

Connections

A Newsletter from the Family Guidance and Bereavement Program at LPCH

The Family Guidance and Bereavement Program supports LPCH families and their communities who are facing the death of a child. Our services are offered at no cost in English and Spanish. All are welcome to participate.

Dear families,

I hope this newsletter finds you well in 2022. I want to share that I will be stepping down from my position as manager of the Family Guidance & Bereavement Program because my family is moving out of the Bay Area. It is with sadness that I leave such deeply meaningful work and a compassionate team of staff. We hope to hire a new manager very soon. To all the families reading this who have known me as part of their family's journey over the years, I want you to know that you and your child will always be in my heart.



In this issue we feature an article written by Patricia Lozano about what has contributed to her healing after the loss of her baby. We also present a beautiful poem written by a mother describing the myriad of ways she remembers her daughter. These two works speak to profound grief, the sense of connection that parents have to their children after death, and the deep and personal ways that children impact parents' lives. Finally, this issue includes a special article focusing on our Memory Bear program and the seamstress who creates these keepsake bears for families. We hope you find inspiration and comfort in these pages.

Wishing you and your loved ones health and peace,

Krista Reuther,
Manager, Family Guidance & Bereavement Program

Family Perspectives

Parent Reflection

By Patricia Lozano, mom of Katherine

My name is Patricia (Paty) Lozano and I am 34 years old. My family is made up of my husband Raúl, my son Emiliano and my daughter Katherine. On August 12, 2020, our second child, Katherine Rodríguez-Lozano, was born. She was born with several problems that had been detected at six months' gestation. From the moment that we were informed about her complications, we felt that our world had crumbled. Our days were full of uncertainty, anguish (entire days spent weeping) and praying to God that the doctors were wrong. That was not the case, however.



Half Moon Bay, CA / Photo credit: Anne-Laure Chaillou, PICU Patient Care Manager

The day my daughter was born, there was a rush of mixed feelings. I felt happy to be able to meet, touch, and hold her; however, there were many tubes all over her tiny body (she was very ill) and, as parents, our hearts were filled with agonizing pain impossible to describe in words. On her second day of life, the doctors told us that her diagnosis was not at all encouraging. They explained that, even if she were to spend one, two or five months connected by all of the tubes, there was no hope for recovery due to all of her complications. On August 15, 2020, after her baptism in the hospital, she was disconnected. I implored my daughter to fight because I did not want to lose her and we begged God for a miracle, but it was not meant to be. Our daughter died a few minutes later. As with all processes involving and dealing with loss, it has been painful. There was so much sadness in my heart the first few days that I just wanted to stay in my room and cry. This made my son Emiliano's own grieving process even more painful. My husband offered both our son and myself words of encouragement but his eyes betrayed his sadness, too. The days following, we received many calls from our friends and family. One of my sisters called me on the phone every day for a week offering me her love. But, after 2 weeks, it was only my pain and my son's and my husband's pain. No one called me anymore to ask: "How are you feeling?" I had only my sadness and the memory of my daughter. At that moment, I understood that my only responsibility was to move forward and that I needed to be ok for myself, for my son and for my husband, just as they also needed to be ok for themselves.

My mother, Enriqueta, has played an essential part in this grieving process. Her exemplification of love, gratitude and bravery have taught me, since the death of my 40-year-old brother Miguel Ángel (who died in December 2018), how to overcome grief. Reflection, meditation, and prayer have been paramount to her healing process and now to my own. I always recall her strength and the way she has navigated her grieving process. I can clearly understand every helpful piece of her advice. My mother has passed on so much strength to me through her example. This is something that I have always wanted to embrace, and now I am fortunate enough to be able to pass it on to my son, Emiliano.

At his young age, (he was seven then) he began the grieving process for the loss of his only little sister. Now he feels love and not pain when he looks at her photos and he always depicts her as an angel whenever he draws family pictures.

