



The Kentucky Folic Acid Partnership Meeting Minutes-**REVISED**
For: May 25, 2006, State Lab Building, Frankfort, KY

Members Present: Diane Sprowl, Linda Lancaster, Jill Ford, Laura Carroll, Susan Borders, Linda Litzinger, Betsy McDowell, Katrina Thompson, Christie Penn, Mary Sue Flora, Dr. Ruth Ann Shepherd, Carolyn Robbins, Sally Brunner, Paula Watson, Shari Stewart, Sandy Cleveland, Amy Stein and Susan Brown. **Members who contacted me that they were unable to attend:** Dr. David Adamkin, Linda Dunsmore, and Lorry Marvin.

Call to order: Susan Brown called the meeting to order and welcomed those in attendance to the meeting. Old and new members introduced themselves to the group. New member Christie Penn attended representing our newest partner: Mental Health and Mental Retardation. Other new representatives in attendance were: Carolyn Robbins, Sally Brunner, Betsy McDowell, and Linda Litzinger.

Chairman's Report: Dr. Ruth Ann Shepherd stood before the group to deliver her report beginning with a warm welcome expressing how good it is to see many new faces present at the table. "I'm relatively new to public health myself, since I've only been here eight months, but I'm not new to this group, or the people in this group. In my previous life, I was a neonatologist, practicing in eastern KY in Pikeville, for almost 17 years and before that I was in Louisville practicing for 4 or 5 years. So I've known of this group and worked with this group for many, many years, and it is one of the most dynamic groups—to be attached to state government, it really gets a lot done." Laughter from the group: I'm still on that other side just a little bit, but I'm very pleased to be here and to be a part of this group and look for great things to come from this group. And now that the group has broadened from just folic acid into more perinatal health issues, we can see how that has affected the facets of people that we now see sitting around this table.

What changes have occurred in Frankfort? The Commissioner for public health, Dr. Bill Hacker has recently been promoted to the Under Secretary for Health in the Cabinet for Health and Family Service. He is now wearing two hats, which is very common in state government. And Dr. (Steve) Davis, who was in my position before me, is Deputy Commissioner and he now basically handles everything that comes out of the Commissioner's office. Another Commissioner position that has recently changed is the Medicaid Commissioner. Shannon Turner has resigned to go to Passport in Louisville. We don't know yet, who her replacement will be.

Legislative session: Finished a few weeks ago, and it was a good session for mothers and babies:

- ATV helmet law passed
- Graduated driver's licenses
- Newborn screening tests: We went from 4 tests to 30 tests and we're about 6 months into the switch with over 100 kids having been identified with abnormal readings out of the 25,000 tests that have been done. About 30 of those kids with further testing have been identified as having either full disease, or as a carrier of the disease. KY is also doing additional testing that is not officially listed on the profile. In addition, this legislative session passed the "Evergreen Law" so that any time a new national test standard is recommended, we in KY can add it on without having to go back through the legislature to make the necessary changes.
- Bills about lead: Dr. Shepherd called on Linda Lancaster to share information on this topic and she stated that the bottom line is the fact that we will now get reports from all labs run, versus, how in the past we received only the lead readings that were above the level of 20. Lead poisoning was considered to be a level of 20 or above, but that changes on July 1, 2006 when it lowers to a level of 15. Those who work in LHD were told that the PHPR would be updated to reflect those changes at that time. Also, Dr. Shepherd shared with the group that those who work with pregnant women need to know that although the CDC's level of concern is officially 10/ug/dL, there is no normal blood lead level and there are reports of levels as low as 5-7 ug/dL that have toxic and lasting effects in young children. A 2010 goal is to eliminate lead poisoning, and it is recommended that lead levels be done on pregnant women. This statement triggered questions from the group asking about Medicaid and doctor's offices. We were informed that Medicaid requires a lead level at 1 and 2 years. Private offices??? We don't know, while it

is recommended, it can certainly affect a physician's overhead costs. Dr. Shepherd said we'd be looking at targeted areas—like certain zip codes. She added that there isn't a blanket policy, because there's no national policy, it's just a recommendation. All eligible Medicaid patients however, must be drawn since it is a *requirement* to be done at 1 and 2 years, for Medicaid policy.

