



A Personal Point of View: The Downey Family Story

Contributed by Cristin Cuozzo, BS, Graduate Student, FFAC, FSHN/University of Florida

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"It was just surreal; you don't ever expect it to happen to you. We were faced with this thing we never imagined we'd be faced with," said Maggie Downey as she recounted her family's experience with a neural tube defect (NTD)-affected pregnancy. A few years after having a healthy baby boy, Maggie became pregnant with her second child. "The pregnancy was going fine and there didn't seem to be any troubles; life was great," remembered Kevin Downey, Maggie's husband. However, 18 weeks into the pregnancy, Maggie's obstetrician gave the Downey family some shocking news. He informed them that their baby had a condition called anencephaly, a fatal NTD in which part of the brain is missing or exposed. Maggie and Kevin were faced with a decision most of us cannot even begin to imagine and quickly came to realize just how vulnerable anyone can be in this type of situation. No one in Kevin or Maggie's family had a history of any type of birth defect, and Maggie had done everything her obstetrician recommended to ensure a healthy pregnancy. Something they once thought only happened to other people

actually became a reality for their family.

Several months after the pregnancy, Maggie and Kevin met with a pediatric genetic counselor and learned about folic acid and its importance. Maggie knew it was important to take prenatal vitamins during pregnancy, but she did not recognize folic acid as a component of the vitamins until after her experience. In the months following her pregnancy, she learned ***it is important to have folic acid in your system prior to conception*** since many women do not realize they are pregnant until after the neural tube is completely developed. Maggie also learned that if she began planning another pregnancy, she may be at greater risk for having another baby with an NTD. She would need to take extra doses of folic acid to help protect her from another NTD-affected pregnancy.

Maggie followed the recommendation to take folic acid before conceiving. Shortly after her visit with the genetic counselor, Maggie became pregnant with her third child, Grace, who is now a healthy, athletic little girl.

After Grace was born, Maggie began her involvement with the March of Dimes. The Downey family was contacted about having Grace become the "ambassador" for the North Central Florida Chapter of the March of Dimes. The family accepted and Grace was named the March of Dimes poster child in 1999. After Grace became the poster child for the March of Dimes, the Downey family was contacted by a group of OB/GYN nurses to share their story with another family who was facing a similar situation. The Downey family agreed because they believe it is "nice for people to see another family on the other side of the situation and to realize that life goes on and you can get through it."

A few years later, Maggie and Kevin had their fourth child; a healthy little girl named Annie. Today, Maggie sits on the board for the Florida Chapter of the March of Dimes, and she helps to raise money at Shands at the University of Florida (UF) through bake sales and other campaigns. Kevin recalls how

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Folic acid can help prevent birth defects of the brain and spine and other defects as well.

A Personal Point of View: The Downey Family Story (continued)

persistent and dedicated she is to the cause each year. The family also made a trip to the capital in Tallahassee in 2000 to help with the lobbying effort for the development of the Birth Defects Registry. They acted as the “face” of a family who was affected by an NTD to show others that it can happen to anybody and no one is immune to such a situation. In addition, the family’s teenage son, Danny, has walked in the March of Dimes for nine consecutive years, and Maggie has participated in studies on the factors affecting folic acid absorption in the Food Science and Human Nutrition Department at UF.

In 2006, the Downey family accepted an invitation to serve as the spokes-family for

the Florida Folic Acid Coalition to promote National Folic Acid Awareness Week.

Maggie and Kevin also feel it is important for organizations promoting folic acid to have a spokesperson who has had a personal experience with an NTD-affected pregnancy. People relate more to personal stories than to facts written on a page. Maggie and Kevin are happy to share their story with others because they believe people need someone with whom they can relate. Hearing the story from a “real” family helps a person relate to the problem and realize that an NTD-affected pregnancy is not just something that happens to other people. Maggie and Kevin both think it is important to talk about birth

defects and get the information out in the open for people to hear. Maggie advises all women of childbearing age to take a multivitamin with folic acid and to eat a healthy, balanced diet that includes foods high in natural folate. It is especially important for women to realize that by the time most women discover they are pregnant, the neural tube has already formed. Since almost half of all pregnancies in the United States are unplanned or mistimed, it is important for women to always plan for the unexpected by taking a daily multivitamin with folic acid.

