

Helping Hands

Helping After Neonatal Death

Summer 2001

The story of Troy and my baby photo retouching service

By Marty Mueller
HAND of Santa Cruz Co.

In late 1998, my husband Tony and I, after many long months of going back and forth trying to decide if we were up to the challenge of parenthood at our ages, came to the conclusion that we would never regret having a child together and we should at least try.

Tony was so happy, he was going to have a son! I was so happy at the thought of the new life we would share.

I was 41 and Tony 38; I have a teenager from my first marriage. This is a second marriage for us both.

Troy was conceived two months after we began trying. We were

thrilled and thought it must have been "meant to be."

My pregnancy went smoothly, no complications. My weight and blood pressure were good. We had an ultrasound and amniocentesis at 16 weeks. Our baby was genetically normal and everything looked great!

Tony was so happy, he was going to have a son! I was so happy at the thought of the new life we would share. Troy was due in early October, 1999.

After many long months of anticipating our son's arrival, the unthinkable happened just days before he was due. On Sept. 22, 1999, while at the doctor's office for one of my final weekly visits, my doctor

and I were shocked to find my baby's heartbeat was not detectable.

An ultrasound confirmed that there was no heartbeat and my baby was dead.

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I was so stunned I couldn't even move. Although I could barely talk, I somehow managed to call my husband at work and ask him to meet me at the doctor's office.

Once he got there, seeing the pain in his eyes, I fell apart. How could this have happened? What did we do wrong? We racked

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Memorial Funds

Keep baby's memory alive

More often than not, friends and family of grieving parents struggle to find some meaningful way to express their love and support. The parents have only one desire: to have their baby back safe and sound. Short of that, they often want to be with other parents who have lost a child -- peers riding the same roller coaster of emotions. In such company they feel safe and understood.

Those of us who have received HAND of the Peninsula's support know it made and continues to make an enormous difference. We also know the need for HAND's support will not end with us. Parents will follow and they will need our support.

HAND of the Peninsula's fundraising committee chaired by board member Christy Conklin, is exploring ways to ensure we have a steady and reliable stream of funding so peer support may continue. Grants are still being sought but are not guaranteed, no matter how worthy our cause. Grantors want to see a strong financial commitment to the organization from the "insiders." In HAND's case that would be the parents seeking support, their families, friends and others benefiting from HAND's services.

Recently, HAND of the Peninsula opened an account at Charles Schwab & Co. to allow donations of securities and recurring direct deposits from donors' bank accounts (similar to payroll direct deposits). Funds from the eScrip program continue to trickle in as more people sign up and patronize participating merchants. To encourage signups, the annual \$10 dues will be waived for a limited time. Please call HAND's office to sign up if you haven't already.

We never want to forget and would like those close to us to never forget our precious baby. Giving to HAND of the Peninsula regularly, in memory of our baby, keeps their memory alive and continues the support HAND of the Peninsula extends to parents just beginning their long, painful journey.

Helping After Neonatal Death

Chapters:

HAND of the Peninsula
P.O. Box 3693
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(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
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HAND Santa Clara Co.
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Contra Costa Counties**
(800) 963-7070
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Helping Hands

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Mother's grief spawns service

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our brains to try to think about Troy's movements within the last 24 hours.

I'd noticed a slowing down of movement but I remembered reading that was normal as the baby prepares for birth! I'd noticed rapid hiccuping a few days before but dismissed that as normal too. We were totally and completely devastated! We didn't even know such a thing could happen so late in a pregnancy.

In a daze, we went to the hospital where labor was induced and we waited. Troy was stillborn in the early hours of Sept. 23, 1999. He was 8 pounds, 2 ounces and looked perfect! His color was so good that our doctor commented that he had only recently died.

He was so beautiful and looked so normal that both Tony and I found ourselves whispering in his ear, "wake up Troy" in a desperate attempt to make what was happening only a terrible nightmare. But it was all too real. He was gone.

We spent the day holding him knowing that this would be the only

time we would ever have with him. Our nurse lovingly cleaned him, dressed him and took photos of him in our arms. The chaplain came and we had a religious ceremony for him.

By the end of the day, still in a dazed state, we released him to the mortuary we had selected. His little body was cremated a few days later. We keep his ashes and his pictures in a place of honor in our home. I am confident, that day was and will always be, the saddest day of our lives.

He was so beautiful and looked so normal that both Tony and I found ourselves whispering in his ear, "wake up Troy" in a desperate attempt to make what was happening only a terrible nightmare.

Analysis of the cord and placenta found no abnormalities. Ultimately, his death was ruled a "cord accident."

When he was born, the umbilical cord was wrapped around his neck but that does not necessarily mean that was the cause of death.