- The youth development council: passed and it comes under Tom Emberton. Although this doesn't directly affect MCH, it certainly does peripherally.
- Governor's Wellness Program: funded for \$2.5 million dollars, that will first focus on getting kids more physically active and also to become more knowledgeable in nutrition, and to make better choices.
- Osteoporosis: We have funds to start a statewide osteoporosis education program. If you speak to osteoporosis treatment, then you speak about older women, but when you speak about prevention then you speak about young girls 9-13—the "tween" years. Visit the CDC website called Strong Bones to learn more—it's designed especially for young girls and is set up and ready to go, complete with materials about osteoporosis.
- Centers for Excellence in Diabetes: In TN they have targeted \$45 million dollars to kids for diabetes prevention
- KIDSNow: Previously the dollars to fund these programs generated from tobacco monies that has now been cut more than half. Sandy Cleveland shared that this means starting July 1, 2006,
 - Limit vitamins to a three-month supply (1 bottle of 100 tabs) after folic acid counseling instead of a year supply with the ability to purchase an additional three bottles of vitamins at \$1.25 per bottle to complete the full year supply.
 - Reduce payment for counseling for the benefits of folic acid from \$8.00/Pt/Yr to \$4.00
 - This service will be provided to all women of childbearing age who have not had a hysterectomy and will not be limited to a certain age group due to the fact that all women of childbearing age are entitled to this service and should be informed of NTD preventive measures and are still capable of conception

Awareness about folic acid is good, but actual consumption isn't as high.

What's new in the Division: Several focuses:

- Smoking in pregnancy: Overall smoking in KY is down, but smoking in pregnancy in KY is almost the highest in the nation (if it wasn't for West Virginia!). We're trying to re-focus and decide what interventions are needed there and what we can do to empower the local communities to address this issue.
- FIMR-Fetal Infant Mortality Review: Carolyn Robbins is working on this project that also includes childhood injuries and SIDS deaths. She'll be getting a group together from local communities to assist with this.
- Preconceptual care: Big topic all across the nation with the new CDC guidelines published two weeks ago and the PHPR (public health practice reference) has been changed ("beefed up") to reflect the new recommendations beginning July 1, 2006. Those partners in private practice can contact their local health departments to find out what the most recent standard of care is for preconception guidelines from the PHPR. Preconception seems to be a "hot topic" at most national conventions held across the country this spring.
- Title V Block Grant: We're in the process of writing our Title V block grant and we're hoping to really broaden that over the next 18-24 months to include everyone across the state. We'd like to know that everyone has an opportunity to give input and therefore, we plan to develop a survey to find out "what you think the problems in maternal child health are" and to help make people more aware of the Title V grant. You may have heard already that many federal grants are being cut, and the Title V Block Grant has been cut as well, but what you might not have heard is that it may also be eliminated. Can you imagine what states would do without Title V? How do we make people at the national level aware that this grant is important to mothers and babies and communicate the fact that we can't do without it?
- Prematurity: Dr. Shepherd said that this is one of her favorite topics and she acknowledged that the presentation she presented at the last KFAP meeting is on the website: www.kfap.org and available to download. She has taken the presentation to many groups including the last group who were obstetricians. We have actually prepared a manuscript for the KMA journal, which is the journal for the Kentucky Medical Association, and the prematurity presentation will also be given at the Kentucky Perinatal Association's conference on June 4-6, 2006. In addition, several people are looking at research to the problem of prematurity, and Lorie Chesnut (a long-time, original KFAP member) is working on looking at prematurity geographically, to see if there is any difference in urban areas as compared to semi-rural areas, and rural areas. Another person is looking at this from an economic standpoint to see if economic disparities within a community affect prematurity. Those kinds of systems' issues affecting global community population issues are more likely to affect prematurity outcomes. Another really exciting topic is the fact that the National March of Dimes' Organization is interested in KY and our prematurity rates. We are one of three states being considered for a large grant (we heard "through the grapevine" that it is down to only two states and we're still in the running). Dr. Carla Damus who serves on the National March of Dimes' Board of Directors (and those who attended the prematurity summit held in Louisville last November,

will remember her as a dynamic speaker that day) has been very supportive of the work being done in Kentucky. Our rates will be at close to 16 percent as we start the next fiscal year.

- Kentucky Perinatal Association Conference: Dr. Shepherd distributed brochures for the “Annual Meeting Summit on Prematurity June 4, 5, 6, 2006” conference at Lake Cumberland Lure Lodge Lake Resort, in Jameson, KY. On Sunday, June 4th, all attendees are invited to the KPA Reception Dinner. This two-day conference will host several excellent speakers and will feature various exhibits and activities. For only \$35.00 attendees receive free CEU’s/CME’s for each conference day, registration, and meals at the KPA Annual Meeting.
- Healthcare Professionals Education on Prematurity New Online CME/CEU Course: The KPA cordially invites you to participate in a new online CME/CEU course developed by KPA board members under the leadership of Dr. Henrietta Bada, President-Elect of the KPA and Head of Neonatology at the University of Kentucky, who lead the design and implementation of this course under a grant awarded by the Greater KY Chapter of the March of Dimes. This course is geared toward busy healthcare professionals to help bring state-specific information. If you want to participate go through the KPA website: <http://www.kentuckyperinatal.com/Education.html>
- A meeting on “Centering Pregnancy” A model for group prenatal care An instructional workshop for healthcare professionals: Will be June 16th & 17th from 8-4:30pm at the Trover Foundation Center for Women’s Health—lodging is available at the conference site, The Hilton Suites Lexington Green, or other nearby hotel facilities. Hilton Suites will provide complimentary transportation to and from Blue Grass Airport (six miles) to registered hotel guest. Complimentary on-site parking. Fees: \$325 with a special rate of \$275 for additional people attending from the same facility. Students may attend at the reduced rate of \$150. The Centering Pregnancy Handbook is available, for this workshop, at the discounted rate of \$125. It must be ordered ahead on the registration sheet.