Any organization that promotes folic acid or NTD prevention should consider searching for a spokesperson

who has faced an experience like the Downey family’s. Personal stories can be shared through media outlets (newspapers, television stories, or Web sites), newsletters distributed to patients and health care providers, or at health fairs. Organizations should contact their local March of Dimes chapter to find out if there is an available spokesperson in their area.



The Downey Family outside their home in Gainesville, FL.

FFAC Reaches out to Professionals Across the State

Contributed by Ron Lutz, MSN, ARNP, FFAC Coordinator, FSHN/University of Florida

An important goal of the Florida Folic Acid Coalition (FFAC) is to, “Promote folic acid education as a routine and standard part of the delivery of preventive health care services to Floridians.” One way FFAC works to accomplish this goal is to exhibit at professional meetings around the state. The FFAC exhibited at the Governor’s Conference on Women’s Health in Orlando, May 18-19, 2006, which was attended by approximately 260 participants. Several FFAC partners including the Florida Department of Health, Vita-Grant, and March of Dimes

Florida Chapter also exhibited. The FFAC exhibit included informational literature on the benefits of folic acid for the prevention of birth defects and for health across the life span. Booth visitors were treated to information and exciting promotional items. Copies of folic acid literature, health literature on the nutritional value of citrus, FFAC newsletters, and folic acid promotion pins, magnets, key chains, and pens were available for conference participants. The Florida Department of Citrus provided complimentary orange juice, T shirts, and other items. Elsevier Publishing

provided the FFAC with two textbooks on women’s health, which were used for a free drawing for conference attendees. We appreciate all our partners that made the exhibit a success.

The FFAC also will be exhibiting at the following meetings:

- Florida State Association of Occupational Health Nurses - 46th Annual Florida Occupational Health Conference, at Disney’s Coronado Springs Resort Lake Buena Vista, FL. The conference title is, “The

Magic of Occupational Health Nursing.” For details visit <http://www.fsaohn.org/conference2006.html>.

- Partners in Perinatal Health, Sharing Solutions Conference, planned for Fall 2006.



All women of childbearing age should take
400 micrograms of folic acid every day.

Florida Convenes State Leaders to Advance Women's Health

Contributed by Lacy Fehrenbach, MPH and Ron Lutz, MSN, ARNP, FFAC Coordinator, FSHN/UF



The Florida Department of Health's Women's Health Initiative hosted the first Governor's Conference on Women's Health in Orlando on May 18-19, 2006, during National Women's Health Week. The goal was to improve understanding of factors affecting women's health across the lifespan, knowledge of disparities in health outcomes among Floridian women, and recognition that women's health encompasses more than physical health.

Rony François, MD, MSPH, PhD, Florida's Secretary of Health, opened the conference on May 18. Toni Jennings, Lt. Governor, opened the second

day of the conference on May 19. The conference featured an update on the health status of women in Florida and presentations on the impact of women's health on the well-being of children and society as a whole, women's access to healthcare, women's health problems across the lifespan, social and environmental determinants of health, best and promising practices in women's health, and health disparities. The FFAC exhibited at the conference as did their partners, the Florida Department of Health, VitaGrant, and the March of Dimes Florida Chapter. Two FFAC members presented at the conference: Lynn Bailey, PhD, Professor, Food Science and Human Nutrition Department at the University of Florida, Institute of Food and

Agricultural Sciences and Elizabeth Jensen, VitaGrant Manager, March of Dimes Florida Chapter.

Dr. Bailey presented, "Folic Acid: Health Throughout the Life Span," focusing on the health benefits of folic acid for reducing risks for neural tube defects and other birth defects. She highlighted research that suggests folic acid may reduce risks for certain chronic diseases such as cardiovascular disease, stroke, certain cancers, and cognitive disorders like Alzheimer's disease and dementia. Elizabeth Jensen presented, "Better Birth Outcomes through Better Preconception Health Services," focusing on the importance of preconception health interventions for women in Florida. One activity of the VitaGrant program is to pro-

vide no cost multivitamins with folic acid and folic acid education materials to non-pregnant women of childbearing age in medically underserved areas to reduce risks for birth defects.

Deputy Secretary Nancy Humbert, ARNP, MSN, is the Women's Health Officer. In addition to coordinating the Governor's Conference on Women's Health and ensuring that policies and programs use a gendered approach to respond to women's health across the life span on an ongoing basis, Deputy Secretary Humbert is responsible for developing a statewide women's health plan.

For more information, please visit <http://www.doh.state.fl.us/family/wh/index.html>.

