SUMMER NEW SLETTER

BOSTON CHILDREN'S HOSPITAL BEREAVEMENT PROGRAM

July 2024

Dear BCH Families.

And just like that, spring has transitioned into summer. Time is strange when it comes to grief, where we often find ourselves just trying to get from one moment to the next—minute by minute, hour by hour, day by day. Time can feel distorted, as though it is standing still; and yet, time still manages to race by and we somehow find ourselves already in the next season and more than halfway through the calendar year.

Summer is another season that seems counter to the experience of grief. While the weather helps encourage us to get outside, summer also carries many transitions for families, with routines upended by the ending of school and typical activities. For some, the free time can create some relief, while for others, the lack of established structure can create challenges in knowing how to navigate the day to day. This may also be the first summer without your child, and the idea of resuming trips to your traditional vacation spots, or taking a family vacation without him or her for the first time may feel overwhelming. While the slowing pace of the summer may complicate our capacity for self-compassion, we hope there is still space to find gentleness and grace.

We know that change is loss, and loss is change—and both are hard. As you continue to navigate your loss and all the associated changes, we encourage you to focus on maintaining and nurturing your connection and bond to your child in all the ways that feel right to you. Perhaps this means bringing their photo along with you to your favorite place or on your next summer vacation so they can be present there with you; or taking a trip to the place you talked about going together and leaving a mark of your child there. No matter what, we hope you continue carrying them with you through this season, and always.

With gratitude,

SoYun Kwan BCH Bereavement Program Social Worker

Grief in Summer

<u>Summertime and Grief - this article</u> from the Dougy Center features suggestions and activities for grieving families in the summer months

Coping with Summer after Loss:
How Seasons Affect Grief - this
post from Still Standing is written
by a bereaved mom, who shares
her experience of grieving in
summer



BCH Bereavement Program Upcoming Offerings

When Grief is New

Thursdays, September 12, 19, and 26

12-1 pm via Zoom

"When Grief is New" is a 3-part series for parents/caregivers who have experienced the recent death of their child. This series is a gentle introduction to group work and incorporates an educational component with an opportunity to connect with fellow bereaved parents. Ideally participants will attend all 3 sessions, which include:

- Understanding Grief
- Preparing for Firsts
- Navigating Changing Relationships

If you are interested in registering or want to learn more, please contact: <u>bereavement.program@childrens.harvard.edu</u>

HOPE: Healing Opportunities/Parent Exchanges

Tuesdays, September 24- November 12

6-7:30 pm via Zoom

HOPE is an 8-week support group comprised of bereaved parents whose children were cared for at Boston Children's Hospital. This group is intended to be a deeper exploration of the grief of losing a child alongside the connection with other bereaved parents. Some of the topics explored include navigating special days and holidays, changing roles and identities, and strategies for coping with grief. HOPE group facilitates connection amongst bereaved parents, encouraging opportunities for sharing of experiences, stories, and memories of your children. To get the greatest benefit from the group and to enhance group coherence and trust, we encourage participants to join in all (or most) of the 8 sessions.

If you are interested in registering or want to learn more, please contact: bereavement.program@childrens.harvard.edu

Save the Date for our Keeping Connections Conference Keeping Connections is a day-long event held in the Fall for families who have experienced child loss. The conference includes a panel presentation by bereaved parents, and small group discussions facilitated by hospital staff. The day also incorporates groups and activities for siblings age 5 years and older. The day closes with a remembrance activity and closing ceremony.

This year's conference is tentatively scheduled for November 2.

Having an opportunity to join with other parents who truly understood what it was like to wake up each day without your child was powerful... I had this incredible feeling of being

completely seen, heard, and held.

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Upcoming Community Events and Programs

Family Night

<u>The Children's Room</u> hosts free monthly virtual gatherings that provide families the opportunity to connect centered around a creative arts activity. Extended family are encouraged to participate! Materials are mailed to all participants prior to the evening. If you are interested, register using this <u>contact form</u>.

Newly-Bereaved Support Group

August 5 or September 9 3-5 pm

<u>Care Dimensions</u> holds a free, one-time workshop for a those who have experienced a loss within the last three months. Please RSVP by Thursday before group by emailing <u>grief@caredimensions.org</u> or by calling (855)774-5100.

<u>Camp Stepping Stones</u>

Glen Urquhart School, Beverly Farms, MA September 14 9 am-3:30 pm

Camp Stepping Stones, facilitated by Care Dimensions, is a grief support camp for children age 4 to 18 and their families who have experienced the death of someone important. This day-long event is a space for parents/caregivers and kids to connect with other grieving families, to honor and remember those who have died, and have some fun.

This event is free for all participants, but space is limited. Register for Camp Stepping Stones at: www.caredimensions.org/grief-support/childrens-programs/camp-stepping-stones-registration. Email Camp@CareDimensions.org to be added to their contact list to receive information about future Camps and other children's grief program opportunities.



