

The Kentucky Folic Acid Partnership
Minutes
September 21, 2000
Frankfort, Kentucky

Members present: Susan Brown, Eugenia Smither, Donna Chapman, Adam Jones (for Pat Seybold), Delena Young, Kristen Royalty, Jackie Klee, Missy Schadler, Sharon Owen, Dr. Steve Davis, Gil Lawson, Katrina Adams, Linda Villwock, Emma Walters, Lynnett Fortney, Paula Watson, Renee Neace, Audra Smith, Laura Dicks, Laura Senn, Ethel Castle, Cindy Sullivan, Linda Lancaster, Cheri Johnson, Rita Hayes, Denise Maples, Jackie Baker, Jackie Simmons, Kathy Daly-Koziel, and Joyce Robl. **Unable to attend:** Dr. David Adamkin- in Baton Rouge, Louisiana, Bonita Bobo-training in Louisville, Diane Sprowl and Gracia Pruitt-training at Mammoth Cave, Susan Borders, Pat Seybold and Kris Paul other meetings.

The meeting was called to order by Chair, Dr. Steve Davis. The motion was made and seconded to approve the minutes of May 25, 2000 with a correction to page 2 changing KY Birth Surveillance Registry to read Kentucky Behavioral Risk Survey.

Welcome and Chair's Report-Dr. Davis: Dr. Davis acknowledged and welcomed all of the new members. All thirty members present identified themselves to the group. Dr. Davis referred to the 9 major initiatives of the **KIDS NOW!** Program describing it as, "hard core with very concrete deliverables." He challenged the Partnership to remember that this is not Dr. Davis', Linda Lancaster's or Susan Brown's campaign... it is the Partnership's and the state of Kentucky's campaign. He praised the unique make-up of the Partnership stating, " we have local and state health departments; nurses, physicians, health educators, dietitians, social workers ... but we also have representation from the private sector. Healthcare of the future will integrate staff and monies. Patients, their families and their communities will become one. I see the public, private, school and community working together. Technology takes out the redundancy of healthcare and enables integration for better systems of the future." **Chair's report:** Although there are nine initiatives, today we'll put the other eight aside and focus on folic acid. Presently there are 80% of our Health Departments actively participating in the folic acid initiative (providing a year's supply of folic acid tablets and counseling on folic acid and NTD'S) and 20% are not, because we've exhausted the supply of folic acid. October 1St a large shipment should arrive for the state. Linda Lancaster is heading up that program and Dr. Davis had much praise for all the hard work Linda has done. (See the attached **FOLIC ACID NOW** handout. She also recently submitted a lengthy article on folic acid for the "Kentucky Epidemiologic Notes and Reports" that is full of facts and studies about folic acid as well as info on the Partnership and the KY Birth Surveillance Registry. Terrific job, Linda!) Dr. Davis also shared that the train the trainers' workshops- five across the state in July trained 110 professionals who will now go back and train their peers: nurses, RD's, health educators etc. Training for physicians is scheduled in Lexington November 10th and 11th. It is invitation only and entitled "The Genetics' Champions." There will be national speakers from the CDC. "It is important that we now train the private sector." There have been several conferences recently where Folic Acid and the Partnership were

represented with a booth. Those were: The KY Family Physicians Association, The Infant Toddler-600 registered; MCH-900+ registered; KMA-600 registered. Dr. Davis reminded the Partnership how important reporting is. We have to have the data to back up the money being spent. As an example, Dr. Davis stated that he must give a monthly report to the Governor on the progress of the folic acid campaign. He shared how Susan was able to send him a summary of the activities that had been reported on the new activity/media reporting form. All members need to be keenly aware of the importance of reporting activities to Susan Brown. Susan tells us-"Those in the Health Department System need to continue reporting on the Community Health Services Report Form and our other Partners need to continue to use the new form. However, a little scribbled note or short email is also acceptable and extremely appreciated. There are also some HD's that still fill out the new form as well, since at this time the Community report only allows one activity code to be recorded. That means if you did immunizations but you also did folic acid teaching- your report would reflect the immunizations but would lose the folic acid teaching. We need to know **all** folic acid activities. We don't know what's been done **if you don't tell us!**" It is more efficient to report to one person- the statewide coordinator. That way Susan is aware of all activities and can easily pass that information along when needed-**great in theory** but needs "**ALL OF US**" to make it work. Dr. Davis then reminded us of our four major goals: 1. Knowledge: (awareness) general public 2. Consumption: (taking) the folic acid 3. Knowledge: among Professionals 4. A decrease in the number of neural tube defects

How will we accomplish these goals? As far as education, the March of Dimes has developed kits with the \$10,000 from the state to provide to physicians and health professionals throughout the state. Gil Lawson, also shared the agenda for Governor Patton's recent press conferences promoting the KIDS NOW Initiatives. In Crittenden County he spoke about immunizations and how KY is third in the nation. At the State Fair and in Hopkinsville he spoke about vision and hearing testing. On September 29th at 3:20PM he is scheduled to speak in Ashland at or near the FIVECO District Health Department on folic acid. The address of FIVCO District is 2924 Holt Avenue Ashland, KY (We're told it is across from the Boyd Co. Health Center). A press release will be sent that day statewide. Your local media should receive this info, so be aware of the opportunity for publicity/exposure for the Partnership and our folic acid message.