The leaders: Sharon Schindler Rising, CNM, MSN, FACNM, the creator of Centering Pregnancy and the Executive Director of Centering Pregnancy and Parenting Association...and by Karen McGee, CNM, who has participated in Centering Pregnancy workshops throughout the country. Questions? Contact LeAnn Todd 270-836-2546 stodd@trover.org or Sharon Schindler Rising 203-271-3632 rising@centeringpregnancy.org This new model provides prenatal care for women in a group setting, incorporating the three elements of prenatal care: *assessment, education, and support* into an integrated format that takes place within the group. The program has a structured component for providing individual attention within the group setting, thus eliminating the need for traditional exam room visits. There is a systematic educational program that facilitates learning through interaction and sharing among members. A strong aspect of the model is the involvement of women in self-care activities and the availability of a variety of self-assessment tools.

- Another “hot topic” in perinatal circles is Perinatal Depression: Dr. Shepherd recently returned from a national conference in Tampa where she learned that Virginia has a web-based education program on depression: www.perinataldepression.org One can go online get free CEUs with this program. In KY, we are looking at several pilot projects for sites in Kentucky to look more deeply into this issue. Sandy Cleveland also offered information to the group about the Birthcare Network, a group of professionals out of the Louisville area (including one member from Southern Indiana), who are hoping to raise awareness about the problem of postpartum depression and the fact that there aren’t many (any?) resources available to assist women with this very real problem. The Birthcare Network is holding its’ 4th annual conference next weekend, Friday, June 2nd and Saturday, June 3rd with this year’s theme: Birth in the Bluegrass “Achieving Balance in Childbirth.” Unique to this conference will be the offering of a play at 8pm both nights: Birth, The Play—Journey through the lives of seven women & their life-changing birth stories. Visit the website at <http://www.birthcarenetwork.com/> their philosophy reads as such: By facilitating communication between interested consumers and birth professionals, we hope to encourage informed birth practices for those women and the families who desire them. We further hope to raise consciousness of the viability of these professions and the positive outcomes associated with their use. The Birthcare Network is an organization of pregnancy, childbirth and postpartum professionals who are dedicated to providing options for positive, informed childbirth in the Kentucky/Indiana area. We support and encourage the practice of doulas, midwives, childbirth educators, breastfeeding support professionals and other family support professionals. FREE REFERRAL LINE (502) 499-4418. Birthcare Network 1009 Dupont Square N Louisville, KY 40207 INFO@BIRTHCARENETWORK.COM Sandy has attended a committee meeting that is working on the problem of not having names and phone numbers to refer women to who suffer from problems with postpartum depression. Apparently the woman who has been designated as a contact for women in KY, who feel they have pp depression issues, has received multiple calls and has been very frustrated with the fact that there are no resources identified to offer help to these women. The women aren’t necessarily looking for a “pill” to solve their problems but instead seem to need reassurance that they aren’t going crazy, and have a need to talk

to someone else who can say, “You know, it happened to me as well, and now I’m okay, but this is what worked for me when I felt the way you’re feeling.” If any KFAP member is interested in joining the Birthcare Network postpartum depression committee work group, please contact Sandy Cleveland for more information, as they are a new committee just beginning to address this issue. Sandy.Cleveland@ky.gov

- Dr. Shepherd also encouraged members who are interested to plan to attend the Infant Toddler Conference in August 2006. This year’s conference will be focused largely on First Steps and Early Intervention.
- The KMA Conference is held in late September, usually around the 25th or so (in Louisville). It’s the conference you need to keep in mind if you’re trying to reach an audience of physicians. Reaching out and building bridges with the private community connecting public health to private practice is definitely the direction to go in. Booths are an easy way to get your message across.

