

# Helping Hands

Helping After Neonatal Death

Summer 2000

## A father's story

### *Pain eases but wound yet to heal*

By Craig Papeyan  
HAND of Santa Clara County

Three years ago, I was really looking forward to the birth of our first child. Having gotten married later in life, I was both excited about having a baby and anxious about all the usual first-time dad fears and concerns. I was trying to balance a job which required a lot of travel with getting prepared to be a good father and husband. Fortunately, the anxiety subsided as the pregnancy progressed and my thoughts turned more to the future. That is, until "The Day".

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*"She was perfect in every way, but brain dead."*

When my wife Julie was 32 weeks along in her pregnancy, I was returning from a trip and called her from the car to let her know I would be home in an hour. She was very upset and said the baby had not moved in the evening. I told her to get to the hospital and I would meet her there.

When I arrived, Julie was being monitored and the baby's heart rate was very fast. At 6 a.m. the following morning, the doctor decided an emergency cesarean section was needed to save the baby. Even at this point, I had a strong belief that things were going to work out fine. Call it blind faith or ignorance, but it seemed like whatever the problem, there was sufficient medical technology to fix

it. My primary concerns were to be there for Julie and to comfort her.

I don't recall Emily making any sound, although Julie remembers two distinct cries. Emily's APGAR score was only 2 out of a possible 10 so she was rushed to the neonatal intensive-care nursery.

The doctors included both of us in discussions of options, treatments, and outcomes, but it became clear I would have to be the decision maker and the champion for what my wife and

I wanted to do. The nurses were very focused on caring for Julie and Emily and tended toward the "human" side of the issues. I really appreciated that. It was all I could do to try and take care of my wife, baby, and work through the technical discussions and choices that I felt were on my shoulders to understand enough so Julie and I could make the best decisions for Emily.

Over the next three days, we dealt with the agonies of watching our baby in the

**FATHER** *continued on Page 7*

### Benefit to mark baby's 5th

By Carolyn Wilson  
HAND of the Peninsula

Nearly five years ago, our journey with HAND and a new life began. Our first child, Amanda, was born on June 29, 1995. She was a healthy and beautiful eight pound baby girl.

When Amanda was six weeks old, a mysterious skin rash appeared on her body. At first it seemed harmless, but it wouldn't go away. After about a month, a skin biopsy revealed a diagnosis of *histiocytosis*, a rare, and in her case, fatal disease of unknown cause in which white blood cells multiply

wildly and attack skin, bones, lungs and other organs.

Other than her rash, Amanda didn't seem sick, but doctors recommended she undergo further testing. She was three and a half months old when we took her to Lucile Salter Packard Children's Hospital at Stanford University in Palo Alto for a routine visit.

Doctors there found Amanda to be much sicker than we had thought. She was admitted to the hospital for an emergency blood transfusion.

**BENEFIT** *continued on Page 8*

## An easy way to support HAND

Fund raising is the thorn in every non-profit group's side. HAND of the Peninsula is no exception. For years, our only source of funding was the generous donations made by bereaved parents, their family, friends and sometimes even employers.

But times have changed and HAND of the Peninsula is growing. Our little support group has moved from the church to a rent-free office, received grants from community foundations, hired a part-time administrative assistant and is on the verge of hiring our very first executive director. The changes are dizzying and exciting and scary. How is HAND of the Peninsula going to afford this growth?

Fund raising. Until we find a few generous donors with very deep pockets, we each have to help HAND raise the funds needed to continue supporting grieving families. There are many different ways to raise money: Bake sales, raffles, dinner-dances, auctions and of course grant writing. All are very labor intensive and time consuming. Although HAND parents for the most part are very grateful for the support they receive from the group, those still grieving the death of their baby simply do not have the energy and mindset needed to generate significant donations from outside sources.

Enter eScrip, a very simple and extremely popular fund-raising method local schools have embraced. Businesses such as grocery stores, want to be good citizens and give back to the community. Through the scrip program merchants can donate a percentage of sales to the organization of the customer's choice.

eScrip keeps track of every transaction enrolled shoppers make electronically using either a credit, ATM or debit card to pay for their purchases. The non-profit group receives monies generated on their behalf and the participants receive a paper account of their contributions.

The beauty of this method of fund raising is once you've signed up and paid your \$10 annual dues, you simply go about your life and let eScrip do the rest. In its brochure, the San Mateo based group explains that the information on your application is confidential and will not be revealed nor will your purchase information be sold. It is strictly so eScrip may track and collect the percentage of sales merchants want to donate to non-profits.

