

# Perinatal Progress

# Volume 12 Issue 2

### NORTHERN VIRGINIA PERINATAL COUNCIL, A HEALTHY MOTHERS HEALTHY BABIES COALITION

The Northern Virginia Perinatal Council is dedicated to improving the health of women and infants

in Northern Virginia. Members.tripod.org/ nvperinatalcouncil



Dona Dei, Chair of the NVPC, and her new grandson Zachary

Lessons Learned from the Fetal Infant Mortality Review Project

> Northern Virginia 1998-2000

Fetal Infant Mortality Review (FIMR) is a community process that addresses the concerns of infant mortality from a multidisciplinary point of view.

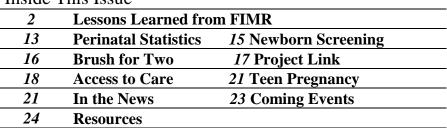
Communities across the United States have been using FIMR since its development by the American College of Obstetricians and Gynecologists in 1990 to review infant mortality from a multidisciplinary perspective. The Northern Virginia Perinatal Council began a comprehensive FIMR project in 1998.

The FIMR process allows us to gain insight into the medical, social and environmental factors that contribute to infant mortality. FIMR goes beyond death certificates and statistics to find out what happened during pregnancy, birth and the baby's short life.

The data and statistical information gleaned from FIMR can help a community improve its maternity care and reduce its infant mortality rates, but it is the personal stories of the families whose babies have died that are the most significant aspect of FIMR.

The families we have met through this project have opened their homes and their hearts to us. They have volunteered to participate in the study in the hope that other families will not have to suffer what they have endured. They have offered support and

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encouragement to other families whose babies have died. They have walked and run in fundraisers for the March of Dimes and for SIDS to raise money for research to prevent more babies' deaths. They have lobbied the state legislature to change the laws to help prevent infant deaths from metabolic disorders. They have participated in training programs for hospital and medical staffs to educate them about perinatal loss. They have spoken at Memorial Services, and created poems, stories, quilts, memory boxes, photographs and special mementoes to keep their babies' memories alive in their hearts. It has been an honor and a privilege to get to know them. FIMR's objectives are:

June 2001

- To examine the significant social, economic, safety, and health systems factors associated with fetal and infant mortality by reviewing individual cases
- To plan a series of interventions and policies that address these factors to improve the service delivery system and community resources
- To participate in the implementation of community based interventions and policies
- To assess the progress of the interventions

FIMR also provides important benefits to bereaved families. The home interviewer can help facilitate the grieving process, as well as make appropriate referrals to support groups or counseling programs that may be needed. In addition, the home interviewer may identify medical problems in the mother, and may be able to provide significant information to prevent problems in subsequent pregnancies.



Priorities for FIMR in Northern Virginia

- 1. To provide a model for community wide review of fetal and infant mortality, with recommendations for improvement of the health care system when applicable.
- 2. To incorporate cultural sensitivity and competence into the FIMR process.
- 3. To develop a methodology ensuring that the data gathered is used to improve care.

By working together across agency and disciplinary boundaries, the Northern Virginia FIMR Project discovered meaningful information to enable the reduction of infant deaths and improvement of pregnancy outcomes.

### Northern Virginia

Perinatal Region V, Northern Virginia, comprises Alexandria, Arlington, Fairfax, Loudoun and Prince William Counties and Health Districts. 27,959 babies were born in Northern Virginia in 1999, the latest year data is available from The Virginia Department of Vital Statistics.

Northern Virginia's population in 2000 was 1,764,897, a 30% increase from 1990. Northern Virginia accounts for about 28% of Virginia's population but yielded a greater than 40% population increase. Fairfax and Prince William Counties are the two largest counties in Virginia, in population, and Loudoun County is the fastest growing county. The region is increasingly multicultural.

Although Northern Virginia is considered to be quite affluent, there are significant pockets of poverty, particularly among minorities. A large population of recent immigrants from all over the

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globe constitutes the greatest challenge to health care.

Minority populations have increased dramatically in the past decade, so that 1 out of 4 persons in Northern Virginia today is a member of a racial/ethnic minority. Half of the states multiracial population lives in Northern Virginia, and minority groups accounted for at least 70% of the region's population increase. In Fairfax, the Hispanic and Asian populations both more than doubled in 10 years. Language, literacy and culture all have major implications on health care expectations and the delivery of care.

- The number of foreign-born residents in Northern Virginia increased in to about 25% of the population.
- Over 250,000 immigrants in Northern Virginia comprise 66.3% of the total number of immigrants in the Commonwealth of Virginia.
- Of the various ethnic groups represented in the numbers of new residents, Blacks and Hispanics comprise the largest numbers of disadvantaged in Northern Virginia.
- The average Hispanic in Northern Virginia has a per capita income of \$12,431, 53% of the regional average and significantly less that that of the black per capita income.
- 1 in 9 Hispanics live below the poverty level, which is approximately \$1200 a month in Northern Virginia.
- Tuberculosis is a problem in Northern Virginia, primarily among foreign born individuals
- About 90 % of Northern Virginia's health department's maternity cases and WIC cases are foreign born

Specific challenges to health care providers in Northern Virginia include:

- Language
- Literacy
- Cultural attitudes
- Acceptability of providers, i.e. in some cultures it is not acceptable for a male physician to treat a female patient
- Communication (bilingual staff, interpreters)
- Accessibility of services (extended hours, week-end hours, outreach to community)
- Transportation
- Bicultural or bilingual staff

English is not the primary language spoken at home for more than 15 % of the population in Northern Virginia. Almost 48,000 Northern Virginians speak English poorly or not at all. Most (27,000) live in Fairfax County, but another 15,400 live in Arlington and Alexandria. According to current projections, about 900,000 immigrants will continue to arrive in the United States each year and Northern Virginia's immigrant population will continue to grow. Many immigrants lack adequate health insurance, and the challenge of dealing with the numerous languages and cultural beliefs is tremendous. This results in a tremendous burden on the health care system.

By far the largest challenge to health care providers in Northern Virginia is meeting the needs of the multicultural population.

### **Infant Mortality**

A community's infant mortality rate has long been recognized as a significant indicator of its health status. Northern Virginia's infant mortality rate in 1999 was 4.8 per thousand live births, well below the Healthy People 2000 goal of no more than 7 infant deaths per thousand live births. The Black Infant Mortality of 5.5 infant deaths per thousand live births is also well below the Healthy People 2000 goal, and is particularly significant because for many years the Black Infant Mortality Rate has been almost twice as high as the White Infant Mortality Rate.

### **Case Identification**

#### The Northern Virginia FIMR team reviewed 193 cases of fetal and infant deaths between 1998 and 2000.

Cases were selected from the medical records of Inova Alexandria and Inova Fairfax Hospitals. Infant deaths and a random selection of fetal deaths greater than 20 weeks gestation were included in the study.

After a case was identified, a letter expressing condolences and requesting the family's participation in the project was mailed to the family, with a March of Dimes bereavement kit and a list of local support services.

Once the family agreed to participate, a home visit was arranged by one of the nurses who were specially selected to conduct the home interviews. Home interviews were scheduled at the time that was most convenient for the families.

The nurses who conducted the home visits were all skilled in patient interviewing, and all were certified bereavement counselors. One was a retired nurse midwife,

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with over 40 years nursing and midwifery experience. The other two nurses worked in Labor and Delivery at Inova Alexandria Hospital, and were able to visit patients they had cared for, thus providing significant continuity of care for the families. One of the nurses was Spanish speaking, enabling us to reach out to Latino families.

Information was gathered from the medical records, as well as the home interview. The information was entered into a database, and an abstraction of the information was used to conduct case reviews of each case. The National FIMR database and software were used in the study.

The FIMR Case Review Team met 4-6 times a year. At each meeting, 3 or 4 cases were discussed, and the case review team made recommendations for improvement in care.

The case review team was comprised of local physicians, nurses, social workers, and support group leaders from the public and private sector.

The Case Review Team discovered quickly that FIMR is an excellent quality assurance mechanism. We found good evidence of identification of high-risk obstetrical conditions early, with appropriate medical intervention. However, we also found that too many women did not know about folic acid, few women really understood the risks and symptoms of preterm labor, and only about half of the pregnancies were planned.

