FALL NEWSLETTER

Boston Children's Hospital

September 2024

Dear BCH Families.

Fall has arrived, and with it, the mornings have become reliably colder, and the sun sets ever more quickly each evening. Grief can feel pronounced in September—a time marked by the frenetic energy surrounding the return to school, which can amplify the loss of future felt by so many parents after child loss. Waves of grief may hit at the most unexpected of times, and regardless of how much time has passed, it is not an easy feat to keep going after child loss. We hope you give yourselves grace and remind yourselves:

"It takes inordinate strength to wake up every morning and consciously step back into a world in which someone you love is missing. Give yourself credit."

Please know that we see you when it is exhausting to get out of bed and get dressed each morning; to go to work; to resume routine social gatherings; and to complete the tasks necessary to get yourself and your family through each day. Know that you are not alone, and that as surely as grief waves flow, they will eventually ebb.

As we approach the 1-year mark of establishing this Bereavement Program Newsletter, we want to emphasize that you are all part of a hospital community who understands the tragedy of child loss. In each of our newsletters, we share information about community bereavement groups, and hope you have already or may consider participating as a source of connection and support. At BCH, we offer several virtual group options, including our upcoming Fall HOPE group, an 8-week parent group set to begin on Tuesday, Sept. 24th. We also invite you to attend our upcoming Keeping Connections family conference on Saturday, November 2nd. Keeping Connections is an intimate, day-long event for BCH families that involves a variety of groups and activities. Parents or entire families (siblings ages 5+) are both welcome, and you can read more or register for HOPE group or for Keeping Connections in the Upcoming Offerings section below. In the Family Spotlight section, we also highlight Sarah, mother of Molly, who shares her family's experience of attending Keeping Connections last year, and its impact on her and her family.

We hope you will consider joining us.

With gratitude,

SoYun, Ellie, and Fiona The BCH Bereavement Program Team

Grief in Fall

<u>"Fall is My Grief Season"</u> from WhatsYourGrief.com

<u>"An Invitation to the Bereaved Parents Club"</u> by Erin Jean

March of Dimes Wall of Remembrance
A tribute wall for Pregnancy and Infant
Loss Awareness Month, recognized in
October

<u>Back to School Grief</u> offers tips and strategies to support a grieving child in the back-to-school season



BCH Bereavement Program Upcoming Offerings

HOPE: Healing Opportunities/Parent Exchanges

Tuesdays, September 24- November 12

6-7:30 pm via Zoom

HOPE is an eight-week curriculum based virtual group for bereaved parents and caregivers offered in Fall and Spring. Each week, the group will discuss topic and themes of grief, such as navigating holidays and special days, continuing relationships with your child, and complex feelings of grief. There is also space for open discussion based on the needs and interests of the group, as well as opportunities for connection with other bereaved parents. This is a closed group in which registration includes all 8 weeks.

If you are interested in registering, please fill out <u>this form</u>. If you have any questions or would like additional information, please contact: <u>bereavement.program@childrens.harvard.edu</u>

<u>Grupo Esperanza</u>

Martes, 24 de septiembre al 12 de noviembre 6-7 pm

Esperanza es un grupo de apoyo de 8 semanas creado para padres y madres que han perdido a sus hijos, quienes fueron atendidos en el Hospital Infantil de Boston. Este grupo tiene como objetivo explorar en profundidad el duelo por la pérdida de un hijo, junto con tener la oportunidad de conectarse con otros padres y madres que también se encuentran en duelo.

Es un gusto poder escuchar sobre ti y tu hijo(a). Si deseas inscribirte o tienes preguntas, por favor contactanos con este correo: bereavement.program@childrens.harvard.edu. Grupo Esperanza se ofrece sin costo alguno y se lleva a cabo de manera virtual. Regístrate aquí.

Keeping Connections Conference

Saturday, November 2, 2024 8:30 am - 3:30 pm Boston Children's Hospital 9 Hope Avenue Waltham, MA 02453

This annual, day-long event provides parents/caregivers and siblings (ages 5+) with a space to honor and remember their child and an opportunity to connect with other bereaved families. Parents/caregivers and siblings will have both separate and family-based programming options available throughout the day, including a panel of bereaved parents, small discussion groups, creative/expressive arts groups, and movement activities. The event will conclude with a memorial slideshow and a closing ritual.

To register, please complete <u>this form</u>. Please contact the BCH Bereavement Program with any questions by calling 617-355-3195 or emailing <u>remember@childrens.harvard.edu</u>

Upcoming Community Events and Programs

Family Night - The Children's Room

The Children's Room hosts free monthly virtual gatherings that provide families the opportunity to connect centered around a creative arts activity focused on memories and meaning-making. Extended family are encouraged to participate! Materials are mailed to all participants prior to the evening. If you are interested, please register here.

<u>HEART play Bereavement Groups</u>

HEART play offers a variety of bereavement groups for children, teens, and young adults of all abilities in Newton, MA and online. All groups are offered on an ongoing basis during the school year, and some groups include a co-occurring caregiver support group. To register for a group, complete this form. Please contact jwiles@gscommunitycare.org or call 508-309-5107 with any questions.

Camp Stepping Stones

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 <u>here</u>. Email <u>Camp@CareDimensions.org</u> to be added to their contact list to receive information about future Camps and other children's grief program opportunities.



