KFAP Minutes from January 26, 2006
State Laboratory Building Frankfort, KY 11:00-1:00PM

Members Present: Susan Brown, Diane Sprowl, Laura Carroll, Jill Ford, Stephanie Rizzo, Linda Dunsmore, Leigh Lindsey, Deanna Hanson, Susan Borders, Pat Dintaman, Dr. Ruth Ann Shepherd, Sandy Cleveland, Lorry Marvin, Mary Sue Flora, Amy Stein, Roxanne True, Kristin Augustine, Joy Hoskins, Linda Lancaster (and Linda's helper-Justin) and Dr. Steve Davis.
Members unable to attend: Shari Stewart**,** Ardith Davis, Katrina Adams-Thompson, Dr. David Adamkin, Karen Turner, Emma Walters, Fran Hawkins, Rosemary Morris, Betsy McDowell, Joyce Robl and Darlene Cain.

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. Mary Sue Flora is now attending as Joyce Robl's replacement. Laura Carroll for the Green River District HD now attending as Jaime Rafferty's replacement. New member representing the Epilepsy Foundation of Kentuckiana was Amy Stein. Leigh Lindsey and Deanna Hanson have replaced Beverly Seigrist for Western Kentucky University, and Kristen Augustine attended for Ardith Davis from St. Elizabeth Medical Center.

Approval of the Minutes: The minutes from May 26, 2005 were approved as written with the added notation from Linda Lancaster that on page 2 paragraph 2, it states she would provide members with the article clarifying the differences between "evidence based" versus "science based" practices and this was not completed. She has searched, but to date hasn't been able to find the article mentioned. So noted.

Special Presentation: On behalf of the KFAP, Susan Brown presented Dr. Steve Davis with a plaque to honor his seven years of service to the Kentucky Folic Acid Partnership. The plaque reads: "Steve Davis has chaired and nurtured the Kentucky Folic Acid Partnership for seven years. His influence has impacted the health of mothers and babies all across the Commonwealth of Kentucky. This plaque presented on the 26th day of January in the year 2006 is in appreciation for his unwavering dedication to the development and implementation of the Kentucky Folic Acid Partnership founded in December of 1998." Members received a piece of cake and a drink, compliments of Emma Walters (who baked the cake-thank you Emma), and Linda Lancaster who provided the drinks, cups, plates, and napkins for the reception. Dr. Davis was filled with emotion as he eloquently accepted the plaque, "Thank you all so, so, much. This is what

those late nights are all about. Recognition like this is not taken lightly, and it is very much appreciated, thank you all so very much."

Chairman's report:

1. Memories and Expectations for the Future:

"We've hit a lot of home runs and I'd like to think that the kids are a little better off today than maybe they were a while back, all because of the work we've all done. But the biggest message I want this group to hear today is that when I look at the words "where do we fit in the big picture" and "what are our expectations for the future?" you must know that we can never, ever, ever, stop what it is that we've been doing or else we'll lose the momentum. We need to keep that constant drive and compassion and it's not about the '06 budget, or the '07 budget, or the '08 budget, but it's really forever, and we have to keep the bar raised. If we set the bar or the expectations high, our partners will rise to the new height. I see this group as being a statewide, very organized, very dedicated and very compassionate group that is outcome driven with a focus on perinatal health issues.

2. New roles and where everyone fits in the Big Picture:

It's important that we always remember to share and pass on the foundation and traditions that are a part of our fabric and convey their importance to our new members as they come onboard. Then these new members can take pride in the history and the struggles that came before. We need them to feel that they too are a part of the blood and sweat of what we're all about, so that they will continue to carry it on when we are no longer around. For example, Dr. Shepherd and I spend a lot of time late in the evening talking about Maternal and Child Health Issues and during those talks I'm trying to pass onto her the previous 11 years of continual knowledge that I've been blessed to gain, and then transfuse it over to her. (Mentoring).

3. Introduction and Welcoming of Dr. Ruth Ann Shepherd:

I was so proud when I was able to recruit Dr. Shepherd to become my replacement. To take her skills, and her abilities, and her strong leadership and bring her into this position was wonderful to me. She and I had worked hand in glove 24/7 helping very sick babies for many years. This reminds me of a book that I would encourage all of you to read, Jim Collins' "The Good to Great" book. It focuses on the fact that good is really the worst enemy of organizations. How do you become a great organization? You strive to do great things and encourage others to do great things. This is why I spend a lot of time with Dr. Shepherd. When you are in a position or you have a project that has been successful and now suddenly you need to step away from it, you naturally want to put a person in there that has the same kind of outlook and passion that you have into that position.

4. What Dr. Davis wants for the KFAP**:**

I want to stress to you today that I want the members of the KFAP to be the voice of perinatal health in all the counties of Kentucky. This is the group I have leaned on in the past, and the group that I've asked for certain things to happen before and you've all delivered. Here we are in 2006, a very, very, strong and knowledge based perinatal group. My goal or my wish is that we will still be here and be just as strong in 2016 and in 2026, because that's the only way that we're going to make any difference in perinatal care. If we continue to do the same old, same old, we're going to get the same old, same old result. We've got to be innovative and we've got to go out on a limb and take risks. I have another meeting today at 12:00 o'clock where I'm going to be asking organizations

to take $4 million dollars out of their payment centers and put it on the table to take a risk, and I can do this because I know in my heart that the outcome (if they do this), will work. I know it will work and my role is to convince them that it will work.

