

Helping Hands

Helping After Neonatal Death

Spring 2001

A Tale of Two Inservices

Parents share their loss experiences

By Christy Conklin
HAND of the Peninsula

A team of HAND volunteers has been giving regular inservice presentations to medical professionals and emergency workers in recent months.

The goal is to spread the word about HAND's services and help professionals, who are on the frontline at the time of a loss, understand what they can do to best serve their grieving patients.

In November, Dori Ives and I spoke to firefighters from the San Mateo Fire District. First, I went through our powerpoint presentation that summarizes HAND's services, the stages of grief, and what are helpful and harmful responses to grieving parents.

Then Dori bravely shared the story of how her baby died from SIDS several years ago. That was, of course, a difficult story to hear, but it opened the group up to an excellent discussion of the sorts of situations firefighters are faced with and what their responses are.

Virtually every firefighter in the audience had responded to at least one SIDS call. "It goes with the job," one said

sadly. They said losing children is the very hardest thing they face, and they usually respond by refusing to stop treating a child until they get to the hospital.

Even though (emergency medical technicians) EMTs have the authority to pronounce a death, they usually won't do it, out of hope. Theirs is a very active role and they often don't have much time for comforting parents. We emphasized that a few kind words can go a long way.

Losing children is the very hardest thing EMTs face and they usually respond by refusing to stop treating a child until they get to the hospital.

Firefighters are also often called when a woman is in the middle of miscarrying, and they have to be the ones to tell her what is happening, since she is in denial and shock.

Firefighters have a hard job, and though they might not be the touchy-feely types, I felt they were very compassionate, competent professionals who would do everything possible for parents in crisis.

They even agreed to carry HAND brochures on all of their trucks, so HAND's phone number will always be close at hand.

This past January, Stephanie Allen and I spoke to the nurses of the Neonatal Intensive Care Unit at Lucille Packard Children's Hospital.

Following the same format as the firefighters' inservice, we talked about experiences that are particular to the NICU. We emphasized that most parents want to be present in the NICU as much as possible, and that anything the nurses can do to make them feel welcome and part of the medical-care team is the best approach.

Stephanie said her experience at Stanford was excellent, and the nurses seemed to sympathize deeply with the needs of parents.

The nurses asked if dads or teen parents attend HAND meetings. Yes! The nurses requested additional brochures to include in their own grief and loss information packets.

Both inservices were very successful and should be repeated whenever there is sufficient staff turnover.

Retired Pediatrician

Ron Shapera M.D., elected HAND board president

Dr. Shapera chose pediatrics because he loved playing with children. "Of course, little did I know that it was going to be very, very different with kids in an office when they are ill and their parents are emotional about their illness," he said.

Born in Montreal, Canada, he completed his undergraduate degree, medical and residency training at McGill University, the only English-speaking medical school in Canada. After a three-year fellowship in infectious diseases at the University of Minnesota in Minneapolis, he returned to McGill to teach infectious diseases and run the microbiology lab for the next three years.

In 1975, at the age of 29, he, his wife Peggy, son and daughter moved to Palo Alto where the Shapera's have lived ever since. Before retiring from Kaiser Hospital in Redwood City in late 1998, Dr. Shapera served as staff pediatrician, assistant chief of the Department of Pediatrics for more than 10 years, head of the quality assurance department and consultant on pediatric infectious diseases.

Dr. Shapera has been a HAND of the Peninsula supporter since its founding in 1981, and has also served on its board since 1998. His job today, he says without joking is . . . bicycling.

"I would like to see HAND of the Peninsula become more visible in the community so people know about our services," he said. "I think we are only scratching the surface. Roughly seven babies die before the age of one out of every 1,000 live births nationwide and this isn't counting early miscarriages. Society tends to downplay the significance of early pregnancy loss. But it is quite meaningful to the mother."

Helping After Neonatal Death

Chapters:

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(650) 367-6993 office
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HAND of Santa Cruz Co.
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Helping Hands

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next issue:**

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Could You Please Just Listen?

