

Connections

A Newsletter from the Family Partners Program, an initiative of the LPCH Palliative Care Program

The Family Partners Program at Lucile Packard Children's Hospital Stanford is a group of bereaved family members who work on a variety of initiatives designed to improve aspects of care for families facing the death of a child.

Each of us has a unique background. While we may be defined by our culture, religion, ethnic makeup and even our familial relationships, we celebrate our differences. Like a song I remember my daughter would sing in pre-school, we are each special in our own way. Yet through the deaths of our children, we are also members of a 'club' that none of us ever imagined joining. Although our losses are uniquely different, we are connected to one another in a profound way. In this aspect, we are the same.

It is through these connections (as the title of our newsletter suggests), that we hope you will gain a measure of comfort and strength. We wish you well in the days ahead as you strive to find meaning, share a laugh or a smile and treasure the precious memories of your child.

Warmly,

The Family Partners



New Office Location!

Our offices have moved next door to the new Ronald McDonald House. We are pleased that this new location offers more counseling and meeting space. Our new address is:

Family Guidance and Bereavement Program
Packard Administrative Suite
520 Sand Hill Road
Palo Alto, CA 94304



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Our Mission Statement

The Family Partners Program supports families and their communities facing the death of a child.

The Loss of a Twin

by Family Partner Kat Barnett

What is it to lose a twin? For us, it was to live continuously in two worlds. In one world, we were grieving parents, raw and wanting to hide away from everyone and everything that would remind us of the loss of our tiny baby, Naia. In the other world, we returned daily to the hospital where she died, supporting her fragile sister, Jenna. We attended a support group for parents who had lost a baby, and appreciated the understanding we found there. At the same time, at that group, we felt the awkwardness and guilt of still having a living baby to go back to. As Jenna experienced the ups and downs of the NICU, our anxiety was heightened by the intimate knowledge that she too might not survive. Jenna was a continual reminder of Naia, and a continual consolation for her. To look at her was to see both of them, to imagine what Naia might have been like had she lived, and to mourn the loss of that special bond of twins they might have had.

When Jenna was finally ready to leave the hospital, 3 ½ months after her birth and a little over 3 months after Naia's death, we stepped out into the world of "normal" babies and parenthood, and found how little we fit there as well. The realm of bright-eyed hope at Babies-R-Us was difficult to face while still grieving. The stresses of new parents, dealing with round-the-clock feedings and lack of sleep, had nothing to do with our pain of loss, and heightened fears about Jenna and her development. At the same time, it was clear that it was unfair to all those normal people to rain on their parade, just because we were the unlucky ones who had lost a baby. We were fortunate enough to have a group of friends who came through this time with us, because otherwise it would have been so easy to have hidden away,

focusing all our attention on Jenna, and protecting ourselves from the callous, happy world who couldn't know better. From the clerk at Babies-R-Us who said, when I came in to return an extra swingy chair I'd been given, "well, of course you don't need it, you don't have twins, right?" I was stunned, struck to the core, with no idea what to say, because of course I didn't, not any more.

To go out into the world with a little baby is to attract attention. Friendly inquiries from strangers about how old Jenna was were complicated to answer, as she was 3 months older than she appeared to be, than she should have been. The eternal questions a grieving parent dreads, "Do you have other children?" or "Is she your only one?" were posed by well meaning strangers at the grocery store and Starbucks. And again, despite the need to grow thick protective skin quickly, it was impossible to blame these well wishers for not suspecting we were hiding such grief just under the surface.

As Jenna grew, new complications surfaced. How to deal with birthdays? How do we celebrate Jenna without forgetting Naia? How do we create rituals that will grow with her? How do we raise her to understand she had a sister, a twin that she can not remember? And later, how to explain the same for her younger brother, who never met her?

At the time, I wanted everyone to know of Naia's death. But I didn't want to have to tell them. That appalled look on their face when they realized what I was saying was more than I could handle face-to-face. Even now, 9 years later, I hate telling new people. But how can I not say anything, without betraying Naia's memory? I navigate the line between telling the people who matter, and perhaps not the clerk at the post office, with a glib paragraph that deflects their immediate reactions.