Discussion occurred around the room related to prematurity rates and the role physicians play, as well as a comment about LEEP procedures and what indication, if any it played on prematurity rates? LEEP procedure is a treatment that is done on certain women who have had an abnormal pap smear. Electrodes are used to “burn” certain areas that are suspected to have abnormal cells, and the flesh sloughs off during the healing time, sometimes leaving the cervix significantly thinner than before. This is another area that we’re looking at to see if these procedures have had an impact on the PTB rates, or not. Dr. Shepherd told the group of her experiences in Pikeville with obstetricians who offered to stop PTL on their patients, only to be told by the patient that they didn’t want him or her to “stop the labor” because they were tired of being pregnant and wanted to go ahead and have the baby now, if the baby was going to be fine. If a woman says this to her physician and s/he stops the labor and later there is a problem with the baby, s/he is liable. The AGOG guidelines state that if a mother is at term, and she requests a C-section then it can be done, but otherwise, an elective C-section should not be scheduled before 39 weeks. But what happens if a mother requests an elective C-section at 35 weeks? The physician should say no, but the reality is that it’s very hard for practitioners to do. And that’s why the work of this group is so very important, because what we need to do is the same thing we did with folic acid, and raise awareness among mothers and grandmothers and mothers-to-be, to say that babies that are born between 34-37 weeks will survive, but that’s not the issue. They’ll survive but they have problems at a much higher rate than babies born two weeks later than that. And until the public is convinced of that we’ll continue to have a lot of problems. Eighty percent of our preterm babies are born at 34-37 weeks gestation. Eighty percent, both in KY and nationally. Someone mentioned that they were surprised that the insurance companies don’t do more to prevent this problem. Dr. Shepherd said that would be difficult due to the medical legal issues. There isn’t a need to preauthorize a C-section unless it’s a scheduled C-section. So if a mother comes in with a few contractions and she’s 36 weeks, it’s hard to make a case that she wasn’t starting labor. And of course, insurance companies do not make those sorts of medical decisions, and probably should not. Other examples were shared among members and while often there was frustration voiced that educating the public is absolutely important, it was voiced as well, that there is frustration that when the public is educated and they are empowered to speak up to the physician about this, we have seen some physicians brush the mother’s concerns aside. It was voiced that the problem is definitely two-fold. The public must be educated and believe in what they have learned, but just as necessary is the need to have the professional committees educate their peers. Dr. Shepherd’s response was this: In public health it’s about changing systems of care, it’s not about trying to influence individuals. **We may do systems training in the KFAP sometime...**I’ll put it on the agenda! Dr. Shepherd compared it to the smoking cessation problem, and the fact that no matter how hard we try to convince individuals to stop smoking, the thing that truly makes a difference is systems change. Changes like higher taxes on cigarettes, and buildings and cities that are going smoke-free, these are the types of systems changes that can make a difference in public health where smoking is concerned. Louisville and Lexington are smoke free and several other communities have gone smoke-free as well. Sandy mentioned her concern about her place of employment and the people who line up outside the building smoking on their breaks, and what kind of image that gives in front of a public health establishment. Dr. Shepherd again voiced that we cannot make these changes one individual at a time, but we need to instead focus on changing the system—not the individual. One individual saying something to a doctor or one doctor saying something to an individual isn’t going to make the changes that we need to see happen. Changes in the systems of care can. Dr. Shepherd was asked if the near term data had now been published? She replied that it has, it appears in the Journal of Perinatology and it has it’s own supplement, and the article refers to the babies as Late PT infants, instead of near-term infants. This change was made because near term implied that the babies were indeed that—nearly term and therefore not really a problem. But they’re not—they’re late preterm infants and they do have problems.

Linda Lancaster commented how much she appreciates hearing Dr. Shepherd speak using Public Health 101 terminology, being able to see public health with fresh eyes and helping to make it seem easier to understand, even to those who have been working in public health for many years.

Another member mentioned an article that appeared in last week's Courier Journal that discussed SIDS and other health disparities. A woman was interviewed who happened to be African American, and she said that no one ever mentioned the back to sleep campaign to her throughout her pregnancy, nor while a patient in the hospital. Dr. Shepherd mentioned the "Know What to Do for Life," campaign a national campaign that addresses these disparity issues. Susan shared with the group an article that appeared about a year and a half ago, also in the Courier Journal, that reported African American women had been educated to place the baby on it's back to sleep, both from their doctor and while in the hospital. The article stated that their babies began sleeping on their backs and the women reported doing so at the 2-week checkup, but by the 2-month checkup they stated they were no longer following that advice because "Grandma" had said babies sleep better on their tummies. It's a well-known fact that African American women listen to the Grandma in the family over what anyone else may tell them to do. But now this new finding is even worse, if they're reporting they were never even told to place the babies on their backs. Dr. Shepherd commented that just because they say they never "heard it" doesn't mean the hospital or doctor never said it. But again, it's not about individuals, it's about systems of care.

Open Discussion: While questions were asked as needed during Dr. Shepherd's Chairman's Report segment, at this time the floor was opened to any other questions or comments the group wished to discuss. Carolyn Robbins and Sandy Cleveland made several more comments about disparity issues including the Hispanic population. Diane Sprowl shared that when the BRDHD held focus groups with Hispanic pregnant/postpartum women and they were asked what the biggest barriers to care were to them—they mentioned the fact that they would prefer to talk with the healthcare provider in private, rather than having an interpreter with them in the room. The group agreed that they could see where this would be an issue, but saw the only resolution to that as having all physicians be bilingual, or for all patients to be fluent in English speech as well as English comprehension.