5. Stepping down as chair:

In closing, I just want to say officially that I will be stepping down as the Chair and I'm going to ask that Dr. Shepherd assume that role for me as the Director of the Division of Adult and Child Health for Public Health. I know that you're going to find in Dr. Shepherd, exactly what I've found in Dr. Shepherd. I've worked with her many, many years sharing blood, sweat, and tears over some very, very sick babies. Dr. Shepherd has come on board and hit the ground running with her vision and her passion. Her passion for perinatal health issues is second to none. I handpicked her because I wanted to leave this role knowing that the MCH program would be in the hands of a great leader and role model. But I am NOT going to be out of the picture, and I just want you all to know that, and Ruth knows this too.

6. So here's my challenge to you today:

As you know, in the past our monies have been closely tied to the tobacco monies and those dollars have been tied to the national formula. And the national formula simply says: As tobacco sales go up, more money is made available to the states. The more tobacco sales go down then less money is made available to the states. There may be $2.5 million dollars less money made available to the states this year meaning less money for those perinatal programs that fall under the KIDSNow program. For those of you who are in the local health departments you are aware that we provide other pots of flexible dollars to the local health departments-a significant amount of money. So what I'd like you to do is to go back and talk to your LHD Directors about the need for these early interventions. If you don't pay attention to your maternal/child health needs then you're trying to play the game with two strikes against you. You've got to care about getting newborns here safely and then once they're here you want them to be healthy, you want them to be wanted and loved, and accepted and nurtured. That's what starts the strong family structure.

7. There's work to do locally:

Talk to your local elected officials and let them know your passion for perinatal health issues and convince them that the need is there. Keep perinatal health issues on the forefront. About $63 million dollars in funding has been requested—most all for very solid programs and very good ideas. Some stand out because they are concise and explain exactly what it is they are going to do. For example: Here's how we see the problem, this is our data and this is how we're going to fix it, and in this amount of time. Simple and outcome based: for this, we'll do this, for this we'll do this, and we'll do it in this timeframe. And here's how we're going to measure it, and this is how we're going to report it to you; very clean and very crisp. That's why we've been so successful in everything we've taken on. So I leave by reminding you to wear your hat as a Kentucky citizen and to use your abilities to talk to whomever and also wear your hat as a professional worker in your local communities using that influence to keep perinatal health issues in the forefront. And with that said, I just want to thank you again for coming onboard and taking on this huge challenge.

8. Dr. Davis' Summary of Dr. Shepherd's many responsibilities and budget:

Some of you may not know this, but in the Department for Public Health we have a budget of "a little over" $300 million dollars and a total of about 90 health programs being served with that amount of the budget. Of those 90 health programs Dr. Shepherd has about 60 of them on her plate, and about $220 million of the "a little over" $300 million is the amount that she is responsible for budgeting and managing. It is humanly impossible for her to do it all on her own in 24 hours a day and she'll need your leadership, and she'll need your strength, she'll need to be able to call on you and say "Hey, I need three or four of you to come and help with this," or maybe, "We've got a grant we're going to write, so let's do a slam dunk here and get three of you to come up and sit around the table and help." You know… that's the kind of message I want to send. Let's use folks like this, the Folic Acid Partnership, as an extension. An extension to let her (Dr. Shepherd) know that her limitations are only limited by how well she can put it all together and think about how she can use her many talents. And I think she will find that you all (KFAP) are some of the strongest and most talented people that she has. You people (KFAP) will do anything—so just ask them (to Dr. Shepherd)! Laughter. You know, I really hope we find that extra $2.5 million dollars… I'm on a real crusade!

9. **Dr. Davis-Q & A:**

Susan Brown asked if Dr. Davis wanted to remain on the email list and continue receiving KFAP notices and updates and he responded, Oh my, YES! Even though I'm stepping down as chair, I'm still living it every day in my work. I just think it's appropriate and because of my respect for Dr. Shepherd that she be given the opportunity to take over as the chair of the partnership, as head of the Division of Adult and Child Health. Dr. Davis was also asked to share his comments about the expanded metabolic screening program and we were told that already 5 children have been found that would not have been found without the added screening protocol. These are illnesses that the child would have died from or would have been severely, severely, impaired if not detected. The state lab (this building) does the testing—the hospitals collect the blood, the lab runs it, and then reports the results to Dr. Shepherd and Linda and everybody that's involved, it's a real team approach to get the job done. We then track down the families and make sure they get hooked up with medical centers that have a specialist to treat these children. There's a whole network that we have in place. Kentucky is now—according to the Mayo Clinic—one of the best metabolic screening programs in the nation. So…some really good things have been happening in Kentucky. With no additional questions we proceeded to Dr. Shepherd's presentation.