Contrary to the conventional wisdom that infant mortality is more prevalent among poor, uneducated single mothers, the

majority of patients in this study was well educated, middle-class, employed and married. 6 % of the infant deaths occurred to teen mothers, but 23% percent of the deaths occurred to women older than age 35.

### **Infant Deaths**

The causes of infant deaths fell into two main categories: prematurity, especially less than 24 weeks gestation, and congenital anomalies. Seven deaths were attributed to SIDS.

### FIMR Facts At A Glance

- 38% of deaths were less than 24 weeks gestation
- 32% of deaths were 25-35 weeks gestation
- 31% of deaths were greater than 36 weeks gestation
- 12% were multiple births
- 6% of the mothers were cigarette smokers
- 4% of the mothers used alcohol or other substances
- 42% of the deaths were due to prematurity
- 29% of infants had serious infections
- 7% of the mothers had chorioamnionitis
- 36% of the deaths were due to congenital anomalies
- 15% had lethal cardiac anomalies
- 52% of the mothers were Caucasian
- 20% of the mothers were Black
- 19% of the mothers were Hispanic
- 9% of the mothers were Asian
- 37% of the mothers were foreign born
- 6% of the mothers were teen mothers

- 23% of the mothers were older than 35
- 5 had no prenatal care.
- 67% had > 5 prenatal visits
- 59% lived <1 day
- 60% had private insurance75% of the mothers were
- married
  63% of the mothers were employed during the pregnancy
- 44% of mothers or infants were transfers or transports

### Recommendations

1. Every woman of childbearing age must take the recommended amount of folic acid daily

Research has shown that taking 400 micrograms of folic acid daily prior to and in the first few weeks of pregnancy can significantly reduce certain birth defects, including neural tube defects, cleft lip and palate, limb deformities and some cardiac defects.

However, half of all pregnancies are unplanned, and awareness of the need to take this vitamin prior to pregnancy is limited. The Northern Virginia Perinatal Council and the March of Dimes embarked upon a public awareness campaign on the need for every woman of childbearing age to take 400 micrograms of folic acid daily. We also need to address the cultural differences of our many immigrants in the area and their need to learn about folic acid and take a multivitamin daily.

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For some women, a public awareness campaign alone will not result in their taking folic acid. Therefore, the Perinatal Council sought and received a grant from the National Capital Area Chapter of the March of Dimes to purchase folic acid in bulk and distribute a 6month supply to women receiving care from various agencies in Northern Virginia. The project coupled one on one explanation and education about folic acid along with the six-month supply of the vitamin. At the end of the project, patients were surveyed to determine if they were still taking folic acid if they had to buy it themselves.

In the Pilot Project, folic acid was distributed to the Alexandria Health Department and to the Arlandria Neighborhood Clinic, Arlington's Project Family, Prince William WIC, Fairfax Resource Mothers, and the Prince William Family Health Connection in an effort to increase the intake of folic acid among immigrant women who have a higher rate of babies born with birth defects. Results from the surveys were encouraging, so additional funding was obtained from the National Capital Area Chapter March of Dimes, and folic acid was distributed to an additional 1500 women at risk.

2. Twins and other multiples must be treated as high-risk pregnancies

With the increase in multiple pregnancies, occurring both naturally and with assisted reproductive technologies, health care providers must remember that twin pregnancies are high-risk pregnancies and must be treated as such.



3. Signs of preterm labor must be taught to all women, and physicians and staff must heed them. Bacterial Vaginosis, Group B strep and other infections in the prenatal period must be treated more effectively, particularly if we are to reduce infant mortality in African American babies.

Several mothers told the home interviewer about suffering from a constant, rhythmic backache but were either "afraid to bother" their physician, thought that backaches were normal in pregnancy, or their physicians did not investigate the seriousness of this symptom. Mothers also told us that they had symptoms of preterm labor, which they ignored, based on advice from colleagues or relatives. Several others told us they contacted their doctor's offices with symptoms of preterm labor, but were told by a receptionist over the phone that backache or lack of fetal movement in pregnancy was normal.

One model of preterm birth prevention, which is very successful in Northern Virginia, is the Kaiser Permanente "Tender Loving Care Program." In this project, patients

identified as being at risk for preterm labor are paired with an advice nurse. Patients are given intensive education about the signs and symptoms of preterm labor, and encouraged to phone the TLC nurse whenever anything unusual happens, or if she just needs to talk. Through networking with members of the FIMR Case Review Team, Kaiser has begun to refer teens and young adult patients to the Resource Mothers component of Healthy Start/Loving Steps in Alexandria, increasing the support that these patients receive during pregnancy.

### **Infections in Pregnancy**

In the first year of our FIMR project, 18% of the mothers in the study had chorioamnionitis, and 85% of the preterm infants who died, died of sepsis. The obstetric department began a concerted effort to aggressively treat infections in pregnancy. In the two subsequent years of the project, we saw the rate of chorioamnionitis decrease to 7%, with corresponding decreases in infant mortality due to infection in the premature infant. This decrease in infant mortality was particularly striking among the Black population, whose infant mortality decreased from 8.5 per 1000 live births in 1998 to 5.5 per 1000 live births in 1999.

In addition, we recognized the need to provide more accurate information to pregnant women about signs and symptoms of preterm labor and the need to educating the office staffs about appropriate patient counseling.

Patient education materials in multiple languages on Preterm Labor and Healthy Pregnancy Behaviors were distributed to all doctors' offices and prenatal clinics

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in Northern Virginia, as well as to libraries and other public places. We also distributed information about the "Brush for two " campaign promoting good dental care in pregnancy as a means of reducing preterm births.

The Northern Virginia Perinatal Council conducted two large trainings on "Optimal Prenatal Care" aimed at office staff, clinic staff. public health nurses. Resource Mothers and Family Support Workers. The goal was to ensure that professionals and paraprofessionals working with pregnant women would understand the signs and symptoms of problems in pregnancy and could convey them to pregnant women. Both programs were very well attended and we have received feedback that the information was extremely useful for staff in helping them assess and advise patients about risk, symptoms and treatment of preterm labor.



4. 63% of the mothers in the study were employed during their pregnancies. Employers and pregnant women must be aware of risks to pregnant employees and modify work conditions accordingly.

On-site workplace education programs like "Babies and You" have proven to decrease costs to employers associated with premature births. The Washington Business Group on Health recommends such programs, and we should encourage businesses to utilize such programs.



5. 37% of the infant mortality in this study occurred among foreign born families. Outreach education regarding the need for early prenatal care and risks of birth defects must be provided to the foreign born population, especially Middle Easterners and Latinas. Education and public awareness campaigns must be done in appropriate settings and need to be culturally and linguistically appropriate.

- We have enlisted the aid of DC United Major League Soccer Team to provide public service announcements and to promote preconception and prenatal care and healthy infant care at their well attended soccer games.
- We have made culturally appropriate patient education materials available to clinics and private physicians offices in Northern Virginia, and have worked with the Northern Virginia AHEC to provide trainings on cultural competency.
- We plan to seek grant funding to expand the outreach into the immigrant communities and provide more education and genetic counseling to these populations at risk.

6. 7 of the deaths in the study were attributed to SIDS. SIDS continues to be the leading cause of post-neonatal mortality in the United States. The Back to Sleep campaign has improved the mortality rate from SIDS, but more needs to be done.

- With the Northern Virginia SIDS Alliance, we have promoted the Back to Sleep Campaign and other preventive messages regarding SIDS at Health Fairs, hospitals, clinics and day care centers in Northern Virginia.
- We have provided numerous patient education materials in multiple languages to hospitals, clinics, health care providers and day care providers in the Northern Virginia area.
- To capitalize on the Healthy • Families Program, we used outreach workers to remind families of the need to be consistent with SIDS Risk Reduction practices. We provided SIDS risk reduction training and gift bags for families to all the Healthy Families sites in Northern Virginia as a means of getting the Back to Sleep message directly to at risk families. Several local stores and companies provided prizes as



ncentives in this project, which reached 500 high-risk families.

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- The NVPC and the Northern Virginia SIDS Alliance produced and distributed 10,000 copies of a brochure aimed at African American Families: **"Reducing the Risk** of SIDS."
- The Northern Virginia SIDS • Alliance and the NVPC have providing trainings to nurses, childcare providers, and hospital staffs throughout Northern Virginia on SIDS risk reduction strategies. We are currently conducting a research study to examine hospital nurses attitudes toward the Back to Sleep campaign, and providing education to encourage nurses to put babies to sleep on their backs in hospital nurseries so that parents will model the behavior they see.
- The NVPC, National Capital • Area March of Dimes and the Northern Virginia SIDS Alliance sought and received funding to hire a part time executive director for the NOVA SIDS Alliance, who will have office space provided by the March of Dimes. This will enable the education, advocacy and support provided by the NOVA SIDS Alliance to expand its scope to encompass SIDS and Other Infant Deaths in the near future.

