

The Kentucky Folic Acid Partnership Meeting

Minutes

State Laboratory Building, Frankfort, Kentucky
January 22, 2004

Members unable to attend: Linda Dunsmor, Joyce Robl, Christi Vincent, Dr. Robert Kuhn, Samantha Karrick, Irene Centers, Linda Lancaster, and Lisa Heck

Members present: Dr. Steve Davis, Susan Brown, Kelly Owens, Annette Harston, Diane Sprowl, Bonita Bobo, Becky Derifield, Fran Hawkins, Donna Chapman, Shari Stewart, Emily Anderson, Rhonda Kays, Shellie Ryan, Dr. David Adamkin, Greg Kleinke, Paul Hopkins, Sandy Cleveland, Jaime Rafferty, Katrina Thompson, Sallie McClain, Paula Watson, Roxanne True

Call to Order, Welcome, and Approval of the Minutes: Chairman Dr. Steve Davis called the meeting to order, “Many of us drove across the street, but some of us drove many hours, and I certainly do appreciate it, and I want to welcome each of you here today.” The partners each shared who they were and which agency they were representing.

The minutes of the last meeting—September 25, 2004 were approved as written.

Committee Reports:

Media: Shari Stewart reported and distributed a “Please Help Us!!!” information sheet that read: We are developing a “guide” for all KFAP members to use when approaching the media for PSAs, interviews, print requests, and even whom to call for large projects (such as billboards). If you have a “trick” or a “tactic” that has worked for you, please share it! You may FAX or email it to the Media Committee. We are also planning to include addresses and phone numbers for TV and radio stations throughout the state—if you have that information for your particular area, we ask for you to also include that information. Thank you in advance for your input. Hopefully this will help us all!
PS Please include your name and KFAP affiliation.

Members of the MEDIA COMMITTEE:

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| Shari Stewart, RN Central Baptist Hospital 1760 Nicholasville Rd. Lexington, KY 40502 859-260-6357; FAX: 859-260-4153 sstewart1@bhsi.com | Lisa Heck, RN Kenton County HD 634 Scott Street Covington, KY 41011 859-363-2110 lisa.heck@ky.gov |
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Linda Lancaster: 502-564-2154 x 3766 Linda.Lancaster@ky.gov

Shari reported that the Media Committee hopes to produce a media kit as well as a pamphlet to enable the partners to more easily inform the public about KFAP events. The media committee is still seeking members and plans to meet for a short time after this meeting to discuss objectives for 2004. A conference call with interested KFAP members will be scheduled soon for further FU. Susan Brown also delivered a packet of materials from the CDC containing free materials available from the CDC with ideas to promote

folic acid campaigns through the medium of media. Susan also distributed the one-page summary report that was sent to the NCFA on January 20, 2004, as part of the symposium opportunity open to all members of the National FA Council. Three states will be chosen to speak/present their states' campaign at the National Conference in July.