Presentation: Dr. Ruth Ann Shepherd—The Premature Infant Challenge

(Dr. Shepherd's proposed twenty-minute presentation ran twice that long through no fault of hers. The KFAP members in attendance were spellbound by the data that was shown. In my opinion, we could have spent the entire two hours of the meeting entirely on this presentation, and would have still wanted to hear more. I have asked Dr. Shepherd for a copy of her PowerPoint presentation so that those of you who missed it will have access, and also because I know those who attended would want it as well. I will try to convey the highlights of the presentation as best as I can in narrative form). Dr. Shepherd began by announcing that when the March of Dimes' National Prematurity Campaign began about 2 ½ years ago, the catch slogan was "Prematurity—it's a bigger problem than you think!" Unfortunately, that didn't get anyone's attention, so they decided on a stronger

message: "Prematurity is the #1 killer of newborn infants." And that caught a lot of attention. We were told that Kentucky's prematurity rate is twice as high as the national rate for prematurity. There were slides that compared Kentucky's rates to those of our neighboring states—both to the North (Ohio, Indiana and Illinois) and to the South (Tennessee, West Virginia, and Virginia). Kentucky's rates again, were twice as high. It's not the multiples that are causing the increase in prematurity. In fact, the prematurity rate is 13.1 percent for singletons and 14.1 with the multiples included. She shared that the problem causing an increase in our prematurity rates is in fact, the 34-36 week gestation babies. Research shows us that it's not the micro preemies that are increasing the C-section rate and it's not the PIH pregnancy cases that are increasing the C-section rate. In fact, PIH is also not the cause for the increases in 34-36 week preemies. So what is? There will be a national conference next month (March 27-29, 2006) that will look at the problem of increased C-section rates done per maternal request. It is sponsored by the CDC and NIH/FAES (National Institute of Health Foundation for Advanced Education in the Sciences). Maybe we can get some answers there. What we do know is that bigger babies have problems too! When people think of preemies, they think of micro preemies as being the ones with all the problems. But the data doesn't support that thinking. The statistics we were shown compared the very low birth weight babies (less than 1500 grams or less than 3 pounds), to the low birth weight babies. While the numbers for the very low birth weight babies really hasn't changed that much over the years, the bigger babies' numbers have changed. A review of the most recent literature from the March of Dimes over the last 2-2 ½ years gives the following as major risk factors for prematurity:

- Unintended pregnancy
- Extremes in maternal age
- Percentage of live births

Dr. Shepherd stated that "unintended pregnancies" are hard to measure but it is estimated that about half of all pregnancies are unplanned in the US. "Extremes in maternal age" refers to the teenage mom and the older mom. But when we look at teenage pregnancy rates those numbers are actually dropping while the prematurity rate is going up. But that doesn't measure up. So then we looked at the older moms (over 40) and their rates of delivery are going up, as are their rates of prematurity. And this makes some people think that the issue must be infertility after all we're looking at older moms. But when they filtered out all the moms over 40 who were treated for infertility it only came to 1% of the group. In fact, overall infertility treatments for the over 40 mom was a smaller percentage than for moms younger than that. It came to only about 26 moms, which doesn't really affect the numbers that much. So the problem of prematurity to the older mom is not due to infertility treatments. When looking at maternal race and ethnicity all across the country, blacks have a much higher prematurity rate (sometimes almost doubled) just as they do for infant mortality and morbidity and any number of other factors.

There were various slides that compared prematurity with vaginal births versus C-section births and singletons versus multiples. Slides showing gestational age with the very low birth weight or very premature babies (less than 28 weeks) physically stay pretty stable whether born vaginally or by C-section. But surprisingly, it's the bigger babies that are having the problems: 34, 35, 36 weeks gestation babies are at a much higher risk of going

on a ventilator. And in fact, there is a very eloquent study coming out of Emory that is in favor of giving steroids to 35-36 weekers, which now is not being done.

"Near term babies" (or late preterm babies) those 34-36 weeks gestation are the babies who typically get into trouble because they're big enough. The HCP says, "Oh well if you deliver now the baby's big enough to do just fine." Not true, all of the baby's organ systems are immature. So these are the babies who either go home right away or may go to the NB nursery a bit and then go home only to be re-admitted with a bilirubin of 30 because they're dehydrated or simply because their bilirubin shot up and it wasn't read in time. Those re-admits are almost always 34-36 week babies. You've heard of the re-emergence of kernicterus. It happens in these premature babies. Some of the sickest babies we see in ICU's are these bigger babies, 35-36 weeks gestation who develop pulmonary hypertension because they don't transition well between oxygen and basically because they're big babies it's thought to be wet lung, but it's not wet lung and they get into really big trouble and end up getting nitrous oxide when it wasn't wet lung.

