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When Your Baby is Stillborn

By **Patricia L. Leh, M.S.**,
Catherine A. Reiser, M.S.,
Richard M. Pauli, M.D., Ph.D.

You may not have heard of stillbirth until you experienced it. When a baby dies before delivery, many people commonly think of miscarriage. Both stillbirth and miscarriage are types of pregnancy loss, but they differ by when the loss occurs. A miscarriage (sometimes called a spontaneous abortion) is when a baby dies before the 20th week of pregnancy. Stillbirth is the death of a baby after the 20th week of pregnancy but before delivery. Whenever parents deal with the death of their baby, whether it be early in pregnancy, late in pregnancy, or sometime after birth, there can be a great sense of disappointment, loss, and suffering. Stillbirth and miscarriage are separately defined not because one or the other is an easier or more difficult loss with which to deal, but because they differ in many ways. Stillbirth and miscarriage have different causes, need different evaluations, and differ medically and in the ways in which parents and families can best be helped.

Stillbirth is common. It may affect anyone. There is no way to predict when stillbirth will happen or who will experience it. Stillbirth occurs in families of all races, religions, and income levels. Each year in the United States about 25,000 babies, or 68 babies every day, are born still. This is about 1 stillbirth in every 115 births. Most often a stillbirth is detected while the

baby is in the mother's uterus, sometimes not until labor is underway.

Why Was Your Baby Stillborn?

Following a stillbirth, parents frequently ask, "Why did this happen?" Sometimes a reason is found; other times a specific cause remains unknown. Extensive and careful evaluation of the baby and placenta following delivery may help identify a reason in about 40 to 50 percent of stillbirths. When a specific cause is not identified, evaluation may still be helpful by at least ruling out potential high risks for recurrence.

Identifiable causes of stillbirth generally fall into one of three different categories: birth defects in the baby, problems with the placenta or umbilical cord, or maternal illnesses or conditions which may sometimes affect pregnancy.

* Birth defects are common but often overlooked causes for stillbirth. About one-fourth of babies who are stillborn have one or more birth defects that are responsible for their death.

* The placenta and umbilical cord are the baby's "lifeline" for oxygen and nutrients. Problems in either one may completely cut off or severely interfere with the needed flow of blood, oxygen, and nutrients to the baby. Although commonly pointed to as the likely cause for death of a baby, problems with

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tions in memory of the fol-
lowing people:

Bill Minor, Sr.

Ellen Bradley

Alfred Oscar Roberts, in-
fant Peter Bergero, son of
Yvonne Bergero, on the
occasion of his 20th birth-
day

My uncle, Ramon Cardona

My parents, Lucio Y.
Bernabe and Juanita C.
Bernabe

Debby and Leslie Mekbeb
In memory of Jahua Mek-
beb-Gillett

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Forbes

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Kushner, on behalf of Jor-
dan Nicole Reddy's 4th
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Emily Ann Dybsetter

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ory

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ory of Maria Corpos

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Louie, in memory of Baby
Louie the First

Debra and Kam Raoufian,
in memory of Neema
Shams Heydari

Network For Good — in
loving memory of Talia
Elise Nelson Twicken

Helping After Neonatal Death

Chapters:

HAND of the Peninsula
P.O. Box 3693
Redwood City, CA 94064
(650) 692-6655 crisis line
(650) 367-6993 office
Web site: <http://www.handsupport.org>

HAND of Santa Cruz Co.
P.O. Box 3693
Redwood City, CA 94064
(650) 367-6993 office
(831) 438-4513

**HAND of Santa Clara,
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1-888-908-HAND

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the placenta or umbilical cord actually account for only a moderate number of stillbirths.

* Although uncommon, maternal conditions may be responsible for stillbirth. Certain illnesses in the mother, such as diabetes or hypertension, and their treatments, sometimes cause stillbirths. An increased risk for stillbirth is also associated with the use of certain recreational drugs, particularly cocaine.