The decisions that my husband and I made after Katherine's diagnosis were always made with our daughter's well-being in mind. We did what was within our power so that our daughter would be ok. These decisions have left us with a small measure of peace. When I have sad moments or days, I hold photos of my daughter and my brother, and I tell them how important they are to me and how much I love and miss them.

Erika, my therapist from the Family Guidance and Bereavement Program, has also played a key role on this journey. She has helped me to understand that my daughter came into our lives with a purpose, which I now understand and have decided to honor. Today I am still in therapy working on understanding my emotions. Therapy has helped me to understand my reality, to develop self-awareness, and to allow me to be who I am. This is what has helped me find myself. I like "the Paty" that I am discovering. Before my



*Moon Shadow Rose, Oakland, CA
Photo credit: Walter Bryen, Chaplain*

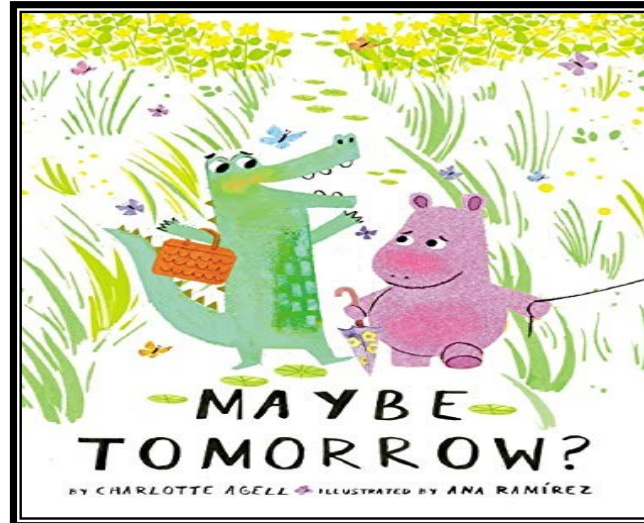
loss, my life was different. I now live and think differently. I feel like I will never be whole because I have lost two loved ones who I will never see or hold again (my daughter and my brother).

Grief changed me, but I decided that it would serve to make me be a better version of myself – to love more and fight less, to be more tolerant and empathetic, to appreciate my loved ones who are still here more and tell them every chance I get that they are so precious to me. One day I heard a grief therapist say that in death, only one person dies, not two. I try to keep these types of comments in mind so as to never forget them. They keep me moving forward and help me realize that I must not be dead in life because I am a daughter, a sister, a mother, and a wife. I have the responsibility to be well, first for myself and then for my family. I do not want pain to define the rest of my life, so my husband and I have asked ourselves: “Are we prepared for a third pregnancy?” And our answer is “yes”, a “yes” believing that everything will be fine, but also a “yes” with our feet planted very firmly on the ground. It is possible that this same painful story may repeat itself. We have asked ourselves what we would do if this were to happen, and our response is still the same - give our all as parents.

BOOK REVIEW

By Krista Reuther, LCSW

Maybe Tomorrow by Charlotte Agell, illustrated by Ana Ramírez González



This beautifully illustrated children’s book is about the healing power of friendship and kindness in grief. Elba, a pink hippopotamus, is carrying around a big block of sadness wherever she goes. Norris, a gentle alligator, befriends Elba and helps her carry her block to the sea for a picnic; and Elba gains new insights about her experience in the process. It’s a sweet story showing a character learning to engage in life again after a significant loss through the support, empathy, and love of a friend. The reading level is up to grade 2, but adults will also find comfort in the tenderness of the story and the hope it offers in living life meaningfully while tending to sadness within.