Analyzing data-plan for the future: Linda Lancaster-Linda will be utilizing the March of Dimes' Kentucky Folic Acid Council (KFAC) to assist with evaluating the data that is received from many different gathering tools like the KY Behavioral Risk Survey, the KY Birth Surveillance Registry, MOD'S MIOP Benchmark Survey, Evaluation of the Supplemental Folic Acid Program along with other local and national data that we have access to. The KFAC was formed back in December of 1998 when the whole "idea" of a folic acid campaign for the state of KY was just beginning to evolve. Now the council acts as a steering or executive council for the larger KFAP. Linda also opened up participation from any interested KFAP members to assist in this project. The goal will be to analyze the data with outcomes as the focus to plan for the future. A need is seen for developing a polished Kentucky Folic Acid Partnership Report that could be published for use by others. Probably by August of 2001, we could have a report that is publish worthy to document our Folic Acid Campaign here in Kentucky that is valuable to KY

and others. The first brainstorming session for this project will be on November 30, 2000 in Louisville at the March of Dimes Office on Sherburn Lane. If you are a Partnership member but not a Council member and you are interested in this type of work, please contact Linda Lancaster or Katrina Adams to offer your services and to receive more information.

Committee Reports: Community-Susan Brown for Diane Sprowl. Susie Burckhart has resigned from the March of Dimes so Katrina Adams will fill in for Susie until Susie's replacement is hired. Diane reviewed the committee's 2000 plan and noted that some of the activities have already been completed or have at least had some progress. The database and media and community forms were discussed as have been mentioned already in this meeting. Promotional items, several options and target audiences were discussed and a KFAP bookmark will be designed by Diane and Susan to submit back to the committee for final approval. Donna Chapman and Toni Turpin from Bluegrass Family Health agreed to ask one of their pharmaceutical reps about sponsoring the printing. Good job! The next meeting for community will be Thursday, November 30 in Louisville at 1:00 PM EST at Ruby Tuesday Restaurant 5001 Shelbyville Rd. Media: Linda Villwock- An honorable mention award was received on the press release kit used at the kick-off campaign September 7, 1999. Congratulations! Linda and the committee have been very busy and Linda touched on several different projects they are working on. She reminds us that as state releases come down remember to put your local "stamp" (local contacts and quotes) to them to make them more appealing and personal to your community. There are 7 Divisions for the Greater KY Chapter of the MOD's and Linda is involved in helping them with media as well. Media is working on a postcard or refrigerator magnet using Crystal Montgomery (wife of country singer-John Michael Montgomery and fellow Kentuckian and mother) to promote the folic acid message (she spoke at our kick-off campaign last Sept. 1999). Also working on the New Years Resolution idea that was suggested last year but too late to act on at that time, using Crystal promoting the resolution to take folic acid every day for the baby you may have someday. She shared the "window of opportunity" time when working with the media that happens right after Christmas and just before New Years when it is a little bit easier time to advertise after the Christmas rush. Great job! I do not know when the next meeting for media is scheduled- please contact Linda Villwock if interested in participating on the media committee. **Professional:** Joyce Robl- The next meeting of the Professional committee will be after this meeting at Appleby's on Hwy 127. (Typically, this group meets after the KFAP meeting every four months). Joyce announced that Audra Smith had agreed to help co-chair this committee in the future. Professional committee was involved with the five train-the-trainer sessions that occurred across KY in July. The group currently is writing articles for publication in Professional Journals to spread the folic acid message. We have an article to write for the PCC News published by University Hospital as part of the IPO project (Improved Pregnancy Outcomes) on folic acid December 1st that reaches large numbers of healthcare providers and agencies across the state. We ask all partners who have websites to give hot-links to the folic acid message. Thanks Joyce-good job!

Featured speakers: Linda Villwock-"Interview Survival Skills" (I wish everyone had been able to hear this presentation)! Key points: 1. "Babies being born healthy because of the work we do!" 2. Communicate to all (wide range of knowledge from PhD to no education) 3. Whether it's media or a physician remember that you are the expert. EX: An OB, when Linda tried to share the folic acid message with him said, "Oh, you should really talk to pediatricians about that." (Didn't understand prevention). When preparing for an interview **KEY POINTS:** 1. Preparation (The more you talk about it, the more comfortable you will be with the information). 2. Background (Have all the information. Contact Joyce Robl, Dr. Davis, Linda Lancaster, Linda Villwock, Katrina Adams at the March of Dimes, or Susan Brown if you feel you need some resources to draw from).

