

# Helping Hands

Helping After Neonatal Death

Fall 2001

## One Death Is Too Many

### *A Doctor's Perspective on Neonatal Death*

#### **Secret Wonders**

by Dr. James Berman, M.D.

*Born silent, born still,  
With the beauty of an angel,  
Elizabeth passed from my waiting hands,  
Into the hearts of her parents.  
First breath, last breath,  
Breathed within  
A body full of love;  
Youthful, hopeful, anticipating.  
Now a body full of sorrow.  
Elizabeth . . . a mother's child,  
Embraced by three mothers,  
Gave tiny footprints, inked mementos of  
What might have been.  
Yet as with life itself we are  
Guided by fleeting moments of  
Sweetness remembered  
And promises dreamed.  
The veil of death's darkness  
Will disappear like melting snows  
In springtime.  
Mercifully, prayers will turn  
Cries into song,  
Loneliness will fade.  
Life will move on.  
Elizabeth has touched us all.  
But her death will not harm us,  
for she has summoned the secret wonders  
Of what means love.  
And we have now become her children.*

**This poem was written for Elizabeth who was born still on Oct. 28, 1999. Dr. Berman shared the poem at her funeral.**

By Allison Campbell

Physicians are very familiar with the pain felt by family members when they lose a loved one.

The families may not realize, however, that the physicians also often suffer an emotional loss when a patient, especially a young one, is lost.

Dr. Lorry Frankel, the Service Chief of the Pediatric Intensive Care Unit at Lucile Packard Children's Hospital at Stanford, says, "A neonatal death is tragic and extremely disheartening. I lose sleep over it and work hard to avoid it."

Even the doctors who may appear numb to emotions when dealing with patients, are often deeply distressed by neonatal death.

Dr. Thomas Wisler, a family practitioner at the Palo Alto Medical Foundation, says that dealing with neonatal death is "emotionally

more difficult than anything else in my profession."

The degree of emotional attachment a doctor feels to his patient depends on several factors. In general, doctors become more emotionally attached to patients they've treated extensively for long periods of time.

A less obvious factor is that doctors who have been in practice longer may feel more for the patients' families.

After practicing emergency medicine for over 20 years, Dr. Bruce Campbell says, "Early in my career I was often so focused on the details of providing optimal care/resuscitation that I maintained more personal distance from the situation.

"Now I'm less distracted by facts and formulae and more

**Doctor's**

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## Heard from HAND Lately?

If you have received a call from a HAND volunteer lately, you know we are doing a phonathon to all HAND members to update our database. It's also an important way for HAND board members and key volunteers to connect with the membership and get a sense of what we are doing well and could be doing better.

As someone who is still trying to start a family following three miscarriages, I have really enjoyed my conversations with many "old-timers" who have been through the worst and come through the other side. It was particularly reassuring to talk to one woman whose loss was very like my first (premature labor at five months) and learn that she now has an 8-year-old son.

And it has been so gratifying to hear from people how much HAND helped them through their grief and loss. As I hoped and expected, the vast majority of HAND members are very thankful for the support HAND provided in their time of need, and many want to support HAND in turn by giving their time or money to help other parents in need.

If you've gotten a phone message or two, but haven't completed the survey, please call Judi at the HAND office (650) 367-6993 to verify your address and answer a few questions. And if you can help with any of the following volunteer activities, please contact the HAND office!

**Database Expert:** Do you know about various non-profit database programs and have experience setting them up? If you can advise us or help with the actual programming, we'd love to have your help. This is a short-term project that would require one or two meetings.

**Inservice Coordinator:** Our inservice coordinator is expecting, so we need a new volunteer to coordinate our inservices to hospitals, colleges, etc. This role requires an organized person to schedule presentations and assign inservice presenters by phone and email. It requires 2-3 hours a month, and the timing is flexible.

**Subsequent Pregnancy Meeting Facilitator:** Can you help facilitate these monthly meetings? They occur on the second Wednesday of each month at 7:30 p.m. and we try to have two facilitators at each meeting.

Finally, many thanks to all the board members and other volunteers who did the phonathon. Our new and improved database wouldn't be coming into existence without each and every phone call!

*Christy Conklin*  
HAND board member

## 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 Santa Clara Co.**  
(408) 732-3228  
South Alameda &  
Contra Costa Counties  
(800) 963-7070  
Central Valley  
(209) 823-5503

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## Helping Hands

*Editor:* Leslie Muennemann  
leslie@muenn.net

*Contributors:* Allison Campbell, Christy Conklin  
*Printing:* P.J. Hawkins

**Submission deadline for next issue:**

**OCT. 15, 2001**

## *A son remembers*

# **Yeah . . . moms, they never forget**

I was seven when my mother had a miscarriage. Twelve years later, the issue still bothers me as I struggle with coming to grips with the changes and uncertainty fate plays in all our lives.

I have two other brothers, both younger. And yet, I can imagine I could have had a third. He'd be 12 now, right in between my 14-year-old brother who just graduated from middle school and my 5-year-old brother just finishing kindergarten.