VitaGrant Campaign Targets Florida's Colleges and Universities

Contributed by Elizabeth Jensen, Project Manager, VitaGrant

June 2006 brings the March of Dimes Florida Chapter to the midpoint of the three year Florida VitaGrant project. The \$2 million grant was awarded by the Florida Attorney General's Office as a result of a settlement with multiple vitamin manufacturers. The grant is a partnership between the March of Dimes Florida Chapter, the Florida Department of Health, the Florida Folic Acid Coalition and the Florida Birth Defects Center to promote the use of folic acid in women of reproductive age throughout Florida. Through the grant, participating sites receive free

multivitamins and folic acid education and preconception educational materials to distribute to underserved or underserved women of childbearing age.

This summer, in conjunction with the distribution of materials and vitamins taking place statewide through community health clinics and social service providers, the VitaGrant project has launched a campaign to help educate college students on the importance of taking a daily folic acid-containing multivitamin. Universities with pharmacy services are

being provided with folic acid stickers to place on oral contraceptives dispensed. In addition, the universities are providing free multivitamins and educational materials to give to students who otherwise may not be able to purchase the vitamins. VitaGrant is also partnering with community colleges to provide opportunities for educating students on the importance of folic acid through participation in health fairs and other student activities on campus.

For more information about the VitaGrant project, or to

become a distribution site for vitamins, contact the VitaGrant Project Manager, Elizabeth Jensen, at ejensen@marchofdimes.com or at (850) 245-4465.



Research Update

Contributed by Gail Rampersaud, MS, RD, LDN, Assistant in Nutrition Research and Education, FSHN/University of Florida

The following summaries offer the results of recent research studies or nutrition and health policies regarding recommendations on folic acid.

- Two recent reports indicate that folic acid supplementation is not associated with a reduction in risk of a second heart attack in patients with heart disease or patients recovering from a heart attack. In contrast, a new study provides evidence that folic acid fortification is associated with a significant reduction in the rate of deaths due to strokes in the general population in both the US and in Canada. Researchers from the Centers for Disease Control and Prevention analyzed the rate of stroke-related deaths over a 12-year period; between 1990 and 1997 (before folic acid fortification) and between 1998 and 2002 (after folic acid fortification). The average decline in stroke deaths in the US accelerated from 0.3% per year between 1990 and 1997 to nearly 3% per year between 1998 and 2002 resulting in 12,900 fewer deaths. The decline in deaths due to strokes during this time period was even greater in Canada. In contrast, stroke mortality in England and Wales, where there is no mandatory folic acid fortification, did not change significantly. The accelerating decline in stroke deaths could not be explained by changes in other major risk factors, such as cigarette smoking,

hypertension, or total cholesterol levels. This study provides supporting evidence for an association between increased folate intake and primary risk reduction for stroke. The data are consistent with the hypothesis that folic acid fortification is contributing to a reduction in stroke deaths.

[Lonn E, et al. The Heart Outcomes Prevention Evaluation (HOPE) 2 Investigators (2006). *N Engl J Med* 354:1567-1577.

Bonaa KH, et al. (2006) *N Engl J Med* 354:1578-1588.

Yang Q, et al. (2006) *Circulation* 113:1335-1343.]

- The National Institutes of Health recently held a conference on Multivitamin/Mineral Supplements and Chronic Disease Prevention. An expert panel assessed the evidence on the safety and effectiveness of multivitamin/mineral supplements and made recommendations regarding certain supplements, including folic acid. The panel reinforced the message that every woman of childbearing age should consume 400 micrograms of folic acid daily for prevention of birth defects of the brain and spine. To watch an archived Web cast of the conference, go to <http://videocast.nih.gov/pastEvents.asp?c=998>, or refer to NIH State-of-the-Science series, <http://nih.gov>.

- Researchers at the CDC, March of Dimes, and Rynne Marketing assessed health-care providers' (HCP)

knowledge and practices regarding folic acid. Surveys were sent to 611 OB/GYNs and family/general physicians (FAM/GENS) and 500 physicians' assistants, nurse practitioners, certified nurse midwives, and registered nurses. Over 88% of HCPs knew when a woman needed to begin taking folic acid to prevent NTDs and over 85% knew that folic acid supplementation beyond what is in the diet is necessary. However, 42% did not know the correct folic acid dosage (400 micrograms) and only half knew that 50% of pregnancies in the US are unplanned. Nurse practitioners in OB/GYN settings were most likely and FAM/GENS were least likely to recommend supplements. The strongest predictor for recommended folic acid was whether the provider took a multivitamin. All HCPs who have contact with women of childbearing age should seize the opportunity to educate them about folic acid intake recommendations.

