



Helping Hands

Fall 2010

Mom shares her journey of loss

By Barb Knopf

As I write this, it has been over a year since I attended a support meeting and I have missed going to them. My son Daniel Brett was born December 27, 1994, and died January 17, 1995, but I still feel the need to talk about him. My family, husband and everyone around me was very supportive of my feelings at the time of Danny's death, and even for a long time afterward. But now, at this time (1999), it has been four whole years since his death. It feels like I shouldn't be crying about Danny anymore, and everyone assumes that four years should surely be enough time to "get over it." Right?

Maybe, but it is not a matter of "getting over it." The death of my own child is not something I am going to get over, like a cold or a grudge. I feel changed, like I am on a different road than I was before. I still enjoy going to support meetings and talking about my son. It is the only safe place to still cry about him and talk again about his precious little life, the life of my Danny.

My son was born full term with the anticipated diagnosis of Holoprosencephaly, a condition of the brain that is incompatible with life outside the uterus. He lived at home with his father, sister, and myself for three weeks. And then he died silently while I slept next to him.

The three weeks we had with Danny were a miracle, a gift and a blessing. He was supposed to die before or immediately after birth. But instead, we were given three weeks to get to know him, create memories by spending time with him and to wait for and prepare for his death. It was a little capsule of time that now seems so awesome and monumental and yet, so hard to believe it was real. The decisions that we had to make about Danny's medical care were impossible decisions, but I do not have any regrets. My family has provided absolutely wonderful support, as has my husband. But I still struggle to find "positive resolution" for myself.

I still try to find the meaning behind what happened to my son. I try to stretch my brain, think harder and deeper. I challenge my values and my character to see if I can come up with a lesson that I learned or a way in which I am a better person. Sometimes, I think I understand and I am at peace. Sometimes, days go by and I don't think about Danny, but if I close my eyes, I can feel my arms holding his body and it all comes back with shocking realism. I can feel his fuzzy head under my fingertips and the warmth of his green flowered blanket. I can see his blue and gray eyes. I can almost, but not quite, hear him cry. I can see myself half-smiling as I walk down the aisle of the church at his funeral. I was operating on adrenaline and it sort of felt that it wasn't really me

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HAND of the Peninsula

Ways to support HAND parents

Among the many ways one may honor the memory of their children is to give back to the organization and ensure that HAND of the Peninsula will continue to provide the caring support and other vital services for which it has become well known over nearly three decades in existence.

As a 501c3 non profit, HAND of the Peninsula is governed by a Board of Directors which welcomes new members who bring fresh ideas, talent and energy to our common endeavor. The Board meetings are held quarterly in the evening on the fourth Wednesday of the month. HAND of the Peninsula is run predominantly by parents who have experienced a loss and financed entirely with donations from parents, family and friends. Without their support, HAND would cease to exist. Consider getting involved in any of the following ways:

- * **Schedule and/or facilitate inservice trainings where a sharing parent tells their personal story to healthcare providers interested in learning how to be more sensitive and helpful to parents experiencing a loss**
- * **Library organization and management**
- * **Write and edit the quarterly newsletter, *Helping Hands*, get it to the printer and post office**
- * **Distribute brochures to area hospitals which in turn give these to parents experiencing a loss**
- * **Bookkeeping and accounting**
- * **Fundraising (donations are our sole support)**
- * **Helping with special events like the annual Service of Remembrance, Volunteer Appreciation Picnic, updating the recommended book list**
- * **Anniversary and Special Dates remembrance**
- * **Schedule meeting facilitators**
- * **Attend training and become a meeting facilitator or phone support volunteer**

If you have a talent you wish to share or would like to learn more about ways to get involved and support parents please email: volunteers@HANDsupport.org or call (650) 367-6993.

Helping After Neonatal Death

Chapters:

HAND of the Peninsula

HAND of Santa Cruz County

HAND of Antioch

HAND of San Francisco

P.O. Box 3693

Redwood City, CA 94064

(650) 579-0350 crisis line

(650) 367-6993 office

<http://www.HANDsupport.org>

Helping After Neonatal Death

Santa Clara, Alameda, Contra Costa and Central Valley counties

P.O. Box 341

Los Gatos, CA 95031-0341

(888) 908-HAND (4263)

<http://www.handonline.org>

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Helping Hands

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NOV. 1, 2010



HAND of the Peninsula

**Invites you to our annual
SERVICE OF REMEMBRANCE**

Huddart Park's Miwok Shelter in Woodside

**10 a.m. until Noon
Saturday October 9, 2010**

*All parents, family and friends are invited to
join us to remember our babies.*

*Infants' names, dates, poems and short stories
submitted by October 2 to
fandl@muenn.net*

*will be included in the printed program and 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 volunteer and for any other information, please
email info@HANDsupport.org or call (650) 367-6993.*

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.

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: (650) 367-6993

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

Dates: Sept. 1 and 15
Oct. 6 and 20
Nov. 3 and 17
Dec. 1 and 15

Location: Follow signs to Palm Room at Mills Health and Wellness Center, 100 S. San Mateo Dr., San Mateo

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. 15
Oct. 20
Nov. 17
Dec. 15

Location: Congregational Church of Soquel

HAND of Antioch

Support meetings are held on the first Thursday of the month. Contact Elham Raoufian, (925) 437-3406 for location.

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

Dates: Sept. 2
Oct. 7
Nov. 4
Dec. 2

HAND of San Francisco

Support meetings are held on the first and third Wednesday of the month. Contact: Chris Lehr, LCSW, (415) 282-7330.