Please consider joining this easy fund raiser and ask relatives and friends to support HAND in this way as well. Every little bit helps and in time it will add up to a lot. Applications and a list of participating merchants are available at HAND of the Peninsula's office and website [www.handsupport.org](http://www.handsupport.org) Make sure you include HAND of the Peninsula's ID number 141808774.

### Helping After Neonatal Death

#### Chapters:

**HAND of Santa Clara County**  
P.O. Box 341  
Los Gatos, CA 95031-0341  
(408) 732-3228  
[info@h-a-n-d.org](mailto:info@h-a-n-d.org)  
<http://www.h-a-n-d.org>

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

**HAND of Santa Cruz County**  
P.O. Box 3693  
Redwood City, CA 94064  
(650) 369-6993 business office  
(831) 438-4513

**HAND of Alameda &  
Contra Costa Counties**  
P. O. Box 341  
Los Gatos, CA 95031-0341  
(800) 963-7070

**HAND of Central Valley**  
P. O. Box 341  
Los Gatos, CA 95031-0341  
(209) 823-5503

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#### Helping Hands

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next issue:**  
**AUG. 1, 2000**

## Mom gives poetic voice to dad's grief

By Anne Musial  
HAND of Alameda County

My husband and I lost our baby girl on Christmas Day 1999. I think it is safe to say his grief runs very deep. He would often come home from work and mention how he wishes he would be rushing home to see his girl. His heart was broken and it only broke mine all the more.

While I was pregnant with our daughter, Natalee, my husband Paul's voice would always get her going. He picked out her name, and when he came home from work and she would hear his voice, she would start moving and rolling like crazy. She was truly a Daddy's girl very early on and my husband loved it.

To help deal with my own grief, I write in a journal and write some poetry. My husband had asked if I could write a poem for him since he couldn't express himself quite as easily.

### Daddy's Girl

Natalee Elizabeth Musial,  
born still Dec 26, 1999

*Every day I follow you,  
I wish that somehow, you knew.  
In every thought you have of me,  
In everything you do.*

*I know how much you love me,  
I wish you wouldn't cry.  
Although I wanted to be with you,  
My soul was meant to fly.*

*You know Dad, I am happy.  
I am safe from any harm.  
Just imagine eternity,  
Protected in your arms.*

*So Daddy, please remember,  
Whenever you are down.  
I am always with you.  
When no one else is around.*

*I'll always know you love me.  
Until you leave this world.  
Then we'll be together,  
Forever, Daddy's Girl.*

## MY DAUGHTER

By Dan DiVerde

*Although the pain has eased,  
I still do cry.  
I'll never forget the day  
We said hello and goodbye.*

*You looked like a heavenly angel  
Dropped from the skies.  
I wanted nothing more  
Than for you to open your tiny little eyes.*

*A gasp for air, a sudden cry . . .  
I held my baby begging her to try.  
Holding your hand and kissing your face  
It finally sank in you had gone to a better place.*

*Oh Baby Girl, please don't go . . .  
I am your Daddy you never got to know.  
Why did this happen?  
Who took you away?*

*A man is supposed to be strong,  
But I want to cry every single day.  
On many occasions I'm filled with anger and grief,  
Then I look at your picture and get instant relief.*

*No matter what, with all the years to come,  
Your mother and I will always be down by one.  
Goodbye for now,  
My precious little angel.*

## 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 Santa Clara County

Support meetings are held on the first and third Thursdays of the month.

**Time:** 7:30- 9:30 PM

**Dates:** June 1 and 15  
July 6 and 20  
Aug. 3 and 17  
Sept. 7 and 21

**Location:** Our Savior's Church, downstairs library, 1224 N. Winchester Ave., Santa Clara (between Pruneridge and Scott), Santa Clara. Call (408) 732-3228 for information.

**Facilitators:** Nadine, Sherri, Carmen, Ellen, and Susan.

### HAND of the Peninsula

Support meetings are held on the first and third Wednesday of the month.

**Time:** 7:30-9:30 PM  
**Contact:** Celia Hartnett

**Location:** Sequoia Health and Wellness Services, 702 Marshall St., Redwood City. Call (650) 367-6993 for information.

**Dates:** June 7 and 21  
July 5 and 19  
Aug. 2 and 16  
Sept. 6 and 20

### 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:** June 21  
July 19  
Aug. 16  
Sept. 20

**Location:** Congregational Church of Soquel

**Facilitators:** Kristie Shulman (831) 438-4513

Kelly Passanisi Tartala (831) 662-0263

### HAND of So. Alameda County

Meetings are currently being held on the first and third Wednesday of each month.