Near term babies have twice the risk of dying as full-term babies. Near term babies have twice the risk of dying from SIDS. The brain of a 35-week baby compared to the brain of a 37-week baby (just two more weeks) is 30 percent smaller. So you know that neurologically they're not ready yet either. As far as the cost of prematurity, if you look at the whole population yes, there's a huge cost associated with the micro preemies, but there's very few micro preemies. If you check the cost of hospitalizations for all these bigger babies and multiply it by the number of babies, you actually have more costs. In fact, the Kentucky data I have here states: the hospital charges for prematurity in KY were $147 million dollars for just the initial hospitalization (not counting readmits). The cost that Medicaid actually paid out for those charges in 2004 in KY was 7.5 million dollars. When we look at this according to gestational age based in 2-week increments: less than 26 weeks, 26-27 weeks, 28-29, 30-31, 32-33, 34-35, 36-37 etc. Which category do you think was higher? Medicaid paid more—paid 10 times more for the 35-36 weekers than they paid out for micro preemies. So it's a huge issue. You know we're concerned about the morbidity, and another concern is the cost, and it is really about both. And if we can improve their outcomes and have less morbidity, and also less cost – that would be the bonus. So it's huge numbers.

The other issue is that we've found out after studying all of this that being born premature also puts you at risk later in life. Prematurity is 1 ½ times more likely to develop coronary artery disease than a full-term baby is. A premature baby is 18 times more likely to develop diabetes or insulin-resistive disease than a term baby. A healthy people 2010 goal is to have a prematurity rate of 7.6% and we're twice that number. Some of our good stats were the fact that most prenatal uninsured women can get PN care in KY and that's better than the national average. And most get prenatal care early (in the first trimester) in KY, also better than the national average. Our mortality rate is better than the national average. We're doing some things very well. The statistics for folic acid for example had 39.6% of the women taking folic acid on a regular basis in 2001, and in 2004 it was 45.6% of the women taking folic acid on a regular basis according to the behavioral risk survey. The HANDS program was recently evaluated and was shown to have a positive effect on preterm birth. An example given was moms who come into the program early

and get at least 16 visits or more are half as likely to have a PTB. If they got in during the third trimester they were a third less likely to deliver preterm. So, this program has a huge impact. With low birth weight, if a mom got in during her 1st trimester there were no low birth weight babies. So there are ways we can prevent this, and HANDS is one of them.

What are our challenges? We don't have enough high level care centers to care for the micro preemies (less than 3 pounds). The goal is to have 90% availability for this type of care and right now we're only at 52%, we have a long way to go to meet that challenge. If a baby is born prematurely—it must go to a center where it can receive the high level of care it deserves. Smoking in pregnancy is another challenge—we have twice as many smokers in KY than in the rest of the country. And although our smoking rates are beginning to go down by adults and by teenagers, it is not going down among pregnant women. This puts them at risk for very low birth weight babies and 5 times the risk for having a SIDS death than for non-smokers.

Next was a slide for the KPA and their free online CEU educational trainings on prematurity that are available.

Sandy Cleveland asked Dr. Shepherd if while going around the state presenting this data, whether or not any physicians had questioned or discussed "why the physicians think these near term babies are being delivered early? Or if not, did she think it warrants a survey to ask these questions to the physicians who do deliveries? Sandy added, so then we can see where we need to intervene or see where the education needs to be focused?"

Dr. Shepherd responded: "What we're doing is, we're looking at a way to collect more data, and what we have to do is to find a way to separate out this population (34-36 weeks) and have the hospitals complete a data sheet. We don't have a datasheet as yet, and we still need to come up with one and that would really help, because although we get data from the birth certificate it really doesn't provide everything that we need, or it may not be completed with the detail that we're searching for. And it really doesn't tell us why a delivery was done. And there's really not consistency with who fills out the birth certificate; it can vary from hospital to hospital. That can be a problem because the person filling it out may not be aware that this was a macrosomia baby and that the mother had gestational diabetes, or whether this is a stillbirth or a fetal demise. We need a tool that will help us to see the "true" reason that this baby was delivered at 34-37 weeks.

Dr. Shepherd continued: One of the points that was brought out Tuesday night in Ashland was this: if you presume that we're doing all the C-sections to hurry up and pull the baby out before it dies, or so we don't have a stillborn at term, then our stillborn rate should be going down. Makes sense so we're looking at that, but we don't think that it is, but I don't have those actual numbers yet. The stillborn rate is NOT going down, so we can't presume that stillbirth is the reason for these babies. We don't really have a good handle on it, and nobody's going to admit that they're doing a C-section because it was a Friday afternoon and they were going on vacation next week. Laughter. And nobody's going to document if a mother comes in and says: I don't want my labor to be stopped I'm tired of being pregnant and I want to go ahead and have this baby. To me, that's the role of this group, because we need to get the word out to all those moms and grandmothers out there to say "just because the baby's going to live if delivered at 35 weeks does not necessarily

mean that everything's going to be okay. Near term preemies have problems too." That's what this group needs to take on as a public health awareness campaign that helps people realize that this is a mission they really need to know about and just because a baby can live at 35 weeks and maybe do okay—that's not the reason to deliver at 35 weeks. As you've heard preemies have problems, and we haven't even addressed the educational problems. Preemies can have behavioral problems and learning disabilities, readmissions, and asthma, to name only a few.

