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COMMUNITY BRIDGE OF SUPPORT

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PEDIATRIC E-JOURNAL WORKGROUP
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Issue Topic: Community Bridge of Support Part Two

Welcome to the 80th issue of our Pediatric e-Journal. As explained in the introduction to Issue #79, this subject brought us an unusually large number of contributions in which authors describe ways in which individuals, programs, and communities are working together and can work together in support of pediatric hospice and palliative care. As we have learned from the large outpouring of articles on this subject, working together can take many forms, many of which depend on the individuals involved and the communities in which their efforts are located. Because these are large topics, we have divided the contributions we received into two parts: Issue #79 was Part One and this issue #80 is Part Two. We recognize that even two issues will not be capable of providing exhaustive coverage of these matters, but we hope that the articles offered here will spark broad discussion of this important subject area.

This e-Journal is produced by the Pediatric e-Journal Workgroup and is a program of the National Alliance for Care at Home (the Alliance), formerly the National Hospice and Palliative Care Organization. The Pediatric e-Journal Workgroup is co-chaired by Christy Torkildson and Melissa Hunt. Chuck Corr is our Senior Editor. Archived issues of this publication are available at allianceforcareathome.org/pediatric-e-journal/

Comments about the activities of the Pediatric e-Journal Workgroup or this issue are welcomed. We also encourage readers to suggest topics, contributors, and specific ideas for future issues. We are open to suggestions for the next issue that will follow in 2025. Our tentative plans are for Issue #81 to discuss issues involving adolescents and young adults, and for Issue #82 (our first issue in 2026) to address trauma and trauma-informed care. If you have any thoughts about these topics or other subjects for future issues in 2026 and/or potential contributors (including yourself?), please contact Christy Torkildson at Christy.Torkildson@gcu.edu or Melissa Hunt at melissa.hunt@handsofhopese.com

Views expressed in this and other issues of the Pediatric e-Journal are exclusively those of the authors and do not necessarily reflect the views of the Pediatric e-Journal Workgroup, the Pediatric Council, or the National Alliance for Care at Home.

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Ashley Ham

This author writes that when in 2019 she became an NICU Mom, her "high-risk pregnancy was filled with appointments, diagnoses, and uncertainty, but nothing could have prepared me for the isolation of the NICU." Like many millennial mothers, she turned to the internet, "but instead of comfort, I found more questions, more overwhelm, and a deep sense of grief." However, when another NICU mom messaged her on Instagram, they "met, shared our stories, and instantly bonded. That's when I discovered the life-changing power of community, and the idea for Dear NICU Mama was born." She explains that "Dear NICU Mama exists to remove any and all barriers for a NICU mother to receive the life-changing power of peer support. Our goal is to meet her exactly where she's at, without judgment or expectation, and offer her the option to engage with this global community whenever she's ready."

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Christina Naughton, Licensed Funeral Director

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This article explains the importance of post-mortem tissue donation. The author then addresses the role of pediatric palliative and hospice care workers in supporting "Gift from a Child (GFAC), a national program enabling families to donate their child's tissue post-mortem, [a program that] provides an opportunity for families facing unimaginable loss to contribute meaningfully to the future of pediatric brain tumor research." The author notes that "Gift from a Child was founded by families who had lost a child to brain cancer," explains how this program supports families and care teams, and offers a way to learn more about this program.

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Glass Child

Stephanie Ballard,
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Some lessons in life don't come loud. They drift in like a whisper, quiet, powerful, and easy to overlook. I learned this the hard way, through years of parenting, heartbreak, and the blinding light from the pulsing flames created by flash fires.

When my son Braeden was born with Hypoplastic Left Heart Syndrome (sometimes referred as half a heart syndrome), our family's world shattered. My newborn baby needed three surgeries just to survive. Our days became a blur of hospital rooms and waiting rooms. In the background stood Colin, my older son. He was seven years old and already shouldering more than most adults. He held Braeden's hand in the I.C.U. at C.S. Mott Children's Hospital at the University of Michigan. Often he would repeat bedtime stories through the baby monitor, never asking for anything in return.

Colin was what some call a "Glass child"—the sibling of a child with special needs. Not because he was fragile, but because he was "see-through." Always there, yet often invisible. While I poured everything into Braeden's care, I didn't always see the sweet boy beside me, trying to be brave, trying to be enough.

But Colin loved his brother fiercely. Their bond was built in silence, midnight giggles, shared glances, and gentle touches.

In Braeden's final days, when he was in hospice and too weak to get out of bed—his body dulled by pain and heavy with medication—Colin didn't say a word.

One summer afternoon, Colin stepped into the dim room, the air thick with stillness, and gently bent down beside his brother. With arms that had grown strong over years of caretaking and love, he lifted Braeden against his chest. His walk up the basement stairs was slow, careful—anchored in a tenderness only he could offer. After navigating the kitchen and an uncooperative door wall, he stepped out onto the deck.

Colin had built a small campfire in the backyard earlier, something his brother loved. He settled Braeden in front of the flames in a lawn chair and sat beside him. As the fire crackled there was a dim casting of a golden light over them. Colin didn't say much. I was watching from

the kitchen widow over the counter. Staring, I could see their shoulders touching, letting the space between breaths do the talking.