[Williams JL, et al. (2006) *Maternal and Child Health Journal*. Epub ahead of print.]

- A cross-sectional study assessed serum folate concentrations in over 9,400 women who entered prenatal care in southern California in 1999 and 2000 (after folic acid fortification of grain products). After adjusting for vitamin use, being in the lowest quartile of serum folate level was

independently related to being black, Hispanic or Asian/Pacific Islander race/ethnicity, being younger in age, and being overweight or obese. Despite food fortification, disparities remain among certain groups of pregnant women with regard to folate status and these women need focused efforts to encourage intake of supplements containing 400 micrograms of folic acid as part of a healthy diet.

[Lawrence JM, et al. (2006) *American Journal of Obstetrics and Gynecology*. 194:520-526.]

- Data from over 2,500 women collected for the National Birth Defects Prevention Study indicated that 53% of pregnant women began taking a folic acid supplement during the periconceptional period (3 months before until 1 month after conception). Women who did not take a folic acid supplement during this time period tended to have lower education, be younger than 25 years of age, be nonwhite, speak Spanish, be nulliparous, smoke, have nonplanned pregnancies and eat less breakfast cereal. This study identifies subgroups of women to which folic acid intake recommendations and interventions should be particularly focused.

[Carmichael SL, et al. (2006) *American Journal of Obstetrics and Gynecology*. 194:203-210.]

Fifty percent (50%) of all pregnancies and 80%-95% of teen pregnancies in the U.S. are unplanned!

Online Training Module Now Available for the "Folic Acid Every Day" Toolkit

Contributed by Cristin Cuozzo, BS, Graduate Student, FFAC, FSHN/University of Florida

The "Folic Acid Every Day" toolkit is an educational program and resource kit for learning and teaching about folic acid and neural tube defects in a variety of health care settings. The toolkit was developed in 2000 by faculty in the Food Science and Human Nutrition Department (FSHN) at the University of Florida, UF/IFAS. The toolkit was recently updated with a grant from the March of Dimes Florida Chapter and is available for purchase through the IFAS Extension Bookstore.

In Spring 2006, a training module for the toolkit became available on the Florida Folic Acid Coalition's Web site (www.FolicAcidNow.net). The training module was developed by faculty and staff in the FSHN Department at

UF/IFAS as part of a March of Dimes Florida Chapter grant. The training module was designed to help health care professionals learn about the materials in the kit and how to use them effectively for different audiences. The toolkit includes an Educator's Guide with lesson plans and handouts, a DVD with two videos, a CD-ROM with a PowerPoint® presentation and PDF files of the handouts, and an interactive learning tool for designing meals that emphasize inclusion of folic acid fortified foods and foods that are naturally rich in folate. The materials found in the toolkit can be used to instruct and educate health care professionals, consumers, and patients. The training module describes each component in the kit and provides instructions and

suggestions for use in different health care settings. The online training module is free, user-friendly, and can be accessed at any time.

What is available in the training module?

- A description of the components in the toolkit.
- An explanation of how materials are used with health care providers, clients, or patients.
- An animated demonstration of how to use the meal planning activity in the toolkit.

Accessing the training module

- Go to the Florida Folic Acid Coalition's Web site at www.FolicAcidNow.net.
- Click on the "Health Professionals" button.
- Click on the "Toolkit Training Program" tab.
- Enter a valid email

address to access the training module. (A short survey will be sent to you after you complete the training to help evaluate the effectiveness of the module.)

Ordering the toolkit

The "Folic Acid Every Day" toolkit, in English or Spanish, is available for purchase at the IFAS Extension Bookstore by calling (352) 392-1764 or at the bookstore Web site at www.ifasbooks.com.