Susan Brown presented the following comment to Dr. Shepherd: "Dr. Shepherd since January of 2002, many people have come and met at this table to say that they're having difficulty with the physician feeling that the 34-36 weeker is a preemie compared to the very premature. And we've even had a situation in Allen County in 2004 where a HANDS worker was scolded by a physician for "preaching" PTL symptoms to one of their patients who actually delivered early. And you know, it's been tough and for two years we've been beating our heads against the wall. It's as if that's not really "premature" (34-37 weeks), and yet, what do they use for these dates? The dates are based on last menstrual period, which can be accurate, or may not be; and ultrasound, which also can be a week or two off (at least), so you may think that you're doing a C-section on a 35-weeker who ends up being a 33-weeker. It's so senseless."

Dr. Shepherd responded: Well, let me tell you how fast that's changing. In November, we had our March of Dimes Prematurity Summit and we had Dr. Carla Damus from the National March of Dimes there. We met afterwards with the heads of OB from UK and U of L and the head of KY ACOG along with some other folks who were invited and Dr. Damus at that meeting said, "I just can't get National March of Dimes to pay any attention to the fact that it's the bigger babies. She said everybody's focused on the micro preemies, they're focusing their research that way, and they're talking about costs that way—it's the bigger babies and I can't get National March of Dimes to focus on that. Well, in December I went to the CDC's epidemiology conference on MCH issues. We had two primary presentations from National March of Dimes, and guess what they talked about? They talked about the big preterm. It was exactly this same data, only on a national level and they are seeing exactly the same spread, exactly the same trend. National March of Dimes had a big conference this past summer in Texas, with all the researchers about the bigger preterm baby. And that's going to be published in the literature in a monogram this spring. And that's going to get everyone's attention.

What we plan to do is publish a whole series on prematurity and the morbidities of the premature baby, in the University of Louisville's PCC newsletter that all the physicians get. So, we're going to get their attention and also the head of KY ACOG and the heads of OB at both the medical schools are on board with us too. So, we will get the message out to the doctors. That's going to be the role of the professional group and we have that covered. What we need this group to do is get the message out to the public. To say, you don't want to deliver at 35 weeks. Susan commented that it's been frustrating in the past when this message has been delivered to the public and then the family goes back to their physician and it's shot down. Dr. Shepherd said the literature has not yet been published, but the difference will come when it is published. The literature will confirm that these babies are really at high risk for not only initial problems but also for long-term

problems—all through their life just for being born premature. And that will be established in the literature coming this spring. Someone commented about the medical liability issues with this new research and Dr. Shepherd agreed that she thinks the data will be convincing and she thinks once we get the risks established in the literature that physicians will be thinking more about their medical legal risks—if the bottom of the literature says that these babies are high risk for a number of morbidities then we should not be trying to deliver these babies too early.

Linda Dunsmore commented how she remembers from 30 years ago hearing young, pregnant women saying they wanted to deliver early because they wanted to have a little baby because it wouldn't hurt so much to have a little baby. Dr. Shepherd added that she has heard that many pregnant women take up smoking for the same reason. Linda continued stating that the black churches come to her mind, she sees some of those strong women leaders being educated about this and then going out and being our messengers and reaching the younger women that need to hear this message. Dr. Shepherd agreed. She said that with folic acid the public was actually educated about FA before the physicians were, and they began to educate their doctors. Someone commented that we should try to get a spot on Oprah.

Sandy Cleveland commented that she thinks Dr. Shepherd providing the presentations for the physicians is going to be the biggest boost we have because physicians listen to other physicians and having ACOG onboard is a plus. She also thinks the medical liability issue is a catch-22 for the physicians because in her experience with the physicians in labor and delivery, was that there were times they were scared and because liability has been tremendous the last ten years, they many times deliver these babies because of the fear that something is not just quite right on that fetal monitor, or with the non-stress test so they deliver the baby early because they think the baby needs to come out early. So it's kind of like, well do I go ahead and do it for this reason right now, or if I'm worried about long-term problems in the future do I wait? I think OBs probably go with what's happening right now (the immediate perceived fear). Dr. Shepherd commented that she thought they'd also be influenced by what the mother's attitude is about it all, as well as what the ACOG practice standards state: that you try to stop the labor if the outcome can be improved by it. She again stated that the studies going on at Emory about steroids being giving for elective C-sections without labor for diabetic moms at 35-36 weeks are going to help us say there may be a reason. So those kinds of things are coming down the road, and being able to offer steroids at 35 weeks are things that are going to help us. I still think that the biggest task for this group is to educate the public that prematurity is not okay, and that there are risks. Susan Brown mentioned the statistics that showed diabetes as being a much higher risk for preemies (18 times higher than for a FT). Add that to the risk of the C-section being scheduled because the mom is a diabetic or gestational diabetic mother at 35-36 weeks. Seems ironic since a diabetic mother genetically passes on a higher risk to her child for diabetes, and then we add on the double whammy of getting the baby born prematurely with its' additional risk of diabetes. Dr. Shepherd commented, "Isn't that amazing?" Susan responded. "Yes!" Linda Lancaster commented to the group that Susan works with pregnant mothers all the time and Sandy wanted Susan's opinion about whether or not she sees a pervasive attitude in the mothers that it's okay to have a smaller baby or an early baby? She replied that she

does and that she is told that their physician isn't concerned so why should she be concerned? Linda Lancaster continued that she thought the initiatives Dr. Shepherd has planned would really help with this attitude. Dr. Shepherd shared that there is more data to come and more analysis to be interpreted. She also shared with the group that the National March of Dimes is interested in doing a project here. She said to let her know if any health departments would be interested in participating.