That was their goodbye, simple, sacred, and heartbreakingly beautiful. In that moment, as I look back now, Colin's being, as a "glass child," refracted light into a rainbow I will never forget.

Glass appears delicate, but it's forged, like steel, through fire. Like a vase or ornament, Colin was shaped by the heat of responsibility, anticipatory grief, and fierce love. He became something beautiful—clear, strong, and full of light. Often, I didn't see him because I was again blinded by flashing flames of another medical crisis.

When Braeden passed away that July at seventeen, our house shattered into a heavy silence. At the funeral, Colin stood at a podium in front of family and friends, speaking for the first time about what his brother meant to him.

"Braeden was my silent mentor," he testified. "He taught me how to be stronger, even when things felt impossible. Watching him fight through daily pain and still able to create moments of joy gives me the courage to face my own battles. After my duty as a soldier, I became a surgical technician for a team of cardiac surgeons. My mom often wonders if it was because of him."

He ended with, "Every time I help repair a heart, I feel like I'm honoring his."

After his speech, the nodding and tears from friends and family were what ignited me to tell this story about the Glass children. It didn't come loud or through grand gestures but in the quiet way Colin moves through life—with compassion, strength, and unshakable love. The kind of love shaped long ago in chaotic hospital rooms, story whispers, and the steady grip of a brother's hand forged by fire.

My hope now is that other mothers of children with life-limiting conditions hear the lesson I learned, through this recent prayer I wrote down.

"I see you Colin. I see the child I missed in the shadows of survival. I see the boy who loved his brother with his whole heart. And I see the man you've become—strong not in spite of your tenderness, but because of it.

Braeden's half a heart may have been weak, but the love between my boys was the strongest thing I've ever known. And in that bond—in the glass forged from fire—I found the quiet, indestructible heart of our family and that's what makes me whole now."

Love,
Mom

From Isolation to Connection: Building Bridges Through Dear NICU Mama

Ashley Ham,
Executive Director + Co-Founder
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In 2019, I became a NICU mom.

My high-risk pregnancy was filled with appointments, diagnoses, and uncertainty, but nothing could have prepared me for the isolation of the NICU. We spent time in two hospital NICUs: one with an open bay of beds and another with a private room. Having our own space became a blessing, but it also added a layer of loneliness. I could no longer look around and see other mothers beside their babies. Connecting with other NICU moms took intentionality and energy—something I usually didn't have.

Like many millennial moms, I turned to the internet. But instead of comfort, I found more questions, more overwhelm, and a deep sense of grief. The resources I found might have helped a clinician, but not a mom looking for hope. I was met with statistics, PTSD diagnoses, and outcomes that left me wondering if I'd ever truly heal.

Halfway through our NICU stay, another NICU mom messaged me on Instagram and asked if I wanted to grab coffee. We met, shared our stories, and instantly bonded. That's when I discovered the life-changing power of community, and the idea for Dear NICU Mama was born.

When the pandemic hit shortly after our launch, we shifted everything online—support groups, podcasts, social media—so moms could connect no matter where they were. One mom shared, "Dear NICU Mama felt like a life raft when I was drowning... I felt seen. I clung to this community in our darkest days and still find comfort in it daily."

Dear NICU Mama exists to remove any and all barriers for a NICU mother to receive the life-changing power of peer support. Our goal is to meet her exactly where she's at, without judgment or expectation, and offer her the option to engage with this global community whenever she's ready. As one mom said, "To me, Dear NICU Mama is a safe space for healing and nurturing. It's a positive platform where raw emotion can meet tangible support."

As Bessel van der Kolk says, "Traumatized human beings recover in the context of relationships." This is the bridge of support Dear NICU Mama is here to provide.

Connect with Dear NICU Mama:
Website: www.dearnicumama.com
Social Media: @dearnicumama
Podcast: Dear NICU Mama Podcast

A Lasting Memory: How NILMDTS Helps Families Capture Precious Moments

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Each year in the United States, nearly 40,000 babies are either stillborn or die within the first month of life. And while there is a plethora of parenting resources available, very few address parenting in the face of loss. Though it may initially seem counterintuitive to encourage parenting in these situations, it greatly improves the psychosocial outcomes for these families when we facilitate this type of memory-making.

For over 20 years, **Now I Lay Me Down to Sleep** (NILMDTS) has provided professional remembrance photography to families experiencing the loss of a baby. By capturing these fleeting moments, NILMDTS helps parents honor their child's life, create lasting memories, and find comfort in the years to come. Through partnerships with hospitals and dedicated volunteer photographers, NILMDTS has served tens of thousands of families, ensuring they have the opportunity to document and cherish their baby's existence.

Families rarely regret the memories they make—but they often regret the ones they didn't. Parents frequently share how they wish they had known to hold their baby longer, dress them in a special outfit, or capture more photos. In times of shock and grief, they may not think to take pictures or even realize they can embrace their child. Care providers play a crucial role in gently guiding parents through these moments, encouraging them to create meaningful memories while they still can.