7. Families, professionals and employers need to be more aware of bereavement services, and support for families who have suffered perinatal loss must be improved.

The Northern Virginia Perinatal Council works with the Perinatal Loss Committees in the hospitals, sponsors the Resolve Through

Sharing Bereavement Counseling Programs in Northern Virginia, and works with the support groups "Miscarriage, Infant Death and Stillbirth" and the "Northern Virginia SIDS Alliance" to promote bereavement support. The Perinatal Council has developed a list of support groups, counselors and Internet sites specializing in perinatal loss. This resource list is given to all families whose babies die in Northern Virginia, along with the March of Dimes Bereavement kit and the booklet "When Hello Means Goodbye". Bereavement materials are available in Spanish and English. These materials are provided whether the family participates in the FIMR study or not.

In addition to these preventative measures, we have worked with hospitals in the region to develop Perinatal Loss programs and Memorial Services to meet the needs of the families whose babies die.

Several of the hospitals in Northern Virginia sponsor perinatal memorial services every year, and the annual SIDS Memorial Service is held in December. These services provide a special opportunity for families to come together to mourn and remember their babies.

Some local resources for support when an infant dies include:

#### Northern Virginia SIDS Alliance 703-435-7130 Email <u>novasids@yahoo.com</u> Website www.novasids.org

SIDS Network For information on SIDS and other infant death issues <u>www.sids-network.org</u> www.sidsalliance.org

- MIS (Miscarriage, Infant Death and Stillbirth) Support Group 301-460-6222 703-536-6275
- In Loving Memory: A Group for Parents With No Living Children 703-435-0608
- The Counseling Center of Fairfax 703-385-7575
- Compassionate Friends www.compassionatefriends.org



### Excerpts From Interviews of Parents Whose Babies Have Died

<u>Never Forgotten</u> Nancy Brouphy, RN Inova Fairfax Hospital

To lose a child is to lose a part of yourself. Unborn children represent a parent's future, hopes and dreams. Experiencing such a loss leaves those hopes and dreams

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unfulfilled. With time, some family and friends expect you to forget.

How do you forget when just the knowledge of this child's existence filled you with such joy?

How do you forget when the sound of this baby's heartbeat caused you to catch your breath or when watching the ultrasound rendered tears of sheer amazement?

How do you forget feeling awed by the movement of a child within you?

How do you forget bonding with someone you haven't yet met knowing you are this child's parent?

How do you forget the sadness of the labor, birth and the stillness of the bundle placed in your arms?

The truth is you never forget. You cherish the limited time together and remember this small person with a name, a birthday, and a place in your heart.

Today, take the time to remember. Light a candle in memory of your child. Allow yourself the opportunity to cry, to vent the frustration over being able to see them become happy, productive teenagers and adults.

But also find some solace in knowing they are at peace and that they knew how much you loved them during their brief time in this world. It is all right to remember, for you remember them with your love.

### 8 Work Stress

Many mothers discussed the stress they felt while working during their pregnancies. One woman told us that she complained of the enormous amount of work and the large geographic territory she had to cover as part of her job. After she delivered her preterm baby, who died, the company hired 3 additional people to do the same job. Another mother told us of receiving a bad performance review 3 months after the death of her baby, because she was "grieving too much".

One patient experienced spotting for three days before seeing her midwife who sent the patient to the hospital for a non-stress test. Although no contractions were evident, the patient was advised not to walk, not to drive, and to stay home from work. Her job involved driving from office to office, from DC to Reston and other places in metro area.

The patient nevertheless went to work. She then suffered premature rupture of membranes and was hospitalized for two days. Preterm labor ensued, and the baby died of sepsis. The mother had severe chorioamnionitis. Although the mother was informed of the risk to the baby, she chose to not quit work. She stated she experienced a great deal of stress and tension from her work, but after she went on maternity leave they hired more people to do her job. This was her third miscarriage. She plans to quit work if she gets pregnant again.



### <u>A Love Song</u> By the Mother of Gregory

The mention of my child's name May bring tears to my eyes But it never fails to bring Music to my ears If you really are my friend, Please, don't keep me From hearing the beautiful Music It soothes my broken heart And fills my soul with love

# Twins who died at 22 weeks gestation

"When I think of the babies I just get angry with my physician. I kept telling him I had back pain and he just ignored me."

### An immigrant from Ghana

One patient recently emigrated from Ghana after waiting for 9 years to come to America. She was pregnant, and had serious PIH which was diagnosed and treated in Ghana, before she boarded the plane for America. The baby died in utero. The mother delivered a

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macerated stillborn one-week after arriving in America.

### **Social Workers**

"I wish I could have met with a social worker while I was still in the hospital"

Several mothers whose babies died on the weekends were disappointed that no social worker was there to give them support and information. The FIMR study proved to us the value of social worker support in the hospital, and demonstrated a need for increased staffing in the social work departments.

### Whisper to Me

Whisper to me my little one Your scent remains It fooled my heart For an instant The joy of your presence was here! But too soon My mind remembered.

Whisper to me my little one If only in the wind That rocks in the empty swing 'Between my two that remain I think of how it should have been I think you may still be here If only in spirit.

Whisper tome my little one Come visit me in my dreams Let me see you If only once more Let me see your eyes, brown or blue? Your hair it has curls! Or is it straight? What parts of me carry on? May I just touch you, hold you If only in my dreams.

Do you se your balloons every year? Can you smell your flowers?

Did you see your Christmas presents? That I never got to wrap? How long to braid the hair of my third little girls Whisper to me Stay with me always.

Whisper to me my little one Speak to my ear It's frozen in time To the place we once were

### Trisomy 13

Trisomy 13 was diagnosed at about 20 weeks by ultrasound. The patient and her husband found the SOFT support group on the Internet. (Support Organization for trisomy 18, 13 and other related disorders) The patient felt she received good information, and she subsequently interviewed the neonatologist and social worker at Inova Fairfax Hospital for Children to discuss her options. The parents decided against an abortion and chose to go to term.

When the mother went into labor, she said, "I knew it was time to meet her" The father baptized the baby, and they held her till she stopped breathing after about an hour. Funeral arrangements had already been made and the baby was cremated. They had private childbirth classes with another couple who had previously had a stillbirth, and offered to help other couples with trisomies deal with their pregnancies and births.

Some of this mother's comments: " I wished that the sonographers could have given me more information or showed me pictures of trisomy 13. I got that from the SOFT group on the Internet. Also, I could hear them talking about us while I lay there"

I wish more people had respected our decision to carry the baby to term"

"The nurses on the gyn floor need more training in caring for maternity patients. They did not massage my uterus or check me all night and I had to be catheterized in the morning."

"We wanted (our daughter) to be born in privacy and with dignity." The nurse in L&D did not know what trisomy 13 was, and the mother worried about how the nurse would handle the situation.

"This pregnancy was very hard, but it brought us and our families closer together. We appreciated our little girl and our lives much more. We learned that most things in life don't really matter."

Several months later, another patient whose baby died of Trisomy 13 said:

"Every physician and nurse was very caring and sympathetic. We appreciated the L&D nurses for how they introduced the baby to us. The NICU nurses took pictures that look almost professional and a family friend has created a very sensitive display."

### 20 week triplets after IVF

The patient was advised to have a fetal reduction from 5 fetuses to 3. She and her husband went to Jefferson Hospital in Philadelphia for this procedure, and told nobody in their families about it. It was a very difficult decision for them. The pregnancy continued then normally, until 20 weeks. The mother worked as a math teacher. She was on her feet all the time at work, and could take no rest breaks. The mother tested positive for beta strep. At 20 weeks, she had signs of preterm labor, followed by a rapid labor and delivery. One baby

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was stillborn, and the other 2 died shortly after birth.

