



Charlie Crist
Governor

Ana M. Viamonte Ros, M.D., M.P.H.
State Surgeon General

**Fetal and Infant Mortality Review (FIMR)
Conference Call Minutes
June 24, 2009**

Toll-free number: (888) 808-6959
Conference Code: 0281037#

Facilitator: Louise Jones
Recorder: Chris LeClair

Attendance:

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.	
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	
Dani Noell, FIMR Technical Assistance	X
Mirine Dye, Florida Keys Healthy Start Coalition	X
Cheryl Carpenter, HSC of Osceola	X

Department of Health Attendees: Mike Mason, Marie Melton via phone, Louise Jones, Maureen Ahearn, Julie Beaman, Chris LeClair, Leesa Bebley.

Welcome- Louise Jones, facilitator:

Louise Jones welcomed all to the quarterly Fetal and Infant Mortality Review (FIMR) conference call.

Topics:

1. Jane Parker, Perinatal Loss Doula, Guest Speaker

Mari Detres of the Healthy Start Coalition of Pinellas County, Inc. introduced Ms. Parker on the call. Ms. Parker, RN has been a labor and delivery nurse for 30 years. She has been a doula for 15 years. She has been with the Bay Area Perinatal Loss Consortium since its beginning in 2004. This consortium provides its doula service free; it has served 233 families since its beginning. This service is available 24 hours per day 7 days per week and holidays at three of the birthing hospitals in Pinellas County.

A doula is a non medical lay person who assists a woman during labor and delivery of the baby. A doula is often hired by the family to make the birth process “nicer,” and to make the woman feel comfortable. The doulas receive multidisciplinary training and are in a supportive role. Doulas view the birthing process as a natural life event, and seek to integrate labor and delivery. Doulas usually stay with the woman during the entire time of labor until the birth of the baby. They are involved in both medicated and non-medicated births, and their involvement is believed to help lower the rate of C-Sections. If the baby is known to have an anomaly, doulas will assist the families in beginning the bereavement process. If the baby has died spontaneously, then the doula meets the mother/family when she is admitted to the hospital for birth. They are there to listen and provide a “quiet presence” while giving the woman and family time to express emotion and process the loss of the child. During this time, the mother and family have an opportunity to make memories with their baby. The mother and family have an opportunity to hold the baby, bond with the baby, and express their love for the child. Ms. Parker states that 99% of families hold their babies. The baby is often bathed with sweet smelling fragrances. The Hospice of the Florida Suncoast volunteers make clothes tailored to fit the baby, no matter what the size of the baby. The families are given keepsake boxes with their baby’s footprints. The Chipola Healthy Start Coalition stated that there are local artisans in its area who make the memory boxes and may be able to donate some.

This is a very tender and touching time requiring much sensitivity to the scope of the loss. Families are given information about funeral arrangements, list of local funeral homes, cost, etc. Cremation services for fetuses over 20 weeks gestation are provided at no cost for eligible families by Pinellas County. The doula also provides the family with individualized packets of information intended to meet the needs of all family members. There is a book especially for siblings. A list of the contents of these packets will be sent to those who request it. Hospice social workers are trained in dealing with loss. They facilitate RTS support groups.

The yearly cost for some of these services including fabric for clothing, foot molds, boxes, etc. is about \$25,000.00. As stated above, these doulas are volunteers; however, depending on the length of the labor and delivery, they may receive a small stipend of \$100.00. The funds for this service are held by the Hospice of the Florida Suncoast. The Healthy Start Coalition of Pinellas County, Inc. has funded some of these services.

Ms. Parker stated that this has been the most fulfilling role of her career. She will be a speaker at the annual Florida Association of Healthy Start Coalitions in July. She also does perinatal loss training and speaks on this topic nationally. Her email address is JP_sail@msn.com in the subject line please type: FIMR or Prenatal Loss; she welcomes questions and comments. It is evident that she is passionate about her involvement with these families. Her presentation was moving and provided the participants with valuable information about this sensitive service.