Photographs serve as more than keepsakes. They act as a bridge to this type of parenting, as well as offer healing for years to come. The journal Illness, Crisis & Loss says that remembrance photography "did not simply produce mementoes, but invited families into a parenting role, to celebrate their baby's life, to tell their story, and to help make meaning of their experiences in an often overwhelming and chaotic medical space" (Martel & Ives-Baine, 2014).

Having these moments is especially important for parents in order to help construct the future identity of their family. Many loss parents are faced with difficult questions down the road, such as "Do you have any children?" or "How many children do you have?" These are difficult questions to answer because, as outlined in an article in the journal Death Studies, "Parents facing early child loss/perinatal death suffer no less, yet they are faced with the additional burden that their baby is not socially recognized as significant" (Blood & Cacciatore, 2014).

In order to facilitate as much memory-making as possible, we recommend the following:

- **Introduce the idea of photographs early and often**. Contact NILMDTS to see if a photographer is available and encourage parents and caregivers to take as many photos as they wish.

- **If your facility offers care packages for families experiencing loss**, introduce that early and go through the contents with them so that they understand everything inside and can incorporate them into the memory-making process.
- **Don't forget to capture photographs** of the details of the day-room signage, flowers, memory box items, stuffed animals, special clothing, etc.
- **Call their baby by name and treat them as you would any baby.** Point out features of the baby—cute noses, tiny hands, curly hair. Refer to family members as "mom," "dad," "grandma," "grandpa." This may be the first time they've ever heard themselves called by those names.
- **Encourage parents** to hold their baby as long as they want.
- **Have parents** dress and diaper their baby, bathe their baby, and brush their baby's hair.
- **Take handprints, footprints, and molds** (if your facility offers them). Make multiple copies.

Always encourage family members to take pictures above and beyond what NILMDTS or you as the caregiver takes. They can never have too many. Let parents know that they never have to look at these pictures or keepsakes, but that they will always have them for when they are ready.

Suggestions like these and many more can be found in our updated course *Remembrance Photography as a Best Practice in Perinatal Loss Populations*. This nursing continuing professional development activity was approved by Colorado Nurses Association, an accredited approver by the American Nurses Credentialing Center's Commission on Accreditation. This course is ideal for any practitioner that deals with patients experiencing perinatal loss and will help them to reach families that NILMDTS is unable to serve due to availability, time of day, condition of the baby, or shortened timelines. With the knowledge and skills taught, providers will be able to give their bereaved parents the best patient experience possible under the circumstances. More information can be found at www.nowilaymedowntosleep.org/continuingeducation

Additional Information on NILMDTS

Now I Lay Me Down to Sleep (NILMDTS) gifts remembrance portraits to parents experiencing the death of a baby. Since 2005, over 75,000 families from around the world have received photographs free of charge from NILMDTS.

Testimonials

"As a labor and delivery nurse, the hardest days are the ones where we send families home without the sweet babies they have longed for, nurtured, and loved. The services provided by NILMDTS allow me to assist in supporting those families by honoring the little lives lost. Working with NILMDTS fosters the preservation of memories for these families during a whirlwind of heartbreak."

–Ada Murdock, Registered Nurse

"I don't know the name of the nurse who took a few photos for us but I am grateful that she was there. To all the nurses and hospital staff that step out of your roles and into the rooms of grieving families to capture the few moments we have with our babies. Thank you!!!"

–Krysten Rivera, Jakob's Mommy

How to Find a Photographer

NILMDTS will assist in locating a local affiliated photographer to capture images for a bereaved family. It is recommended that you call as soon as possible, even during the admission process, for the best chance of locating an available photographer. Local photography contacts can be located on the NILMDTS webpage.

Guidelines for Services

At the request of the parents or medical staff, we will have a NILMDTS affiliated photographer, if available, come to the hospital or hospice location for a private and sensitive photography session. Our affiliated photographers are dedicated to making the photography session as loving, sensitive, and private as possible. When searching for a local NILMDTS photographer visit www.nilmdts.org for contact information in your area.

NILMDTS photographers provide the free gift of professional quality portraiture. Gently retouched black and white or sepia toned portraits are delivered digitally.

Retouching

If a NILMDTS photographer is not available, please utilize the Remembrance Photography Guide for Hospitals located on the NILMDTS webpage. The guide includes instructions for submitting images for retouching to NILMDTS. Providers are also welcome to complete our updated course, *Bereavement Photography as a Best Practice in Perinatal Loss Populations*, for direct access to our retouching pipeline. More information can be found at www.nowilaymedowntosleep.org/continuingeducation.