Approval of the Minutes: The minutes from the January 26, 2006 meeting were approved as written with no corrections and no additions.

Committee Reports:

1. Media Chair: Shari Stewart: Shari first encouraged new members to consider joining the media committee, and assured them that this committee is not solely responsible for all the TV, radio, print, etc. types of media from the state level for the KFAP. It is responsible for helping to develop ideas for how the KFAP can get their message across to the local media outlets as we carry the message back home to our individual communities. She explained that all the committees are intertwined and that all of us are responsible for the entire plan, but individuals may have more passion or special skills for one type of committee over another and therefore we allow members to choose which committee they wish to serve on. Shari also read one of the activities from the 2005 plan for placing billboards about folic acid in a community and she shared that Allen County had met that goal. She shared that last year the committee had felt there was a need for a media kit for the partners to utilize when targeting their local media outlets that helped communities who weren't aware of the protocols or timeframes involved in reaching out to the media for stories you hope to pitch. She explained that the kit has never been finalized but is sitting in bits and pieces and could certainly be ready to use with a little time and attention given to it. Shari also mentioned the KFAP website and that it could certainly be utilized more by the partners, being a great source for information of where to get materials to use in the campaign. Katrina Thompson also interjected that the MODs has a new prematurity "Blitz" campaign that is already packaged and ready to go that just needs to get out to the local media. These should be arriving any day in the MODs' offices and then Katrina can get them to Shari who can get them out to the members to circulate in the local communities. Linda Lancaster also interjected that the plan needs to reflect what we're aware that we'll be promoting, for example "Prematurity Day" on November 15th, 2006, and the entire month of November is focused on prematurity. Many "photo ops" are available during National/statewide/local campaigns. Usually local media want to interview local people for campaigns that affect the nation down to the local level. Paula Watson asked Katrina about press releases etc being available for these special dates, and she replied that they weren't available yet, but would be soon and are very simple to plug into with your own local information. "Healthy Self," is a section of the community newspaper in Clark County that is devoted to local news that promotes good health. There's no fee and the health department utilizes this service with several articles every month, and Paula Watson sees this as being a perfect spot for the information about

Prematurity Day and month. The key to the plan is to remember when these special dates come up each year and to plug the numbers in as expected. {January is Birth Defects Prevention and Awareness Month—an opportunity to promote folic acid as well as prematurity. February is Heart Month and Valentine’s Day—a perfect tie in for the other benefits of folic acid: lowering homocysteine levels. Valentine’s Day is all about LOVE...and we want moms to want to LOVE being pregnant for nine months! (My in-laws were married on Valentine’s Day and exactly nine months later, on November 14th my brother-in-law was born). March is nutrition month: foods for folate/folic acid, and foods for eating for two could be highlighted. April is spring break, Easter, new beginnings, Baby Galas, Baby Showers, Bridal Fairs, Spring WalkAmericas, etc. another easy way to link to babies and mothers. May is prom, graduation; Mother’s Day...June is Father’s Day, vacations, weddings, dairy month...July is the 4th of July and hot summertime events, ...August is Back to School, the Infant Toddler Conference and Breastfeeding Awareness Month, September is fall WalkAmericas, and the KMA convention, October is Halloween and harvest-time and Breast Cancer Awareness Month-folic acid can help reduce the risk of certain cancers like breast cancer, ovarian and colon; and now we’re back to November and the Prematurity Summit, Prematurity Day and Month and Thanksgiving; December is also Holiday time when alcohol is more likely to be offered at parties and get-togethers. FAS would be 100% prevented if pregnant women didn’t drink. Drinking is also associated with more women becoming pregnant while under the influence. Important to make women aware that folic acid needs to be taken daily PRIOR to becoming pregnant whether planning a pregnancy or not}. It was also mentioned that many hospitals generate a newsletter to their employees and some insurance companies (like Bluegrass Family Health) circulate a newsletter to their subscribers that contain health related articles. Maybe we could hook up with some of those...Shari mentioned that at least with Central Baptist many of those come “canned” from a larger corporation or network, but perhaps we could contact the higher up source to get our information included to an even broader range of audience. Dr. Shepherd mentioned a magazine that is published and distributed to all the hospitals across Kentucky, and she felt that if we gave them March of Dime’s information it would be accepted fairly easily, since that organization is well-known as being solidly researched based and the material comes packaged quite well in addition to not being anybody’s agenda—it’s simply solid and respected March of Dimes’ information. Dr. Shepherd asked Katrina if the March of Dimes had any FACT sheets or other information out as yet on the late preterm baby? Katrina responded that she hadn’t seen any come out as yet, but she would suspect it’s coming any day now. Dr. Shepherd said that would be something press release worthy, and she also commented that getting information to the physician’s office manager is usually a better way to reach the patients and the doctor, since the office manager is the one responsible for what information is placed in the waiting room area. New members alert: This is where the lines begin to get fuzzy as to what is media, what is community and what is professional education. It’s very true that the work of each of the three committees often do overlap with one another. This is why all KFAP members work together to ensure the KFAP plan is completed in its’ entirety. Paula Watson mentioned Homemakers and the Extension Offices as being other really good sources for getting information out to the public. “Especially when we were mentioning how influential grandmothers can be to the disparity groups of women.” Linda Lancaster asked if the Homemaker’s newsletter would be seen as community based or media based? Homemaker’s is seen as a community based activity but a newsletter would be media generated information source. The group discussion/brainstorming session was an excellent opportunity for Shari to gather ideas for the 2006 and 2007 media plan especially, since she is currently a committee of one. Shari encouraged all members interested in joining the media committee to meet at O’Charley’s after today’s KFAP meeting for a working lunch and the sign-in sheet was circulated around the room once more, in an effort to entice uncommitted members to choose a committee.