He would have been another mouth to feed, another fidgety kid to dress. He would have not eaten his vegetables and not practiced piano like mom told him. He would have needed someone to look at his homework and caused me to wait another 20 minutes while he collected his stuff from his closet at school. And yet, I would have loved him all the same.

It's hard to grieve as a child. How do you cry for someone you've never seen? How do you express outrage over something you barely understand? Looking back on that moment I saw my mother happy and tired when she came back from the hospital. And though I didn't realize it at the time, her eyes only hinted at her sadness. A friend, who's mother also had a miscarriage, told me once, "Yeah, moms. they never forget."

I was an innocent child. I was not disappointed then because I didn't know what to expect. My younger brother was two at the time and I simply saw him as another loud, fleshy person taking up

space. To imagine two such beings occupying my house was unthinkable. I hugged my mom. Another baby would just be more trouble. Charles was crying enough as it is anyway.

Over the next few days, my mother was quiet and calm. She never failed to kiss me on the forehead at any opportunity. While pleasant at first, this occasion quickly became a nuisance when there were GI Joe battles to be fought and pictures of battleships to draw.

Over the next few months, my mother regained her composure and went back to work. Months then turned into years. And our lives went on.

I am neither Catholic, nor Muslim, nor Buddhist. I suppose at best I would be labeled as an agnostic. "God's in His heaven, all's right with the world." His works can be both miraculous and incomprehensible. But whether we as people were meant to understand them remains to be seen. The best we can do is to continue on, and remain firm in the belief that we live our lives in the best possible way.

I do wonder what it would have been like to have another brother. But I love the ones I have all the same. And though my mother never forgets, she will forever remain my mother. And I do love her as well. I love her for what she has endured, for the spirit she has instilled in me, and for the unwavering love she has for all her children, both here and departed.

*Name withheld at author's request*

## 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:** Sept. 5 and 19, 2001  
Oct. 3 and 17  
Nov. 7 and 21  
Dec. 5 and 19

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

### HAND of Santa Cruz Co.

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. 19, 2001  
Oct. 17  
Nov. 21  
Dec. 19

**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.

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

**Dates:** Sept. 12, 2001  
Oct. 10  
Nov. 14  
Dec. 12

Call (650) 367-6993 for more information.

HAND of Santa Cruz's subsequent pregnancy meetings are held on the first Wednesday of each month.

**Dates:** Sept. 5, 2001  
Oct. 3  
Nov. 7  
Dec. 5

Call ((831) 438-4513 for more information.

## 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.

In memory of Kate Droppelman, daughter of Jeff and Jennifer Droppelman  
Christy Conklin, Sherokee Ilse and Cathie, donated some wonderful and much needed reference books to HAND's library

Wilma Burchell, Christian Counseling International, in appreciation of the inservice training conducted by HAND of Santa Cruz

Via United Way, Rob and Anna Strong, in memory of their son Andrew

Kathleen and Miguel Varas, in memory of Paul Daniel Varas

Carl R. Nash, M.D.  
Janet and Robert Conklin, in honor of Christy Conklin

Katie and Jim Potts, in memory of Kevin Flanagan

Edith Muennemann, in memory of her husband of 60 years, Gustav Muennemann

## Special Thanks

A special thank you to the HAND parents who provided inservice trainings as volunteer presenters or sharing parents: Christine Reeve, Christy Conklin, Laura Hawkins, Carol Vega, Sara Braden and Su-Mien Chong

Thanks to Laura Hawkins for making two hospital visits to parents needing support at Kaiser

**Donations** *continued on page 5*

# Donations

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Michele and Mark Hollar, in memory of our son, William Adam Hollar  
Margaret and Danny Shen, in memory of Alison Quinn Wei-Yi Shen  
Esther and James Roberts, in memory of Jerome Patrick Roberts  
Carol and Fernando Vega, in memory of Ruthie Vega  
Sara and Jason Braden, in memory of Gregory Hartnett  
Shoneen Erskine, in memory of Jessica Luck Erskine on Father's Day  
Santa Cruz Mothers of Twins Club  
Lisa, Kevin, Lauren and Julianna Kirkpatrick, in memory of Daniel James Kirkpatrick  
Kathy Olson, from the Olson Family in memory of Dana Kelly Olson  
Dr. Gary and Laura Aden Mar and Matt Hershenson, in memory of Baby Hershenson  
Carolyn and Bill Wilson, in memory of Amanda C. Wilson on her 6th birthday, June 29th  
Kelly Eickman, in memory of Sandra Lopez  
Kara and Darrell Carlyle, in memory of Christopher Zane Carlyle  
Mary and Dave Avelar, in memory of our son, Joseph Thomas Avelar  
Diane and Michael Vanni, in memory of Mitchell Davis Buckley  
Jane Dirks and Stephen Hirtle, in memory of Amelia Janet Dirks Hirtle  
Margo and Jerry Estruth, in memory of Molly Kristin Estruth  
Richard Dioli, in honor of Emily Corpos  
Janet and Alan Burr, in memory of Joseph Avelar  
Jones Mortuary