Sources:

Blood, C., & Cacciatore, J. (2013). Parental grief and memento mori photography: Narrative, meaning, culture, and context. Death Studies, 38(4), 224–233. https://doi.org/10.1080/07481187.2013.788584

Martel. S., & Ives-Baine, L. (2014). 'Most prized possessions': Photography as living relationships within the end-of-life care of newborns. Illness, Crisis, & Loss, 22(4), 311-332. https://doi.org/10.2190/IL.22.4.d

My DIPG Navigator: A Nationwide Nurse Navigation Program for DIPG/DMG Families in the Fight

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In 2022, the ChadTough Defeat DIPG Foundation launched a nationwide program called My DIPG Navigator, designed to give much needed, FREE, individualized guidance for patients and their families facing a childhood brain cancer diagnosis, specifically DIPG (diffuse intrinsic pontine glioma) or DMG (diffuse midline glioma).

Pediatric brain cancer is now the leading cause of cancer-related deaths in children. While DIPG/DMG tumors are responsible for nearly half of those deaths, the disease is still considered rare, affecting 300-400 patients annually. Gaining access to the most up-to-date treatment information has been challenging for many patients and their families, as most physicians across the country have not directly treated a DIPG/DMG patient.

Working through the shock of the diagnosis and prognosis, patients and their families often find themselves alone in navigating treatment plans and managing side effects. They must quickly make important decisions that will impact the patient's care, and they often struggle to find the help they need. Additionally, systemic healthcare inequities, often linked to racial and socioeconomic factors, can impact the ability to access information and navigate a DIPG/DMG diagnosis, particularly in finding highly sought-after clinical trials.

My DIPG Navigator, led by dedicated nurses with years of experience in pediatric oncology, empowers patients and their families with the proper information and resources necessary to make the most-informed decisions throughout their cancer journey. Recently, the foundation brought on a full-time social worker, allowing the nurses to focus on the medical side of service, while families receive the comprehensive emotional and practical support they need during their devastating journey. This service is completely free for any family able to be treated in the United States.

"The devastation that comes with a pediatric brain cancer diagnosis can leave patients and families in shock and disbelief," said Director of Nurse Navigation, Daniela Ciccolini. "We want to ease their journey as much as possible by helping them understand the disease, connect with the proper resources, and make informed decisions as quickly as possible."

The program will:

- **Provide immediate support,** with guaranteed response within 12 hours of initial contact to the organization
- **Ensure EVERY patient and/or family** has the ability to access the information they need regardless of socioeconomic status or cultural ethnicity
- **Provide disease education** to patients and/or families
- **Guide patients and/or families** in identifying experienced DIPG or DMG physicians, according to patient's location or preferred expertise preference
- **Connect families with other resources** to meet other needs like financial, travel, or mental health
- **Provide encouragement and serve as a liaison** to improve physician-patient interactions

> "Our nurse, Ashley, has been a huge help. She's given us information and most importantly hope! I don't know where we would be if it wasn't for her. We are forever grateful."
>
> **–My DIPG Navigator Family**

My DIPG Navigator stems from the vision of Jace Ward, an amazing DIPG/DMG advocate, diagnosed in 2019, nine months before his 21st birthday. Jace died believing all families should be able to quickly access the most current information about best practices and DIPG treatment options. This free program is made possible not only by the ChadTough Defeat DIPG Foundation and its Family Partners, but also through the generous support of its Navigator Partners.

"ChadTough Defeat DIPG Foundation has and will continue to fund incredible research that we know will one day lead to a cure," said co-founder Jason Carr, who lost his son Chad to DIPG in 2015. "But for me, being able to help make a difference, right now, is so meaningful. We are giving people the guidance that we didn't have to make important decisions, and that is really game changing."

To date, My DIPG Navigator has helped nearly 450 families.

For more information on the program, visit mydipgnavigator.org.

About the ChadTough Defeat DIPG Foundation

The ChadTough Defeat DIPG Foundation is a recognized leader in childhood brain cancer research, funding, and direct family support. Our mission is twofold: to fund groundbreaking DIPG research and to provide critical, one-on-one support to families facing this devastating disease.

With a dedicated team of experienced registered nurses and passionate nonprofit professionals, we have a deep understanding of the challenges families face and are committed to honoring the children who inspire our efforts. Our collaboration with major medical institutions and leading researchers ensures that families receive high-quality, evidence-based guidance tailored to their needs.

ChadTough CEO Ann Friedholm (pictured center) with the nurses of My DIPG Navigator

To date, the foundation has committed over $36 million to 90 researchers across 44 institutions, making it one of the largest and most influential funders of DIPG research in the world. We are also guided by a Scientific Advisory Council composed of renowned experts in pediatric brain cancer, ensuring that our efforts are driven by the latest advancements in the field.

To learn more about the foundation visit www.ChadTough.org.

Supporting the Often Overlooked: The Mission of Bus Stop Club

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When a child is diagnosed with a chronic illness or special needs, significant attention is naturally directed toward their care and well-being. However, an often-overlooked aspect of this reality is the profound impact on their siblings. These children, though not directly affected by the diagnosis, frequently experience emotional and social challenges that go unnoticed. Recognizing this need, Dr. Brian Sheridan, a third-year pediatric resident at the Children's Hospital at Albany Medical Center, founded Bus Stop Club in 2005 in Upstate New York. This organization was created with a singular focus: to provide emotional and social support for the siblings of children with special needs or chronic illnesses.