It has been so long, that these days I tend to assume all of our friends and colleagues know our story. But even recently, a close friend made a big deal about how Jenna and her daughter were born on the same day and at the same hospital, like twins. I was shocked at the horrible resentment and envy that bubbled up in me, that their memories of that time were so pure, while mine were so dark and painful and conflicted and difficult. And I realized, after struggling with my reaction for a few days, that they simply didn't know about Naia. And telling them, though difficult, set all of us free.

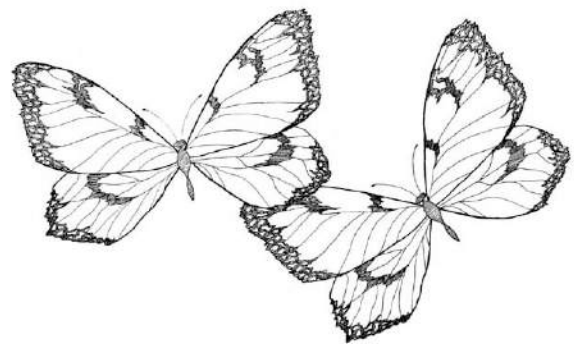
Death is part of our human reality. When I felt so out of touch with the modern world, it helped me to remember that for the majority of human history, losing a child was a normal part of life. And the discomfort that our modern society has with death in general, and especially the death of a child, came to seem as its problem, not mine. Somehow, without diminishing my loss, this perspective gave me a connection to the strength of parents through the ages, who experienced what I experienced, and survived as I too would.

I recently read Viktor Frankl's book, "Man's Search for Meaning." There is so much that spoke to me in his book, but one of his most profound insights is that humans need to find meaning in our lives, and if we can do so, then our ability to survive and cope with difficult experiences is much greater. I realized how important it was to me to have Jenna in the wake of Naia's death. She became my purpose, my meaning for the time. I could not make her less fragile or shield her from the dangers she was facing. But I could be there with her, giving her the touch of my hands and my heartbeat in that all important "kangaroo time" when we took her, with all her wires and tubes, out of her

incubator to hold her against my chest. I spent every day with her in the NICU, as a full time job, until she was ready to come home. She gave me a reason to get up, a purpose to my days, a routine to hold onto.

Ultimately, of course, I needed to grow past this dependence. For not only is it unhealthy to define one's self in terms of a loss, the meaning of my life is too great a burden to give anyone, especially a tiny child. I have found my meaning in my own growth and transformation. I am a different person after Naia's death than I was before. I am a different mother to Jenna, and now to her younger brother, Zane, than I would have been had Naia not died. I am a different doctor than I was before, bringing my intimate experience of loss to the task of helping my patients and their families manage and plan for the end of life.

As Frankl says, "Life ultimately means taking the responsibility to find the right answer to its problems and to fulfill the tasks which it constantly sets for each individual." I could not choose the cards that we were dealt, but I can choose how to play them. It is up to me to make sure that the person I become is better, more complete, more compassionate, and more in touch with myself and those around me, than I was before. And so I remember Naia.



Events and Programs

Men's Group

This fall we will be offering a support group for grieving fathers. The details are in the works, but the group will be offered in the evening. If you are interested or have questions, please call the office at (650) 497-8175 or email bereavement@stanfordchildrens.org.



Newsletter Mailing List



In an effort to save resources, we'd like to offer an email version of this newsletter to those who would prefer to receive an electronic copy. If you'd like to be included in the mailing list, please call the office or send your name and email to bereavement@stanfordchildrens.org. Thank you!

Family Partners Bereavement Library

A source of information and support for child loss

The Family Partners Bereavement Library has a growing collection of books on child loss for all ages. Categories include books for parents, siblings, grandparents, caregivers, schools and the community. The library also includes Spanish language sections for children and adults.

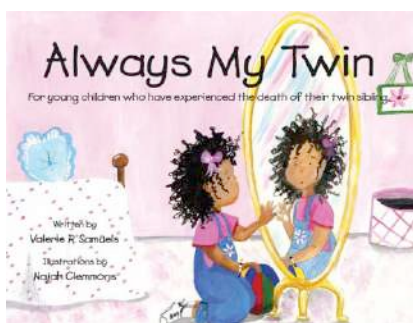
If you would like to donate a book in memory of your child, we offer bookplates that can be dedicated with a beautiful personal note.