2. Community Chair: Diane Sprowl: Diane informed the group that while her committee used to be quite large it has dwindled in recent months, and that while she sympathizes with the media group, she doesn’t want to lose any of her current members over to that committee. (Laughter throughout the room). She discussed the different topics her committee has worked on over the past few months including preparing a list of materials that are available to partners free of charge. She mentioned the Pamphlet Library as a good option for ordering materials in bulk, but cautioned that occasionally only limited numbers of certain materials can be sent at a time. She suggested using the KFAP website www.kfap.org to access the activity report forms and report the activities you do to Susan so she can key them into the database and generate the monthly reports and bullets. Another goal of the community group was to enlist the help of pharmacists to spread the folic acid message through prescription medications with the printout a patient receives with their RX to also give information about folic acid. Dr. Robert Kuhn has been a member of the KFAP in the past and due to health problems has been unable to complete this activity to the level the committee was hoping for (all across the state). Diane asked if anyone had heard from him recently and Susan

said that she had contacted him after the last committee meeting and he apologized for his absence and stated that he had some issues that he wasn't at liberty to discuss, but that very soon he would either be leaving his job, or would once again be able to join our group in a more active role. Since she hasn't heard anything since, she believes he must have moved on and that we should find another contact. Diane asked the members to think of someone we could recruit to the membership who is a pharmacist. Paula Watson stated that she has a friend who is a female pharmacist and who is also a mother. She'll check and get back with us as to her friend's interest. Sandy Cleveland also mentioned David Salings and thought that perhaps if he cannot join himself, he might identify someone who could. Dr. Robert Kuhn had many contacts in the private sector although he worked through the UK school of pharmacy. Shari Stewart said she would also check with Central Baptist. She questioned what kind of a commitment would be necessary? Susan suggested attending the meetings three times a year, or at least an agreement to be available within email reach for sharing of ideas etc. Diane mentioned that it might also be open to the pharmacist's interpretation of how to assist us with ideas. Sandy Cleveland asked if we were talking about consult services? Susan replied that Dr. Kuhn wasn't paid any consultation fees, he became a member and became very involved and simply wanted to help. Diane resumed her committee report and mentioned several activities her committee has worked on including the prematurity toolkit that is currently being developed by a committee of six (Diane Sprowl, Linda Lancaster, Sandy Cleveland, Shari Stewart, Katrina Thompson and Susan Brown, with input and guidance from Dr. Shepherd). The toolkit will probably be geared for community use, a tool for those to use who would be going out into the community to talk to lay people about prematurity. Diane shared that one of our components is trying to convince pregnant women that they really don't need to deliver early. "I'm becoming more and more convinced that this is what needs to be the focus for this group (the KFAP) it's something that we can do to make a difference." Dr. Shepherd expanded on that idea and mentioned the March of Dime's folic acid kits as being the role model for the development of our prematurity toolkit. She explained how the FA kits consisted of a box filled with ideas of how you would address a FA campaign in your community. It was equipped to provide a person with talking points for FA whether you were going out to do a health fair or speak to the noon rotary club. Everything was at your fingertips. One of the things we did with the FA campaign was to go around to all the doctor's offices and educate their staff about folic acid, so that they too, could begin to educate their patients about the importance of taking folic acid daily. The point being that the talking points utilized when educating doctors' offices were different than when you wanted to educate the women's group, or the junior league, or a prenatal class, later in the day. Linda Lancaster (Prematurity update): also expanded on those thoughts reminding the group that prematurity is very different than folic acid. The folic acid message was clear-cut and straightforward with one solid message coming through loud and clear no matter whom your audience might have been. Prematurity is much more political, and we on the committee have discovered how difficult it is to word the message. In fact, as Diane was just commenting about "convincing women not to have babies early," I found myself, sort of reacting to that, because sometimes babies really do need to come early. When we really get into it and we're trying to decide exactly how to word things, it becomes very tricky and we're very aware of the politics that Dr. Shepherd was just talking about (referring to physicians and the standards of care, and how insurance companies need not get in the middle of all of that, etc.). I think we're getting there (the prematurity toolkit committee) because we've narrowed down our focus to be providing a community toolkit since Dr. Shepherd has been focused on providing her prematurity presentations to the physician audience, we're focused on (and this could change) these three main target audiences: 1. Pregnant women, 2. Women of childbearing age, and, 3. The community in general. The prematurity kit will be patterned directly from the B Attitude kit, as we are using their format as our guide. We would like to have something ready to pilot in August with three areas (Central Baptist Hospital, Louisville Metro Health Department, and the Barren River District Health Department) to be certain we have all the kinks worked out before offering it statewide. Dr. Shepherd mentioned that Dr. Lockwood will be coming in to speak at the next March of Dimes' Prematurity Summit toward the end of November and it was suggested that perhaps this date, or November 15th (Prematurity Day) would make a great kick-off date for the prematurity toolkits. Dr. Lockwood is "the main guy" in prematurity circles having had his writing published in the New England Journal of Medicine on prematurity. This would be a perfect opportunity to hold a press conference/kick off. Members agreed that it would. Diane continued with her report and added that she herself is very excited about the prematurity toolkit. "As Linda said earlier, with folic acid it was: take a pill and help prevent neural tube birth defects. With prematurity, we don't even know all the causes of premature birth, so it's harder to say: here's the problem and here's the solution. And there are a lot of subtleties involved too. So I've had a hard time personally, kind of wrapping my arms around it and being able to say, okay, here's what I need to do. But I think once we have this toolkit available, it will begin to help all of us to know what we can do to help with these issues." Linda agreed with Diane and added: "The