There are numerous support programs available for children diagnosed with medical conditions, as well as for their parents and caregivers. However, Dr. Sheridan identified a critical gap in services for siblings—children who also undergo significant emotional and familial changes due to their brother or sister's diagnosis. The goal of Bus Stop Club is to ensure that these siblings receive the understanding, coping strategies, and support necessary to navigate the complexities of their family dynamics in a healthy and constructive manner.

The sibling relationship is often one of the longest and most influential bonds in a person's life. When one sibling is diagnosed with a medical condition, it is essential to provide support for the other children in the household. Many of these children experience a range of emotions, including anxiety, worry, jealousy, resentment, sadness, anger, frustration, and a sense of responsibility. At Bus Stop Club, participants are encouraged to acknowledge and express these emotions in a safe and supportive environment, reinforcing that their feelings are valid and that they are not alone.

Program Offerings and Impact

Bus Stop Club conducts monthly sessions designed to help members express their emotions, develop coping skills, and build friendships with peers facing similar challenges. Each session provides a safe space where children can share their experiences and concerns while engaging in meaningful discussions and activities. Themes often focus on understanding their sibling's

diagnosis, family changes, and stress management. To create an engaging and relaxed atmosphere, sessions incorporate interactive elements such as therapy dogs, art and music therapy, and even magicians.

In addition to these sessions, Bus Stop Club extends its support to the Melodies Center at Albany Medical Center Hospital. Through the Bus Stop Club Cart, children in the waiting room—both Bus Stop Club members and their siblings receiving treatment—are provided with activities to help them stay engaged and at ease. These activities allow parents to take a brief respite while their children enjoy a moment of normalcy.

Beyond regular meetings, Bus Stop Club organizes special outings and events focused solely on its young members. Participants have had the opportunity to visit the Statue of Liberty, Boston Children's Museum, the Bronx Zoo, Six Flags New England, and local sporting events. These experiences allow children to step away from the responsibilities and worries of home, even if just for a few hours, and simply enjoy being kids.

Recognizing the financial strain that medical expenses can place on families, Bus Stop Club ensures that all its services remain free of charge. Additionally, the organization hosts family events, offering entire families the chance to bond in a comfortable and understanding environment. These gatherings provide a valuable opportunity for parents to connect with others facing similar circumstances, fostering organic support networks.

A Lasting Impact

The influence of Bus Stop Club extends far beyond its sessions and events. As one family member shared:

"This is an amazing program! My niece participated in Bus Stop Club for many years. Our family was so grateful that she had something that made her feel special and not overlooked in the complex dynamic of raising a child with Down Syndrome. I'm proud to say my niece recently passed the bar exam and is now a lawyer! In some way, I know Bus Stop Club played a part in affirming that her dreams and aspirations always mattered."

Currently operating in the Albany, New York area, Bus Stop Club has recently expanded with the establishment of a chapter in Geneseo, New York, initiated by a former member now attending college.

For more information on starting a Bus Stop Club chapter or to learn more about its programs, please contact Angela Tobin at Angela.Tobin@BusStopClub.com or call 518.221.4402.

Bus Stop Club remains committed to supporting the often-overlooked siblings of children with chronic illnesses and special needs, ensuring they feel valued, understood, and empowered to navigate their unique family journey.

Help for Pregnancy and Infant Loss

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When a family is happily expecting the arrival of a new baby, the last thing most expect is that the baby will die either before or shortly after birth. Yet approximately 15-25% of all pregnancies end in miscarriage (the death of a baby before 20 weeks), and approximately 1.2% of pregnancies greater than 20 weeks up until 30 days postpartum end in stillbirth or neonatal death. The death of a baby either during pregnancy or after birth can be a traumatic, life-changing experience that affects not only the mother and her partner, but also their immediate and extended family and friends. Complicating the situation, many parents who experience the death of a baby during pregnancy or in the newborn period often face indifference from their loved ones, which can leave them feeling isolated, misunderstood, and unsure of how to carry on. The grief bereaved parents experience may encompass a wide variety of difficult emotions such as guilt, anger, and fear, and these emotions can be challenging for parents to deal with if friends, family, co-workers, and society in general do not acknowledge the depth of what the parents are experiencing. This is where SHARE can step in and help grieving families navigate the difficult emotions and experiences that the loss of a baby can entail.

SHARE has been touching lives, healing hearts and giving hope since 1977 when the organization was founded by Sister Jane Marie Lamb, OSF.

Touching lives...

SHARE is there for grieving families from the moment of their loss. One of the SHARE programs is the SHARE Companion Program. SHARE companions are bereaved parents and grandparents who have taken several years to grieve and begin to heal in healthy ways who then want to give back and help others through their own loss and grief. Often, companions will be at the bedside when a mom is in labor, through delivery, and then help with memory-making activities after the baby is born. They attend a funeral or memorial event and are there for support when parents attend group meetings. They are available to talk on the phone or meet for coffee—whatever the newly grieving parent needs at the time. The companions have a unique role—not only are they there to support the family, but they allow the newly grieving parents to see that one can experience such a devastating loss and survive it. They show that one can find joy and happiness again with time while always honoring and remembering one's baby.