Some of the mother's comments:

- "The nurses urged us to hold the babies and we did. I am so glad that we did."
- "Don't put the patient whose baby has died on the floor with other women and babies."
- "Be sure that bills that should not be sent to the family are not sent"
- "Don't give out mothers name and address to companies who solicit for baby items, insurance, etc"

### Three Little Angels

Written by a mother whose triplets were born prematurely and died May 29-30, 2000

Three little angels asleep in our arms Three little angels safe from all harm We held you and kissed you and felt our hearts break Our three little angels who would never wake.

You came on my birthday with the evening star Three little angels eight minutes apart All was perfection-your hands, your feet Your bodies, your faces-frail and sweet

Three little angels born too soon Just 15 weeks within my womb Too young for your lungs to know to draw breath Too young to live, your birth was your death Now three little angels sleep among the stars Three little angels, forever ours.

### 10 Mothers of Preterm Babies who Died in NICU

"When my baby was dying they called me in my hospital room instead of calling my husband at home. I was sedated. I wish they had called him first."

A mother whose private obstetrician sent her to the perinatologists at Inova Fairfax Hospital because of the NICU there:

"It would have been better if my doctor and the perinatologists talked to one another. They were not always in agreement and it was confusing for me. It would have helped if someone had sat with me to tell me what my husband was feeling and how to help him, and sat with him and told him what I was going through and how he could help me. It has only been this past month that we can talk about it (the baby's death) together. This should occur while the mother is in the hospital and be repeated after 2 or 3 months."

### <u>Jonathan</u> By Joan Volk

He was of daffodils and sunshine. For three months I held him close to me. He was warm and sweet. Perfume, almost That with air And time Evaporates. Leaving only the fragrance

### Congenital Cardiac Anomalies

" It would have helped if the nurses and doctors communicated more, and showed their sorrow over the death of the baby. We needed help and advice in what to do about burying the baby."

"I wish that when I had my fetal echocardiogram that it had been done by a Pediatric Cardiac specialist. Then maybe they could have seen that there was a problem and when the baby was born we would have known why he was sick and they would not had to cause him unnecessary pain with the spinal tap."

"The nurses and doctors at Fairfax Hospital were wonderful to us. It was so terrible at the end. I couldn't stand watching her suffer any more."

" Our son came home with hospice care. Everyone was very professional. The hospice services and personnel were outstanding. The hospice helped us with therapeutic services such as counseling and Healing Touch. We will go back around the holidays because we know it will be a difficult time."



One family used this poem at their memorial service for their son.

For Beck Heaven is Better Than Spring

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We watched for the springtime together Throughout the long winter, so cold We wished for the grass and the flowers With Dandelions spattering gold We hoped for the budding of lilacs We listened for robins to sing We watched and we wished and we waited But Heaven is better than spring.

We planned for a bed of petunias We thought of the crocus in bloom We mentioned the roses we'd gather To add a fresh touch to our room We dreamed of vacation time, picnics The sandbox, the slides and the swing And found them to be an illusion For Heaven is better than spring

We selfishly mourn that he left us We think of the things we could share But God gives a sweet consolation And lifts us above the despair There's no pain or sorrow or darkness Within the bright realm of our King There's joy and sweet peace there forever And Heaven is better than spring.

### **Cultural Differences**

A Pakistani mother told us she had no one to talk to about the loss of her baby, who died of a congenital cardiac anomaly. The mother and her husband are first cousins, which is common in their culture. The mother said she could not discuss the loss of their baby with him because when she had his first miscarriage, he had a bad

automobile accident and was out of work for 4 months. Her family expects her to accept the pregnancy losses as Allah's will.

# A mother who attends the MIS support group

" It would be good to have a doctor come to a group meeting and explain some of the reasons why babies die."

### Parents of Premature Twins

"The nurses urged us to hold the babies. We were afraid at first, but we are so glad we did"

### In the Quiet

In the quiet before dawn When the world still sleeps My waking mind calls your name In the sun bright morning When the children play My questioning eyes seek your face

In the warm afternoon When naptime comes I listen for your quiet breath In the dark of night When the tired soul rests I go down to the darkness alone.

As the hours that are Replace the hours that cannot be As the memories that are Replace the memories that would have been As the emptiness that is Supplants the happiness that should be I remember A mother whose baby died at 3 days of age. The autopsy was inconclusive.

"Before she was born we worried about baby clothes and strollers and bassinets. We worried about which preschool she would attend. which high school and college. We worried about what it would be like if she got married and moved away from home. All this before we ever laid eyes on our beautiful daughter. We didn't know enough to worry about Newborn Screening. Our worries now are which funeral home to call, which cemetery to bury her in, which headstone to choose, and how to pick up the pieces of a broken heart."

### The mother of a baby with Down Syndrome and cardiac complications

"It was so terrible at the end. I couldn't stand to see her suffer anymore. My husband and I help one another. One day I'm down, and then he is down the next".

# Mothers' Comments About the FIMR Project:

• I wasn't sure if I was going to call (to participate in the FIMR study) but then I figured it might help, to feel like we might be able to help or even prevent this happening to others. We are glad we participated. It really helps to talk about it and so few people realize that. The Home interviewer was very nice and compassionate.

# **Perinatal Progress**

- I am greatly impressed with the follow through and commitment the FIMR project has shown in striving to find improvement in the health care system as it relates to infant mortality. Our baby son's death was a tragedy, but no one could have anticipated his serious health issues while in the womb. He was God's baby. Thank you for trying to make it better.
- I just hope the information is used to help others not have the same problems.

### Northern Virginia FIMR Case Review Teams

### FIMR Staff

Debbie Byrne, RN Betty Connal, RN, MS Margaret L. Gallen, CNM Michelle Kite, MSN

### <u>Inova Alexandria Hospital</u>

Alecia Brubeck, RN Barbara Fahimi, RN Lisa Goldberg, MD Alessandro Guidini, MD Arlene Hewitt, MSW Vicki Lanni Korker, RN Maria Reid, MSW Brenda Rolander, RN Karen Thongtavee, RN Orpha Weinhold, RN

# **Perinatal Progress**

#### Alexandria Health Department

Kathy Benjamin, RD Debbie Bowers, RN Charles Konigsberg, MD Uzma Quareshi, RD Judy Southard, RN Persis Sosiak, MPH

#### Inova Fairfax Hospital

Janet Hilliard, MD Robin Landry, Risk Management Amy Lewanda, MD Renee Martin, RN Fred Mecklenburg, MD Brenda Mohile, RN Claire Pagano, RN Beth Suddaby, RN Candice Sullivan, RN Sara Vincent, MSW

#### Fairfax Health Department

Evy Duff, RN

Northern Virginia Urban League

James Gallman Florene Price, RN Valerie Talford, RN

Kaiser Permanente Sue Schoen, RN, MEd

Momease, Inc. Carolyn Alexander

Northern Virginia SIDS Alliance Liz Builta, RN, PNP Judy Rainey

March of Dimes Dona Dei, MSN, PNP

# Perinatal Council Meetings

Phone Betty Connal at 703-204-6778 or email <u>bconnal@aol.com</u> if you would like to attend. All meetings are open to anyone interested in improving maternal and child health in Northern Virginia.

May 21 11:30am to 1:30pm Alexandria FIMR Case Review Meeting Third OB Conference Room Inova Alexandria Hospital

June 18 10 am to 1 pm Caring for Infants and Toddlers with Disabilities Gemini and Orion Rooms Inova Telestar Court Conference Center \$35

June 19 11:30 am to 1:30 pm FIMR Case Review Team Meeting Kaiser Room Inova Fairfax Hospital

June 25 9 am to 4 pm When Hello Means Goodbye Perinatal Loss Training Gemini and Orion rooms

Inova Telestar Court Conference Center \$35



**Brush for Two** 



Low birth weight and preterm delivery is the leading cause of infant mortality among African Americans in the United States, and the second leading cause of infant mortality among Caucasians. Researchers have studied many potential causal factors, including tobacco use, genitourinary tract infections, multiple births, and genetic history. However, 25% to 50% of these births occur without any known cause.

One area of promising research is the effect of periodontal disease on preterm delivery. Periodontal disease is a chronic infection, and the inflamed tissue of periodontal disease can infect other areas of the body, including the uterus. The infection can disturb the balance

# **Perinatal Progress**

between hormones and cytokine, which can affect the onset of labor.

Dr. S. Offenbacher found a relationship between periodontal disease and preterm births in 1996. His research estimates that as much as 18% of preterm birth may be attributable to periodontal disease. Early findings of research from the University of Alabama and the University of North Carolina at Chapel Hill suggest that treatment of periodontal disease early in pregnancy may help prevent preterm births.

