consumption of folic acid to reduce the risks of NTDs, the Texas Department of Health is involved in two efforts aimed at identifying Texas babies with birth defects. These efforts will provide data about the incidence and distribution of NTDs, information that could take us closer to determining the causes of these defects.

The first effort is the establishment of a birth defects registry. The Birth Defects Prevention Bill, signed into law on June 15, 1993, by Governor Ann Richards, authorized the Texas Department of Health to create the state's first system to identify and track major birth defects. The law funds the development of pilot surveillance projects in coastal and south Texas counties.

Texas map with birth defect area highlighted

#34

There are two types of surveillance approaches - active and passive. A passive system relies on reporting from providers throughout the state.

Passive Surveillance

- * Reports from facilities
- * Relies on existing data and reporting systems

#35

An active approach employs staff to go to hospitals, clinics and offices where a new case is likely to be diagnosed to collect the needed data. This approach is more effective in identifying the largest number of cases. The law requires the Texas program to use active surveillance methods. This program will give us accurate information on the incidence of birth defects and provide valuable data for investigations of the causes of the NTDs in Texas.

Active Surveillance

- * Trained staff reviews records
- * Questions persons involved
- * Info recorded on standard forms

#36

The second Texas surveillance efforts focuses exclusively on neural tube defects. In October 1992, TDH received a five-year grant from CDC for expanded NTD surveillance, educational activities, folic acid intervention, and risk factor evaluation. These activities are being carried out in 14 counties along the Texas-Mexico border.

Additionally, the Environmental Protection Agency, in cooperation with the Texas Air Control Board and the Texas Water Commission, plans to further investigate the environmental pollutants along the border to determine what types of contaminants the border population may be exposed to.

Cutaway map of 14 counties

| #37 The high incidence of NTDs identified in the Valley brought the importance of women's health-care issues to the forefront. | photo of mom and healthy baby |
|--|-------------------------------|
| In response, TDH has distributed free vitamins to women of child-bearing age in Cameron and Hidalgo Counties, mounted a statewide media campaign to promote the consumption of folic acid, and produced educational materials. Ongoing activities include the border surveillance and intervention project, studies to better understand risks for NTDs, and the birth defects registry. | |
| This is an example of how a very simple public health intervention can make a major impact on a public health problem. | |
| 10/93 | |

Instructions for Administration of Pre- and Post-tests

- 1. The primary purpose of the pre- and post-tests is to evaluate the effectiveness of this presentation. The pretest gives us a measure of the listeners' knowledge base before they receive the information. The post-test measures their knowledge of the topic after the presentation. The difference between the pretest score and the post-test score measures the amount of knowledge transfer that has taken place.
- 2. <u>Before</u> the slide show, distribute the pretests and answer sheets and ask participants to record answers in the first column of the answer sheet. DO NOT check the answers to the pretest or discuss the questions. Instruct participants to keep their answer sheets. Collect all pretests before starting the slide show.
- 3. After the slide show and any discussion about the topic, ask participants to take the posttest and record their answers in the second column of the answer sheet. Have participants check the answers to their own post-tests. Go over each question and discuss any areas of interest or concern.
- 4. After checking the post-tests, read the answer key for the pretest so participants can check their pretests and record the number of correct answers for each test at the bottom of the answer sheet.
- 5. Collect all answer sheets and send them to: *Name, Texas Department of Health, 1100 W.* 49th St. Austin, TX 78756. Please include the name of the presenter, the date and location of the presentation.
- 6. We are interested in your feedback as a presenter. Please let us know how the slide show could be improved to better serve your needs.

Neural Tube Defects Pretest provided by the Texas Department of Health

Select the **best** answer for each question.