Community: Diane Sprowl reported that the Community committee met September 25th after our last KFAP meeting, and they discussed the need for feedback from the KFAP on the types of materials available and/or needed by polling the partnership. There was one request for more info on the link between folic acid and cleft lip and palate, but unfortunately we couldn't really find any solid documentation to support this link at this time, from an indisputable source. Most people said their needs were being met, but at times the issue was one of not being able to order large quantities of materials at once. The Green Ribbon campaign is underway this month. Diane mentioned that the BRDHD brought 200 extra green ribbon bookmarks and green ribbons to the meeting today to share with the partners who may not have participated until now. Please take them with you and distribute them in your local communities. Diane asked for a show of hands as to how many members have been participating in the green ribbon campaign thus far and several members raised their hands. She shared some of the activities the BRDHD has done this month including the Health and Wellness Expo where thousands of green ribbons/bookmarks were distributed over the weekend. A folic acid message was placed on the sign in front of the HD that read: (Top line) "Helps prevent some birth defects by 50-70%" (Bottom line): "What is folic acid?" the BRDHD provided a threefold display board and table with freebies related to the green ribbon campaign in the lobby of the health department that has been quite popular-we've had to restock several times per week; bookmarks/green ribbons were placed in all staff employee mailboxes; a press release to all papers, radio stations and TV in the 8 county district was sent; live TV and radio interviews were given, and the press releases were also placed on our website: <http://www.barrenriverhealth.org/> Diane encouraged all the partners to be certain they take credit for their hard work and report their activities to Susan using the folic acid activity/media forms. Another topic discussed at the last community meeting was the need for "Welcome packets." She states that Susan sends out packets to new members of the KFAP welcoming them into the partnership. One group, however, that may have been overlooked is when one member leaves and another member replaces them. We brought this to Susan's attention and she will be more aware of that need in the future. It is noted, however, that some members who leave do pass down their KFAP information: i.e.: Libby Hess moved to Florida and passed her info on to new member, Kelly Owens. Community has also been interested in developing a website for the KFAP. Diane was notified this week that a grant she submitted to the March of Dimes has been approved (for the BRDHD) and it will help to provide funding for a new and much needed KFAP website. She will be learning the new soft-wear and exploring new challenges as she learns to become a web-master. She requests pictures from the partners that could be used on the website, showing various folic acid activities occurring around the state. She has a scanner available and will return your pictures after they have been scanned. **Head's up:** Expect more emails from Susan as she gathers input from everybody as to what we need to place on the website and also any ideas! Diane envisions using it as a place you can go to download reporting forms, minutes, etc. And also for folic acid information and as a way to link to other useful sites like the March of Dimes, the CDC etc. This way people

can get information about the partnership, as well as information about folic acid and birth defects. The community committee plans to work on the goals for 2004 at today's meeting.

Susan Brown heard from Sarah Chaffin this week, and she requested a pamphlet to illustrate all three types of neural tube defects. Currently, only illustrations showing spina bifida seem to be available. Diane states it is on the agenda for discussion today.

Susan also shared the planned **retirement date for KFAP member Sarah Chaffin**, from the Pike County Health Department is on August 2nd. Susan expressed her sadness at this news. Sarah has been a dedicated one-woman dynamo in her work for folic acid since the beginning (It may take three people to fill her shoes!). Susan added what a huge chunk from the partnership it will be for Sarah to leave. Sarah told Susan that she has several people in mind to take over for her, and Paul Hopkins, Director of the Pike County HD confirmed that. "Yes, Sarah is already telling me what to do... she's always told me what to do." Quickly, Dr. Davis added, "And that's why Paul is here today, right?" Laughter was shared by all, as we so often do, when we can't bear to feel our true sadness. Paul told the group that Sarah is one of those people who "live" their passion—it is who she is. She takes the folic acid message (or any of the other messages from her many programs) wherever she goes: church—vacation, it doesn't matter if she's working or on her own time, she never misses an opportunity to educate. Note to Sarah: You will be truly missed by us all! Thank you so very, very, much for all of your hard work!!!!!!!!!!

Professional: Susan Brown reported in Joyce Robl's absence since she is attending an out-of-town conference this week. Joyce, in her ever-efficient style provided a typed report for Susan to read to the KFAP. The professional committee met after the last meeting to discuss activities to meet the objectives for 2003. All objectives have been met with the exception of recruiting other professionals to participate in the partnership. All organizations represented on the KFAP should have received the packets promoting Birth Defects Prevention Month, as well as the video on folic acid the March of Dimes purchased for us that we viewed at the last KFAP meeting. If you did not receive a video, please let Susan know. There are 8 spares that she would like to use in the Welcome packets for new members. Please submit any 2003 professional (community and media are also desired) activities that have not been reported to Susan ASAP.