In addition, there are many other rare causes of stillbirth. Whether or not a specific cause for your baby's death is identified, it is most important to remember that stillbirths most often are not caused by something you did or did not do.

What Is Involved In An Extensive Evaluation Of The Baby?

Following delivery of a stillborn, parents may be asked to provide consent for extensive evaluation of their baby. This evaluation involves many different studies, including an internal post-mortem examination (autopsy), a physical examination, photographs of the baby's face, body, and any unusual features, X-rays, and genetic testing of some of the baby's tissues. If permission is given, evaluations are started soon after the baby's delivery. Detailed results are usually available and communicated to parents in a few weeks to a few months.

These studies can be helpful for many reasons. They may provide answers or insight to some of your questions including the frequently asked, "Why did it happen?" and "Will it happen again?" as well as those about manage-

ment and care in future pregnancies. Even if some questions remain unanswered, there may be comfort in knowing that as much as possible was learned about the baby and that important information may be added to medical knowledge which could help other babies in the future. The baby is treated respectfully at all times.

Agreeing to a comprehensive evaluation does not prevent a family from spending time with their baby or choosing to have a funeral, memorial service, cremation, or burial. Such evaluation is valuable to most parents as they try to deal with the full impact of their loss. In fact, very few parents express regret for having the suggested evaluations done. Nevertheless, some may think that such assessment violates their baby and intrudes upon their grief. Parents must choose what is best for them. Whatever the decision, it is respected.

What About Future Pregnancies? Will Stillbirth Happen Again?

Generally one stillbirth does not predict another. On average, there is approximately a 3 percent chance for stillbirth to happen again the next pregnancy - or approximately a 97 percent chance that a future pregnancy will not end in stillbirth.

Extensive evaluation of the baby may provide information that allows a geneticist, genetics counselor, or your doctor to determine more accurately what the chances are that stillbirth could happen again. Finding a specific cause may imply a much higher or lower risk than this average one. Specific causes, when discovered, more often result in a decrease in the estimated

risk that stillbirth may happen again and, less often, in an increase in that estimated risk. In almost all circumstances, subsequent healthy pregnancies are possible.

Making Sense Of What Happened

In the natural course of life events, babies are least of all expected to die. The loss of a baby through stillbirth can be overwhelming and devastating. Although surprising to some, the stillbirth of a baby is a great loss, as great as that of an older child or any loved one.

When stillbirth occurs, parents who are anxiously awaiting a baby suddenly are not. It is natural for you to grieve deeply for your baby who has died and for the hopes, dreams, and wishes that will never be; hopes, dreams, and wishes that, for you, were real long before the anticipated birth of your baby.

You may feel a strong sense of sadness, anger, or maybe bitterness at the unfairness of this tragedy. You may experience feelings of loneliness and longing, helplessness, or, because of the intensity of your emotions, confusion. Many parents also feel guilt. They often wonder if they did something to cause their baby's death; this is rarely true.

These intense emotions are real and a normal part of grieving. Grieving is a process of making meaning out of your loss and of life without your baby. Grieving is not easy. It is long, unpredictable, and requires a lot of energy. But you need time to grieve since grieving is necessary to work through pain toward healing.

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Support Meetings

Support meetings are informal gatherings where parents can receive and give support by sharing common experiences as we work through and resolve our loss. We cordially invite you to attend.

Meetings may start out with a topic of discussion, but everyone is free to bring up any questions or aspects of their loss which may concern them.

Attending your first meeting does take courage, but parents who attend find a comforting network of support, encouragement, friendship and understanding.

Nothing is required of you. There are no dues or fees. You need not speak one word. Even if you no longer need the meetings for yourself, come and share your experiences with someone who has recently suffered a loss.

HAND of the Peninsula

Support meetings are held on the first and third Wednesday of the month. Contact: Celia Hartnett (650) 367-6993

Time: 7:30-9:30 P.M.