The staff of the national SHARE office are trained as peer companions and offer phone support when a grieving parent, grandparent, or other family member calls. The national office sends out free packets containing information and booklets specific to their type of loss. The national office also connects parents nationwide with a SHARE companion if one is wanted.

Healing hearts...

SHARE offers seven different support groups each month: One in-person group at the national office, three weekly bereaved parent support chats, one monthly pregnancy after loss support chat, one monthly chat for those who terminated their pregnancy for medical reasons, and one monthly Zoom meeting. In addition, parents can find support in one of three closed Facebook groups: A general bereaved parent group, one dedicated to those who are pregnant again after their loss, and one for those who have terminated a pregnancy for medical reasons. Each of these groups is moderated by SHARE staff members, making them safe places to share difficult emotions and situations. Except for the in-person support group, these groups are available worldwide.

SHARE also offers quarterly burial and memorial services for miscarried babies in conjunction with a funeral home free of charge. These remembrance events give families who experience early pregnancy losses the validation they need to know their baby is very much loved and honored.

There are more than 75 SHARE chapters in 29 states around the country, and many of them provide the same services the national SHARE office provides: Companions, memorial events, support groups, and more.

The support SHARE provides encompasses not only care for the parents, but also grandparents, other family members, and the baby's siblings. SHARE provides memory kits for grieving children and has hosted events specifically for the siblings and grandparents.

SHARE's reach extends to Spanish-speaking families. All SHARE brochures, booklets and memory books are available in Spanish, and there are two Spanish-speaking bereaved parents on staff who offer online support chats as well as a closed Facebook group.

While SHARE's primary mission is to support grieving parents, the secondary mission is to provide education and support to professionals such as physicians, nurses, social workers, genetic counselors, therapists, and others who care for grieving families not only at the time of their loss but also in the following months and years. There are online workshops and quarterly Zoom workshops available, some of which offer continuing education credit to nurses, and SHARE staff members often travel to provide in-person companion and other training workshops. They also send educational packets to professionals detailing what SHARE provides.

Additionally, SHARE's website contains a plethora of information and resources not only for grieving families but also for caregivers who work with families who experience pregnancy and infant loss. The SHARE staff keeps a current list of pregnancy and infant loss support groups and organizations around the country, and that is also available on the SHARE website.

Giving hope...

SHARE prides itself on making hope tangible. When a family experiences the death of their beloved baby, they often feel as if their parenting role has been severed. SHARE provides ideas and opportunities for them to be able to identify ways to weave their baby into their family's story as they begin to heal and try to figure out how to live their lives in meaningful, joyful ways.

SHARE provides numerous events throughout the year that families are welcome to attend for as many years as they want to. One of the largest events is the Share Walk for Remembrance and Hope, held each year in October. During this event, nearly 600 baby names are read. Those who register for the walk receive a T-shirt with their baby's name(s) printed on the back. Baby names are also printed on a wall that is displayed at the walk, where families can take photos and leave flowers. This event is attended by nearly 2000 people each year and provides a way for extended families to support their grieving loved ones.

Other events throughout the year give families more opportunities to honor their baby. The holiday season is often difficult, even years later, and SHARE hosts an outdoor candlelight vigil in December, as well as a holiday memorial event just before Christmas called The Light of Hope. At this event, baby names are read, candles are lit, and families are given a keepsake ornament to take home for their tree. Whenever possible, SHARE hosts events for parents to create keepsakes in honor of their baby, such as an annual bracelet-making night for moms and grandmas.

All support provided to grieving families is free of charge, and several fundraising campaigns throughout the year ensure SHARE is able to continue its mission so that no family has to go through the devastation of the loss of their baby feeling alone.

Contact SHARE Pregnancy and Infant Loss Support at info@nationalshare.org

“The Smallest Caskets are The Heaviest”: Some Thoughts From A Funeral Director

Christina Naughton,
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Handling deceased babies and children is one of the most heartbreaking and challenging situations that funeral directors face. It goes against everything the human race has been taught about the circle of life. Parents aren’t supposed to bury their children, and I don’t care how many of these precious families I have helped over the years, it never gets easier.

It is always so very important to realize that it is not about the age of the child to their parents—it it’s about what they hoped their child would be. It is also extremely difficult for parents to come to the realization of all of the milestones that they will never experience with their baby or child.

As a local funeral director, it is vital that you “direct” these parents (because most of them have no idea what to do) and let them know all options available to them to celebrate their infant or child’s short life.

We work very closely with our Children’s Hospitals and our Labor & Delivery teams at our local hospitals. I always request that the facility allow me to make the transfer of babies and children from their hospital room and request that the medical team does not take them to the morgue. As a parent myself, I wouldn’t want my baby or child to be in a cold morgue. This practice also allows the family to get to know me and that’s where the trust begins. They want to know WHO is caring for their precious babies and children. This is also very important to me that I have the opportunity to meet the parents face to face.