Chairman's Report: Dr. Davis wanted us to all to be aware that what we are doing is definitely making a difference. The rates of children who are born with a NTD is going down. (This is unpublished as yet). We're getting ready to report that in our last reporting year it looks as though we're going to have 29 children that have been born with NTDs in Kentucky. We still have to two more reports to check before we hit the streets with this figure. I'm not here to say that we can all take total credit for this, because it has to do with all of our other partnerships nationally like the March of Dimes, FDA, USDA, and the list goes on. But when we sit here and remember that we all began this as a vision—there were 66 babies being born with NTDs in Kentucky, in 1996. It dropped to 43 babies in 2000, and was down to 26 babies in 2001. Joyce Robl really keeps me grounded, because there are times when I feel like we need to run out in the street and wave a flag and tell everyone that we've just hit a major homerun, but Joyce keeps me grounded and

reminds me that next year it might be 31 instead. (And in 2002 it did go up to 29 babies compared to 26 in 2001). We are also getting ready to report the lowest infant mortality rate we have ever had in the state: 5.9. Of course, mortality rate is based on the number of babies born who make it to their first birthday. Dr. Adamkin and I (Dr. Davis) can both remember when the infant mortality rate was in the low 20's, so 5.9 becomes significant. Then we ask ourselves, what is it that affects infant mortality? Well, birth defects and preterm birth are the big causes of infant mortality. Babies need to be born healthy, wealthy and wise and the best way to ensure that is with good prenatal care. Dr. Davis praised each and every one of the members of the partnership for the wonderful job we do. He stated that what sets the Folic Acid Partnership apart from others in the KIDS Now program, is the concrete goals and objectives that we set for ourselves, and the good, hard data that we have to back up what we have accomplished. Am I nervous about the budget? Yes, but I think we're in a good position. Better than most? Yes. We're on track with our budget, it's tight and we know where we are at any given moment. We have a plan and a good design and our people are trained. We're implementing, and we're evaluating what we're doing. He explained to the partners (at length) that today's meeting was a chance to explore what lies ahead on the horizon for our future and he hopes it will stimulate discussion. He reminded us that the National March of Dimes' campaign has turned its' focus from folic acid towards preterm birth, with \$75 million dollars committed over a five year period. He quoted the March of Dimes' philosophy as "we're going to be an inch wide and a mile deep." What they mean by that is that they are going to be very focused. Just as they did with polio, surfactant, and folic acid, they are now doing with preterm birth prevention. Dr. Davis is working with the March of Dimes serving as the Chairperson for the prematurity campaign and as part of that responsibility he met with a group of specialists in Louisville a few months ago. He also participated in another discussion meeting that included Diane Sprowl, and Susan Brown via conference call along with Joyce Robl, Sandy Cleveland, Katrina Thompson, Fran Hawkins, and Linda Lancaster. (If I omitted anyone I apologize). The thought occurred to Dr. Davis that the KFAP knows how to get the job done, and prematurity is a job that needs to be done. The group of specialists is excellent as an advisory committee, but they don't have the opportunity, due to time restraints, to go out and tackle prematurity out and about in the community. I need to know if the partnership is interested in expanding, and that expansion could perhaps involve a new name. One that shows we are a committee that addresses other perinatal health issues **in addition to** folic acid

Discussion: Dr. Davis called on Dr. Adamkin and Greg Kleinke for their opinions, and also asked for any other members who had questions or concerns to please come forward. He also held up a piece of paper that he shared with the partners, on which he had written "The State Perinatal Health Committee" as a possible new name. Sandy Cleveland, Katrina Thompson, Fran Hawkins, Diane Sprowl and Susan Brown each added comments as to what they remembered being discussed at the Dec 17th conference call. It was mentioned that the name was important, because the KFAP logo is recognized in the community. A suggestion was made that perhaps a second line could be added to the present name/logo to include: "A Perinatal Health Committee." Dr. Davis drew a big X across the name he had written on the page and assured the KFAP members that he would not pursue this further without the agreement of the partnership. And, if we wanted