| Select the <u>best</u> answer for each question. | |
|--|--|
| 1. Neural tube defects are major birth defects of: | a. the brainb. the spinal cordc. the lungsd. the brain and spinal cord |
| 2. There are main types of neural tube defects. | a. two b. three c. four |
| 3. The neural tube develops in the fetus: | a. in the third month after conceptionb. between days 28 and 40 after conceptionc. between days 16 and 28 after conception |
| 4. Concerns about NTDs arose in Texas because of an unusually high number of cases in Cameron County. | a. spina bifidab. anencephalyc. encephalocele |
| 5. A neural tube defect occurs when: | a. the neural tube doesn't grow long enoughb. the neural tube is too bigc. the neural tube doesn't close properly |
| 6. Although the definite causes of NTDs are unknown, some factors associated with an increased risk include: | a. alcohol and drug abuseb. previous NTD-affected pregnancyc. intelligence |
| 7 are most at risk of having an NTD-affected pregnancy. | a. Asians or Pacific Islandersb. Anglo-Americansc. Mexican-Americansd. African-Americans |
| 8. Based on estimates, the rate of NTDs in Texas is the rate for the U.S. | a. lower thanb. higher thanc. the same as |
| 9. Folic acid is: | a. a proteinb. a mineralc. a B-vitamin |
| 10. Women who should be counseled to consume folic acid include: | a. all women of childbearing ageb. all women of childbearing age who are capable of becoming pregnantc. women who are planning a pregnancy |

| 11. Women should consume less than | a. 400 micrograms (0.4 milligram) |
|--|-----------------------------------|
| of folic acid each day, except under the care of | b. 800 micrograms (0.8 milligram) |
| their physician. | c. 1000 micrograms (1 milligram) |

| 12. Anencephaly is usually fatal. | True | False |
|--|------|-------|
| 13. Most multivitamins contain 400 micrograms (0.4 milligrams) of folic acid. | True | False |
| 14. Consuming adequate folic acid in the last trimester of pregnancy will reduce a woman's risk of having a baby with an NTD. | True | False |
| 15. Good food sources of folic acid include fortified cereals, enriched cereal grain products, orange juice from concentrate, dried beans, liver, spinach and other leafy greens, peanuts and sunflower seeds. | True | False |
| 16. Folic acid that is found in foods is as easily absorbed by the body as the folic acid in vitamin supplements and fortified cereals. | True | False |
| 17. Most women get enough folic acid from food alone, without paying much attention to their diet. | True | False |
| 18. The folic acid content of a food can vary, depending on how long it is cooked and whether it's fresh, frozen or canned. | True | False |
| 19. To prevent NTDs, a women needs 400 micrograms of synthetic folic acid in addition to a healthy diet. | True | False |
| 20. Consuming enough folic acid before and during pregnancy can reduce the risk of NTDs by about half. | True | False |

Neural Tube Defects Post-test

Select the <u>best</u> answer for each question.

| Concerns about NTDs arose in Texas because of an unusually high number of cases in Cameron County. | a. spina bifidab. anencephalyc. encephalocele |
|--|--|
| 2. Based on estimates, the rate of NTDs in Texas is the rate for the U.S. | a. lower thanb. higher thanc. the same as |
| 3. Neural tube defects are major birth defects of: | a. the brainb. the spinal cordc. the lungsd. the brain and spinal cord |
| 4. The neural tube develops in the fetus: | a. in the third month after conceptionb. between days 28 and 40 after conceptionc. between days 16 and 28 after conception |
| 5. There are main types of neural tube defects. | a. two b. three c. four |
| 6. A neural tube defect occurs when: | a. the neural tube doesn't grow long enoughb. the neural tube is too bigc. the neural tube doesn't close properly |
| 7 are most at risk of having an NTD-affected pregnancy. | a. Asians or Pacific Islandersb. Anglo-Americansc. Mexican-Americansd. African-Americans |
| 8. Although the definite causes of NTDs are unknown, some factors associated with an increased risk include: | a. alcohol and drug abuseb. previous NTD-affected pregnancyc. intelligence |
| 9. Folic acid is: | a. a proteinb. a mineralc. a B-vitamin |
| 10. Women should consume less than of folic acid each day, except under the care of their physician. | a. 400 micrograms (0.4 milligram)b. 800 micrograms (0.8 milligram)c. 1000 micrograms (1 milligram) |

| 11. Women who should be counseled to | a. all women of childbearing age |
|--------------------------------------|--|
| consume folic acid include: | b. all women of childbearing age who are |
| | capable of becoming pregnant |
| | c. women who are planning a pregnancy |