messages are the hard part and we've really struggled with those, but it was a good struggle. And not that it's perfect by any means, but it's a good start, and we have a better understanding of what it is we're trying to accomplish through our goals and objectives." Susan agreed and added: "We're a committee of 6 and we've met three times thus far and we'll be meeting again on June 15th. We each have our assignments, so we really are plugging along." Diane concluded her community report by inviting any interested members to join them today at O'Charley's for a working lunch immediately following this meeting. "It's good to participate on a committee because you get more of an idea of what you can do to help when you return to your own community or workplace to help promote our causes."

- 3. Professional Chair: Katrina Thompson:** The professional committee targets healthcare providers and train the trainers, and we work on articles and newsletters geared to the professional journals like the PCC. Recently, Dr. John O'Brien did a piece that appeared in the PCC about targeting the 20 week OB visit that encouraged healthcare providers to use it to evaluate and talk specifically about prematurity to the pregnant woman during that time, while emphasizing the risks and what the signs and symptoms of PTL are. The professional committee also promotes the KFAP website and ensures that we link to other professional organization's websites that have common missions to ours to ensure a solid educational base. The professional committee is also interested in and supportive of the prematurity summit that we have each year. We're very excited about this year's summit with Dr. Lockwood coming, it will be a solid science-based summit and we hope to target the OB's for a big piece of the audience this year, along with other professionals. And the KPA as always, since we work very closely with them, will be instrumental in providing materials and helping us to support any other changes or issues that come along this year in dealing with the legislature and things of that nature as they relate to prematurity issues. Katrina also invited those members interested in joining the professional group to stay and meet for a working lunch at O'Charley's immediately following this meeting. (Great job, Katrina! We really appreciate you stepping in to take over as chair of the Professional Committee-thank you so very much)!
- 4. Linda Lancaster: Update on the prematurity toolkits:** Discussion about the toolkits occurred throughout the community report, please see above for details.

Old Business:

- 1.** Katrina Thompson has filled the professional chair.
- 2.** The 2006 and 2007 plans are due to Susan by July 1, 2006. Subcommittee members will work with the chairs during today's subcommittee meetings to draft and develop the goals, objectives and activities to accomplish the 2006 and 2007 plans.
- 3.** Recruits: We have 6 new members bringing our individual KFAP members' total to 89 and KFAP agencies/organizations total 77.
- 4. Activity forms:** It is necessary to complete an activity form when you provide an activity for folic acid, prematurity, disparity education, or any other perinatal health issue. All KFAP members need to provide this information to Susan, whether you work in public health or for the private sector. Those **members who work in LHDs** and who have already reported the activity via a CHS report form: and your activity was coded to: 1212- or 1216- would still need to send an abbreviated activity form (this is **Activity Form #2**) to Susan. Submitting the information allows Susan to key it into the database in narrative form to access it as part of the monthly bulleted report. **Members who work for other businesses or organizations will always complete activity form #1**, a more detailed, but easy to complete form. **Also, local health department members will use activity form #1 to report any activities that you have not reported via a CHS report using a 1212- or a 1216- objective program code.** Susan called on Sally Brunner from the Franklin County HD, (attending her first meeting), to ask whether she felt attending today's meeting had given her any information that may be useful to her to take back to her agency? Sally works in the HANDS program and she shared that while there is a whole curriculum they follow while working in the HANDS program, she is very interested in the ideas about depression that were mentioned earlier in the meeting, as well as the prematurity issues; and she can certainly see where they could perhaps make a few adjustments to the protocol to enhance the program with these new ideas. She did add that HANDS has excellent numbers for helping women to carry their babies to term, and that they stress wanting to stay pregnant for the whole nine months. Dr. Shepherd shared additional statistics on the HANDS program proving that this kind of information really does work and overall HANDS clients have cut their numbers of prematurity in half, and in fact, if the mom was enrolled in the HANDS program even earlier, receiving 16 visits instead of 14 visits, the numbers increase to a cut of two-thirds. Dr. Shepherd explained that these are first-time moms and mostly teen moms, who qualify for the program (Dads can be multi-dads). If the moms get into the program early and receive the support and education they needed all the way through their pregnancy, then they were only a third as likely to have a preterm infant. She added that we know these kinds of programs work, and that's... HUGE! It was

suggested that Susan send an email out to the partners encouraging them to visit the website and to encourage them to access the activity forms and minutes from the site. [We are very aware that many activities occur around the state that we aren't aware of. The activity forms help us to give you credit for the work you are already doing. The database makes the job of tracking the numbers more accurate. The KFAP is a statewide partnership that depends on all of its' members to make a difference in the fight against prematurity and the health of mothers and babies]. Diane added that she would very much like to receive pictures that show you actively doing an activity. These can be posted on the website to help make the website more "catchy." Linda commented for the benefit of our new members, that the Barren River District offered many years ago to man the official KFAP website and they have done a great job! Understand that the website is for everyone. It's not associated with any one health department or organization, it stands on its' own and belongs to the KFAP. Diane Sprowl serves as the Webmaster and lends her technical assistance to the KFAP in order to provide this service for us. (And it is through the support of the Barren River District Health Department's Director, Dennis Chaney, that she is able to do this for us). The website is simple and easy to remember: www.kfap.org

New Business:

1. There was no new business at the May meeting to discuss since we discussed the prematurity toolkit under the committee reports.
2. Ideas for new business at the next KFAP meeting in September may include Dr. Shepherd's idea to train members in "**Systems of Care.**"
3. Other new business for the September meeting will include an update on the organizational planning for the prematurity summit, toolkit kick-off and the press conference. (Members include: the KFAP media committee, along with MOD's personnel: Lorry Marvin, and her Ohio Valley Program Services' Committee and the Louisville office of the Greater KY Chapter of the March of Dimes).
4. The 2006 KFAP plan will be evaluated to see if we are on track for completing our goals, and assignments given, if needed, to reach those goals.
5. The 2007 plan will be distributed at the September 28, 2006 meeting for implementation beginning January 1, 2007. January is a very busy month with the promotion of birth defects prevention and awareness, and the national folic acid awareness campaign. These national campaigns provide huge media opportunities at the local and state levels. Many KFAP partners provide folic acid displays in the lobbies of their workplace during the entire month. In the past, TV, radio, and print media outlets have eagerly picked up the stories and have been generous to feature local contacts to provide a more grassroots take on birth defects and the folic acid campaign. By the time we meet in January (the 27th) most members' activities would have already occurred and we can take some time to share those experiences during the meeting time.
6. Amy Stein brought pamphlets and flyers to the meeting on pregnancy and epilepsy for members to take home, and also information about the pregnancy registry.

Adjournment

With no further business to discuss, the meeting was adjourned with all members being encouraged to join us for a working lunch at O'Charley's.

Addendum to the meeting: Sadly, Amy Stein with the Epilepsy Foundation of Kentuckiana, has informed me of her recent decision to leave her current position and return to law school. She plans, however, to ensure that the Epilepsy Foundation remains on as an active member of the KFAP. Although Amy was a newer member to the partnership, her presence and insightful contributions to the KFAP were felt immediately. Amy... on behalf of the KFAP, we wish you well—both in your studies, and in your future. We are very sad to see you go, and we realize that because of you, the Epilepsy Foundation of Kentuckiana will continue as a partner to the KFAP. We thank you for all that you've done!

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Per, Susan Brown, Kentucky's Folic Acid Campaign Coordinator