When dealing with the media you need to understand their job and the deadlines of the specific media you are dealing with. **Key questions:** 1. What do they need? 2. What's the deadline? 3. OK to say you'll get back with them. **Useful Tips:** For a newspaper story call at least one week ahead. TV and Radio interviews think in "sound bites." A 30-minute interview will be edited down to about 8 seconds on TV ... stay on message! Have one or two quotes ready. **INTERVIEW TIPS:** 1. Don't assume the reporter knows anything about your subject. Manage the opportunity and deliver in a logical sequence. 2.

Remember- you're the expert! 3. When asked a question that seems off the subject **you are allowed to bring it back to your point.** (Transitional questions... "While I could talk about that- today I'm here to talk to you about folic acid..."). 4. Correct false information. Ex: If a survey is mentioned that you haven't seen you can say-"I haven't seen that information but I will look it up and get back with you, however what I can say is that ... "folic acid decreases neural tube defects by 70%." (Whatever your main point for doing the interview is). 5. Make reference to large groups (KFAP)-large groups have more credibility. Easier to get PSA's run when the group supporting it has 38 partners. **The nuts and bolts of folic acid: WHAT?** (Call to action). We encourage all KY women of childbearing age to take folic acid **every day** to prevent birth defects of the brain and the spine. (Or, some of the most serious birth defects). **WHY?** Research shows that folic acid can reduce the incidence of neural tube defects by up to 70%. KY **estimates** that it has twice the national average- 1 in 500 births. **What is folic acid?** A "B" vitamin found in most multivitamins (Need 400 mcg or .4 mg-use one or the other very confusing when you mention both). **What are NTD's?** Most common is spina bifida and can be from mild to severe and anencephaly, which is fatal. **When to take it?** All women of childbearing age need to take it every day since half of all pregnancies are unplanned. It is readily available and inexpensive. (Tout its other benefits as well: helps to lower the risks of heart disease, colon and cervical cancers, stroke and Alzheimer's disease). **What is the KFAP?** The Kentucky Folic Acid Partnership consists of over 38 agencies like health departments, hospitals and non-profit organizations who are dedicated to increasing the number of women taking folic acid every day to ultimately decrease the number of babies born with serious birth defects of the brain and the spine by 50% over the next ten years. **What is the KY Birth Surveillance Registry?** The KBSR was started in 1996. A new section was formed about two months ago (July 2000) that focuses specifically on NTD's. There have been 275 records generated thus far. The purpose is to gather and to monitor numbers of children born with NTD's.

Linda's presentation was only about 30 minutes, however, it was packed with concise, concrete and extremely useful information in dealing with the media. I hope the information makes sense to those of you who weren't present. If not, **please** contact Linda Villwock- you owe it to yourself. She did an outstanding job! Thank you, Linda, so very much!

Second Featured Speaker: Denise Maples-Denise is a Social Worker with 7 Counties of Louisville. She is a member of the KFAC and the KFAP, and is an adult with Spina Bifida. Denise was born in 1971 and her parents were told "that they could either leave the baby there to die or take the baby home to die." For that reason, Denise's first baby picture wasn't until the age of three months. In 1977, she was the poster child for the March of Dimes in Washington State. She shared an album of pictures of her growing up years with the group. Her first surgery, as with all babies with spina bifida, was performed in the first 24 hours of life to close the spine. She had shunts replaced at age 2 and age 5. Her favorite toy was an orange "whiz wheel" with black handles that she could spin around in. She recalled a time at about age 10 when she was having trouble with her feet turning in. A doctor spoke about "needing to break it and then cast it to resolve the problem." This was said in front of Denise and it horrified her to think or imagine the doctor just reaching over and snapping her foot in two! We need to be aware of how we as healthcare providers sometimes only see the illness or disease and forget to see the person. Denise also shared that she's not sure what to expect from the future. She'll be 30 years old next year and that's 30 years longer than the doctors expected at her birth. **WOW!** What a wonderful speaker! Thank you, Denise.

Old and New Business: We have 18 new members and seem to grow every day. Welcome and spread the word. The more members we have the easier it is to reach across the Commonwealth.

Dates for KFAP in 2001: Mark your calendars now! **January 18th, May 17th, and September 20, 2001. All meetings will be held at the State Lab Building in Frankfort, Kentucky-Eastern Time 10-12:30.**

Respectfully submitted,

Susan Brown RN ICCE IBCLC
Statewide Folic Acid Campaign Coordinator