Signs of gum disease may include red, swollen or bleeding gums but there maybe no obvious signs at all.

Unfortunately, for many lowincome pregnant women, an affordable source of dental care is not available to them. The Northern Virginia Community Dental Hygiene at the Annandale Clinic at the Northern Virginia Community College Campus at 8333 Little River Turnpike provides dental care for the very low fee of \$25 per year for adults, and \$10 a year for children. The student dental hygienists work under the supervision of a dentist.

Instructors who are registered hygienists check all work carefully and frequently.

Services available include:

- Routine examination of teeth and soft tissues
- Scaling and polishing
- Home care instruction
- Fluoride application
- Diagnostic radiographs
- Blood pressure screening
- Oral cancer screening
- Sealants
- Nutritional counseling
- Periodontal screening.

Call 703-323-3349.

# Project LINK of Northern Virginia

serving pregnant and postpartum substanceabusing women

Project Link is

• An innovative communitybased interagency project serving substance abusing pregnant and postpartum women and their children

- Aimed at coordinating and enhancing existing services throughout Northern Virginia
- Sponsored by the Fairfaxfalls church Community Services Board, Alcohol and Drug Services as the lead agency
- Include the participating CSB's of Alexandria City, Arlington, Loudoun and Prince William Counties
- Funded by Virginia DMHMRSAS

The philosophy of Project Link is that women must be engaged in the process of change and that addiction is a health problem rather than a moral problem.

Encouragement, education and acceptance will promote a nondefensive self-evaluation of substance use and its consequences.

Women's issues such as domestic violence and abuse must be recognized and addressed in order to achieve long-lasting, stable change.

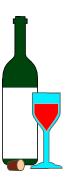
Project Link's long-term goals are to:

- Increase early identification, referrals and follow-up of pregnant substance-abusing women
- Enhance availability and accessibility of prevention, early intervention, and treatment services
- Increase substance abuse treatment accessibility by providing funds for transportation, childcare

# **Perinatal Progress**

and other supportive services

- Increase interagency collaboration, both public and private
- Decrease the incidence of alcohol tobacco and other drug use among pregnant and post partum women



The LINK Implementation Team will assist with start up efforts, identify priorities in each jurisdiction, and will include representatives from the Northern Virginia Perinatal Council, each participating CSB, each Health Department, SAARA, and others.

The Project Link Coordinator is CJ Arban. She can be reached at 703-934-5467 or by email at cj.arban@co.fairfax.va.us

# Suggestions for Working with Substance Users

### 1. Obtaining a Meaningful Drug Use History

Direct questioning regarding drug use in pregnant women is often unsuccessful. Patients may be afraid of losing their children if they respond truthfully. Several techniques may help in obtaining an honest drug use history.

- 1. Be Empathetic. Patients may respond better to expressions of empathy than to direct questioning. Examples of this form of questioning might include: "you have a lot of stress in your life. Tell me how you deal with that. Or "Things seem to have been very hard for you. Have you tried to get some help from drugs?"
- Be non-judgmental. Make it clear that you ask specific questions of every new pregnant patient. Avoid issues of suspicions or prejudgment.

### 2. The Health Habits Survey

Tell the patient that this survey will give you information to help you care for her pregnancy. Instruct her that topics related to diet, exercise, drugs and any other habits that may affect the pregnancy will be covered. Make it clear that you ask these questions of every patient.

In this interviewing technique, it may be useful to avoid eye contact. Instruct the patient to interrupt you when a question is raised that is of particular concern.

Topic areas to be addressed include:

- 1. Dietary history
- 2. Have you ever been in the hospital before?
- 3. Do you have any medical problems?
- 4. Are you taking any medications that a doctor has prescribed for you?
- 5. Are you taking any medications that a doctor did not prescribe?
- 6. How many times a week do you smoke cigarettes?
- 7. How many times a week do you drink alcohol,

wine, beer, malt liquor, hard liquor?

- 8. How many times a week do you use marijuana?
- 9. How many times a week do you use cocaine or crack?
- 10. how many times a week do you use any other drugs?

### Access to Health Care for Children

For information about CMSIP/FAMIS call:

Call 1-877-VA-CMSIP Or

Or 1-877-KIDSNOW Or The Virginia Department of Medical Assistance Services 804-225-4280

The Shriner's Kena Temple Access to Care for Children in Need of Orthopedic Care



The Shriners are a fraternal organization in the Masonic family of organizations, who operate 19 Orthopedic Children's Hospitals and 3 Burn Children's Hospitals in the United States, Canada and Mexico. The Shriners Hospitals are completely free. In fact, none of

# **Perinatal Progress**

the Shriners Hospitals has a billing department.

There are no restrictions on what child can be admitted to a Shriners Hospital, other than that the child, up to age 18, needs care that the Shriners Hospital can provide.

The Kena Temple on Arlington Boulevard in Fairfax coordinates referrals to the Shriners Orthopedic Children's Hospital in Philadelphia and operates three vans providing transportation for the approximately 250 local children currently being cared for at the Philadelphia Hospital. The hospital is a three-year-old state of the art children's orthopedic hospital, caring for children with spina bifida, clubfoot, limb deformities, scoliosis and other orthopedic problems.

To refer a child to the Shriners program, the family or a health care provider can call 1-800-237-5055 or 703-573-4202 to request an application.

### Access to Health Care Consortium

- The Northern Virginia Access to Health Care Consortium's mission is to promote access to health care for all Northern Virginians through:
  - Development of coordinated efforts to extend care to the underserved, and
  - Expansion of existing programs and improved collaboration to provide medical homes for persons and families lacking access to primary care and other essential medical services.

The Northern Virginia Access to Health Care Consortium meets the fourth Thursday of each month from 9:30 to 11:30 am at the Northern Virginia Regional Commission office, 7535 Little River Turnpike, Annandale

The Access to Health Care Consortium hosts a variety of excellent speakers at its monthly meetings, and new members are always welcome. information.

Phone 703-642-0700 for more



### Breastfeeding

The Virginia State Breastfeeding Task Force meets quarterly in Richmond. For more information contact Nancy Pribble at NPRIBBLE@VDH.STATE.VA.US 804-692-0681

#### Helpful Resources:

LaLeche League 703-960-0568 LaLeche League Helpline for the Metropolitan Washington Area 202-269-4444

# **Perinatal Progress**

WIC Program 1-888-942-3663

University of Rochester's Breastfeeding Drug Hotline 716-275-0088

Lactation Education Resources www.LERon-line.com

#### "Working and Breastfeeding, Can You Do it? Yes, You Can!"

can help breastfeeding women make the transition back to work with recommendations on how to balance the daily priorities of parenting, working and breastfeeding. **Now available in Spanish.** 

Bulk copies are available at \$.51 each, as well as other excellent materials on breastfeeding

**Best Start Social Marketing** 

3500 E. Fletcher Avenue, #519,

Tampa, FL 33613

Phone 1-800-277-4975

### **Perinatal Education**

The Education Committee develops patient education materials and conducts professional education programs.

Some of the Patient Education Materials available include:

- HIV Testing in Pregnancy
- Healthy Pregnancy Planner
- Healthy Newborn Planner
- High Blood Pressure in Pregnancy

- Gestational Diabetes
- Approaching Grief
- Tender Hearts, Tough Decisions
- Preconception Planning
- Should You Breastfeed Your Baby? Absolutely Yes!
- Developing a Workplace Breastfeeding Program
- How Does Your Baby Grow
- Preterm Labor Prevention
- PROM
- The First Few Weeks at Home
- Never, Ever Shake Your Baby
- Your Pregnancy and Bedrest
- Hey Dad!
- Parents' Survival Tips
- Communicating With Your Teenager
- Hepatitis B Vaccinations
- Crying: Baby Talk
- Choices for Birth Control
- Loving Your Baby, Loving Yourself
- Obstetrical Guidelines
- Playing with Your Child
- Your Child and Discipline
- Your Child Ages 1-5
- Reducing the Risk of SIDS
- Warning: Preterm Labor
- 10 Tips to Have a Healthy Baby

Many of the materials are available in Spanish.

Phone 703-204-6778 if you would like copies of any of these materials.



### The Northern Virginia Area Health Education Center Medical Interpreter Services

The NV AHEC is a not-for-profit organization whose mission is to recruit, train, educate and support primary health care professionals who work in underserved areas and communities.