**"Folic Acid Every Day"
Toolkit**

Updated for 2006

Around the State

Compiled by Ron Lutz, MSN, ARNP, FFAC Coordinator, FSHN/University of Florida

Broward County

The Seminole Indian Tribe "Health Fair" in Hollywood was held on 5/17/06. VitaGrant participated with an exhibit booth, and distributed folic acid educational materials and multivitamin starter kits to eligible participants. [Submitted by Alisha N. Bright, S. FL VitaGrant Outreach Worker]

Collier County

The Seminole Indian Tribe in Naples held a "Health Fair" on 5/23/06. VitaGrant participated with an exhibit booth, and distributed folic acid educational materials and multivitamin starter kits to eligible

participants. [Submitted by Alisha N. Bright]

Duval County

Magnolia Project held a "Spring Celebration" health fair on 4/22/06 in Jacksonville. VitaGrant participated with a booth providing periconceptional health literature, folic acid information, and multivitamin starter kits to eligible women. VitaGrant also participated in the NAACP of Jacksonville Health Fair on 5/13/06. [Submitted by Stefani Lesser, VitaGrant Outreach Worker]

Hillsborough County

Florida Covering Kids and Families held their second

annual Kid Fair for a Florida KidCare event on 5/6/06. VitaGrant was there to distribute nearly 100 multivitamin starter kits and related educational materials. [Submitted by SaraMarie Sargent, VitaGrant Outreach Worker]

Lee County

The "Women's Health Forum: Act Now for Good Health" was held on 5/20/06 in Ft. Myers, FL. The forum consisted of numerous free health screenings and education geared to the health concerns of local women. MOD provided multivitamins and folic acid education.

[Submitted by Tricia Christian, Director of Program Services & Communications, MOD Southwest Coast Division]

Orange County

Emmanuel Baptist Church in Orlando held a health presentation for Haitian Creole speaking women on 5/28/06. VitaGrant provided folic acid educational materials and multivitamin starter kits for participants. [Submitted by SaraMarie Sargent]

St. Lucie County

The St. Lucie County Healthy Start Coalition held a "Kids – WIC & Nutrition Event" in Ft. Pierce on 5/30 & 5/31/06. [Submitted by Alisha N. Bright]

Up to 70% of neural tube defects could be prevented if all women of childbearing age took folic acid.

Florida Folic Acid Coalition
University of Florida/IFAS
PO Box 110720
Gainesville, FL 32611-0720

Phone: 352-392-1978 Ext. 406
Fax: 352-392-1988
Email: rlutz@ufl.edu

Florida Folic Acid Coalition

Mission:

to decrease the incidence of folic acid preventable birth defects and to reduce chronic disease risk in Floridians.

Vision:

As a result of the Coalition's efforts, this simple primary prevention strategy will result in fewer pregnancies affected by folic acid preventable birth defects. More Floridians will experience the indirect health benefits of taking a daily multivitamin to enhance health throughout their lifespan.

VISIT US ON THE WEB!
WWW.FOLICACIDNOW.NET

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Editors & Reviewers

Ron Lutz, MSN, ARNP
Gail Rampersaud, MS, RD, LD/N
Lynn Bailey, PhD
Sondra Cornett, MS, RD, LD/N
Jane Correia, BS
Cristin CUOZZO, BS

Kimberlea Hauser, MBA
Gail Kauwell, PhD, RD, LD/N
Laura Levine, BSN, RN
Lori Reeves, MPH
Janet Spink

Current & Upcoming Events

September 11, 2006:
National Council on Folic Acid's Annual Meeting, Atlanta, GA. The conference will be held at the Global Communications Center at the CDC. For details visit <http://www.folicacidinfo.org/detail.php?id=207&type=news>.

September 12-14, 2006:
National Health Promotion Conference presented by CDC's Coordinating Center for Health Promotion (CoCHP), Atlanta, GA. The conference theme is, "Innovations in Health Promotion: New Avenues for Collaboration." For details visit <http://www.cdc.gov/cochp/conference/>.

October 26-28, 2006:
Florida State Association of Occupational Health Nurses, 46th Annual Florida Occupational Health Conference, Orlando, FL. The conference title is, "The Magic of Occupational Health Nursing." For details visit <http://www.fsaohn.org/conference2006.html>.

November 4-8, 2006:
American Public Health Association's 134th Annual Meeting and Exposition, Boston, MA. The conference title is, "Public Health and Human Rights." For details visit www.apha.org.

December 6-8, 2006:
CDC, Maternal and Child Health Epidemiology (MCH EPI), 12th Annual Maternal and Child Health Epidemiology Conference, Atlanta, GA. The conference title is, "Making Methods and Practice Matter for Women, Children and Families." For details visit <http://www.cdc.gov/reproductivehealth/MCHepi/2006/AboutConference.htm>.