| 12. Consuming adequate folic acid in the last trimester of pregnancy will reduce a woman's risk of having a baby with an NTD. | True | False |
|--|------|-------|
| 13. Consuming enough folic acid before and during pregnancy can reduce the risk of NTDs by about half. | True | False |
| 14. To prevent NTDs, a women needs 400 micrograms of synthetic folic acid in addition to a healthy diet. | True | False |
| 15. Most women get enough folic acid from food alone, without paying much attention to their diet. | True | False |
| 16. Good food sources of folic acid include fortified cereals, enriched cereal grain products, orange juice from concentrate, dried beans, liver, spinach and other leafy greens, peanuts and sunflower seeds. | True | False |
| 17. Folic acid found in foods is as easily absorbed by the body as the folic acid in vitamin supplements and fortified cereals. | True | False |
| 18. The folic acid content of a food can vary, depending on how long it is cooked and whether it's fresh, frozen or canned. | True | False |
| 19. Most multivitamins contain 400 micrograms (0.4 milligrams) of folic acid. | True | False |
| 20. Anencephaly is usually fatal. | True | False |

Answer Sheet

| Pretest | Post-test |
|-------------------|-------------------|
| 1 | 1 |
| 2 | 2 |
| 3 | 3 |
| 4 | 4 |
| 5 | 5 |
| 6 | 6 |
| 7 | 7 |
| 8 | 8 |
| 9 | 9 |
| 10 | 10 |
| 11 | 11 |
| 12 | 12 |
| 13 | 13 |
| 14 | 14 |
| 15 | 15 |
| 16 | 16 |
| 17 | 17 |
| 18 | 18 |
| 19 | 19 |
| 20 | 20 |
| | |
| Pretest # correct | Pretest # correct |
| Post-test correct | Post-test correct |

Answer Key to PretestSelect the <u>best</u> answer for each question.

| Neural tube defects are major birth defects of: | a. the brain b. the spinal cord c. the lungs d. the brain and spinal cord | |
|--|--|--|
| 2. There are main types of neural tube defects. | a. two b. three c. four | |
| 3. The neural tube develops in the fetus: | a. in the third month after conceptionb. between days 28 and 40 after conceptionc. between days 16 and 28 after conception | |
| 4. Concerns about NTDs arose in Texas because of an unusually high number of cases in Cameron County. | a. spina bifidab. anencephalyc. encephalocele | |
| 5. A neural tube defect occurs when: | a. the neural tube doesn't grow long enoughb. the neural tube is too bigc. the neural tube doesn't close properly | |
| 6. Although the definite causes of NTDs are unknown, some factors associated with an increased risk include: | a. alcohol and drug abuseb. previous NTD-affected pregnancyc. intelligence | |
| 7 are most at risk of having an NTD-affected pregnancy. | a. Asians or Pacific Islanders b. Anglo-Americans c. Mexican-Americans d. African-Americans | |
| 8. Based on estimates, the rate of NTDs in Texas is the rate for the U.S. | a. lower thanb. higher thanc. the same as | |
| 9. Folic acid is: | a. a proteinb. a mineralc. a B-vitamin | |
| 10. Women who should be counseled to consume folic acid include: | a. all women of childbearing age b. all women of childbearing age who are capable of becoming pregnant c. women who are planning a pregnancy | |

| 11. Women should consume less than | a. 400 micrograms (0.4 milligram) |
|--|-----------------------------------|
| of folic acid each day, except under the care of | b. 800 micrograms (0.8 milligram) |
| their physician. | c. 1000 micrograms (1 milligram) |

| 12. Anencephaly is usually fatal. | True | False |
|--|------|-------|
| 13. Most multivitamins contain 400 micrograms (0.4 milligrams) of folic acid. | True | False |
| 14. Consuming adequate folic acid in the last trimester of pregnancy will reduce a woman's risk of having a baby with an NTD. | True | False |
| 15. Good food sources of folic acid include fortified cereals, enriched cereal grain products, orange juice from concentrate, dried beans, liver, spinach and other leafy greens, peanuts and sunflower seeds. | True | False |
| 16. Folic acid found in foods is as easily absorbed by the body as the folic acid in vitamin supplements and fortified cereals. | True | False |
| 17. Most women get enough folic acid from food alone, without paying much attention to their diet. | True | False |
| 18. 14. To prevent NTDs, a women needs 400 micrograms of synthetic folic acid in addition to a healthy diet. | True | False |
| 19. If a woman wants to get enough folic acid through the food she eats, she should consume between 400 and 800 micrograms of folic acid every day. | True | False |
| 20. Consuming enough folic acid before and during pregnancy can reduce the risk of NTDs by about half. | True | False |