The NV AHEC provides a Health Care Interpreter Service, a multilingual, community based program which supports health care providers by facilitating communication between them and their patients through the provision of qualified health care interpreters

The program offers interpretation in Amharic, Arabic, Cambodian, Farsi, Somali, Spanish, Tigrinya, Urdu and Vietnamese. Interpreters are screened for knowledge of medical terminology and the US health care system as well as language proficiency in English and one or more target languages.

For more information, contact the AHEC at 703-750-3248 or nvahec@aol.com



# **Perinatal Progress**

### LEGISLATION AND ADVOCACY

Governor Gilmore signed into law Senate Bill 1200 providing health care coverage for infant hearing screenings, Senate Bill 1007, newborn screening for congenital adrenal hyperplasia, and House Bill 1982, a child support domestic violence exception for children's health insurance.

To track bills in the Virginia General Assembly, go to

http://leg1.state.va.us/lis.htm

For information about legislation, call legislative services

at 804-698-1500

To contact your legislator, write

The Honorable\_\_\_\_\_

Senate of Virginia

Box 396

Richmond, VA 23219

or

The Honorable\_\_\_\_\_

Virginia House of Delegates

Box 406

Richmond, VA 23218

### **TEEN PREGNANCY**

**Resource Mothers to Come** to Prince William County



A new Resource Mothers Program will soon be available in Prince William County. Prince William, including the cities of Manassas and Manassas Park, has a teen pregnancy rate of 33.3 per thousand teenagers, one of the highest in Virginia. In 1999, 489 babies were born to teen mothers in Prince William.

The new Resource Mothers project has received funding from the Kaiser Foundation to Potomac Hospital, which will function as the lead agency. Potomac Hospital has an outstanding record of accomplishments in providing innovative preventive community health programs in Prince William County. The Prince William Resource Mothers Project will be volunteer-based. For more information or if you would like to volunteer, contact Betty Connal, 703-204-6778 or email bconnal@aol.com

### "WE CAN HELP"

A guide to services for youth in Fairfax and Falls Church is available from the Fairfax Partnership for Youth. For a copy, contact 703-324-5171 or www.co.fairfax. Va.us/rim

### Resources for Pregnant and Parenting Teens

#### Resource Mothers Programs in Northern Virginia

Alexandria	703-836-2858
Arlington	703-228-5628
Fairfax	703-255-1100
Naomi Project	703-860-2633
Birthmothers	1-877-77birth
Loudoun	703-444-4477

### Healthy Families Programs

Alexandria	703-370-3223
Arlington	703-769-4600
Fairfax	703-533-2558
Loudoun	703-444-4477

# **Perinatal Progress**

Prince William 703-680-9358

• Adolescent Family Life Program, Office of Population Affairs

#### 301-594-4004

• Alan Guttmacher Institute

202-296-4012

Advocates for Youth

202-347-2263

- Family Resources Coalition 312-341-0900
- National Campaign to Prevent Teen Pregnancy

202-857-8655

• National Organization on Adolescent Pregnancy, Parenting and Prevention

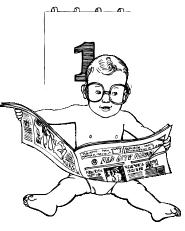
301-913-0378

 Planned Parenthood Federation of America

212-541-7800

• Virginia's Partners in Prevention

804-786-1211



In the News

#### ACOG Releases Recommendations for Management of Recurrent Miscarriage

Women with recurrent early pregnancy loss or miscarriage no longer need to be routinely screened for bacteria or viruses or tested for glucose tolerance and thyroid abnormalities, according to ACOG.

For recurrent pregnancy loss, ACOG does recommend testing couples for genetic abnormalities and testing women for certain antibodies and anticoagulants that can cause a woman's body to reject the fetus.

Recurrent early pregnancy loss is defined as at least 2 or 3, or more, consecutive pregnancy losses in the first or early second trimester, less than 15 weeks gestation. It is one of the most common clinical problems in reproduction, yet a definite cause can be established in only 50% of the cases, sometimes leaving patients distraught and frustrated.

Matters are further complicated by the inundation of widely varying studies and guidelines in the field of recurrent early pregnancy loss. As a result, patients and physicians may turn to alternative therapies or unproven hypotheses. With "Management of Early Pregnancy Loss, " ACOG identifies potential causes and useful treatments in the management of recurrent miscarriage. The practice bulletin reviews the most recent guidelines, studies and other research and offers obstetricans/ gynecologists an evidence based approach to the prevention and management of miscarriage

Among the recommendations:

- Women with recurrent pregnancy loss should be tested for lupus anticoagulant and anticardiolipin antibodies, special protein substances made by the body's white cells for defense against foreign substances. These antibodies can alter the clotting process and lead to strokes, blood clots and low platelet counts as well as miscarriage. If positive for the same antibody on two consecutive occasions 6-8 week apart, the patient should be treated with heparin and low dose aspirin in her next pregnancy attempt.
- Couples with recurrent miscarriage should be tested for genetic abnormalities
- Women with recurrent miscarriage and a double uterus (uterine septum) should undergo hysteroscopic evaluation and reparative surgery
- Couples with otherwise unexplained recurrent miscarriage should be counseled regarding the potential for successful pregnancy without treatment

However there is hope for couples with unexplained miscarriage. Information and sympathetic counseling appears to play an important role. Analysis of recent studies show that between 35% and 85% of couples with unexplained recurrent pregnancy loss who do not receive treatment or who take a placebo during a subsequent pregnancy eventually will go on to have a successful pregnancy.

# **Perinatal Progress**



Asthma in Children Linked to Smoking in Pregnancy



A new study in the February edition of the American Journal of Respiratory and Critical Care Medicine shows that children whose mothers smoked during pregnancy are almost twice as likely to suffer from Asthma. The study indicates that smoking during pregnancy can cause changes to the lungs, which can lead to asthma.

"Effects of Maternal Smoking During Pregnancy and Environmental Tobacco Smoke on Asthma And Wheezing in Children http://Ajrccm.astsjournals.org/cgi/ content/abstract/163/2/429

Commonwealth Fund Report on Health Information Barriers for Low Income Mothers and Children The Commonwealth Fund found that mothers view Medicaid as an

important program and are thankful for the free health coverage it provides. A significant number of focus group mothers said they face barriers to receiving information on child development or expressed dissatisfaction with the way that information was presented to them. Mothers without a regular pediatrician were more likely to feel that their doctor doesn't spend enough time with them. The report summarizes suggestions from he best way to provide them with child development information

- Information should be tailored to the mother's age, parenting experience, language and cultural background
- When telling parents to do something, be sure to explain why
- Pay attention to both the mother and child's well being
- Make materials easily accessible and avoid information overload
- Make home visiting programs responsive to the mother's needs
- The report also identified ways in which state Medicaid programs can address issues raised by the mothers
- Help mothers form relations with their pediatricians, especially by reducing lapses in health insurance coverage
- Extend Medicaid benefits so that mothers can receive services and support for longer period after the birth of their child

Commonwealth Fund release Www.cmwf.org/publist/publist2.asp

Stillbirth Research Agenda

The National Institute of Health convened a workshop on March 26, 2001 to develop a national agenda for stillbirth research. Obstetric, perinatal and pediatric experts from across the country joined with federal officials and representatives of parent groups to evaluate current knowledge and help craft a national plan to address this issue

Currently in the United States, stillborn babies occur at rates of 5-12 in 1000 births. In 1996, there were approximately 3.9 million live births and 65,163 babies who died before birth. Of that number, 35,990 were losses before 20 weeks gestation and 29,153 were stillborn after 20 weeks gestation. About half of these stillbirths have no determined cause of death. Currently there is no significant funding for research into the etiology and or pathogenesis of stillbirth.

Nationally, no data are collected on cause of death prior to delivery, although 40 states do use a code for age and cause of death.

Fetal mortality rates vary by race, ethnic origin, marital status and age of the mother. The youngest and oldest mothers experience the greatest risk of fetal mortality. The fetal mortality rate was more than twice as high from Black mothers (12.5/1000) than for white mothers (5.9/1000) in the 19996 data.

It is believed that many causes of late fetal mortality and early infant mortality may have shared etiology. Some of the risk factors for SIDS also increase the risk of stillbirths and other perinatal deaths. A better understanding of thee outcomes would enhance scientific knowledge and help lead to the development and evaluations of improved clinical and preventive

# **Perinatal Progress**

interventions.