Dr. Davis said that he was thinking back to something Sandy Cleveland had said earlier. He mentioned the excellent relationship that we now have with UK and U of L, and thought that this remarkable information should be given on OB grand rounds at both universities, so that the soon-to-be practicing OB's can benefit from this information, and perhaps even a department meeting with residents. Secondly, he mentioned the fact that every year we have an opportunity to present at the KMA's statewide OB/GYN's luncheon. He encouraged Dr. Shepherd of how important these presentations are especially to the new residents and that he would work to getting her linked up with the right people. Dr. Shepherd agreed and also informed us that she had already given several presentations and that she too had talked with the KMA. She said the presentations had been well received and that participants had all been very impressed and more than willing to help. Dr. Davis reminded us of the discussions we had back in January 2004, when we were at a crossroads for how we wanted to continue as a partnership. He shared that he knew then of the changes that were coming down the road and that he is proud that we as a group decided to put our time and attention to include other perinatal issues, in addition to folic acid. He also said he must leave to make his next meeting but before going he wanted to thank Dr. Shepherd on the good job she has done with the prematurity presentation and Susan for keeping things hopping with the partnership.

Linda Dunsmore asked Dr. Shepherd about the exceptional child's programs (for the gifted and talented) and whether it would be a good place to do a survey to gather knowledge about those mother's pregnancies, and how far along they were in their pregnancy when these gifted children were born? And to also do the same for the special needs kids? Dr. Shepherd replied that public health is working on getting electronic medical records, which we will soon be able to link, for instance with our First Steps' kids, an early intervention program with our birth certificates to collaborate that information so we can say how many of our kids needing First Steps were preemie babies and what gestational age were they? My experience has been that those records are not very accurate. But I think you're right, that information is needed and can be very useful. AWHONN (Association of Women's Health in Obstetrical and Neonatal Nursing) is a National organization that is already on top of the problems of the bigger preterm baby.

Linda Lancaster stated that we're looking at developing a toolkit and part of that whole package may be actually this presentation that a nurse could take out to a hospital and present to the nurses. After all, Dr. Shepherd is only one person. I do think I could give that presentation now. I don't think I could answer the questions as well as Dr. Shepherd has but with cues (notes added to the slides) or a list of FAQ's to go by, I think I could go out and talk to the nurses. She's talking to doctors and that's the person they want to hear, but nurses would be very open to hearing another nurse or nutritionist do this presentation. Dr. Shepherd replied that the data really speaks for itself.

Linda Dunsmore commented that if the nurses or dietitians or whomever would go out to do this presentation, they should remember to contact the medical auxiliary group for then they would actually be reaching the doctors as well. “When you train a doctor’s wife, you train the doctor.” She’ll have him there at breakfast quizzing him about his deliveries and whether or not he’s been doing births at 34-36 weeks and didn’t he know the long and short-term effects from that?

Dr. Shepherd commented that she was absolutely right. Many commented from around the room that they would be interested in having a copy of the presentation and Diane Sprowl mentioned that a copy for the folic acid website would be good. Susan thanked Dr. Shepherd for bringing the presentation today and expressed how powerful it was and how much she had learned today because of it. She replied that she appreciated the input.

Open discussion Susan acknowledged that we had open discussion during the presentation, but she wanted anyone who had been “holding back” in anticipation for this segment of the agenda to have a chance to speak. No one voiced a need, so she proceeded to asking Amy Stein from the Epilepsy Foundation of Kentuckiana to share with the group any handouts or information that she brought today. Amy shared that she didn’t bring enough for everyone but the information was passed around the room for all to view. She also shared that epileptic women are not the only ones who are taking anti-seizure medications. Some women with migraines and bi-polar disorders take them as well. Amy wanted us to know about the pregnancy registry where women register if they are in that high-risk group and taking the larger recommended dosage. Part of this is to make certain people aren’t taking medications that can more significantly increase the risk of a severe birth defect needlessly. Depakote raises the risk by 12%, and there are many newer drugs that we don’t know all the risks about as yet, but we don’t think they’re as bad. For a long time women with epilepsy were discouraged from ever trying to get pregnant, but if we can identify the medication being used and encourage the 4 grams of folic acid prior to conception as recommended, then 90% of the time, these pregnancies are healthy. The materials are available free to families in this situation. For the Epilepsy Foundation’s pregnancy registry call: 888-233-2334.

Joy Hoskins who was acknowledged by Sandy Cleveland introduced herself to the group as the supervisor/nurse administrator of the Woman’s Health section. She explained that under that umbrella there are four programs: prenatal, folic acid, family planning and the breast and cervical cancer screening program, and the abstinence program. We welcome both of these new partners!