Answer Key to Post-test Select the <u>best</u> answer for each question.

| Concerns about NTDs arose in Texas because of an unusually high number of cases in Cameron County. | a. spina bifidab. anencephalyc. encephalocele |
|--|--|
| 2. Based on estimates, the rate of NTDs in Texas is the rate for the U.S. | a. lower thanb. higher thanc. the same as |
| 3. Neural tube defects are major birth defects of: | a. the brainb. the spinal cordc. the lungsd. the brain and spinal cord |
| 4. The neural tube develops in the fetus: | a. in the third month after conceptionb. between days 28 and 40 after conceptionc. between days 16 and 28 after conception |
| 5. There are main types of neural tube defects. | a. two b. three c. four |
| 6. A neural tube defect occurs when: | a. the neural tube doesn't grow long enoughb. the neural tube is too bigc. the neural tube doesn't close properly |
| 7 are most at risk of having an NTD-affected pregnancy. | a. Asians or Pacific Islanders b. Anglo-Americans c. Mexican-Americans d. African-Americans |
| 8. Although the definite causes of NTDs are unknown, some factors associated with an increased risk include: | a. alcohol and drug abuseb. previous NTD-affected pregnancyc. intelligence |
| 9. Folic acid is: | a. a proteinb. a mineralc. a B-vitamin |
| 10. Women should consume less than of folic acid each day, except under the care of their physician. | a. 400 micrograms (0.4 milligram) b. 800 micrograms (0.8 milligram) c. 1000 micrograms (1 milligram) |

| a. all women of childbearing ageb. all women of childbearing age who are | |
|---|--|
| capable of becoming pregnant | |
| c. women who are planning a pregnancy | |

| 12. Consuming adequate folic acid in the last trimester of pregnancy will reduce a woman's risk of having a baby with an NTD. | True | False |
|--|------|-------|
| 13. Consuming enough folic acid before and during pregnancy can reduce the risk of NTDs by about half. | True | False |
| 14.14. To prevent NTDs, a women needs 400 micrograms of synthetic folic acid in addition to a healthy diet. | True | False |
| 15. Most women get enough folic acid from food alone, without paying much attention to their diet. | True | False |
| 16. Good food sources of folic acid include fortified cereals, enriched cereal grain products, orange juice from concentrate, dried beans, liver, spinach and other leafy greens, peanuts and sunflower seeds. | True | False |
| 17. Folic acid found in foods is as easily absorbed by the body as the folic acid in vitamin supplements and fortified cereals. | True | False |
| 18. The folic acid content of a food can vary, depending on how long it is cooked and whether it's fresh, frozen or canned. | True | False |
| 19. Most multivitamins contain 400 micrograms (0.4 milligrams) of folic acid. | True | False |
| 20. Anencephaly is usually fatal. | True | False |

Answer Sheet to Pretest and Post-test

| Pretest | | | Post-test |
|---------|---|-----|-----------|
| 1. | D | 1. | В |
| 2. | В | 2. | В |
| 3. | C | 3. | D |
| 4. | В | 4 | С |
| 5. | C | 5. | В |
| 6. | В | 6. | C |
| 7. | C | 7. | C |
| 8. | В | 8. | В |
| 9. | C | 9. | C |
| 10. | В | 10. | C |
| 11. | C | 11. | В |
| 12. | T | 12. | F |
| 13. | T | 13. | T |
| 14. | F | 14. | T |
| 15. | T | 15. | F |
| 16. | F | 16. | T |
| 17. | F | 17. | F |
| 18. | T | 18. | T |
| 19. | T | 19. | T |
| 20. | T | 20. | T |

Pretest # correct _____ Post-test # correct_____

Contact Information For Other Training Kits

Centers for Disease Control and Prevention (for health care providers)

National Center on Birth Defects and Developmental Disabilities 1600 Clifton Road, NE

MS E-86

Atlanta, GA 30333 ph: (404) 498-3800

Florida Department of Health (for health care providers)

10841 Little Rd.

New Port Richey, FL 34654-2533

ph: (813) 869-3900 fax: (813) 863-9734

Puerto Rico Department of Health (for health care providers)

Secretariat for Health Promotion and Prevention Islandwide Folic Acid Campaign 911 Rochester Street University Gardens Rio Piedras, Puerto Rico, 00927-4812

ph: (787) 758-1836