The agenda formulated by this workshop include

- Improvement of record keeping and reporting in each state
- Adoption of a standard postmortem protocol for stillbirths
- Research into the actual causes of deaths in healthy appearing full term infants
- Better education of medical providers and families experiencing stillbirth
- Identification of causal factors of stillbirths
- Increased awareness of the stillbirth problem for the general public
- Dissemination of perinatal loss bereavement resources

www.cdc.gov/nchs/about/major/dus/fetal/96fetal.htm



# **Coming Events**

Parenting Classes General Parenting, Conflict Resolution, Setting Limits, Co-Parenting, and many other topics Fairfax County Public Schools Lacey Instructional Center 3705 Crest Dr Annandale, VA 22003

703-846-8670 Call for a list of classes and locations

#### June 8

"It's More than Words-Communications and Women's Health" Omni Charlottesville Hotel www.womenhealthvirginia.org

June 10-13 AWHONN Convention 2001: A Nursing Odyssey Charlotte N.C. 888-594-6219 Awhonnregistration @jspargo.com

June 11-12 Intensive Review for Lactation Consultants Certification Exam www.LERon-line.com

Third Annual American Baby **Childbirth Educator Conference** Hosted by Babies R Us "A Practical approach to Teaching About Epidurals'' with Henci Goer And "Yes, You Can" Instilling Confidence in Breastfeeding Families with Chelle Goodfriend June 12 and June 19 5700 Leesburg Pike, Falls Church June 10 and June 17 14549 Potomac Mills Road. Woodbridge June 15 and 26 21300 Signal Hill Plaza, Sterling Contact Mary Dove 703-494-7493 dovem@toysrus.com

June 18 What's New in Infant Development? 9 am to 4 pm \$35 Inova Telestar Court Michelle Kite 703-204-6782

June 21-23 RTS Bereavement Training and Coordinator Training Richmond, VA www.gundluth.org/bereave

June 25 When Hello Means Goodbye Perinatal Loss Training 9 am to 4 pm \$35 Inova Telestar Court Michelle Kite 703-204-6782

August 2-4 National Fetal and Infant Mortality Review Program Grand Hyatt Hotel Washington, DC \$275 www.acog.org/goto/nfimr

#### August 6

Making Memories: Photographs, Journals and Other Mementos for Families Suffering a Perinatal Loss Inova Michelle Kite 703-204-6782

September 19-21 Lactation Consultant Training Phase II NIH, Bethesda, MD \$345 23.4 CEU's Lactation Education Resources 703-691-2069 www.LERon-line.com

October 15-17 Connections 2001 Healthy Mothers/Healthy Babies Coalition Biennial Partnership Conference Sheraton Sand Key Clearwater Beach, Florida www.hmhb.org

October 15-17 Foundations of Breastfeeding Support NIH, Bethesda, MD \$335 234 CEU's Lactation Education Resources 703-691-2069 www.LERon-line.com

November 12-16 Lactation Consultant Training Program

# **Perinatal Progress**

November 12-16 George Mason University, Arlington, VA 40 CEU's Lactation Education Resources 703-691-2069 www.LERon-line.com

### Additional Education Resources

Central Virginia Perinatal Council <u>www.perinatalfocus.org</u>

Women's Health Virginia www.womenhealthvirginia.org

Lactation Education www.LERon-line.com

# Resources



Directory of Human Services for Northern Virginia

The NorthernVirginia Regional Commission brings you the Directory of Human Services in three formats: Disk, Print and a Pocket Edition "Quick Guide"

For more information, call the NVRC at 703-642-0700 or

#### www.nvrc.org

### **Domestic Violence and** Sexual Assault Services

Alexandria Domestic Violence Program 703-838-4911

Alexandria Sexual Assault Program 703-683-7273

ACTS-Turning Points: Prince William, Manassas, Manassas Park & Woodbridge

703-221-4951

Prince William Sexual Assault and Victim's Advocacy (SAVAS) 703-368-4141

Arlington Community Temporary Shelter (TACTS)

703-237-0881

Arlington Violence Intervention Program

703-228-4848

Arlington Batterers Intervention Program

703-228-4867

Fairfax County Women's Shelter 703-435-4940

Fairfax Victim's AssistanceNetwork703-360-7273

Loudoun County Abused Women's Shelter

703-777-6552

Rappahannock Council on Domestic Violence

540-373-9373

Rappahannock Council against Sexual Assault

540-371-1666

Virginia State Hotline

1-800-838-VADV

### Transcultural Educational Center

The Transcultural Educational Center produces informative and attractive cross-cultural and health care publications and educational programs. Materials are especially appropriate to familiarize health care providers with Muslim health care issues. Available materials include:

- Death and Dying Across Cultures: A Care Provider's Guide
- A Muslim Patient in An American Hospital
- Seeing through the Veil
- A Guide for Muslim Families
- Family Guide for Raising Children
- Pregnancy to Age 10
- Managing Teenagers

Contact Gihan El Gindy, MSN

Box 3292 McLean, VA 22103-3292

703-759-1914 tecenter@aol.com

### Post-Partum Depression

"Depression After Delivery" 1-800-944-4773

### **Certified Infant**



Massage Therapists Sheila Heim 703-455-4987 Linda Storm 703-440-0179

# **Perinatal Progress**

### FeMail, The Mail Order Pharmacy for Women

FeMail is a mail order pharmacy for women, with the unique service specially designed to make shopping for women's health care needs less expensive and more convenient. If you pay for your prescriptions yourself, or if you file a claim with your insurance company, you can take advantage of FeMail's low prices and great service. Prescriptions can be ordered in 3 month, 6 month or 12 month quantities. FeMail offers full prescription services including

- All brands of birth control pills
- Hormone treatment for infertility
- Hormone replacement therapy.

#### For more information, call:

1-888-336-2451 the toll free order/info line, or email

Femail@bellatlantic.net

FeMail's website address:

<u>www.fe-mail.com</u>

### **Families First**

Families First offers a complete spectrum of classes and services for pregnant couples and new parents. Featured programs are "Mothers Day" and "Relax Refresh & Revitalize." These unique classes are designed to fill the needs new mothers have for individualized, caring, hands-on instruction in baby care and adjusting to motherhood. For brochures and flyers, please call Vergie Hughes, Director of Families First,

At 301-986-5546



### Mother & Baby Matters

Mother and Baby Matters is a highly specialized maternal infant care service designed to support mothers and their families during the overwhelming time surrounding childbirth. A professional staff of doulas, registered nurses and lactation consultants provides care. Labor support, postpartum care and family assistance is available

703-620-3323 or 301-495-3394

### Women's Health Line

#### 1-800-311-BABY

Healthy Start runs this hotline. Callers receive referrals to prenatal care providers in their area and get a wealth of useful information on home visiting services, parenting classes, smoking cessation and substance abuse services, as well as Medicaid, food stamps and SSI.

### Momease

### Preparing a new mom for her new life

Momease is a new, locally owned, company started by a working woman who found that many of the existing materials for pregnant women were out of date, cumbersome, or not geared to the working professional. Momease provides new parents with easy to use innovative products and practical information that enable them to explore the joys, humor and excitement of becoming a parent. Some Momease products are:

#### Mom & Baby Progression Guide:

A striking pictorial guide that clearly explains progressive changes mom and baby undergo during pregnancy.

#### Nutrition at-a-Glance:

Easy to use reference guide with valuable information about the food pyramid, basic food groups, health tips on breastfeeding, sample menus and recommended daily nutritional requirements.

#### **Healthy Baby Passport:**

A pocket-sized booklet to keep track of immunizations and medical facts about baby from birth to 2 years of age.

For a starter kit, or more information about Momease products, Call 1-877-Momease

Email: momeasenet@aol.com

### The Cradle Society

1-800-272-3534

#### www.cradle.org

This organization provides adoption services ranging from counseling and support to legal information, for birth and adoptive parents.