We learned that while one percent of all babies are stillborn, one tenth of one percent are stillborn due to cord accidents. What that really means is doctors don't know what causes death for these babies

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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 PM

Dates: June 6 and 20, 2001
July 4 and 18
Aug. 1 and 15
Sept. 5 and 19

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: June 20, 2001
July 18
Aug. 15
Sept. 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.

Dates: June 13, 2001
July 11
Aug. 8
Sept. 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: June 6, 2001
July 4
Aug. 1
Sept. 5

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

Births

Peter Gordon Alfonsi, Dec. 22, 2000, to Tish and Richard Alfonsi

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.

Celia and Don Hartnett:

- ◆ in memory of all the tiny souls lost during the year 2000;
- ◆ in memory of Gregory Matthew Hartnett who would have been 18 on Dec. 22, 2000;
- ◆ in honor of Leslie Muenne-mann for her dedication to HAND during the past year, both as HAND's President and as Editor of the HAND newsletter;
- ◆ in honor of HAND's Advisory Council for their willingness to support HAND's work;
- ◆ in honor of HAND's wonderful board of directors who work so hard to continue HAND's mission;
- ◆ in memory of Adrian "Bud" Moorman, San Mateo County Coroner and HAND Advisory Board member, for his dedicated service to bereaved families over many, many years;
- ◆ in honor of Marie Violet and Sequoia Health and Wellness Center for their gracious hospitality to HAND during the year 2000;
- ◆ in honor of Marge Sentous and Joan Libman for their work "behind the scenes" on behalf of HAND;
- ◆ in honor of HAND's volunteers, who allow their own sorrow to become a gift of comfort towards others;
- ◆ in honor of Judi Weidenfeld for her positive, cheerful support to HAND families and HAND's board, often above and beyond the call of duty.

El Camino Hospital nursing staff, in honor of the grandchild of our friend, Marilyn Swarts.

Sharon and John Dankwardt, in memory of Clark Elworthy.

Donations *Continued on Page 5*

Donations

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Eleven children's books were donated to the HAND library by Stephanie, Gary, Hobson and Avalon Allen in loving memory of Alexander.

Anne and Kenneth Graham

Tish and Richard Alfonsi, in memory of all the lost babies of HAND parents.

Kim, Philip, Erik and Mark Schiller, in memory of Jessica Erskine.

Patti Leeper and Craig Ball, in memory of Abigail Leeper Ball.

Michelle and Tara Browner, in memory of Clark Elworthy.

Barbara Scott and David Rotstein, in honor of Todd Elworthy and Debbie Reuter.

PipeVine, Inc.
Joanne Regalia
Allan Bernstein, M.D.

Irene Lustgarten, in memory of our niece and cousin, Talia Elise Nelson Twicken.

Paula-Jo Husack, MA, LMFT
Mar and Matthew Hershenson

The Seregin Family, in memory of David Paul Seregin.

Silvia Zerbato, in memory of Stevie David Garcia.

Sara and Jason Braden, in honor of Celia Hartnett.

Audrey Jacob, in memory of Matthew Nathaniel Jacob.

Robin and David Costa, in memory of Alec Robert's 3rd birthday Apr. 12, 1998.

Marie and Patrick Smith in memory of Joseph Daniel Pechacek.

The Ponzini Family in loving memory of the late Mary Ponzini Deutsch.

Carol and Richard Clark in honor of Laurie and Bill Crook

Charmaine Thomas in memory of Marilyn Swarts' grandson and Angie and Chris' son.

Stephen J. Buchner, M.D.
Kathryn E. Matthews, M.D.
Sarah Beekley Ttee

Karen and Lawrence Schwartz in memory of Joseph Pechacek who passed away in the Stanford Children's NICU and is the grandson of Marilyn Swarts.

Marian Urman in memory of Joseph Daniel Pechacek.

John Ochsner in honor of Christy Conklin.

Jim and Louise Meiman
Charitable Gift Fund in memory of Mark Meiman.

Craig Martin and Schwab
Matching Gifts Program.

Marian Filipowicz to Christy Conklin for the Human Race.

Christine and Michael Reeve in loving memory of our sons, Edgar and Christian.

Suzanne Gallie and Gap
Foundation Gift Match Program
in memory of Kyra Moree Mitchell.

Donna and Thomas Baker

Leslie and Frank Muennemann,
in memory of "Opa" Gustav Muennemann

Edith Muennemann

Photos

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but they think it has something to do with the umbilical cord.

Not having a reason why we lost our precious little boy has been extremely difficult; it is still difficult to accept so many months later.

