

**Fetal and Infant Mortality Review (FIMR)
Conference Call Minutes
March 26, 2008**

Next FIMR Call:

June 18, 2008, 9:30 a.m. -10:30 a.m.
(Changed from June 25, due to conflict)

Toll-free Number: 1-888-808-6959

Conference Code: 0381027#

Facilitator: Louise Jones

Recorder: Chris LeClair

Attendees:

FIMR Sites and Support	Present
Northeast Florida Healthy Start Coalition, Inc.	X
Bay, Franklin, Gulf Healthy Start Coalition, Inc.	X
Broward Healthy Start Coalition, Inc.	X
Chipola Healthy Start	X
Healthy Start Coalition of Miami-Dade, Inc.	X
Escambia County Healthy Start Coalition, Inc.	X
Healthy Start Coalition of Flagler and Volusia Counties, Inc.	X
Healthy Start Coalition of Hardee/Highlands/Polk Counties, Inc.	X
Capital Area Healthy Start Coalition, Inc.	X
Healthy Start Coalition of Pinellas County, Inc.	X
Healthy Start Coalition of Sarasota County, Inc.	X
Jason Stamm, BASINET Technical Assistance	X
Dani Noell, FIMR Technical Assistance	X

Headquarter Attendees: Louise Jones, Marie Melton, Chris LeClair, Julie Beaman, Cheryl Clark, Felisha Dickey, Adam Reeves, Maureen Ahearn, Susan Potts, Cynthia Coaxum, Brandy Jones, and Dearline Thomas-Brown.

1. Status of Updated HIPAA Letter – Louise Jones

The letter is available on the DOH website. There was some concern about the signature not being vivid enough; but this has been corrected. Minutes from the quarterly technical assistance conference calls are also available on the Maternal and Child Health link under FIMR on the website.

2. Bereavement Services – Susan Potts

Ms. Potts gave a brief overview of the protocol developed in the early 1990's regarding the provision of bereavement services. At that time, the medical examiner notified the county health departments (CHDs) of all infant deaths. Also, at that time, most unexpected infant deaths were considered to be the result of Sudden Infant Death Syndrome (SIDS). A designated person contacted the family, and bereavement services, including home visits, were provided. A department form was utilized during home visits to collect information about the circumstances surrounding the infant death and the CHD received reimbursement for the home visit. Since 1995 this funding has been no longer available. Results of a recent telephone survey indicate that the CHDs are not being notified of infant deaths by medical examiners. Instead, the CHDs may learn about the death from the Office of Vital Statistics (OVS). It is a statutory requirement that the CHDs should be notified by the medical examiner. This lack of communication causes much concern because the lack of timely notification to the CHDs results in a lag in service provision to the grieving family.

There was good discussion about what the FIMR projects around the state are doing to provide these services and concerns about the timeliness and costs of services. The Sarasota Memorial Hospital and Tallahassee Memorial Hospital offer good bereavement services. Additionally, Hospice and the Florida SIDS Alliance are good resources. Several coalitions send out bereavement packets containing national and regional resources. The March of Dimes (MOD) booklet is very informative, but the MOD brochures are also expensive. One area also sends out packets to women experiencing any child loss, including a miscarriage. Several areas offer support groups and share groups. One area developed a checklist for local hospital nurses. The Miami-Dade area has developed a brochure which has been reviewed and will be distributed to local social workers. Miami-Dade also hosted a seminar on fetal/infant loss and received a very good response from the community. Manny Fermin of the Miami-Dade Coalition emphasizes that Healthy Start funding only covers about ten percent of these services. Thus, the majority of these important services are funded by other sources. Dani Noell informed the group that establishing linkages with local emergency medical services and medical examiner's officer can be an additional means to assist with distribution of brochures and other community bereavement information. EMS providers are a good resource because some of these deaths occur at home.

It is obvious that there is good coordination with FIMR within numerous communities to provide these much need services.

3. Distribution of cases prior to CRT meeting – Jennifer Highland

After attending the National Fetal Infant Mortality Review (NFIMR) conference in the summer of 2007, Ms. Highland states that she found out that many other states distribute their cases for review prior to the Case Review Team (CRT) meeting. This is intended to save time and encourage the reviewers to be prepared before the meeting and still ensure confidentiality.

Per Dani, the Pregnancy-Associated Mortality Review (PAMR) project pre-distributes deidentified cases a week prior to meetings to team reviewers using DHL delivery to give team participants time for review as many team members live in other counties than the meeting place. PAMR has developed delivery and handling procedures to maintain confidentiality. Dani noted that mailing cases are costly as well as take extra staff time. Additionally, it is her experience that not all team participants will read cases before meetings. Projects may consider having deidentified cases available for team members desiring to pick

up at the FIMR office if they wanted to review cases prior to the meetings or set aside an hour of quiet reading time before meetings for those wishing to come early. The primary concern is always maintaining confidentiality and never releasing deidentified information. Manny Fermin states that pre-distributing cases would certainly save time. He asked for a standard to be established by the DOH, and would like the department to develop a written policy. Jason Stamm indicates that BASINET does not have the capacity to pull out the confidential information from narrative text, i.e. case summaries. However, he suggests that these summaries could be saved as an Adobe file and could be emailed after ensuring that all information has been de-identified. Other states have developed innovative ways to pre-distribute their cases by splitting the case information which they release in advance.

