

The Kentucky Folic Acid Partnership Meeting

State Laboratory Building

September 25, 2003

Frankfort, Kentucky

Members unable to attend: Dr. Davis, Dr. Adamkin, Susan Borders, Fran Hawkins, Emma Walters, Jaime Rafferty, Eugenia Smither, Patti Dissell, and Humana's representative.

Members present: Susan Brown, Teresa Bunch, Annette Harston, Christi Vincent, Rhonda Arnett, Libby Hess, Roxanne True, Shellie Ryan, Shari Stewart, Emily Anderson, Dr. Kuhn, Diane Sprowl, Beverly Siegrist, Jan Hatfield, Patty Martorano for Pat Seybold, Sandra Thompson, Jahanna Lane Sandy Cleveland, Joyce Robl, Linda Lancaster, Katrina Thompson, Paula Watson, Lisa Heck, Mary Ann Penner and Jeni Appelman attending from the Buffalo Trace District to observe whether they plan to partner.

Susan Brown called the meeting to order in Dr. Davis' absence. The minutes of the last meeting—May 22, 2003 were approved as written. New members were welcomed and encouraged to listen closely to the three sub-committee reports to assist them in deciding which committee they would be interested in joining.

Committees:

Media: Shari Stewart reported that she and co-chair Lisa Heck are the only members of the Media Committee (that she is aware of), and that they are looking to recruit new members. Shari represents Central Baptist Hospital of Lexington and she states that the hospital may be willing to help with funding new projects i.e.: developing a new media kit, or leaflet that informs others about the KFAP. The idea for the media kit would be to help partners as they are called upon to be speakers by the media for folic acid. She envisions a complete "how to" kit that includes how to do a press release—to the basics of dealing with radio, print and television media. Please consider joining the media committee!

Community: Diane Sprowl reported that the Community Committee would be meeting at O'Charley's after the Partnership meeting today. Her committee consists of about 10 members and has always had an active membership. They are working on a green ribbon campaign for January and ribbons will be dispensed to the partners at today's meeting to use in that campaign. Eugenia Smither is developing a folic acid leaflet that will be distributed with the ribbons in January. She was unable to attend today's meeting, but the leaflets will be distributed prior to January. Community has been responsible in the past for developing the folic acid activity and media reporting forms (thanks to computer guru Diane Sprowl) and making sure the database is compatible with the CHS reporting system through the state. Goals for future projects include a welcome packet and a much needed website for the KFAP.

Professional: Joyce Robl reported that the Professional committee would also be meeting at O'Charley's after the Partnership meeting today. So far this year there have been four "Train the Trainer's" providing education for professional staff. There have been five professional conferences that were provided with folic acid information. One of these even included "branching out" to a different professional group: The Women Lawyer's Conference. The professional committee with the help of Dr. Davis and the President of the KPA, have partnered to reach 125 healthcare providers with brochures and letters thanking them for their help in the fight against NTDs and encouraging them to continue to remember to prescribe the enhanced dosage of folic acid to those women who have already experienced a NTD-affected pregnancy. Professional committee is searching for a prospective new member for the Kentucky Department of Education related to early childhood development as well as health and nutrition. Joyce quoted the latest numbers for 2003 Gallop Folic Acid Report and states she will send Susan a copy to distribute to the partners. * (See attached Adobe file with the minutes). Joyce also reported that

Patti Dissell with the Kentucky Spina Bifida Association was unable to attend the KFAP meeting at the last minute, and she asked Joyce to report that the SBAK (along with the March of Dimes) has designed a bereavement packet for parents affected by miscarriage, stillbirth and infant death. (I have the packet and it is excellent)! She wanted us to know that there are 200 packets available, and to contact Patti at pdissell@sbak.org if you know of a family who hasn't received one. Patti also reports that this year's KY State Fair allowed her to reach 9,940 women with literature and vitamins (the largest ever for the SBAK-way to go)! *Added news: Sadly, Denise Maples is no longer with the SBAK, after taking a job with the University of Louisville. As you consider recruiting new members, keep in mind the possibility of someone who has been affected by spina bifida—either directly, or as a parent of a child with NTDs. As an adult with spina bifida, Denise educated us all in the day-to-day struggles and triumphs of what it means to have spina bifida. We will miss her, and wish her well!

Partners share: After the committee reports, each member was asked to introduce themselves and tell a little bit about what they do, and which committee they wish to join (or already participate in). Media committee was glad to hear that Linda Lancaster, Gil Lawson, and Susan Brown are also members to that committee. Paula Watson from Clark County shared activities she has worked on and seems a good candidate for the media committee as well, although she currently serves on the community committee. (Members can participate in more than one committee if desired, and of course the entire partnership is responsible for completion of each year's goals, no matter which committee you choose). We were pleased to have Jeni Appelman from The Buffalo Trace District HD with us, as they consider becoming members of the KFAP.

ACOG Report from Sandy Cleveland: The latest issue of ACOG contains a folic acid study that was done in England in 2001. (It appeared in the Lancet 2 years ago). This study reports that 400mcg of folic acid daily decreases the risk of NTDs by 36%. This is much lower than the 50-70% decrease we, and the CDC and MODs, have been quoting for many years. The study is a Level III: limited scientific evidence based. Sandy mentioned that Dr. Davis wanted us all to be aware of this study due to the fact that ACOG is a journal many healthcare providers will be reading. Many members voiced their opinions and the group decided we should contact the CDC and MODs for their response to this study. Susan Brown will contact and report back to the group. [I contacted the CDC, and this is what Dr. Mulinare has to say \(please keep in mind he has not yet read the article.\):](#)

Depending on the type of study... is it observational, or clinical trial? We expect to see variation in the risk reduction in different localities. The risk reduction can depend on the rate of NTDs in the population, the way the study was conducted, the size of the population, etc. Our use of 50% - 70% is based upon what we have observed in 12 research and clinical studies over the last 20 years. If the risk reduction is decreasing it may be because the rates of NTDs are decreasing. We can't say much more for sure until we review the article.