Sadly, our heartache continues as I have been unable to conceive successfully again. We've had a miscarriage and many, many months of disappointment. My doctor tells me that we should give up trying. At 44 years old, the odds of a successful pregnancy with my own eggs are ridiculously low.

A few months after our loss, we went to a HAND meeting. There we met loving special people who were personally familiar with our tragic loss. We learned that losses such as ours happen, doctors don't tell you about it but these people sure would.

At one of the meetings, I shared my photos of Troy which I had digitally retouched and improved. My goal in digitally retouching them was to create photos of my Troy that I could display and comfortably share with family and friends without worrying that they were too graphic for public viewing.

Other parents in my HAND group were so impressed that they asked if I could do the same thing with their precious baby photos. I gave it a try.

Photos *Continued on Page 7*

Why We Give to HAND . . .

We give to HAND of the Peninsula financially as well as by volunteering our time to assist with program support and other administrative needs. The support we received when our daughter died, as well as through subsequent miscarriages, was invaluable to us and we try in some small way to give back so that this incredible organization will continue to be available to others in need in the future. We appreciate that HAND of the Peninsula is a volunteer-run organization with a small budget and it makes a little go a long way, which means our financial contributions go directly to providing services to the community. Our daughter is always with us in our hearts, and contributing to HAND of the Peninsula is something we can do in honor of her memory.

Joe Twicken and Jill Nelson
HAND of the Peninsula board members

My 5 1/2-month-old son, Sasha, died in August of 1991. Someone at Weight Watchers, after seeing how devastated I was, told me about HAND of the Peninsula. I started going the very next Wednesday. I attended bimonthly meetings for 1 1/2 years and joined the volunteer committee.

I took the support group facilitator training class and began to facilitate meetings. When I became pregnant with my third son, I began facilitating and gaining support from HAND's subsequent pregnancy support group.

It's been 10 years now since Sasha died and, in many ways, I have gained so much from HAND and hopefully given back to HAND over the years. Now I continue to support HAND of the Peninsula both financially and with my commitment to the board.

HAND was indispensable to me during those horrible first few months and years following our son's death. I have wanted to give back what was given to me. I also feel that HAND of the Peninsula is still one of the few groups where I can celebrate my son's short life and people don't think I am crazy after all these years.

Caryn Goldman,
HAND of the Peninsula board member

Photos Continued from Page 5

I found that with each baby photo I worked on, I felt a sense of joy. It felt good to be able to bring out the beautiful child underneath the discolored skin and offer back to these suffering parents just a little bit of what had been lost to them.

My goal in digitally retouching them was to create photos of my Troy that I could display and comfortably share with family and friends without worrying that they were too graphic for public viewing.

The retouched photos were so appreciated by my HAND friends, and I was so pleased that I could ease their pain just a bit, that I began to wonder if other parents outside our group who had suffered similar losses would be interested in having the same thing done with their photos.

With that in mind I have created a web site offering my digital retouching service to other bereaved parents. The web site address is BabyPhotoRetouch.com. It is a site offering my photo retouching service as well as a site memorializing our lost babies. We would be honored if you would take a look. May God give us all strength for our journey through our grief.

Photo4F@aol.com

Why We Give to HAND . . .

Simply put, I give my money and time to HAND of the Peninsula because it was there for me when I needed it most, and because I want HAND to be there for everyone in the future who also suffers the terrible tragedy of losing a child or children. I give because I know that HAND is entirely volunteer run, and that HAND will not exist unless people just like me step forward to contribute.

My husband and I make several types of financial gifts to HAND. We give annually on the anniversary of our first miscarriage, as a way of commemorating the lives of all four babies; it's a way of not forgetting, and of making those short lives mean more than just grief and loss. We also participate in eScrip, by which a percentage of our grocery and gas purchases goes automatically to HAND each month. It's totally painless and provides HAND a much-needed, reliable income source. Finally, we do the Human Race each May, which gives us a way to get our friends and family to contribute to HAND. It's sometimes hard to ask for their donations, but they're always happy to find a way to show their love and support, when it seems there's so little they can do to help otherwise.

I also give time to HAND, by giving in-service presentations to health professionals at area hospitals, and by serving on the board. There are so many ways to give of your time -- from providing telephone support to grieving parents to serving on a program committee. The two things I know are: that every person has something to contribute and that every contribution is needed!

Christy Conklin

HAND of the Peninsula board member

**Dr. Michael Berman M.D., author of
"Parenthood Lost"
and professor of obstetrics at
Yale University, will speak on perinatal loss
from the perspective of the medical professional**

**3 p.m. Monday June 11, 2001
Sequoia Health and Wellness Center,
702 Marshall Street, Redwood City**

**Sponsored by HAND of the Peninsula, the event is free and open to
the public. Call (650) 367-6993 for more information.**