

MOD's Folic Acid Council Meeting

Minutes from October 7,1999

Louisville, Kentucky

Members present-Diane Spowl, Rita Hayes, Linda Lancaster, Sarah Chaffin, Katrina Adams, Denise Maples, Mary Ann Hindman and Susan Brown.

Members were welcomed and thanked for the wonderful job they did, to help make the September 7,1999, Folic Acid Campaign "kick-off" a great success. Members were reminded of the importance of the council to continue to give direction to the Partnership.

Members were introduced to Susan Brown, State Folic Acid Campaign Coordinator. A part of her duties are to Chair this Council.She shared with the group her background and excitement about the position.Each member, then had the opportunity to tell about themselves and how they came to be involved with the Council . Another, new member present, was Sarah Chaffin,from Pike County,a recent MOD's MIOP grant recipient. New member, but not present, at this meeting, is Sandy Good, Director of Family Services for Kentucky Infant Development Station (KIDS), Inc., in Hazard. She will be assisting, Sarah, with the Big Sandy Area.

The meeting was called to order by Susan Brown. The minutes of the last meeting, July 21,1999,were read by Diane Spowl, and approved by the group as read. The first order of business was Old Business. The Council gave input on reaction to the Press Conference. All were in agreement that it went well and that the only negative comment we could manage was the podium being

inaccessible, to Denise. Mention was made, of the broadcaster who was insensitive (to say the least!) to Denise. Katrina Adams shared with us, a story that occurred the next day. Apparently, Crystal Montgomery had a TV interview at the before mentioned broadcaster's TV station and she made a point of letting the boss know how rude his employee had been. Way to go Crystal!

Next, under Old Business, was the work needed for the 1999 evaluation of objectives as well as the Goals of 2000. Input had already been received from the Chairs of the three sub-committees: Joyce Robl, Diane Sprowl and Linda Villwock concerning evaluation of the 1999 objectives as they pertain to their individual committees. The Council's input was needed to make any suggestions for the 2000 Plan. A change was made to the cover page, which includes the overall goal for the Plan. It originally reads: Goal: DECREASE THE PROPORTION OF BIRTHS AFFECTED BY NEURAL TUBE DEFECTS IN----- CHAPTER, FROM THE CURRENT RATE OF----- TO A RATE OF-----IN 2001. We filled in the blanks to read "Greater Kentucky" (Chapter); 1 in 500; 1 in 1000; and changed the year from 2001 to 2010. On page 1 objective 1.1(# of women reached in 1999 and to be doubled by 2000) was filled in to be 2165. Change to Objective 1.1 Activity 2:we dropped the word "Develop" to read "Council members will recruit "(also deleted "ship to include") On page 2 Objective 1.2 Activity 1:#10 changed to #12. Objective 1.3 Activity 3 "at (\$5,000) each" was deleted. On page 3, Objective 2.1 Activity 1 the #3, was changed to #10 and the #100 was changed to the #1000. A typo in Activity 3 was corrected from "another" to "and other". On page 4, Objective 2.2 Activity 3, we changed the #3 to the #10 and the #200 to the #1000. No changes were made to pages 5 and 6. This Plan was to be turned into the Regional Program Director (MOD's) by October 8,1999 for review and feedback from the RPD.

Under New Business, Mary Ann shared the news of the MIOP Grant being received for Pike County and the Barren River District. She shared with us the difficulty of performing a survey and how many different ways there are to do one. The company that has been consulted is Horizons Research International. The amount budgeted for a pre and post survey is \$12,000. However, this is the amount (approximately) needed for just the pre-survey. Therefore, Mary Ann has written the National MOD's to request that the pre-survey be done in this year's budget and the post-survey be budgeted for the following year. This would also allow the time necessary to best evaluate the targeted audience at 16-18 months.

Sarah then told of Pike County's Press Conference planned for next week, October 14, 1999. Dr. Ruth Ann Shepard will be attending and is very supportive of the Campaign. Anyone needing to contact Dr. Shepard may reach her at 606-437-3572 or FAX 606-437-0945. Roberta Newsome is her secretary. Pikeville Methodist Hospital's Physician Services Coordinator is Glenda Hughes. Linda Lancaster was interested in having her become a link to the Kentucky Birth Surveillance Registry. Linda reminded all of us about the importance of reporting from hospitals within 7 days to the NTD registry, which will be a part of the KY Birth Surveillance Registry. The goal is to have an impact on recurring pregnancies with NTD's. With the present system, it may take a year or longer before the information is received. There will be about six areas targeted and Pike County has been identified as one of those areas. Linda stated she wasn't sure if Bowling Green would be a part of that group or not. The goal is to end up with a National Data Base, that can help with genetic counseling and folic acid recommendations. This will only be accomplished, when local and state agencies pull together, to supply the needed information to a National Data Base in a timely manner.

Linda also shared that she would be meeting with the Education Department to begin to discuss plans for the Train the trainers project for Health Dept. systems that would include information on folic acid." It is still in the very early stages, but we hope to offer it as a teleconference."

Rita Hayes then mentioned that she had received a phone call from a woman from the Pike County Area, who voiced a desire to give money to help the cause in the fight against NTD's. During the conversation she mentioned that she was a Native American Indian and that she felt that there were a significant number of their ethnic group who had children with NTD's. She told Rita that they all knew who each other were and that they had their own informal group support in place. Rita asked input from Sarah if she were aware of a large number of Native American's in that area with this problem. She stated that they had not seen any through the health department system, but she would investigate since she is aware that there is a large community of American Natives, particularly, Cherokee, in the Williamson Area of Pike County.

Mary Ann attended the October 6, 1999 teleconference: "Folic Acid: Putting Science Into Action Across the Nation" presented by the Florida Department of Health. She said it was good, but long at 3hrs. Dr. Lynn Bailey started it off with the food pyramid and Dr. Donald Mattison (physician for MOD's) had 30-40 minutes of basic info on folic acid. Dr. Godfrey Oakley (retired from CDC) Dr. Joe Mulinare and Dr. Jaime Frias (Florida physicians) were also speakers. Tapes may be available to purchase. Susan Brown will check on this and report back to the committee. An idea was suggested that a possible goal for 2001 might be to develop a teleconference using our own celebrities. Mary Ann informed us that Joyce Robl has updated her slide presentation on folic acid and that it is excellent! Let's remember this when those 2001 goals are upon us. Mary Ann also presented the idea of developing a "folder" (basic manila file folder) which has already been done by

a group promoting education about asthma. She passed the folder around. It was done in a bright green color and offered information on all four sides. She suggested that perhaps a folder with folic acid info would be a good project for the Partnership. Some discussion followed with ideas about whom, the folder would best serve: Health Professionals or Legislators? The discussion picked up and took off with many questions being asked and comments made that related to advocacy issues. Linda said she would find out if a bill has been made. If no bill has been made and if the Council is interested in pursuing this, a legislator would need to be recruited to sponsor a bill. Linda made it clear that neither she nor Dr. Davis would be involved since it would be seen as a conflict of interest. Katrina will find out what other states are doing and we decided that these issues should be on the Partnership Agenda for Oct.21, 1999.

The final business for the day was to plan the Agenda for the Partnership. This accomplished the meeting was adjourned with the next MODFAC meeting being scheduled for January 13, 2000, at 10:00 Eastern Standard Time at the MOD's office in Louisville, KY. Respectfully submitted by Susan Brown, Chairperson.