[In other words, this study may have confounders that limit its generalizability. We at CDC have not changed our practice in encouraging all women capable of becoming pregnant to consume 400 micrograms of folic acid daily and believe that it has the capability of decreasing NTDs by up to 70%.](#)

[Again, we can explain this to you further after reading the study.](#)

[Thanks for your interest. I will be in touch.](#)

[Katie](#)

[Katie P. Kilker](#)
[Health Research Associate](#)

Battelle Contractor for CDC
National Center on Birth Defects
and Developmental Disabilities

Addendum: Sandy Cleveland tells us that anyone can contact the ACOG resource center at 1-800-410-ACOG to request a one time free sample of an ACOG practice bulletin. The information listed below is important to ensure you receive the correct article.

ACOG Committee on Practice Bulletins. **ACOG practice bulletin. Clinical management guidelines for obstetrician-gynecologists. Number 44, July 2003. (Replaces Committee Opinion Number 252, March 2001).** [Guideline. Journal Article. Practice Guideline] *Obstetrics & Gynecology*. 102(1):203-13, 2003 Jul.
UI: 12850637

Dr. Karla Damus is Susan's contact for the National March of Dimes. Unfortunately, she was traveling this week, and she will contact Susan on her return.

Feature Presentation: 7.5 Minute Video from the March of Dimes-Susan Brown received two copies of a folic acid video (produced in North Carolina) as a gift from the National MODs. The video was shown during the meeting and after viewing the video, comments received from the partners were quite favorable. Dr. Kuhn did note that folic acid/multivitamins should not be stored in the refrigerator (as one of the women in the tape states she does to remember to take it with her orange juice every morning). All in all the tape gives a wealth of current, accurate information covering a wide variety of women. The March of Dimes was able to print 150 videos for \$330. That does not include shipping. Prices would vary with larger quantities purchased. The members felt this would be a good investment and Joyce Robl mentioned the possibility of sending the video as part of, the annual packet the state distributes for "January is Birth Defects Prevention Month" (most likely to be distributed in late November). Katrina Thompson stated she felt the Kentucky Chapter of the March of Dimes may have funding available to purchase 150 of the tapes. It was suggested that perhaps we should order 225 of the tapes, and in fact Dr. Kuhn stated the School of Pharmacy would take ten of them and pay us \$30 for the purchase. Patricia Martorano (filling in for Pat Seybold) stated that perhaps the Kentucky Developmental and Disabilities Council could cover shipping. Joyce Robl states that there could also be funding available through the KBSR grant, if the March of Dimes is unable to fund the purchase. ****
The March of Dimes has approved purchase toward 150 of the tapes (THANKS!!!!). Katrina will check on the cost for printing a total of 225 tapes. Hopefully, we will be able to proceed with the help of the KBSR and the KDDC.

Pharmacy Activities-Dr. Kuhn: Dr. Kuhn was welcomed back after an absence due to ill health. He looks and feels great and provided us with an agenda of eight points. Many of the things he discussed are not yet confirmed and therefore are not included in these minutes. He does, however, want us to keep our local pharmacies in mind as we continue our community campaigns. Educate them about the KFAP and the interest we have as partners in their role to our communities. Dr. Kuhn shared that there will be great things coming down the road!

Update on the Florida Toolkit-Christi Vincent:

"I have reviewed the University of Florida Folic Acid Toolkit over the last few months. The toolkit has a component for educating health care professionals, as well as several different lesson plans for clientele.

The health professional component includes a primer about folic acid, directions for each lesson plan, and instructions for reaching diverse audiences, case studies, and a video.

The clientele component includes menu ideas, activities, handouts, and tools to use with educational presentations.

I think this is an excellent tool, because of the large variety of activities to choose from. It can be used with contemplators, non-contemplators, and couples that have had a previous NTD affected pregnancy.” [Christi Vincent RN](#)

The usual cost is \$84.00/kit and is available in English or Spanish. Christi is in negotiations to perhaps get a reduced rate for KFAP members.

Letters from the KPA and Recruitment: These were already reported under the Professional committee.

New Business: Green Ribbon Campaign for January-Over 3,200 green ribbons were distributed among the members present -plus100 others were mailed to Pike County HD, per their request. If more green ribbons are needed—members will need to make their own. The March of Dimes no longer carries this item, and we have shared all we had available. We encourage all partners to plan participation in this January event. There are nearly three months to prepare. Please—let’s all try to make this a great community/statewide affair!

Next Year 2004 Meeting Dates:

January 22, 2004

May 27, 2004

September 23, 2004

NEW TIME!!!!!!!!!! It was brought to our attention that Dr. Adamkin has difficulty attending the meetings due to morning rounds. We discussed the possibility of starting the meetings at 1pm—however due to the distance many partners must travel and the need for the subcommittees to also meet in the same day—a compromise was reached. The group voted and unanimously decided to change the meeting times from 10-12 to the **NEW MEETING TIME of 11:00-1pm (Eastern time).**

The meeting was adjourned at 11:50am.

Respectfully submitted 10-7-03 per Susan Brown
Kentucky’s Statewide Folic Acid Campaign Coordinator