Committee Reports:

1. **Media:** Shari Stewart was unable to be here today through no fault of her own and her report did not arrive in time for this meeting. Susan apologized for the media committee, and said that Shari will contact committee members via email to discuss a meeting date for catch up.
2. **Community:** Diane Sprowl distributed the evaluated 2005 Community Plan and also the “very rough draft” for the 2006 Community Plan. She introduced herself as the Chair of the Community Committee and encouraged any new members

who wish to join her committee to do so. She explained that while all of the committees are tied to each other and related by subject, the community committee is focused on activities that are community wide awareness activities or distribution of materials, or often times we tie together the things that media and professional do, but by putting it in a community wide campaign. At one time we were the largest committee, but recently our numbers have dwindled and we're recruiting new members and would be happy to have you join us. Our committee meets after each partnership meeting at O'Charley's Restaurant for a working lunch. Any other business is handled via email or conference call if necessary. She explained the activity forms and how members are to be active participants in the partnership, being sure to report the activities they provide. She explained how to access the forms online via our www.kfap.org website, where monthly reports and bullets are also listed. These are sent to Susan to enter into the folic acid database used to generate our monthly reports. Some history on the website was provided and members were encouraged to explore the website and utilize the information available there. Some discussion occurred about the Cabinet's home page being difficult to navigate and the fact that it may no longer be linked to the www.kfap.org website. The example was given that if you type in the Kentucky Birth Surveillance Registry you get the Cabinet's home page. This will be looked into. Diane shared that the KFAP website is linked to many very good resources, several that Joyce Robl had made available to us. Diane mentioned that she would like to link to the Epilepsy Foundation, and also offered to the other agencies a request that they include the KFAP website as a link from their home sites. The more links you have and the more hits your site is receiving means how easily your site will come up on a search. I'm always asking for pictures to place on the website, but no one ever sends me any pictures. Please remember to take pictures of your activity and send them for the website. Perhaps an exhibit or a bulletin board you've done. Diane shared that focus groups had been done to see why women don't take daily multivitamins. She reported that we do have some data, but not data for all counties, as yet. During discussion Pat Dintaman volunteered the KY Spina Bifida Association to provide a survey to women attending the KY State Fair, if that would be useful. Linda Dunsmore also suggested getting the local Kroger grocery stores involved with having a folic acid message provided in their "specials" ads run weekly. She suggested that perhaps we could have a spot once/month. Maybe… "Talk to your daughter about taking folic acid…" Sandy Cleveland added that if we're looking at something to go out in print to promote folic acid usage we might also want to include another benefit of folic acid (in addition to the birth defects prevention need) that appeals to even more people than just those concerned about birth defects. Diane mentioned the response of some during a Health Fair Expo in Bowling Green where some women would say, "Oh. keep my daughter away from that! (folic acid) and men would say, "No not me, that doesn't have anything to do with me!" and Diane would respond, "Now wait a minute, this is something that's a good health habit that benefits everyone!" Linda Lancaster mentioned that the Community Committee would be meeting after the KFAP to discuss and plan what might be needed in a prematurity toolkit, since there is currently nothing like

that available from the March of Dimes. When the FA Campaign was implemented there was a specific FA kit you could order as well as the CDC's Blue Book that helped guide communities in how to run an effective campaign. We need something similar for prematurity. Any interested members are invited to join the group at O'Charley's for a working lunch meeting.

3. **Professional Committee:** Joyce Robl was unable to attend, as was Dr. Adamkin. However, Joyce sent a detailed report with copies for members to have that included the 2005 Professional Plan Evaluation, and a bulleted report of all the activities provided by the professional committee during 2005. It showed that with Objective 2.1 the committee and the KFAP exceeded their objectives with activities 1,3, and 4; and met their objectives with activity 5. Activity 2 was the only activity not met, meeting only 4 out of 6 planned articles to health publications by 12-30-05. Activity 6, while listed as unmet was actually met with the links on the www.kfap.org website tallying a minimum of ten links to professional education. With objective 2.2 the committee and the KFAP exceeded their objectives with activities 1 and 3, and the objectives for activity 2 were met with a prematurity save the date card and a mailing that went out to all OB/GYNs on the prematurity summit conference. (**We are in need of a replacement for Joyce Robl's position as Professional Committee's Co-chair, to serve with Dr. David Adamkin. Any interested partner—please contact Susan Brown ASAP).** Sandy Cleveland also relayed information from Joyce that it's important for us to realize that in the 1999 MOD survey of HCPs (non-random sample of academic centers with OB/GYN residency programs) showed that only 28.7% always recommended folic acid to their patients. Only 26.8% reported recommending folic acid most of the time. According to the 2001 Gallup Poll, only 18% of women mention their HCP as their source of information on folic acid. **Professional Committee Goal:** All health care providers will counsel women of childbearing age to take a multivitamin with folic acid every day and will make their clients aware of the signs and symptoms of preterm labor.

Old Business:

Prematurity Summit-Lorry Marvin reported that about 100 professionals and para-professionals attended the November Prematurity Summit. She thanked the many faces present at today's meeting who also attended the summit—March of Dimes is always appreciative of any support for their missions. She also shared that the evaluations for the summit overall were good. Susan Brown asked if it was felt that combining the two groups was effective, because she noticed that people seemed to stay the entire day (para-professionals were to meet in the am and professionals in the pm). She replied that she feels that if we really want to reach just the laymen then it would be better to not have them at a professional education conference. She said she and Katrina have discussed possibly providing a brunch in a different setting, not a health fair but something more fun that people will be really interested in attending. She mentioned the Mission Groups that they already have within the MODs structure that would be perfect (where families get to know each other and share their stories and discuss). Sandy Cleveland asked if the MODS had thought at all about focusing in on any of the African American communities as a project for prematurity awareness. Lorry mentioned she and Katrina are just two people covering all programs for the entire state, in addition to their many volunteers.

