

# **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-fetoprotein), 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 under the direction of their health care provider 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.

- C Whole Grain Total, Total Corn Flakes, and Total Raisin Bran (General Mills Inc.)
- C Product 19 (Kellogg's)
- C Just Right with Crunchy Nuggets (Kellogg's)
- C Smart Start (Kellogg's)
- C Multi-Grain Cheerios Plus (General Mills Inc.)
- C 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.<sup>1</sup>

### Carbohydrates:

Enriched Cereals  
Enriched Breads  
Enriched Rice  
Enriched Pastas

Beans and Lentils, Canned or Dry

### Meats:

Eggs  
Liver

### Juices:

Orange Juice from concentrate  
Pineapple Juice, canned

### Vegetables:

Artichokes  
Asparagus  
Avocado  
Collard Greens  
Lettuce, romaine  
Okra  
Spinach, fresh or frozen

### Fruits:

Cantaloupe  
Strawberries  
Kiwis

### Legumes:

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<sup>1</sup> Institute of Medicine. Dietary Reference Intakes: Folate, Other B Vitamins, and Choline: Prepublication Copy. In: Dietary Reference Intakes for Thiamin, Riboflavin, Vitamin B<sub>6</sub>, Folate, Vitamin B<sub>12</sub>, 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.

<b>Nutrition Facts</b>		
Serving Size	1/2 cup (52 g)	
Servings Per Container	8	
		<b>with 1/2 cup Skim Milk</b>
<b>Amount per Serving</b>	<b>Cereal</b>	
Calories	200	240
Calories from fat	25	25
	<b>% Daily Value</b>	<b>% Daily Value</b>
<b>Total Fat 3g</b>	4%	4%
Saturated Fat 0.5g	3%	3%
<b>Cholesterol 0mg</b>	0%	0%
<b>Sodium 240mg</b>	10%	13%
<b>Potassium 200mg</b>	6%	11%
<b>Total Carbohydrate 43g</b>	14%	16%
Dietary Fiber 5g	20%	20%
Sugars 15g		
Other Carbohydrate 23g		
<b>Protein 4g</b>		
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%
<b>Folate or Folic Acid</b>	<b>25%</b>	
<b>25%</b>		
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.
- C Lollar DJ. *Preventing secondary conditions associated with spina bifida or cerebral palsy: proceedings and recommendations of a symposium*. Washington, DC: Spina Bifida Association of America, 1994.
- C Sandler A. *Living with spina bifida: a guide for families and professionals*. Chapel Hill, NC: University of North Carolina Press, 1997.
- C Simeonsson R, Huntington G, Sturz McMillen J, et al. “Development, secondary conditions and quality of life in children with spina bifida.” Paper presented at Centers for Disease Control and Prevention, Atlanta, GA, Dec. 1997. Call (919) 966-5038.
- C Simeonsson RJ, Short RJ. Adaptive development, survival roles, and quality of life. In: Jacobson J, Mulick J (Eds.). *Manual of diagnoses and professional practice in mental retardation*. Washington, DC: American Psychological Association, 1996.
- 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.

- C 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.
- C 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](mailto: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.
- C 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](mailto: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

### 1. There have been both randomized control trials and observational studies showing that folic acid can prevent neural tube defects.

#### 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 not 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 supplementation 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 occurrence 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 neural 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. *Epidemiology* 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 B<sub>6</sub>, folate, vitamin B<sub>12</sub>, 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

- C Holmes L, Harris J, Oakley G, et al. Teratology society consensus statement on use of folic acid to reduce the risk of birth defects. *Teratology* 1997; 55(6): 381.
- C Mulinare J, Erickson D. Prevention of neural tube defects. *Teratology* 1997; 56(1-2): 17-18.
- C Oakley GP. Folic acid-preventable spina bifida and anencephaly. *Journal of the American Medical Association* 1993; 269(10): 1292-3.
- C Centers for Disease Control and Prevention. Use of folic acid for the prevention of spina bifida and other neural tube defects, 1983-1991. *Morbidity and Mortality Weekly Report* 1991; 40(30): 513-6.