There have been many times that I have waited in a hospital waiting room for 2, 3, and even 4 hours to bring an infant or child into my care. Although the family calls the funeral home when they are ready for us to bring their precious baby/child into our care, it is a different story when we arrive to do so. One of the most gut-wrenching feelings is asking permission to physically remove a baby from a mother’s arms. It is wrong on every level, and it is heartbreaking for us as funeral directors.

With the above being said, it is important to allow and support the family as they “feel the “feels.” I have slept on a church pew overnight because the parents couldn’t bear to leave their baby there overnight “alone” as they will tell you. This gives them the opportunity to hold their precious baby and rock him/her during the night. I have brought babies back to their home so that their big brothers and sisters can say their goodbyes in a familiar environment. Basically, if the parents have a

specific request and there is a way to make it happen, I make sure their wishes are met. It is not uncommon for a Mama and Daddy to want to assist in the final preparation of their baby/child's funeral by being the one that dresses them for the last time, swaddling their baby for the last time, or just observing while we, as funeral directors, are performing this emotionally, heartbreaking task. Local funeral directors should be honoring these requests with the utmost compassion and dignity for the family they are serving.

As for new funeral directors that will be serving an infant/child family, I would strongly suggest that you "shadow" a seasoned funeral director a few times before assisting these families on your own. It's best that you have as much of the "leg work" done before they arrive to make funeral arrangements, such as paperwork, death certificate entry, etc. Mama and Daddy's do not want to walk into the funeral home, much less be there for more time than necessary.

I also feel that it is imperative that I call and check in with grieving parents after the services of their beloved infant/child. This give me the opportunity to support the family and to offer them grief resources that may be of help as they navigate through their journey of losing their infant/child.

As I close, I'd like to share with you that I do everything possible not to utilize an infant casket for a public visitation. My preference is always a bassinet. This feels much more natural, and it doesn't seem quite as traumatizing to parents and visitors alike.

Empowering Families and Advancing Research: The Value of Post-Mortem Tissue Donation

Patti Gustafson,
Executive Director
Swifty Foundation/Gift from a Child
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As a pediatric palliative and hospice care worker, you play a critical role in supporting families through some of the most challenging moments of their lives. **Gift from a Child** (GFAC), a national program enabling families to donate their child's tissue post-mortem, provides an opportunity for families facing unimaginable loss to contribute meaningfully to the future of pediatric brain tumor research. Gift from a Child was founded by families who had lost a child to brain cancer.

Why Post-Mortem Donation Matters

Post-mortem tissue donation allows researchers to study tumors in their most advanced state—when they have evaded every treatment. As **Dr. Michael Taylor from Texas Children's Hospital** explains:

> *"Post-mortem tissue is absolutely critical if we want to cure more children with brain tumors. The tumor at the time of death is the one that evaded therapy. Studying it helps us understand how to prevent future losses."*

GFAC's infrastructure, including seven **Centers of Excellence** across the United States, ensures tissue donation is handled with care and respect. These centers are Stanford, CHOP, Children's National, Weill Cornell, Arnold Palmer, Seattle Children's, and Lurie Children's Hospital. Each donation also contributes to the **Children's Brain Tumor Network** (CBTN), enabling global access to the tissue and the data it generates, accelerating breakthroughs worldwide.

The Family Perspective

Families often find donation to be a positive first step in their grieving process. Knowing their child's tissue can help prevent future suffering brings a sense of purpose during an otherwise devastating time.

One parent reflected:

> *"It helped our family to know she was contributing even after death: to know there was one last thing she could do after she'd taken her last breath."*

A 2021 survey of 108 families revealed that **98% were satisfied or very satisfied** with their decision to donate. Families want to be part of the solution and to know that their child's legacy lives on through research.

How GFAC Supports Families and Care Teams

GFAC understands that this process requires sensitivity and respect. Each donation is facilitated by a **Tissue Navigator** from one of GFAC's Centers of Excellence. The Tissue Navigator works alongside the medical team to ensure the family's needs come first. Families are given as much time as they need with their child after passing, and updates on how the tissue is used are shared with them over time.

Additionally, GFAC honors family requests to direct tissue to specific researchers or treating physicians whenever possible. The program provides tools and training to help healthcare professionals approach families with compassion, offering donation as an option without pressure.

What You Can Do

As a trusted presence in a family's journey, you can help ensure that tissue donation is part of the end-of-life care conversation. Families have the right to this choice—one that can bring solace and purpose amidst loss.

For more information about GFAC and resources to support your team, visit www.giftfromachild.org.

Together, we can honor the wishes of families, accelerate research, and move closer to a world where pediatric brain cancer is no longer a life-threatening diagnosis.

Items of Interest!

Please help us keep the items of interest up to date. Share your news, upcoming conferences or webinars. Are there particular podcasts that may be of interest to our readers? Send any items of interest to Christy at Christy.Torkildson@gcu.edu**. Thank you.**

NHPCO is now part of the National Alliance for Care at Home. The Alliance remains committed to pediatric palliative, hospice, and home care, and we continue our work in helping bridge the gaps with education, advocacy, and resources to help our community of pediatrics.