the name to remain the same -then so be it. There was much discussion about the infrastructure of our committees, and whether we should have a folic acid committee, and a prematurity committee etc. Comments were made that the prematurity campaign is a huge task. Fran Hawkins stated that expanding the partnership would help to bring other partners to the table that might not have come before, and thus will only make the partnership stronger. Jaime Rafferty mentioned the tobacco groups that could be brought on board with smoking being one of the most identifiable risks associated with preterm birth and low birth weight babies. Dr. Davis shared that Jaime was exactly on the mark and informed the partners that he had already asked Irene Centers (KY's Department for Public Health Tobacco Cessation and Prevention Head) to join the partnership and she has accepted. She was unable to attend today's meeting due to a prior commitment. Early prenatal care was also discussed and it came to our attention from Jaime Rafferty, that Henderson County's OB's refuse to schedule appointments for pregnant women until they are 12 weeks gestation. They are told that 1 out of 4 pregnancies will end in miscarriage during the first trimester; and the other cause seems to be no medical card until the second trimester. In spite of presumptive eligibility, those docs seem to be leery of accepting a new patient prior to receiving their medical card. Paula Watson also added that some are under the misconception that only health department patients qualify for presumptive eligibility but that's not necessarily so; Clark County's OB/GYNs are doing presumptive eligibility in their offices. Dr. Davis and Dr. Adamkin felt this was certainly a concern and assured Jaime that they felt it was something they could address, and get resolved, and were grateful to have been told of the situation. The discussion turned back to whether expanding the partnership to include prematurity was what we wanted to do. It is indeed the general consensus of the group that we are excited about the possibilities the expansion would present. Donna Chapman from Bluegrass Family Health, and Shari Stewart from Central Baptist Hospital both stated that expansion would be beneficial to their agencies' interests, as did many others who commented. Dr. Davis attempted to sum up what he had heard: "It is the general consensus that we want to maintain our current identity, such as our name; we want to maintain our focus keeping it an inch wide and a mile deep; we are willing to add other perinatal issues to our focus through our existing structure." Then he gave an example of what he thought that would involve. His example did not seem to follow the three previous points he had made. Sandy Cleveland said that the example he used did not demonstrate what she had heard. She reviewed by saying; "I heard that we can do both folic acid and prematurity by multi-tasking. That we do need a uniform message and therefore the experts need to come and offer their guidance, but that we are the workhorses that will get the job done. Other members also shared Sandy's observations and agreed that we are a committee that is used to multi-tasking our activities and therefore we feel it will be fairly easy to "plug" prematurity into our folic acid activities. It was decided that Dr. Davis would go back to the specialty committee and ask for recommendations as to what kind of activities they would want us to focus on. Dr. Davis suggested that we ask the experts to come up with the causes of prematurity (backed up in the current literature) and place next to the causes whatever we know can be done to prevent it. Then he'll take that message back to (us) an existing workgroup that's full of really "go get 'em" workhorses across the state and we'll (KFAP) decide which of those things we can incorporate into our plan that allows us to talk about both folic acid and prematurity at the same time, whether we're doing an activity for media,

community or professional education. Folks, I can tell you that the expert group is going to say, “Thank God,” because they know there are things that need to be done, but none of the experts really have the time to do it, because 90% of their time is spent in the operating room or in the office.

Conclusions: Sandy Cleveland suggested that Susan Brown should also attend the meeting as the KFAP Coordinator, so she can see how the group functions and to help Dr. Davis relay the ideas of the partnership. Katrina Thompson plans to schedule a meeting ASAP. It was also implied that the expert group would become our steering committee, (similar to the Folic Acid Council group we had as a steering committee to the KFAP in the early years). It was noted that the committee chairs had been given a date of March 1st to submit this year’s plan, however, that is no longer feasible, since we will need input from the advisory committee before planning the prematurity goals, objectives and activities to reach those goals.

The motion: The KFAP has helped to make an impact on birth defects, and as we continue that fight, we would like to see if we could also help to make a difference with preterm births. Dr. Davis asked if anyone would like to make a motion as to that effect. Diane Sprowl made the proposal and it was seconded, and all members present voted in favor. **The proposal stated:** I make a motion that the Kentucky Folic Acid Partnership take on other selected perinatal health issues under our current structure. Keeping our name and logo—but perhaps adding a phase to further describe what we do, i.e.: The Kentucky Folic Acid Partnership: A perinatal health group.

The meeting was adjourned.

Thank you all for all that you do!!!!!!!!!!

Respectfully Submitted and Distributed January 28, 2004
Per Susan Brown Kentucky’s Statewide Folic Acid Campaign Coordinator