Available books/pamphlets list:

BOOKS/PAMPHLETS FOR PARENTS/FAMILIES

CENTERING CORPORATION: P.O. Box 4600, Omaha, NE 68104; 402-533-1200;
Centeringcorporation.com

After the Loss of Your Baby (Teens)	ALBC	\$3.50
**When Hello Means Goodbye	WHMO	\$3.00
Miscarriage	MISC	\$3.00
**No New Baby (Toddlers)	NNBC	\$3.95
Remembering Our Baby (School Age)	ROBC	\$4.95

MARCH OF DIMES: 1-800-367-6630; www.marchofdimes.com/catalog

**From Hurt to Healing	009-1133-98	\$112.50/50
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BEREAVEMENT SERVICES GUNDERSON LUTHERN MEDICAL FOUNDATION:

1900 South Avenue, LaCrosse, WI 54601; 608-775-4747

www.bereavementservices.org

**A Father's Grief	RTS 4123-E	\$3.65
**Miscarriage	RTS 4113-E	1.95
**Stillbirth	RTS 4119-E	1.95
**Talking With Children About Perinatal Loss	RTS 4125-E	1.50
Loss of One or More Multiples	RTS 4126	1.95
**Grief of Grandparents	RTS 4116-E	2.50
Family and Friends	RTS 4117-E	.80
Door Cards	RTS 5101-E	.65

2. Distribution of case summaries prior to CRT meetings - Leslie Pearce

Ms. Pearce stated that the case review team (CRT) is often rushed in its review of cases. She asked for suggestions about how to save time in this process. Suggestions included making the cases available at the coalition office one hour before the team convenes to allow for reading the cases. Ms. Pearce stated that The Healthy Start Coalition of Flagler and Volusia Counties reviews quality assurance requirements before the meeting. Broward County distributes its cases one hour before the meeting, and it has organized its case summary in an easy to understand format that is aligned with the deliberation summary. Other options included mailing the cases overnight and requiring a receipt signature and advising the team via email of the mailing. Dani Noell emphasized the importance of the team to be prepared and not rushed when reviewing cases. In PAMR, the cases are mailed out a week in advance with a receipt signature required, as 15 cases are presented during the 6 hour meeting. Whatever method teams use, she reminded that maintaining confidentiality is paramount.

Mike Mason stated that the department does not recommend electronic case submission. If any case information was not de-identified and thus became available, the state would be in jeopardy of losing its funding.

Special Note:

Coalitions must assure compliance with the department's Information Security and Privacy Policy (DOHP 50-10-07) that requires all confidential information that is transmitted over any type of network connection must also utilize device and transmission encryption.

3. Maternal Interviews

The department's expectation is that the Family (Maternal) interview is done face-to-face, not by phone and not through surveys. The department understands this is very difficult however, it is considered a cornerstone of FIMR. The Guide for Communities – Fetal and Infant Mortality Review Manual (Second Edition) lists the purposes of the FIMR maternal interview as the following:

- To learn about the mother's experiences before and during pregnancy
- To learn about events during the infant's life and around the time of death
- To identify community assets and deficits that affected the mother's life during the pregnancy, birth and death of her infant
- To accurately summarize and convey the mother's story of her encounters with local service systems and her loss to the community through the FIMR case review
- To assess the family's needs and provide culturally appropriate health and human referrals as needed
- To facilitate the bereavement process and provide appropriate referrals.

There was discussion about the willingness of women to participate in these interviews. Some asked whether an incentive should be used; there are varying thoughts on this. Some areas send a letter asking for an interview and state that an incentive will be given. The incentive, a gift card is purchased with non-FIMR funds. Others do not

mention that an incentive will be given, but give it after the interview and view it as a courtesy for the woman's time. These interviews can be difficult to get a woman to agree to, but some feel that much depends on who requests it and how it is presented to the woman. It takes a very compassionate and gentle approach to engage a woman in the interview process.

The FIMR process is considered to be a quality assurance/quality improvement process.

We have heard of the success of program like LA Hope in gathering information through surveys and certainly that is valuable information. However, it is **separate** from their FIMR process and is considered to be a research project.

Should a coalition wish to replicate that kind of research, FIMR funds may not be used and the process must be kept completely separate from the FIMR process. There may be no overlap. In addition, it is recommended the coalition contact their local county health department or their contract manager regarding the Institutional Review Board approval of the research project.

Mari Detres stated that the statement in BASINET at the end of the case summary which states that this information can be used for public health research should be removed.

Closing Comments/Announcements - Dani Noell and Louise Jones

Ms. Noell commended Ms. Parker for her dedication to families who have suffered the loss of a baby. She spoke for all when she stated that the reward of this service to families is invaluable and that it takes a community effort for such a program to succeed.

Ms. Jones reminded the participants that CityMatCH has issued a FIMR/HIV Prevention Methodology Request for Applications.

Ms. Jones also shared an email from Jennifer Highlands, Executive Director of the Healthy Start Coalition of Sarasota County, Inc. thanking Jason Stamm and Laurie Lee for the recent and upcoming trainings and stating these trainings were very helpful.

The next call will be, Wednesday, September 23, 2009 at 9:30 am Eastern Standard Time.

CL/lab