### Perinatal Progress Parents Anonymous

### Hotline-1-800-841-4314

Parents can share problems and learn tips and coping skills

### **HIV Resource Library**

Audiotapes, articles, books, Internet access, journals, newsletters, pamphlets and videos

Open 8:30-5 PM, Monday through

At Inova HIV Services

2832 Juniper St, Fairfax, VA 22031

703-204-3780



# **Online Resources**

<u>Northern Virginia Perinatal</u> <u>Council Website</u>

Members.tripod.org/

Nvperinatalcouncil

#### <u>Action Alliance for Virginia's</u> <u>Children and Youth</u>

www.vakids.org

#### Adoption Resources

www.adoption.com

#### African American Resources

www.rain.org

#### The Alan Guttmacher Institute

Family Planning and Population Research

www.agi-usa.org

<u>American Academy of Pediatrics</u> www.aap.org

<u>American College of Nurse</u> <u>Midwifes</u>

www.midwife.org

<u>American College of Obstetricians</u> <u>and Gynecologists</u>

www.acog.org

<u>American Public Health</u> <u>Association</u>

www.apha.org

ASPO/Lamaze Home Page The official ASPO site www.lamaze-childbirth.com

### Association of Reproductive Health Professionals

An interactive website with quizzes: Birth Control and You: Test Your Contraceptive IQ

www.arhp.org

Attention Deficit Disorder

www.oneaddplace.com



www.awhonn.org

#### **BabyCenter**

Guidance and gear for new and expectant parents

www.babycenter.com

### **BabyServ**

Advice, articles, video and weekly development guide

1-888-933-5383

### www.babyserv.com

### **Birth Connections**

Pregnancy and Childbirth Information for Northern Virginia

www.birthconnections.com

### **Bright Futures**

A national initiative dedicated to promoting and improving the health of our nation's children

www.brightfutures.org

### Campaign for Our Children

A unique organization using multimedia to prevent adolescent pregnancies

410-576-9015

www.cfoc.org

<u>Cerebral Palsy Support and</u> <u>Information</u> <u>www.geocities.com/heartland/</u> plains/8950

<u>Child Safety Information</u> www.paranoidsisters.com

# **Perinatal Progress**

<u>Child Trends</u>

www.cyfc.umn.edu

### Children's Defense Fund

www.childrensdefense.org

#### <u>Coalition for Positive Outcomes in</u> <u>Pregnancy</u>

A national partnership of organizations concerned about pregnancy outcomes

www.cpop.org

### Congress on the Web

Congressional votes, bill summaries and committee reports for the House and Senate

www.thomas.loc.gov

### Annie E. Casey Foundation

KidsCount, USA www.aecf.org

<u>Consumer Products Safety</u> <u>Commission</u>

www.cpsc.gov

### <u>COSSMHO</u>

The National Coalition of Hispanic Health and Human Services Organizations,

www.cossmho.org

### <u>Birthmothers: Crisis Pregnancy</u> <u>Support</u>

Birthmother Ministries Provides support to women with crisis pregnancies, whether or not they are planning adoption 25 Morna Comeau 703-749-1411 www.birthmothers.org

DONA Home Page Doulas of North America www.dona.com

Down Syndrome Health Issues www.ds-health.com

<u>Families USA</u> www.familiesusa.org

#### FemmeEd, Inc."Childbirth to Go"

A childbirth class you can experience in the privacy of your own home \$65

1-877-FemmEd8 Email: FemmEdInc@aol.com

<u>Future of Children Journal</u> www.futureofchildren.org

Get Real: Straight Talk on Women's Health www.womens-health.org

<u>Grief Support</u> More than 35 email support groups www.rivendell.org

<u>Healthy Mothers/Healthy Babies</u> <u>Coalition</u> <u>www.hmhb.org</u>

Immunization Action Coalition www.immunize.org <u>National Immunization Program</u> <u>of the CDC</u> www.cdc.gov/nip

Infant Death Support

International Childbirth Education Association

www.icea.org

LaLeche League International 1400 N. Meacham Rd Box 4079 Schaumberg, IL 60168-4079 1-800- LALECHE www.lalecheleague.org

<u>March of Dimes</u> <u>National Capital Chapter</u> <u>703-824-0111</u> www.modimesncac.org

March of Dimes National Birth Defects Foundation

www.modimes.org

# **Perinatal Progress**

<u>Motherisk</u>

Programs, hotlines and articles on how to have a safe and healthy pregnancy

www.motherisk.org

<u>National Campaign to Prevent</u> <u>Teen Pregnancy</u>

www.teenpregnancy.org

#### National Center for Education in Maternal and Child Health

- A searchable database of more than 2000 MCH organizations
- Information about upcoming MCH meetings and conferences
- Descriptions of projects supported by the Federal Maternal Child Health Bureau
- Annotated bibliographies on selected MCH subjects
- Downloadable publications
- Links to other MCH organizations

#### www.ncemch.org

703-524-7802

National Clearinghouse for Alcohol and Drug Information

www.health.org

#### National Guideline Clearinghouse

A comprehensive electronic database with hundreds of clinical practice guidelines published by public and private sector organizations

www.guideline.gov

#### National Perinatal Association

www.nationalperinatal.org

### <u>Needy Meds</u>

Pharmaceutical programs that provide medications to people who can't afford them

#### www.needymeds.com

#### <u>Ask Noah</u>

For on-line information on a wide variety of health topics, ASK NOAH!

www.cuny.edu

NeoReviews

A new online only review journal for neonatal and perinatal professionals

www.neoreviews.org

<u>New York Times on the Web</u> <u>Women's Health</u>

www.nytimes.com/specials/women

<u>Northern Virginia Childbirth</u> <u>Network</u> www.childbirthnet.org

#### <u>Office of Minority Health</u> <u>Resource Center</u>

www.omhrc.org info@omhrc.gov

301-589-0951

<u>*ParentsPlace*</u> A resource site for parents

www.parentsplace.com

<u>Prevent Child Abuse Virginia</u> <u>1-800-children</u> www.preventchildabuseva.org <u>Regional Perinatal Council</u> <u>Virginia Baptist Hospital</u> <u>www.perinatalfocus.org</u>

#### RoseBaby.com

Mother and baby health, Lamaze, alternative therapy, etc.

www.Rosebaby.com

#### Shaken Baby Alliance

www.shakenbaby.com

#### <u>Sidelines</u>

A national non-profit network of support chapters for pregnant women on bedrest

www.sidelines.org

Box 1808

Laguna Beach, CA 92652

Single Mothers Support Group

www.singlemothers.org

### <u>Sudden Infant Death Syndrome</u> www.sidsalliance.org <u>Northern Virginia SIDS Alliance</u> NOVASIDS@yahoo.com

<u>Smoking and Health</u> Www.cdc.gov/tobacco

<u>State and Local Coalition on</u> <u>Immigration</u> Immigrant Policy Project www.ncsl.org/statefed/ipphmpg.htm

### **Teen Health Web Sites**

# **Perinatal Progress**

• Child Trends, Inc.

www.childtrends.org

Campaign for Our Children www.cfoc.org

• Children, Youth and Family Consortium

www.cfyc.umn.edu

• National Campaign to Prevent Teen Pregnancy

www.teenpregnancy.org

### Total Baby Care

www.totalbabycare.com

#### Tyler for Life Foundation

A website addressing issues of newborn screening and related disorders

www.tylerforlife.com

### Virginia Health Information

Information on hospital and nursing homes in Virginia, as well as a list of obstetricians in Virginia

<u>www.vhi.org</u> 804-643-5573

<u>Virginia Vital Statistics</u> www.vdh.state.va.us/stats/index

<u>When Hello Means Good-bye</u> <u>Perinatal Loss</u> <u>Grieving@teleport.com</u>

<u>The Women's Place</u> <u>Midlife Health</u> Http://hsc.virginia.edu/women

Youth Risk Behavior Surveillance

27 Www.cdc.gov/nccdphp/dash

### <u>Listserves</u>

National Center for Education in Maternal Child Health <u>Mchalert@list.ncemch.org</u>

Child Health Information Project www.childrensdefense.org/listserve \_\_\_\_\_chip.html

# **Perinatal Progress**

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Northern Virginia Perinatal Council Inova Fairfax Hospital 3300 Gallows Road Falls Church, VA 22042

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The Northern Virginia Perinatal Council is funded by The Virginia Division of Maternal and Infant Health, as part of MCH Block Grant, Title V, funding. Inova Fairfax Hospital is the grantee for the Northern Virginia Perinatal Council. To ensure that this newsletter meets your needs, we need your comments and participation. Please address any items you would like to contribute, or suggestions for topics for discussion to:

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Members.tripod.com/nvperinatalcouncil