We have heard a lot of concern about the dropping of palliative care from the title of the new organization formed by the National Association of Hospice and Palliative Care Organization (NHPCO) and the National Association for Home Care and Hospice (NAHC) merging. This name was chosen for readability, believing shorter would be easier. However, the commitment of The Alliance remains to all facets of palliative care, hospice, and home care. We remain committed to maintaining as many of our resources as possible as open access in support of this community.

On another note: The Items of Interest are only as valuable as the information shared. Please send us your news to share. E-mail to Christy.Torkildson@gcu.edu

1. **A wonderful resource that may be helpful is "Not if, but When),** a website that "encourage and support sharing good books and stories about death and loss with children and teens throughout their lives." Website: www.notifbutwhen.org/
2. **2025 National Alliance for Care at Home Annual Meeting & Exposition** will be held November 2-4, preconference November 1-2 in New Orleans. For more information, click HERE.
3. **EPEC-Pediatrics Registration** is OPEN at the University of California, San Francisco (UCSF), August 27-28, 2025. UCSF also hosts monthly FREE webinars. More information can be found HERE.
4. **State Coalitions from Pennsylvania and California,** with support from the Shiley Haynes Institute for Palliative Care bring you the Pediatric Palliative Care Webinar Series for 2025 continues, and the PPC webinar series for 2026 will be announced this Fall! Calendar and more information, including how to register can be found at www.ppcwebinars.org/
5. **AAHPM & HPNA Annual Assembly 2026** will be in San Diego, California March 4-7, 2026-. Click HERE for more information.
6. **ELNEC has several upcoming courses;** if you are faculty, you can get free access to the curriculum for your program/courses you teach. Click HERE for more information.
7. **The Coalition for Compassionate Care** is hosting its annual summit, October 6 & 7, 2025, in Costa Mesa, California – near Disneyland! There is a strong pediatric track and Ira Byock is the opening plenary speaker. More information can be found HERE.

8. **Have a conference to submit/share – send us the information to** Christy.Torkildson@gcu.edu.

9. **Courageous Parents Network** provides opportunities for our network of caregivers, clinicians, and others to come together to learn about topics relevant to the shared journey. They host webinars with leaders of the field and parents who have been or still are on their journey. There is a wealth of resources for family members and providers. Click HERE for more information.

10. **The Patient Quality of Life Coalition (PQLC)** hosted a Lobby Day in Washington, DC on Tuesday, July 22. There were 22 states represented, with 88 scheduled appointments with legislators from across the nation, during which they were asked to support PECHETA and funding for palliative care research. Over 50 national organizations, including the Alliance for Care at Home, the Hospice and Palliative Nurses Association, the American Academy of Hospice and Palliative Medicine, and the American Academy of Pediatrics, as well as more than 50 state organizations, support these requests. **You can find updates to legislative issues on the Alliance website** HERE**, on the HPNA website click** HERE**, the PQLC website click** HERE**.**

11. **Academy Health: Enhancing Systems of Care for Children with Medical Complexity Newsletter** is a collaborative project with the University of San Francisco, Family Voices, Boston Children's Hospital, Patient Insight Institute, Patient Advocate Foundation. More information can be found HERE.

12. **The Lucille Packard Foundation for Children's Health publishes the Children and Youth with Special Health Care Needs Network Newsletter** – includes news, policy updates, resources, events, and advocacy opportunities from across the nation. You can subscribe to the newsletter by clicking HERE.

13. **The Pediatric Palliative Care Coalition of Pennsylvania** has created a new resource the Self-Advocacy Tolkit: A Guide for Parents, Caregivers, Children and Adolescents. Click HERE for more information.

14. **The Pediatric Palliative Care Coalition of Pennsylvania, the Greater Illinois Pediatric Palliative Care Coalition, and the Funeral Service Foundation** have created a community resource to guide families through the funeral/memorialization planning process: ***When a Child Dies: Planning Acts of Love & Legacy.***This resource is available in both English and Spanish and is **FREE**, thanks to generous funding from the Funeral Service Foundation. You pay only a nominal shipping fee. More information can be found at When A Child Dies.

15. **The Alliance Pediatric Website Pages** are being updated, please be patient while we update the website for easier searching!

Subjects and Contributors for Future Issues of this E-Journal

Our future issues will be centered on the following main themes. All issues are centered on a central theme, offering perspectives from various disciplines and family members. If you have any thoughts about these or any other topics, contributors, or future issues, **please contact Christy at** Christy.Torkildson@gcu.edu **or Melissa Hunt at** melissahunt3-1@gmail.com

Issue Topics: 2025/2026

- **Issue #81: Adolescents and Young Adults (AYA);** articles due September 20225, distribution November 2025
- **Issue #82: Trauma-Informed Care: Patients and Families;** articles due November 2025, distribution February, 2026
- **Issue #83: Trauma-Informed Care: Providers and Care Teams;** articles due March, 2025, distribution May, 2026
- **Issue #84: Spiritual Care;** articles due May, 2026, distribution August, 2026

Are there any Items of Interest you would like to share, are there resources that you love? Please email Christy at Christy.Torkildson@gcu.edu

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