**From "Getting Through Grief"
By Deborah R. Gemmill**

*My baby has died.
Please don't tell me you know how I feel.
You don't. You can't. I hope you never do.*

*Don't tell me he's with God and I should
be happy. How can I be happy when every
time I go into his nursery all I see is an
empty crib and toys that will never be
played with? How can I be happy when
my arms ache to hold him?*

*Please don't tell me God needed another
angel. It's hard for me to understand why
God would take away this little one who
was so loved. Maybe I'll understand later.
But for right now.....let God find another
angel.*

*Please, please, please don't tell me I'll
have other children. Maybe I will...but my
son was not a puppy that ran away....he
cannot be replaced.*

*Maybe you could just listen when I
remember out loud all the things that we
did together....the walks, the early
morning feedings, the first time he rolled
over. Maybe you could just sit with me
while I cry over all the things we'll never
do together.*

*Please don't tell me it could be worse.
How? I really don't want to hear about
your grandfather's death. It's not the
same. Don't think my pain will be eased
by comparison. Of course I'm glad that he*

*didn't suffer, but I'd be a lot happier if he
hadn't died at all.*

*I know it must be hard for you, but would
you mind looking at his picture just one
more time? We don't have many of him,
and I'm just a little bit afraid that I may
forget what he looked like. He wasn't here
that long, you know.*

*Could you please just listen?
Don't tell me I'll get over it.
There is no "over it," only through it.
Maybe you could just be with me while I
take my first steps through it.*

*Please don't tell me I should be glad he
was just a baby, or that at least I didn't get
to know him. I knew him. I knew him
before I ever saw him. He is a part of me.
And now he is gone. I haven't just lost a
seven-month-old baby. I have lost a part
of myself.*

*I know you mean well, but please don't
expect me to tell you how to help me. I'd
tell you if I knew. But right now I can
hardly put one foot in front of the other.*

*Maybe if you looked around, you could
find some things to do, like taking my
daughter for a walk, or doing the dishes,
or making some coffee.*

*Please don't try to remove my pain or
distract me from it.
I have to feel this way now.
Maybe you could just listen.*

1996 Beachcomber Press

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 PM

Dates: March 7 and 21, 2001
April 4 and 18
May 2 and 16
June 6 and 20

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

HAND of Santa Cruz County

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

Time: 7:30-9:30 PM

Dates: March 7, 2001
April 4
May 2
June 6

Location: Congregational Church of Soquel

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.

Denise and Miles Bresee in memory of Emma Gabrielle Bresee
Suzanne Koch and Andrew Fenselau
Cala Altizer and Rod Pasion, in memory of Zachary Pasion
Trisha and Gerard Inguagiato
Sarah Beekley
Molly Kuzman and Joseph Zimmerer, in memory of Michael Kuzman Zimmerer

Maureen and Jerry McMillan, in memory of Eileen Georgiana McMillan
Sharon and Leo Quilici, in memory of Christina Quilici
Emily and John Corpos, in memory of Maria Angelina Corpos and Juanita Bernabe

Prasanna Menon, M.D.
Esther and James Roberts, in memory of Jerome Roberts
The Razo Family, in memory of Adriana Victoria Razo
Alice and M. Pualuan, in memory of Douglas and Ruby Boatwright, "in honor of your life. We would have loved having you with us.

Love, Grandma and Grandpa."
Cheri and Michael Houle, in memory of Kelly Anne Houle
Denise and Jeffrey Goldman, in memory of Jason Goldman
Karen and Lee Bieber, in memory of Justin and Brandon Bieber
Irene Kennedy
Grace and Todd Moeller, in memory of Isabelle Grace Moeller's 2nd birthday
Lauren Tresnon Klein, in memory of Lowell Davin Klein
Kathleen and Victor Parrette, in memory of Malorie Anne Parrette
Jill Morgan and Doug Keare, in memory of Steven Bradford Keare
Deborah Robinson, in memory of Sean Patrick Robinson

Alicia and John McLucas, in honor of Laurie and Bill Crook
Ada and Bob Lai, in honor of Celia Hartnett. "HAND has done so much for so many parents and we believe that Celia's devotion and hard work have provided the foundation for HAND and the inspiration for all the volunteers who have worked with her over the years. We will be eternally grateful to HAND and especially to Celia for being there for us in 1987 and for her continued support of grieving families.

Christine and Michael Reeve
Emily and John Corpos, in loving memory of Bonny Perry.
Ada and Bob Lai, in memory of Jessica Erskine.
Phyllis Van Hagen, in memory of Sarah

Louise Cook Mills.
Merry Astor, in memory of Bernie Sax
Peggy and Ron Shapera, M.D.
Carl R. Nash, M.D.
Jackie Willson
Joanie and Carl King
Ann and Louie Schaffer
Caryn Goldman and Richard Hull, in memory of Sasha R. Goldman-Hull
Jill Nelson and Joe Twicken, in memory of Talia Elise Nelson Twicken and Isabelle Moeller's 2nd birthday.
Irene Lustgarten, in memory of Talia Elise Nelson Twicken.
Barbara Kirsch, Ph.D., in honor of Celia Hartnett

eScrip Supporters contributed \$569.30 in 2000. They are: Tish Alfonsi, Christy Conklin, Cathleen Findley, Suzanne Gallie, Lori Goldman-Reddy, Celia Hartnett, Lori McLucas, Leslie Muenemann, Ron Shapera, Joe Twicken and Jill Nelson, Judi Weidenfeld, and Jackie Willson.