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## HAND of Santa Cruz County Human Race Donors:

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Harold and Carole Shulman  
Keri Landrum  
Lynn Reno  
Tony and Marty Mueller  
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David and Judy Spence

## In --- services

**April 16, 2001 --** at Kaiser Redwood City:

### Nurses:

Christine Reeve, presenter  
Carol Vega, sharing parent

### Labor and delivery, pediatric and post-partum departments:

Christy Conklin, presenter  
Sara Braden, sharing parent

## *Scouts' display, smocked gowns benefit HAND*

HAND of the Peninsula got a hand when high school juniors Megan Day and Leah DeMarchena teamed with members of "Wee Care" smocking guild for a special Girl Scout project displayed at the San Mateo County General Hospital in San Mateo.

Viewers learned about HAND's services while admiring tiny smocked gowns for preemies. These garments were later donated to HAND of the Peninsula.

Vicky Day, a nurse at the county hospital, said she received lots of feedback from hospital staff who were pleased to learn about both organizations.

"I think it's great that these two young ladies thought of this idea and did this of their own accord," said Celia Hartnett, a co-founder of HAND of the Peninsula and longtime volunteer.

Day and DeMarchena are senior San Carlos Girl Scouts and students at Notre Dame High School in Belmont.

# One death is one too many

**Doctor's** continued from page 1

personally involved with the patient and family."

Some doctors believe they also grieve more for the families of patients because they have children of their own and therefore more easily identify with the family and can imagine the pain inflicted by its loss

Dr. Wisler, who is also a devoted father, expresses the importance of maintaining a human relationship with the parents and grieving the inconceivable loss on a parent to parent basis.

Physicians do all they can to save lives and yet modern medicine is not always able to offer the necessary solutions. This can be extremely difficult for many doctors, such as Dr. Wisler who feels "helpless in the situation because for many conditions there's precious little I can do.

"I am always overwhelmed with a sense of failure, inadequacy and incompleteness."

Dealing with the families of lost patients is always difficult because they are often in shock and overcome with intense grief.

Dr. Campbell tries to treat the family as he would treat his own family. "If they want to be present while we attempt to resuscitate their baby, they may. I keep them updated on the progress, or lack thereof, of the code blue. After the baby is pronounced dead, I allow the family members time with their little one's body and de-emphasize our hospital administrative details for a while."

Families often appreciate the extra time the doctor spends with them after the baby has already died, even though the doctor's medical duties have been completed and there is nothing more the doctor can do for the patient.

Doctors hold a difficult position, as they must carry on with their work, treat more patients, and

fulfill administrative requirements, yet at the same time, they must also take the time to be sensitive to the situation and empathize with the family.

Dr. Frankel says, "The most important aspect of my relationship with the parents is honesty. The family needs to be assured that they have done everything they could and they need to be aware of all the complications with the disease.

He strongly encourages parents to work with support groups.

Whether a baby dies from SIDS or from any other unfortunate event or medical condition, Dr. Campbell, who sees about one such case per month, says, "One death is too many."

Although neonatal death is uncommon, there should still be a network of agencies with the purpose of helping families deal with their loss.

Dr. Frankel says, "Unfortunately we're not as well prepared for neonatal death as I'd like. We need more support for the families in the forms of hospice, palliative care programs and education for physicians and staff."

Doctors at Stanford Hospital and other hospitals around the country feel ill equipped to personally offer sufficient help to the families as they prepare for and deal with the deaths. Their professional experience shows them the overwhelming grief and loss the families feel and convinces them that the families need lots of support, preferably from support groups as well as from family and friends.

As for the doctors themselves, they sometimes need to turn to other doctors, nurses, spouses and close friends. For the doctors as well as the families, neonatal death calls for emotional support from people who understand and care.

*Allison Campbell is a Stanford University student participating in the community service writing program.*

***"I am always  
overwhelmed  
with a sense of  
inadequacy,  
failure and  
incompleteness"***

**Dr. Thomas Wisler, M.D.**

**HAND of the Peninsula**

***Service of Remembrance***

**Huddart Park in Woodside**

***10:30 a.m. Saturday, October 13, 2001***

**Parents, relatives and friends are invited to attend this free event.**

**We will remember and honor our children with music, poetry and readings. Look for details and an RSVP card in your mailbox in early September.**

**A catered BBQ picnic will follow at 12:30 p.m. and is optional.**

**Lunch tickets are \$15 (children under 12 are free). Parking is \$4.**

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

***October is***

***National Pregnancy and Infant Loss Awareness Month***

## ***Inservice Coordinator Wanted***

**HAND of the Peninsula needs a motivated, very organized and detail-oriented individual with excellent communication skills to coordinate inservice trainings.**

**Coordinator arranges for a presenter and sharing parents to speak to hospital, professional and community groups requesting the inservice.**

**Most responsibilities can be handled via email and phone.**

**Training provided**

**For more information contact Judi in HAND's office (650) 367-6993.**