## Folic Acid Information for Health Care Professionals

- C Anthony M, Lin-Fu J. *Folic acid and neural tube defects: a fact sheet for health care providers*. Washington, DC: Maternal and Child Health Bureau, Health Resources and Services Administration, Public Health Service, 1993.
- C 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.
- C Institute of Medicine (IOM). (Dietary reference intakes: folate, other B vitamins, and choline: prepublication copy. In: *Dietary reference intakes for thiamin, riboflavin, vitamin B<sub>6</sub>, folate, vitamin B<sub>12</sub>, 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.

## References on Making Health Campaigns Effective

- C    Andreasen A. *Marketing social change: changing behavior to promote health, social development and the environment*. San Francisco, CA: Jossey Bass, 1995.
- C    Bracht N, (Ed). *Health promotion at the community level*. Newbury Park: Sage Publications, Inc., 1990.
- C    Centers for Disease Control and Prevention. *The prevention marketing initiative: applying prevention marketing* (AIDS Publication.) Washington, DC: Department of Health and Human Services, 1996. Call (404) 639-0956 (CDC Order No. D905).
- C    Glanz K, Rimer BK, Lewis FM, (Eds). *Health behavior & health education: theory, research, & practice*. (2nd ed). San Francisco: Jossey Bass, 1997.
- C    McFarlane J. De madres a madres: women building community coalitions for health. *Health Care for Women International* 1994; 15(5): 465-476.
- C    National Cancer Institute. *Making health communications program work: a planner's guide* (NIH Publication). Washington, DC: National Cancer Institute, 1998.
- C    National Cancer Institute. *Theory at a glance: a guide for health promotion practice*. (NIH Publication No. 95-3896). Washington, DC: National Cancer Institute, 1995. [Online]. Available: **[http://rex.nci.nih.gov/nci\\_Pub\\_Interface/Theory\\_at\\_glance/HOME.html](http://rex.nci.nih.gov/nci_Pub_Interface/Theory_at_glance/HOME.html)**.
- C    Piotrow PT, Kincaid DL, Rimon JG, Rinehart W. *Health communication: lessons from family planning and reproductive health*. Westport, Conn: Praeger, 1997.
- C    Sutton SM, Balch GI, Lefebvre RC. Strategic questions for consumer-based health communications. *Public Health Reports* 1995; 110: 725-733.
- C    University of Toronto. The Health Communication Unit. *What works! Effective strategies for health communication* (participant workbook). 1996. Pdf format, 59 pages, 203 kb. [On-line]. Available: **<http://www.utoronto.ca/ca/hcu/hcu-publications.html#Other>**.

## **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](mailto:bestart@mindspring.com).
- C *The American Journal of Health Communications*. To subscribe: write Turning Point Communications, P.O. Box 7070 Loudon, NH 03301 or 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.
- C Butterfoss FD, Goodman RM, Wandersman A. Community coalitions for prevention and health promotion: factors predicting satisfaction, participation and planning. *Health Education Quarterly*. 1996; 23(1): 65-79.
- C Capper SA, Duncan WJ, Ginter PM, et al. Translating public health research into public health practice: outcomes and characteristics of successful collaborations. *American Journal of Preventive Medicine* 1996; 12(4 Suppl): 67-70.
- 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.
- C Eng E, Parker E, Harlan C. Lay health advisors: a critical link to community capacity building. *Health Education and Behavior* 1997; 24 (4): 413-7.
- C Newsome AE. Using a chamber of commerce as a coalition builder. *Journal of Cultural Diversity* 1994; 1(3): 63-64.
- C Wagner L. *Presenting your health promotion program*. Palo Alto, CA: Stanford Center for Research in Disease Prevention, 1990. Telephone (415) 723-1000.
- C Yenney S. *Small businesses and health promotion: the prospects look good: a guide for providers of health promotion programs*. Washington, DC: U.S. Department of Health and Human Service, 1984.

## 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.
- C 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.
- C 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

- C 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.
- C 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 Reseach 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 20001 or 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). [On-line 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>].
- C 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>].
- C 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](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](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

Salaries	\$1745
Fringe Benefit	\$218.88
Stipends	\$296
Contractual Services	\$145
Equipment	\$113
Supplies	\$1024
Phone	\$55.14
Total Direct Costs	\$3597
Indirect Costs	\$1537
<b>TOTAL COSTS</b>	<b>\$5234</b>

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:  

$$\text{Average} = \text{Total \# of polysyllabic words} / \text{Total \# of sentences}$$
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.

<b>SMOG Conversion Chart</b>			
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 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 noticeboards 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.