**Time :** 7-9 PM

**Dates:** June 7 and 21  
July 5 and 19  
Aug. 2 and 16  
Sept. 6 and 20

**Location:** Washington Hospital, West 2500 Mowry Ave., Health Education Library, first floor. For more information call (800) 963-7070 and ask for "HAND."

## 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 Santa Clara County

Pregnancy support meetings are held the second Thursday of the month on an RSVP basis.

**Time:** 7:30-9:30 PM

**Dates:** June 8  
July 13  
Aug. 10  
Sept. 14

**Location:** Prince of Peace Lutheran Church, 12770 Saratoga Ave., Saratoga, conference room off of sanctuary.

**Facilitators:** Gina (408) 868-9605 or Kathy (408) 848-1716.

### HAND of the Peninsula

Subsequent pregnancy support meetings are on the second Wednesday of every month at 7:30 p.m.. Anyone wishing to attend a subsequent pregnancy meeting may call Celia Hartnett at (650) 367-6993.

### HAND of So. Alameda County

Subsequent pregnancy support meetings are being held as needed. Anyone wishing to attend a subsequent pregnancy meeting may call (800) 963-7070 or (925) 373-4114 and ask for "HAND."

**Time:** 7-9 PM

**Location::** Prince of Peace Church, 12770 Saratoga Ave., Saratoga, conference room off of sanctuary.

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## Donations

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

Nina and Torsten Borchers, in memory of Tara Maria Cherian Borchers

Karen and John Carroll, in memory of Justina Maxime Rose Andrea Cook

Michelle and Jim Olson, in memory of Jamie and Anna Olson

Julie and Craig Pampeyan, in memory of Emily Ann Pampeyan

Pamela Ross, JoAnn Thomas, Mei Mak, Young Kang, Marty Shook and Kathy Radcliff in the name of Kim Lewis and family

Dawn Wojcik, Mike and Sheila Giblin, Mitchell Sprugasci, La Vern Shrum, Brenda Bevil, Marguerite and Lawrence Boyle, and Karen Buchanan in memory of Jason Michael Oliver

Symantec Corporation, in memory of Michael Ryan Geiger

Edgar and Yolanda Thompson Pamela and Jeff Hoffman, Cyder Sinclair and Gerald and Margaret Gagle in memory of Garrett Hoffman

David and Linda Ceresa, in memory of Natalee Musial

Christopher and Patricia Wright, in memory of Ashley Wright

Timo Allison and Diana March, in memory of Callum Allison

Alana and Robert Lee, in memory of Kyle

Robert Lee, Carol Tunney Richard and Camille Coonradt, in memory of Kristina Coonradt

Vincent and Denise Brigantino, in memory of James Brigantino

Sherry Day and Michael McLaughlin, in memory of Brian Day

Larry and Irma Biral, in memory of Emily Biral

Randal and Shonna Helm Patrick and Janet Adamiak Bob and Astrid Warner, in memory of Jessica Marie Sousa

James Pellegrin and Pamela Potech, Peter and Lori Williamson, in memory of Shelby Hemenway Williamson

Stephen and Laura Decker Teri and Jeff Dunkin, in memory of Miranda May Dunkin

John and Janell White, in memory of Jacklyn Mae White

Anne and Peter Moran, in memory of Christopher and Michael Moran

Kathryn and Steven Wahl, in memory of Karyn Jean Wahl David and Kathy Haney, in memory of Jessica Haney

Lon and Jody Ledwith, in memory of Monica Ledwith

Beverly Schifferli, C. Naomi Kanda, Janine Paulsen, and Judith E. Martusin memory of patients of Santa Clara Valley Public Health Department

Elisa and Paul Donovan, in memory of Anthony, Isaiah, Isabella and Alexandra Donovan

**Donations** *continued on Page 6*

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## Births

**Peter Hamilton King**, Jan. 26, 2000, to Joan and Carl King and big sister, Caroline

**Erin Frances Schoemehl**, Feb. 22, 2000, to Melanie Yue and Tom Schoemehl

**Clare Julianna Hawkins**, April 27, 2000, to Laura and P.J. Hawkins and siblings Elyssa, John, Margaret and Kathleen

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## Special Thanks

HAND of the Peninsula is indebted to the generous grants extended by the Peninsula Community Foundation, Woodlawn Foundation and the Sandhill Foundation enabling HAND to continue extending its efforts to support bereaved parents.