Time: 6:30-8:30 P.M.

Dates: Sept. 1 and 15
Oct. 6 and 20
Nov. 3 and 17
Dec. 1 and 15

Location: California Pacific Medical Center, Castro at Duboce Streets, Support Services Conference Room, Level B

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 Wednesday of the month at Mills Health and Wellness Center, 100 S. San Mateo Dr., in San Mateo. Contact: (650) 367-6993.

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

Dates: Sept. 8
Oct. 13
Nov. 10
Dec. 8

HAND of Santa Cruz Co.

Subsequent pregnancy meetings are held on the first Wednesday of each month. Contact: Kristie Shulman (831) 438-4513

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

Dates: Sept. 1
Oct. 6
Nov. 3
Dec. 1

Location: Congregational Church of Soquel

Births

Aliza Harrington — Jan. 25, 2010, to Dan and Kara Harrington and big sister Evelyn

Grace Elizabeth Loehmann — Feb. 26, to Sara and Jeff Loehmann

Alexandria Jade Foster — May 10, to James and Denise Foster and big sister Alyssa

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.

Emily and John Corpos, in memory of Maria Corpos, Eduardo de la Cruz, Maria Vigil and in honor of Celia Hartnett and Chuck Cheshire

Tami and Dan Sell, in memory of Anthony and Jennifer Sell on their fourth birthday

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who was standing there. I can feel the freezing cold rain on my feet as I watched a stranger place the tiny casket on top of my only son's grave.

In retrospect, I wish someone had said to me, "You know your son is going to die. I want you to think about what you want his funeral to be like." And, "I want you to know that the moment of his death and what you do with him when you say goodbye is a memory that will last in your head forever."

The memory is a complex thing and it plays cruel tricks. I want to remember all the happy moments of Danny's life and the little things that we did while he was briefly part of our everyday family life. But the memory that remains carved in my head as if it was yesterday is when I made the phone call to my mother to tell her that her grandson was dead. It still hurts. And it feels lonely, like no one else knows. There is a hole inside of me where my son should be and it can not be filled. That I cannot change.

WHAT HELPS ME

Writing

I keep two journals by my bed. In one, I write anecdotes about my two daughters and in the other, I write the private, confused ramblings, thoughts and poems of a grieving mother. It helps me to get my feelings out of my head and onto paper where I can look at and preserve them. Sometimes my need to write is almost urgent, as if my head is filled with poetry about Danny and I just have to get it out before I forget it. Even now, four years later, I still think of things about Danny that I want to write down.

Sharing

Talking about what happened and how I feel is a release. When I talk about Danny, it can help someone going through a similar situation. Helping others with their pain is probably the number one best thing I can do to help myself. It helps me to realize that I am not the only one in the world who is hurting; it helps me to be less self-absorbed.

Praying

This may take any form. I used to cry every time I said the Our Father, but I don't anymore, which is another small step. I talk to Danny all the time in my thoughts. And I take my daughters to his grave frequently for picnics and special occasions. They play hide-and-seek and bug hunt all

around his grave. In a way, they are praying. My youngest is named Hope, and she believes the angel statue in the St. Charles Memorial Gardens is named after her. I pray for strength, patience, peace and to be reminded of what is important in my life.

Looking for signs

If I notice a sign, I try to accept it for what it is without questioning. A sign is a message. Listen to it. Don't dissect it or doubt if it is real. Real is a relative term.

Honoring

Honor memories in any way that feels right. Emily, my oldest daughter, sends balloons to heaven whenever she gets a chance. My parents planted trees in Danny's name. I myself spent months creating a photo album with all my mementos from Danny's life. I journaled all around the pictures and made pockets for things such as his birth and death certificates and special cards that I received.

Working with my hands to make something tangible for Danny was very therapeutic for me. I needed a very special place to keep all the things that had touched his skin and smelled like him. I only had a few earthly things of his and those things are like diamonds to me. I consider my album one of my most precious possessions.

For about thirty minutes before I went to bed, I used to have a ritual of sitting outside and staring at the stars. This was when I talked to Danny and tried to recreate and understand his short life in my mind, over and over. I wanted to make sure I didn't ever forget anything. I would reflect on what I learned from Danny and how my life, my marriage and everything had changed. I have filled my home with pictures, statues and candles of angels as well as anything else that reminds me of Danny and Heaven. My angels comfort me and help me feel better.

Hoping

I hope I will see Danny again and that thought helps me to move on. I hope he sees us, his family. Now, I hope he knows I love him and how hard I tried to do what was best for him (my husband Dan and I labored over decisions pertaining to life support for Danny). I hope we made the right decisions and that hope always lingers in the corner of my conscience.

Setting no time limits

Not setting time limits on myself has been important, for grief waits, even four years down the road. I do not expect others who have not been

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in my shoes to ever fully understand how I feel. So, it has helped me to write, but I am still not sure of where I am in my journey. Grief is a journey, forward moving, full of bumps and hills, unexpected passes and forks in the road. As I move along it, I grow, change, learn, adapt and adjust at each turn. I am still uncertain and very sad at times, and I still miss Danny. *But, I have made it this far!* And I did not think I would. Danny is helping me. Perhaps he is on a journey, too. Maybe he is growing and rejoicing sometimes, too. We started our journeys as one. Now we are separated, but with love and through prayer, we are together.

This article appeared in the July/August, 1999 (Volume 8/Issue 4) edition of Sharing, the bereaved parent newsletter of The National SHARE Office.