I remember you,

When I wake up each morning, I remember you,
When I put my head on the pillow, I pat you to sleep,
When I achieve something, I celebrate with you,
When I make mistakes, I see you rolling eyes on me,
When I look at a mirror, my eyes are searching for you,
When I eat the food I love, I make you jealous,
When I eat the food you hated, I smirk at you,
When I see a flower bloom, I search for your eyes,
When I see a fallen tree, I remember you,
When I see a butterfly on my hand, I feel you kissed me,
When I see the colors of fall, I want you to enjoy those colors,
When I see the spring bloom, I miss you terribly,
When I see little girls giggle, I am torn,
When I see a child cry, my arms crave to reach out,
When I hear music you loved, tears well my eyes,
When I watch your favorite movie, I reserve your seat,
When I see wonders of the world, I want to hold your hand,
When the new year begins, I feel I am going far from you,
When the year ends, I feel I am coming closer to you,
When I celebrate, I see you smile with me,
When I am sad, I feel you wiping my tears,
When I breakdown, you lift me up,
You live in my heart and in my memories,
The world can't see you, but I feel you,
because I remember you...
because I love you...
because love doesn't die.



-By Milli Seth, mom of Saloni & Founder of Saloni Heart Foundation

In memory of Saloni Seth (April 26, 2005 - Nov 2, 2018)

The Heart and Hands behind the Memory Bears

By Julia Wedeles, LCSW

This introduction is *long* overdue. To you, our Family Guidance and Bereavement Program (FGBP) community, we formally introduce Nancy Knoblauch (affectionately known as “Nan”). For the past seven years, Nan has been lovingly constructing teddy bears for bereaved children and families as the core volunteer with the Memory Bear Project.

A memory bear is a unique way to honor and remember a child. Sewn from the child’s clothing or other fabric, this bear can be a source of comfort and treasured memories. Nan is driven by this mission to create one-of-a-

kind keepsakes for families to cherish. “It brings me comfort to know the bears remind the family of their child in a way and allow them to connect with their loved one,” Nan says.

Soon after she retired from teaching, Nan had a serendipitous encounter with the FGBP’s former director, who had just received grant funding to start the Memory Bear Project. Nan, who began sewing at age 12, created a few sample bears for the FGBP, offering three sizes for families to choose from. Nan has a creative and resourceful personality and is largely self-taught in her sewing capabilities. She is continuously growing and adapting these skills to help the FGBP meet the needs of children and families. It has now been over seven years since those first sample bears, and Nan, our incredibly dedicated volunteer has created nearly 250 teddy bears!

Nan has honed her bear-making process over time, using attention to detail, compassion, and patience to make each bear just right. Nan lays each precious piece of clothing from a family on her dining table, alongside the pieces of her pattern. She then reviews the information received from the bereavement social worker which outlines the family’s preferences for how the bear will look, as well as special requests for preserving details of the clothing. Nan begins a thoughtful, problem-solving process to mix and match the provided clothing, trial items for different parts of the bear, and supplement with additional cozy fabrics if needed. Once she is happy with the layout of the pattern, Nan will leave the fabric out for a few hours, sometimes coming back a few times to rearrange before making her first cut. Once each piece of the pattern has been carefully cut, Nan moves her project to her sewing room, to stitch each piece together, add the bear’s nose and eyes, and finish off with her signature ribbon tied in a bow.

Nan speaks with empathy and care about her work with the bereavement program. She recalls the details of *many* bears, highlighting those that required some unique problem-solving to capture details “just so”. Nan has created bears with accessories attached (like headbands, hats, and jewelry), matching sets of bears, bears with



sports team logos, even a bear with a changeable sari. What stands out when Nan talks about the bears is her compassion and pride for this project. Her friends and family all know that she is “the bear maker”. They see the finished bears waiting to be brought to the FGBP office, they field her inquiries about coordinating fabrics and nuances in clothing items, and they share in our astounded refrain “we don’t know how you do it!” Each bear is a work of art. Nan’s motivation to continue is rooted in her compassion for the children and families served by the FGBP. Each bear presents “an opportunity to give something to families facing an unbearable loss”, to provide a piece of comfort.

Nan’s generosity, dedication, and humility are true gifts to the Family Guidance and Bereavement Program. Thank you, Nan, for all you do!