The department will research this issue and report on the next call.

4. Presenting data to community – Leslie Pearce

The Flagler-Volusia Coalition has established a FIMR data committee for a year and a half. The committee has put their data on a spreadsheet, but is unsure how to release this information to the community.

The Northeast Florida Healthy Start Coalition shares information with its community through a report on its website which can be accessed at www.nefhealthystart.org. The Healthy Start Coalition of Pinellas County has included FIMR data in its recently developed community newsletter. These are several good suggestions on how this data can be presented to the community.

5. Conflicts with Fetal Death Certificate and Death Certificate – Tamara Taitt

There are discrepancies regarding race and ethnicity on the death certificates used to record Infant Deaths vs. the Fetal Death certificate and BASINET. Ms. Taitt is seeking guidance on how to properly record race and ethnicity in the BASINET system.

At this time, if the race is not one that is listed in BASINET, then it is recorded in the “other” category. Jason Stamm stated that changing BASINET to correct this would be a “work around” and would not be difficult to do. Someone asked if there is any plan to change the death certificate. Cheryl Clark of program office stated that there is no plan to update the death certificate at this time. The death certificate in BASINET follows a national template. Any change to the birth or death certificates is a very lengthy process requiring much collaboration. The birth certificate was changed in 2004, and the death certificate was changed in 2005. There was discussion addressing the complexity of race and ethnic distinctions; accordingly, race and ethnicity are difficult to specify, especially when category options are limited.

Mari Detres of Pinellas County inquired as the best way to designate race in BASINET when it is listed as “Hispanic” on the birth certificate. Jason Stamm advised to select Race = Other and then enter any known ethnicity; if no ethnicity is known, then select Ethnicity = Other.

6. BASINET Update/Questions – Jason Stamm

The Healthy Start Coalition of Pinellas County asked about the status of any change in the race and ethnic designation on BASINET. Jason Stamm confirmed that race has been added

as a selection criterion to BASINET's User-Defined Reports. Users now have the ability to run statistics based on individual categories of race.

7. Black Infant Health Project Initiative Update

There was not enough time for discussion on this topic during the call and therefore we are providing you with a written update on this initiative.

- The Black Infant Health Practice Initiative was created in July of last year via House Bill 1269 to study racial disparities in infant mortality rates.
- Criteria was given in the legislation for areas with the greatest disparities, and 8 counties were identified who fit the bill. They include:
 - Broward
 - Dade
 - Duval
 - Gadsden
 - Hillsborough
 - Orange
 - Palm Beach
 - Putnam
- Contracts were developed with the Healthy Start Coalitions representing each of the 8 counties selected, and were executed January 1, 2008.
- The University of South Florida and Florida A&M University have been contracted with to provide training and technical assistance throughout the initiative and to provide further data analysis and recommendations for diminishing the disparities.
- A large workshop took place in January involving all of those in the collaborative to address the issue at hand, present information, and develop the methodology for carrying out the initiative.
- Three separate workgroups were developed to narrow the focus of different aspects involved in studying the issue, with the hopes of tying all of the information together at the project's end. They are:
 - Qualitative
 - Quantitative
 - Community Engagement and Mobilization
- The workgroups meet periodically via conference call to update their progress, share information, and discuss findings and recommendations.
- Coalitions are currently involved in:
 - updating and reviewing Perinatal Periods of Risk (PPOR) data
 - conducting medical records abstractions and intensive case reviews on black fetal and infant deaths
 - conducting community and provider focus groups

- convening community action groups for increased community engagement and mobilization
- working to link PPOR and FIMR data and presenting this information to their communities to help raise awareness about the issue
- Funding is set to end on June 30th of this year, with the final report due January 1, 2010.

8. Questions, Comments, and Announcements

Ms. Jones commended the coalitions for their diligent efforts in their respective FIMR projects. They show good collaboration and maximization of community resources to meet needs and that their efforts had not gone unnoticed. She shared that Kathy Buckley of National Fetal and Infant Mortality Review (NFIMR) had described the FIMR programs in Florida as “some of the best in the country.”

Ms. Jones also announced that Angel Watson will do a presentation on Sudden Unexplained Infant Death Syndrome (SUIDS). This presentation will be on April 15, 2008 from 2:00–4:00 pm on the quarterly Healthy Start conference call. The call in number is 888-808-6959 and the conference code number is 2452962.

CL/dm