But…it's very busy. She did invite the churches within the location area of where the summit was being held this past year, and those members were invited to attend. Susan reminded Lorry that she is not alone. As a partner of the KFAP we are willing and able to assist in any way that we can. Putting these types of goals into the committee plans helps us all to tackle the need and get it done—together. Linda Dunsmore mentioned statewide groups as a possibility to tap into like the Black Baptist Ministries Coalition of Churches. The State Office of Minority Development was also mentioned as a solid contact. Susan Borders of the Jefferson County Health Department mentioned that they have a program already in place that sounds like the perfect pairing for what the MODs is looking for. They will talk after the meeting. (They spoke after the meeting and Lorry was given the name of Sheila Oldham-Smith from the Office of Minority Health in Louisville who provides many health fairs throughout the year where Lorry can have an information booth, etc. This will be in combination with the Prematurity Summit put on by the March of Dimes each year).

1. **Website:** Already discussed during the committee report time

New Business

1. **Membership recruitment**-continue to expand focus to include agencies outside the public health arena, we are a partnership of both public and private sectors and it takes us all to be a strong force within the state.
2. **National Campaign to Reduce African American Infant Mortality**
   Susan Brown shared 4,153 materials with the members present to assist with this campaign. Pamphlets, door hangers, magnets and videos supporting the African American themed Back to Sleep campaign were provided. The KFAP is a supporting member of the Know What to Do For Life campaign and the National Office of Minority Health's Coalition. KFAP members who provide educational or other activities for this cause can also report on the folic acid activity form in the description portion of the form. We will add another selection box to the form probably listed as "other" that can be used for any activity that promotes perinatal health but does not fit the other three choices (folic acid alone, prematurity alone or folic acid and prematurity simultaneously). She also provided the latest CDC bookmark "B Your Best! with Folic Acid" that lists the many other benefits that folic acid provides: "Folic acid is a B vitamin that can help you "B" your best! It's used for the growth and repair of every cell in your body. You lose up to 40,000 dead skin cells every minute of the day. You shed 50-100 strands of hair each day. All day, every day, your body works hard to replace all those lost cells! Start a healthy habit. Get enough folic acid each and every day!" Susan stated that it has become her favorite handout on folic acid because it doesn't just focus on birth defects. The birth defects are very important, we all know this, but to get everybody in and get them to start early—a 5th grade level, to talk and think about a vitamin and how important that is every day. On the backside of the bookmark is the message: "B" your best for LIFE! Your body needs folic acid as you grow. When you're grown, there are other good reasons to get enough each day. Folic acid can prevent very serious birth defects in babies. So, "B" your best today and in your future! Then it has colorful oranges, peas, and strawberries with the caption: Eat plenty of fruits and veggies AND do one of the following each day: Take a vitamin that has folic acid in it every day OR Eat a breakfast cereal that has 100% of the Daily Value of folic acid every day. It illustrates a bottle of

multivitamins and a box of cereal with the Supplemental Facts and the Nutrition Facts enlarged to show 400 mcg 100%DV as the same on each. It ends with "B" your Best! Folic acid, every day! This is available free from the CDC (visit: www.cdc.gov/folicacid or call 1-800-CDC-INFO).

3. **2006 KFAP Plan** Chairs are to submit draft by 2-2-06 approved by KFAP for implementation by 2-9-06. Any project for January 2007 should be included in the 2006 plan. Due to two of our committee chairs' inability to attend today's meeting, these dates will need to be revised. Community committee is the only group able to meet this afternoon. It is encouraged that the other two committees obtain a meeting date, via conference call or whatever option suits them best to accomplish these duties ASAP. The plan influences our strategy to "get the job done," and is key to maintaining a united focus for our goals and objectives.

Susan called upon Leigh Lindsey and Deanna Hanson Western KY University nursing professors to share their thoughts about the things we discussed today and if they feel the nursing curriculum are currently addressing the concepts of folic acid, prematurity and other perinatal health issues effectively? They agreed that they are being addressed well, which was good news to hear. There was some discussion about frustration in dealing with one of the hospitals in Bowling Green that refuses to place babies on their backs, but instead uses the side lying position. Mention was also made of the mentality that all the newborn shots/procedures need to be done within the first 30 minutes of birth due to state law. Not true, but practiced this way in this particular hospital, according to Leigh. (The general policy for good practice is that "routine" eye ointment and the vitamin K shot should be administered within the first two hours of birth). We have much work to do!

The meeting dates for the rest of 2006: May 25, 2006, and September 28, 2006. All will meet at the State Laboratory Building in Frankfort from 11-1pm Eastern Time.

The meeting was adjourned

Minutes Prepared and Distributed February 14, 2006
Per Susan Brown Statewide Folic Acid Campaign Coordinator