The Memory Bear Program is offered free of charge to all LPCH families who have experienced the loss of a child. If you have a memory bear in your family, we would love to hear from you! Please feel free to share your photos and memory bear stories with us at bereavement@stanfordchildrens.org. Photos and quotes about special bears in our FGBP community will be shared in the next edition of our newsletter.

To learn more about the process of ordering your own handmade memory bear, please call the Family Guidance and Bereavement Program at 650-497-8175 or email bereavement@stanfordchildrens.org.



Save the Date

The 17th Annual LPCH Day of Remembrance & Rededication

Sunday, October 2nd, 2022

In-Person & Virtual

Lucile Packard Children’s Hospital’s Palliative Care Program and the Family Guidance & Bereavement Program cordially invite bereaved families to participate in a day of remembrance in honor of their children who have died up to six months before the event. The ceremony will be held at the **Arrillaga Alumni Center on the Stanford campus** and will include a ceremony with bereaved family speakers followed by a garden reception. Our child life specialists will also facilitate memory-making activities for siblings. The Day of Remembrance ceremony has traditionally been held in-person, and we hope to resume the in-person ceremony this year with a virtual option as well.

Afternoon of Remembrance Memorial Service, May, 2022, via Zoom

<https://pathwayshealth.org/workshops-and-memorial-services/>

In May, with the ushering in of Memorial Day, graduations, Mother's Day and Father's Day we are often reminded of the absence of our loved one. As a way to honor those special people whose absence we miss dearly, Pathways offers a time to come together to foster renewal and growth through music, readings, reflections and collectively creating a large flower bouquet.

Camp Kara 2022, July 8th-10th, 2022, Camp Arroyo, Livermore, CA

<https://kara-grief.org/services/camp-kara/>

Camp Kara is a free bereavement camp for children and teens, ages 6-17.



By The Bay Camp, August 5th-7th, 2022, Sonoma County, CA

<https://bythebayhealth.org/by-the-bay-camp/>

By the Bay Health offers a free, all-inclusive, three-day summer retreat for grieving children and teens ages 7-17, 18 if still in high school.

Experience Camps, August 15th-20th, 2022, Vista, CA

www.experience.camp

Experience Camps are one-week camps for boys and girls who have experienced the death of a parent, sibling or primary caregiver. It's a place where kids can laugh, cry, play, create, remember the person who died, or forget the grief that weighs them down. It's a place where they can feel "normal", because everyone there has been through something similar and understands what it's like to lose someone important to them. It's a home away from home.

Opportunity outside of CA: Outward Bound, August, 2022, Mid-Atlantic, USA

www.outwardbound.org

Outward Bound for Grieving Teens is a 7 day program that provides the opportunity for teens, ages 14 to 18, to experience specially crafted outdoor expeditions in beautiful wilderness areas across the United States. By combining personal growth methodologies of Outward Bound with a simple support model that honors the griever, Outward Bound is able to deliver an intensely profound healing experience relevant to the lives of people who are coping with the death of a loved one. Subsidized cost and full scholarships available.



Summer Scamper

Saturday, June 18th, 2022

Support the Family Guidance and Bereavement Program and help us to be the top fundraiser for the 9th year in a row! Registration begins in April: please visit www.summerscamper.org. Join the Family Guidance and Bereavement Program team, come walk or run with us, and then participate in memory making activities at our booth at the Family Festival. Even if you cannot attend the event, you can join our team as a “virtual runner.” We hope you can be a part of this supportive community!



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If so, please send your name and email to:

bereavement@stanfordchildrens.org.

Thank you!

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Additional Hospital Support Services

Social Services: (650) 497-8303

Child Life: (650) 497-8336

Chaplaincy: (650) 497-8538 or (650) 723-7288, pager #27729

Palliative Care: (650) 497-8963 or (650) 723-7288, pager #19474