Dates: Sept. 3 and 17
Oct. 1 and 15
Nov. 5 and 19
Dec. 3 and 17

Location: Sequoia Health and Wellness Services, 702 Marshall St., Redwood City.

HAND of Santa Cruz

Support meetings are held on the third Wednesday of the month. Contact: Kristie Shulman (831) 438-4513.

Time: 7:30-9:30 P.M.

Dates: Sept. 17
Oct. 15
Nov. 19
Dec. 17

Location: Congregational Church of Soquel

Pregnancy Support Meetings

Parents who are pregnant again after a loss have special emotional and psychological needs. Pregnancy Support Group meetings address the concerns of bereaved parents who have started or are thinking about starting another pregnancy. Fathers are especially encouraged to attend.

HAND of the Peninsula holds subsequent pregnancy support meetings on the second Wednesdays of the month as needed. Please call the HAND office (650) 367-6993 if you plan to attend or need more information

Time: 7:30-9:30 P.M.

Dates: Sept. 10
Oct. 8
Nov. 5
Dec. 10

HAND of Santa Cruz' subsequent pregnancy meetings are held on the first Wednesday of each month. Please call ((831) 438-4513 for more information.

Births

Benjamin Maxwell Bliss — July 5, 2003 to Dave and Kellie Bliss

Galen Mockett Hutcherson — July 9, to Phil Hutcherson and Emily Mockett

Shannon Elise Holtz — Aug. 7 to Brian Holtz, Melisse Luzin and big sister Zoe

Donations

Our warmest thanks to those who have sent donations to HAND of the Peninsula. It is through your support that HAND is able to grow and help others.

HAND parent Kristin Steadman collected donations for the Human Race in memory of her son Devin from the following donors:

Tricia and Joe McKinney
Jackie and Brad Erickson
Laura and Mark Deem
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Jorge Deleon
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Gina and Harvey Gaylin
Barr Hogan and Family
Nancy Thrane
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HAND cofounder Emily Corpos collected donations for the Human Race from the following donors:

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Nancy Mason, M.D.
Danielle Marchick
Florence Marchick
Cee Salberg
Richard Dioli

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HAND of the Peninsula

Invites you to our annual
SERVICE OF REMEMBRANCE

Huddart Park's Miwok Shelter in Woodside

10 a.m. Saturday, October 18, 2003

All parents, relatives and friends are invited to join others to remember their babies. Infants' names submitted before October 15 will be read at the service, along with personal readings, music and reflections.

Breakfast beverages and snacks will be served and wildflower seeds to scatter will be provided. To submit babies' names and birthdates, to volunteer and for any other information, please contact Leslie Muennemann at (650) 854-3901.

Huddart Park parking is \$5.

From highways 280 or 101, take the Woodside Road exit. Drive 1.5 miles west past the Woodside Road/Highway 280 intersection to Kings Mountain Road, turn right. Drive 2.3 miles to park entrance on the right. Ranger will direct you to the Miwok shelter area.

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Coping With Your Loss

Dealing with the death of your baby may be one of the most painful experiences of your life. Everyone copes and mourns differently. Perhaps a few of the following suggestions can help you weather some of the difficult times.

* Take care of yourself. Eat well. Get plenty of rest. Stay well physically so that you can continue to heal emotionally.

* Express yourself. Talk about your baby, your feelings, your fears, your grief. Or keep a diary, write a journal, create, start a garden. This may help you to see things more clearly.

* Read written resources. There are many books, articles, poems, and videos that can provide information, guidance, and support.

* Find a support network. Such a network may be your family, your friends, or your faith community. You may want to contact a support group for parents who have experienced the death of a baby, to share your story and feelings and to learn from others who have also "been there."

Above all, give yourself time. Be patient. You will never forget your baby, but you will heal. Healing is an ongoing process; it does not happen overnight. But it will happen.

This article appeared in the March/April, 1999 (Volume 8/Issue 2) edition of Sharing, the parent newsletter of The National SHARE Office.