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.

Both HAND of the Peninsula and HAND of Santa Cruz are currently holding subsequent pregnancy meetings on a as needed basis. If you would like to attend a meeting, please call: HAND of the Peninsula (650) 367-6993
HAND of Santa Cruz (831) 438-4513

Births

Peter Gordan Alfonsi, Dec. 22, 2000, to Tish and Richard Al-

Parenthood Lost

OB/GYN explains medical, genetic causes

By Christy Conklin

HAND of the Peninsula

Some of you may have seen in late January CBS's The Early Show segment on miscarriage. It was a very sensitively and well done piece, featuring Dr. Michael Berman, M.D., a professor of obstetrics at Yale University and author of the recently released book titled "*Parenthood Lost*."

The book is so new that as of early February, copies haven't yet made it to the bookstores. Instead of a proper book review, following is Dr. Berman's own description of the book.

"Losing a pregnancy or newborn is a grievous experience. Today the perinatal death rate in the U.S. -- which refers to fetuses 20-weeks-old through babies 4-weeks-old -- is about 14 per 1,000 births. Many more children die earlier in pregnancy and later in childhood.

" In "*Parenthood Lost*," I share my technique which helps parents deal with their grief and unravels the confusing genetic and medical causes of miscarriage, stillbirth, and infant death. Through original poetry, firsthand stories told by

parents, and articles describing genetic disorders, "*Parenthood Lost*" offers clarification and hope for parents who have suffered this tragedy."

Dr. Berman includes a section on the most common reasons for perinatal losses, with detailed medical information written by practicing obstetricians and a helpful glossary.

Chapters include: Poetry: Comforting Through Time; Cherished Purposes: Selections From a Doctor's Poems; Stories and Views; Parents' Stories of Loss; Caregivers' Views; Reasons for the Most Common Perinatal Losses; Reflections; A Database of Perinatal Losses; an index and bibliography.

Michael R. Berman, M.D., FACOG, is Clinical Professor of Obstetrics and Gynecology at Yale University School of Medicine and attending physician, Yale-New Haven Hospital. He is currently the President of the Yale-New Haven Physician Hospital Organization.

A graduate of New York Medical College, Dr. Berman is the founder and editor of Hygeia (www.hygeia.org), a

Web site devoted to alleviating the angst of a pregnancy loss or death of a child.

He also administers the Hygeia Foundations, Inc., a non-profit organization whose mission is to bring medically indigent and underserved populations, nationally and internationally, interactive information on maternal and child health.

Dr. Berman practices obstetrics and gynecology in New Haven and lives in Woodbridge, Connecticut with his wife and two daughters.

I have been corresponding with Dr. Berman about possibly coming to the Bay Area to speak to the medical community. He says he is "passionate" about making the issues of perinatal loss more accepted to the public and medical profession. He welcomes the opportunity to address audiences, both medical and non-medical.

Investigations into venues and funding continue. In the meantime, buy his book for someone you care about. Proceeds benefit the Hygeia Foundation. And visit his website, www.hygeia.org, for a wealth of information and support.

Human Race May 12, 2001

HAND of the Peninsula parents, friends and families once again will turn out the day before Mother's Day to raise much needed funds for our organization.

5K and 10K Walk and Run (rain or shine) includes activities for children, free t-shirts for finishers and park picnic grounds to enjoy free snacks.

The event will be held at Coyote Point Park, 1701 Coyote Point Dr., San Mateo. Registration starts at 7:30 a.m., the run starts at 8 a.m. and the walk at 8:45.

The annual Human Race is part of a statewide community fund-raising event coordinated by local volunteer centers to benefit nonprofit organizations.

Participants collect pledges to walk or run. This is not a pay-per-mile event. HAND receives 75 percent of the money collected on its behalf up to \$7,500 and 90 percent of everything over that. The Volunteer Center of San Mateo County keeps the rest to cover the cost of the event.

Last year over 1,400 people participated in the Human Race, raising over \$150,000 for 60 non-profit organizations.

Sponsor forms are available at the HAND of the Peninsula office, 702 Marshall St., Redwood City or by calling (650) 367-6993.

Adoption Night

Due to popular demand, we are planning to host another HAND Adoption Night. Tentative date and times are March 14, 7-9 p.m. This would replace the regular subsequent pregnancy meeting.

We will invite families who have adopted and any who might be wondering if adoption is right for them, to come and share upstairs in the fancy Board Room. Call (650) 367-6693 for more information.