Thanks also to Jim and Jeanmarie Zoland, of Santa Clara County HAND, for donating appreciated stock and, with the support of the Peninsula Community Foundation, for hosting a very successful Strategic Planning meeting for HAND of Santa Clara County. Members from Santa Clara, Alameda, Contra Costa, and Central Valley regions attended.

## Donations

*continued from Page 5*

Betty Wong, in memory of my unborn baby boy who would have been a year old this December

Anna and Rob Strong via United Way, in memory of Andrew

Intuitive Surgical Inc.  
UCSF Stanford Health Care  
Certified Staff Leasing

Janella and Harry Thodos, in memory of our daughter, Elizabeth Thodos

Margo and Jerry Estruth, in memory of Molly Kristin Estruth

Michael McDonald, in memory of my children, Angel Marie and Matthew Thomas

Carol and Craig Martin, in memory of Kathryn Martin and Milena Alfonsi

Anna Heffron, in memory of Michael Ada Heffron, who would have been 21 this year.

Sharon and Leo Quilici, in memory of Christina Quilici

Tracey Erwin, in memory of Andy Raznick

Lauren Klein, in memory of Lowell Davin Klein

Joanne Regalia, in honor of our daughter, Merleissa and our son Vincent

Rachel Kindt and Greg Marcus, in memory of our twins

Kathi Vagas, in memory of Michael Akin Stewart

Jane Bigwood, in memory of Katherine Rogers King  
Delia Arrizon, in memory of David Barraza

Jane Dirks, in memory of Amelia Janet Dirks Hirtle

Sofia and Paul Seregin, in memory of David Paul Seregin

Bryce and Shirley Nelson, in memory of Talia Elise Nelson Twicken

Lea Goldstein  
Anne Thomasmeyer  
Margaret Seligson  
Anne Graham, RN

Rasa Gustaitis, author of "A Time to Be Born, A Time to Die -- Ethical Issues in the Neonatal Intensive Care Unit," for donating this book to HAND's library.

Jodi and Wayne Barnes, in memory of their daughter, Amy Barnes' on her 5th birthday

Janella and Harry Thodos, in memory of Little Gunnar Blue-Indorante-Overman

Laurie McLucas and Bill Crook, in memory of Henry McLucas Crook

Carolyn and Bill Wilson, in memory of their daughter, Amanda C. Wilson

Elisa and Paul Donovan, in memory of Anthony, Isaiah, Isabella and Alexandra Donovan

## Fundraising Events

Thanks to those who participated in our fundraising events:

Robert and June Bloom,  
Karen D. Carroll, Irene Corrales, Gina and Blair Glenn, Emmanuel and Rhonda Jose, Anne Moran, Becky R. Mota, Heidi Olson, Craig and Julie Pampeyan, Nadine Silverstein, and Cindy Souza.

## Celia Hartnett honored as Volunteer of the Year

Celia Hartnett was honored as Volunteer of the Year for Women's Services at a luncheon, April 14, 2000, at the Hotel Sofitel in Redwood Shores.

"Celia's devotion to HAND parents over many years deserves recognition and we are very pleased the community agrees," said HAND of the Peninsula President Leslie Muenne-mann.

The event was sponsored by the Junior League of Palo Alto-Mid Peninsula, Inc. and the Volunteer Center of San Mateo County.

Celia came to HAND of the Peninsula from Santa Barbara where she founded a similar support group following the death of her son, Gregory, still-born in 1982.

As she is fond of saying, she "hitched her horse to Emily Corpos' cart." Emily founded HAND of the Peninsula in 1979, following the death of her firstborn, Maria.

The two women have coordinated HAND of the Peninsula services for many years, mostly out of their living rooms.

Thanks to Celia's dedication to bereaved parents' needs, HAND of the Peninsula has never missed a Wednesday night grief support meeting. She has also always found funds to help needy parents bury their baby.

neonatal intensive-care nursery suffer seizures and struggle to breathe. We ultimately came to the realization that, because of a kinked umbilical cord, she had been deprived of oxygen. She was perfect in every way, but brain dead.

The next morning, the doctors told us she was going downhill, and would probably not survive the day. Our minister met us at the hospital and baptized Emily, my wife and myself as a family. Throughout the day, we held Emily, sang to her and read her poems until she passed away just before midnight.

In the early days after Emily's death, we read about infant loss and various people's stories, so I was prepared for the role that I would be cast into. As the father and husband, most people asked me for factual information and how Julie was doing. I think that it is still commonly expected that the man will be in charge of the situation and deal with all the details, while the woman is the one with the feelings. I was fortunate to have some very close female friends with whom I could share my feelings about the situation, and that helped a great deal.