"Too Young to Grieve?" A <u>Dougy Center</u> Children's Grief Awareness Day Webinar

November 21, 2024, 10 am - 11:30 am PST

<u>"A common myth is that children may not be impacted like adults after a death.</u> In fact, it's not uncommon to hear comments such as "They are too young to understand" when referring to children's experiences of loss. Join Dougy Center staff for this free webinar where they dispel myths and raise awareness about children's grief." To learn more and to register, please click <u>here.</u>

Why Me Bereavement Support Groups

Why Me is an organization based in Worcester, MA for families experiencing childhood cancer and child loss from cancer. Why Me offers two bereavement support groups for parents, the Newly Bereaved Group and Circle of Healing. To learn more, please click here.

E-Motion's Boston Movement Community

Heartbreak Running Co. in Newton, MA

Sundays, September 15 - November 24 at 10 am

E-Motion is offering a movement-based community for anyone enduring the life-disrupting loss of a close person. Once per week, participants will come together for a walk or run, and are led through intentional grief practices and grief-informed conversation. Runners and walkers of all levels are welcome. If you are interested in registering or would like to learn more, please contact facilitators Becky at beckynyce@gmail.com or Betsy at efsullivan63@gmail.com. Learn more about the Movement Community Model here.

"RX to Feel"

E-Motion, Inc recently launched a self-guided audio series for grievers, by grievers. It is intentionally designed to be listened to while in motion. The first 12-session series focuses on finding steady ground. It will resonate with people navigating any form of grief, offering a gentle guide to find and maintain steadiness amidst the anguish and chaos of grief and loss.

Learn more about "Rx to Feel" and E-Motion <u>here.</u> The series will also be accessible on SoundCloud and Insight Timer, so you can move while you listen on your phone.



Book Corner

I Promise it Won't Always Hurt Like This: 18 Assurances on Grief by Clare Mackintosh

"Grief is universal, but it's also as unique to each of us as the person we've lost. It can be overwhelming, exhausting, lonely, unreasonable, there when we least expect it and seemingly never-ending. Wherever you are with your grief and whoever you're grieving for, I Promise It Won't Always Hurt Like This is here to support you. To tell you, until you believe it, that things will get easier.

When bestselling writer Clare Mackintosh lost her five-week-old son, she searched for help in books. All of them wanted to tell her what she should be feeling and when she should be feeling it, but the truth – as she soon found out – is that there are no neat, labelled stages for grief, or crash grief-diets to relieve us of our pain. What we need when we're grieving is time and understanding. With 18 short assurances that are full of compassion – drawn from Clare's experiences of losing her son and her father – I Promise it Won't Always Hurt Like This is the book she needed then."

Read an excerpt of the book here.

Listen to a Podcast interview of the author Clare Mackintosh <u>here from Thoughts from a Page Podcast</u>



"GRIEF ISN'T ROMANTIC; IT'S PAINFUL AND UGLY, AS OFTEN FILLED WITH ANGER AND BITTERNESS AS LOVE."

Family Spotlight

Sarah and John are the proud parents of vibrant and precocious identical twin girls, Molly and Emma. In April 2020, when the girls were just 3 years old, Molly was diagnosed with leukemia. Despite the unexpected news, the family remained optimistic about her treatment. However, their world was shaken again just five days later when Molly was diagnosed with a second form of cancer.

Though they live out of state, the family considers Boston their "home" and came to Boston Children's Hospital (BCH) when Molly needed a second transplant. In June 2022, at the age of 5, Molly passed away in the ICU at Boston Children's. Despite the distance, Sarah, John, and Emma returned to Boston in November 2023 to attend the Keeping Connections Conference. They would now like to share their experience of the event with fellow bereaved BCH families.

Dear SoYun and the staff at Keeping Connections,

It has been a few days since our family attended the Keeping Connections program and I have been trying to put into words how meaningful an experience it was for our family and how grateful I am for having this program available to our family.

I will admit I was somewhat hesitant about attending. We had attended a family bereavement day at our local hospital last year, and it was a pretty terrible experience. But from the moment we arrived on campus and were told to "follow the balloons," I knew this was going to be different. 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. As I shared our story and listened to other families share theirs, I had this incredible feeling of being completely seen, heard, and held. The stories were all raw and painful and beautiful.

One of the many losses that comes with having your child die is that of the support from various organizations and groups - for example, to all of a sudden not be invited to monthly meetings of a childhood cancer group. While I know many feel they are doing the right thing by not "bothering" us or "reminding" us that our child is no longer alive (as if we can ever forget), it hurts. During the three months Molly spent at Boston Children's Hospital, we received incredible love and support from the amazing staff on 6W and 7S (I included a link to the piece I wrote for STAT news about this - Continuity nursing helped my family in our darkest PICU moments (statnews.com)). Keeping Connections was a reminder that we are still a part of the Boston Children's Family and that the support we received during Molly's illness is still available to us. I was struck by the number of social workers and child life specialists who were present for the day. To know that they had shown up on a day off to be present with us and support us was such a gift.

Thank you for not forgetting about us. For giving us an opportunity to talk about Molly and share her with other families. And for all that you do.

Sarah



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, please email us at:

bereavement.program@childrens.harvard.edu

<u>Connect with the BCH Bereavement</u> <u>Program on Facebook</u>



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.

SoYun Kwan, LICSW Bereavement Program Social Worker bereavement.program@childrens.harvard.edu



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.

Ellie Frechette, LICSW, APHSW-C Clinical Social Worker, PACT eleanorm_frechette@dfci.harvard.edu

Please reach out for further resources or recommendations