Hours and Location

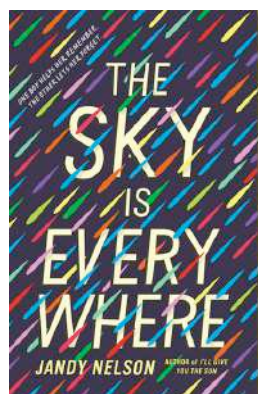
Monday-Friday, 9:00am-5:00pm

Family Guidance & Bereavement Program Office, 520 Sand Hill Road, Palo Alto

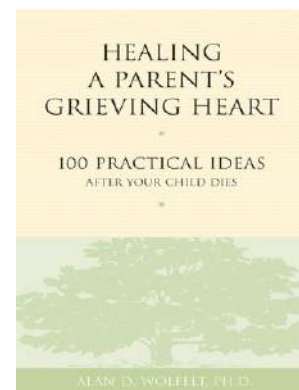
Recommended Books



children



adolescents



adults

Bereaved Grandparents' Brunch

Our latest Grandparents' Brunch was held in February. This event supports the unique challenges that grandparents face after the death of a grandchild. The program included a moving speech by Gary Feldman, a bereaved grandfather, and meaningful memory making activities. Thank you to all the grandparents who attended this special event.



If you know someone who has lost a child, and you're afraid to mention them because you think you might make them sad by reminding them that they died - you're not reminding them.

They didn't forget they died.

What you're reminding them of is that you remembered that they lived, and that is a great gift.

- Elizabeth Edwards

Calendar of Community Events

October 1, 2017	Healing After Neonatal Death (HAND) Service of Remembrance, 1:00-3:00pm An event for families to celebrate the memories of their babies. Features music, poetry, readings and a potluck meal. Family members and friends are welcome. Contact Kelly Symons for information, info@handonline.org , or visit www.handonline.org . Quinlan Community Center, 10185 N. Stelling Road, Cupertino.
October 8, 2017	LPCH Annual Day of Remembrance and Rededication, 1:00-4:00pm
October 8, 2017	HAND of the Peninsula Annual Service of Remembrance, 10:00am-1:00pm Miwok Shelter, Huddart Park, Woodside. All parents, families, and friends are invited to join others to remember their babies. Refreshments will be served. Contact sor@handsupport.org or www.handsupport.org/events .
October 14, 2017	Kara 2017 Walk-N-Run to Remember, 10:00am, Mitchell Park, Palo Alto This annual event is a unique opportunity for individuals and organizations to walk or run in memory of a loved one and support grieving friends, family and community members. For more details, please visit www.kara-grief.org or call (650) 321-5272.
October 2017	Pathways Hospice Through the Holidays, multiple locations As the winter holidays approach, grieving families sometimes struggle; the world celebrates and they grieve. We offer a place to come for exchanging ideas of how to cope, to receive support, and to honor and remember loved ones. Locations and details at www.pathwayshealth.org .
December 7, 2017	Kara Annual Candlelight Service of Remembrance, location TBD Each year Kara invites the community to join together to remember loved ones and significant others who have died. This is a non-denominational service open to all. For more information, please visit www.kara-grief.org or call (650) 321-5272.
December 10, 2017	Pathways Hospice Celebration of Light, Skyline Memorial Park This memorial service brings light and warmth to the winter season in early December by remembering loved ones with music, readings and a candle-lighting ritual. Please visit www.pathwayshealth.org or call (408) 773-4241 for details.

Contact Us

Family Guidance and Bereavement Program • Family Partners Program

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520 Sand Hill Road • Palo Alto, CA 94304 • bereavement@stanfordchildrens.org • (650) 497-8175

Additional Hospital Support Services

Social Services: (650) 497-8303 Chaplaincy: (650) 497-8538 or (650) 723-6661, pager #27729

Child Life: (650) 497-8336 Palliative Care: (650) 497-8963 or (650) 723-6661, pager #19474