I understand that there are many cases where one partner blames the other for the death of their baby, and the divorce rate after the loss of a child is extremely high. We were fortunate to have had a relationship with a counselor from our premarital counseling, and we met with her while Emily was alive and regularly after her death. During the depths of my grief, there were times when I wondered if there was something Julie could have done to prevent this. Intellectually I knew there wasn't but the thoughts persisted. Fortunately, I kept them to myself.

While I didn't feel that my wife blamed me for Emily's death, I did struggle with a lot of feelings of inadequacy. I am a person who is driven to achieve -- to do things well and to do them right. I felt that I had let my wife down, as I was powerless to help her with the physical and emotional pain she was enduring. I couldn't help my baby -- there was nothing that I could do to "fix" her problems and make her better. I felt I had let my parents down too. They were getting on in years and had been looking forward for a long time to a grandchild. I think that this lack of control was a very significant element in my

grief -- the inability to "do" anything to stop or change the course of events.

The experience of losing a child has significantly changed my life and relationships in a number of ways. The most obvious to others, although not to me, was the realignment of priorities. My family is clearly number one now, and I strive to spend as much time with my wife and subsequent daughter, Kristin, as possible. I've also found that I am more confident connecting on a personal level with my business associates. This usually comes about when I am asked, "How many children do you have?" My answer almost always is, "Two. One living and one who didn't survive." I think the loss of my daughter has drawn me closer to my friends who remember Emily and talk about her openly and the effect she has had on our lives.

Everyone has their own way of dealing with grief, and each must deal with it. This seems to be harder for men than women, though either way, it's hard. Seeing a counselor helped us understand our feelings and really get to the heart of the choices we would be making. We got involved with HAND immediately so we could see how other parents were dealing with their grief and learn what to expect. To be honest, at our first meeting a week following Emily's death, we thought we had our act together and all these other people were having a much harder time dealing with their losses. Later, we realized we were still in shock and denial. We had all the same issues to deal with as everyone before us. Had we not stuck with the meetings, I don't think we would have realized this or dealt with our grief as well.

Volunteering to help other HAND parents, contributions to our church and hospital and the sterling bracelets we had made to replicate the hospital identification bands we were given when Emily was born -- all help us remember Emily.

Although it does get easier over time, there are moments that bring me back to the time of our loss. "Butterfly Kisses," by Bob Carlisle came out at the time of Emily's death. It's a song from a father about his daughter growing up and getting married. To this day, whenever I hear that song, it brings tears to my eyes as a reminder of all the things in life I won't get to do with Emily -- watch her play, go camping, walk her down the aisle. It gets easier, but the hole in my heart never goes away.

***" 'Butterfly Kisses,' a song from a father about his daughter growing up and getting married, brings tears to my eyes as a reminder of all the things in life I won't get to do with Emily."***

**BENEFIT** *continued from Page 1*

They also recommended Amanda begin a long course of chemotherapy in which a "central line" would be surgically placed in her chest. Overwhelmed with what we heard, we could only hold her and hope that she would be all right.

After several blood transfusions and two surgeries, Amanda was not doing well and getting sicker. After three days in the hospital, Amanda had endured two cardiac arrests. In the middle of the night on October 10, 1995, doctors told us there was nothing more they could do. We held her tightly in our arms and watched the monitors as her heartbeat slowly came to a stop.

On June 29th, 2000, we would have been celebrating Amanda's 5th birthday. My husband and I wanted to do something very special this year. We decided to have a Golf Tournament fund raiser to benefit the Histiocytosis Association of America. This is the only organization that funds medical research

programs looking for the cause, best treatments and cure of this life threatening disease called *histiocytosis*. Approximately 1,000 new cases are reported annually, primarily among young children. It can cause lifelong problems or be fatal. The cause, cure and best treatments are unknown. And since it is rare, there is no government-funded research regarding the disease.

The golf tournament will take place at 1 p.m. Friday, June 30 at Sharp Park Golf Course in Pacifica (off Hwy 1). Cost is \$125 per person donation and includes 18 holes, cart, lunch, and banquet dinner. Hole sponsors (\$250 or \$500) and donations are gladly accepted. Checks should be made payable to: Histiocytosis Association of America Tax ID: 22-2827069 and sent c/o Bill and Carolyn Wilson 1171 Fairmont Dr. San Bruno, CA 94066 or call (650) 952-4779. You may also contact the Histiocytosis Association of America directly at (800) 548-2758 or visit their website: [www.histio.org/us](http://www.histio.org/us).