Family Activity

Scream Box

from <u>MyFarewelling.com</u>

Giving kids permission (and a safe, even secret place) to scream can be surprisingly appealing to them. This clever box will muffle the sound so those who feel the desire to scream can do so without rattling everyone's nerves.

What You'll Need:

This activity is easily made with things you'll likely have around the house. First, find an empty box. Any empty box with a top will do, such as a cereal or cookie box. Gather old newspapers, a box of tissues, plus a paper towel tube, tape, and items to decorate the outside of the box, such as colorful paper, markers and stickers.

Project How-To:

- Fill the box with crumpled up newspaper. Close the top of the box.
- Mark a circle on the top of the box using one end of the paper towel tube. Then cut out the hole following the circle. Make sure the hole is big enough to insert the paper towel tube.
- Place the paper towel tube into the hole in the box, leaving half of it sticking out of the box top. Tape the tube in place (half in/half out).
- Stuff the tube halfway with tissues.
- If you like, wrap the box and the tube with colorful paper. Keep decorating! Use markers, stickers, or anything you want to personalize the box.
- When you're ready, tell your young one to SCREAM into the box as loud and as often as you would like. (Or scream into it yourself if you prefer!)



Family Spotlight

Jaiden Lyndi Tlapa was a vivacious 8-year old, who loved her family and friends fiercely. She was a bright light, loyal friend, and source of joy to everyone she encountered. Jaiden was critically injured days before Christmas in 2007. Despite the constant love and prayers of her extended family and an entire community, Jaiden lost her battle on January 14, 2008. Even in death she continues to shine through a foundation in her honor that helps families facing the critical illness or loss of a child: www.jaidensangel.org, by spearheading a donation after cardiac death program at Boston Children's Hospital, and by her continued presence in the lives of everyone who had the privilege of knowing and loving her.

The Tlapa family participated in grief programs at Boston Children's Hospital, and their foundation helped several patients and families over the years. Three years after Jaiden's loss, Jaiden's Mom, Holleigh, was invited to participate in the annual BCH Memorial Service. Holleigh had always been a writer and poet, writing a weekly column in her local newspaper called "Candid Exposure," which was a slice of life commentary that revolved around her family and their community ties. After losing Jaiden, she briefly stopped writing, but soon realized how important it was to share her feelings and experiences related to the grief and recovery process of losing a child. Holleigh recognized that our words not only allow us to express ourselves, as part of the healing and remembrance process; but they resonate deeply with others who have also dealt with the most unthinkable loss, and provide a light at the end of the tunnel.

2011 was the first year Holleigh participated, writing a poem called "We are Different Now." She has been writing and reciting a unique poem every year since; her poetry has changed over the years, along with her perspective, and her family. Prior to losing Jaiden, the Tlapa's had four children, and they felt their lives were complete. After losing Jaiden, they had two additional children, and their oldest daughter gave birth to their first grandson in September of 2022. Holleigh continues to be a source of inspiration for other families facing child loss, and she looks forward to honoring Jaiden every year at the Memorial service. She views it as another avenue to keep her bond with Jaiden alive, to honor her memory, and Jaiden's continued impact in their lives of everyone left behind. Jaiden is always remembered, and never forgotten.





That Day By Holleigh Tlapa For Jaiden Lyndi, with all my love, Mom

Divergent paths separate us,
Not chosen,
Or intended.
Assigned
with brutal closure.

The glass wall between us
Is hazy,
Like speckled glass
Made of tears
And
Tomorrows.

My ying, Your yang, Our love; Courses through my veins.

Blue like the skies,
Above.
The ocean
Below.
Your eyes
endless
Your aura,
All around.

You were here.
In this room,
On this beach,
During this life,
Within this heart.

Your story, Altered. Up ahead, Far behind. You linger.

Time Stands still. And races ahead At the speed of light, That fades.

> The sun rises, And your words Resonate. Your love Remains.

You whisper, On paper, In photographs.

You did become an angel, That day. We hope this newsletter provides a space to help connect you with grief resources and programs, and to support shared experiences and connections between BCH families who have experienced child loss. If you would like to contribute to our newsletter by sharing a recommendation for a book, podcast, article, or resource that you believe will be helpful to other families, please click this link to let us know about it, and we will try to include it in an upcoming edition. If you would like to send a letter or poem to share, or to be featured in our family spotlight, also click on the link above or email it to:

bereavement.program@childrens.harvard.edu





SoYun Kwan has been a clinical social worker at Boston Children's
Hospital since 2005. She has worked in the Medical/Surgical Intensive
Care Unit, and in the Liver, Intestine, and Multivisceral Transplant
Program, supporting families facing serious illness. She currently runs the
BCH Bereavement Program, where she is dedicated to offering
bereavement support and programming to BCH families.

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Ellie Frechette is one of the clinical social workers on the Pediatric Advanced Care Team (PACT), who specializes in supporting bereaved parents/caregivers and siblings. Ellie currently runs many of the programs offered through the bereavement program, including support groups, educational sessions, and expressive arts workshops.

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Please reach out for further resources or recommendations

