

# journeys.



# A True, Lasting Friendship

A Message Holli tile CLO
Staff — Who We Are4
Finding Light With Essential Care for Children5
Donor Spotlight6
Perspectives Corner8
Volunteer Spotlight9
Insights From the Bereaved10
How Holding on to Hurt Affects the Bereavement Experience13
Expressive Therapies Spotlight: Art Therapy14
Meaningful Moments16
Spring Bouquet Sale18



Callie, a patient in our
Essential Care for Children
program, has a congenital
heart anomaly. About a
year and a half ago, our
agency received a request
for a volunteer to visit Callie.
Kathleen, a patient support
volunteer living near Callie's
home, was happy to assist.

From the very beginning, Kathleen made every effort to make sure Callie enjoyed their time together, letting her choose what they would do that day, or where they would go. One of their first outings was to a crystal (rock) store that Callie wanted to visit. Since that time, they have enjoyed craft activities, cooking and just visiting with one another. Carol, Callie's mother, shared, "Individuals with developmental disabilities usually do not have a lot of friends, but Kathleen is so patient and kind, and she genuinely enjoys her relationship with Callie. Callie is just beaming after spending time with Kate."



This past summer, Callie went to Boston to see a specialist that included a hospital stay. As fate would have it, Kathleen had previously arranged plans involving travel to Boston during the same time period. Kathleen was hopeful that her schedule would allow her to stop and visit Callie, so she kept in contact with Callie's parents. Unfortunately, due to hospital restrictions during COVID-19, Kathleen was unable to visit. Fortunately, Kathleen was able to meet Tom, Callie's father, to



# A Message From the CEO



Christopher Kerr, MD, PhD

It's difficult to capture the complexity of this past year — from pandemic to social unrest and economic uncertainty. Even amid this stress and fear, there are remarkable stories of perseverance, commitment and dedicated service. I

think you would be proud to know the valued role this organization played during the pandemic.

During the pandemic, care was diverted from hospitals and nursing homes as families sought to keep loved ones safe in their homes. This organization played a much-needed role by supporting these caregivers to minimize COVID risk and avoid separation. For patients who were in facilities, our staff served as liaisons between family and patient — as an extra set of eyes, as advocates, as guides, and as messengers. At times, our teams stepped in, arranging for transfer out of the facility and into our inpatient unit so that the families could reconnect and be put back together when it was needed most. During the toughest days, staff regularly stepped forward and asked, "How can I help?" This dedication is and has always been defining and the reason we have remained sturdy and united, serving over 4,700 patients in 2020.

Throughout the pandemic, our priorities have been to keep staff healthy, while honoring our mission and service to our community. To date, everyone has remained safe, and we are emerging from the worst of the pandemic, grateful to remain fully intact as an organization and secured operationally by the federal funding received. Beyond securing employment, I believe we have done our very best to care for one another. Our end-of-year employee satisfaction

surveys showed overall improvement, despite the hardships of this past year. The circumstances around the pandemic have also driven a great deal of innovation, collaboration and efficiencies. Today, we remain hopeful, and it is a pleasure to report that our organization is at a better point now than during much of the past year.

As we look ahead to the second half of 2021, I just want to highlight two objectives. The first objective is to enhance our psychosocial support systems. We are seeing ever-increasing challenge in the areas of mental and behavioral health, addiction, access to care, health literacy and practical support. For example, on the pediatric side, our charity cases have gone from 30 to 60 percent. We know that the outcomes of illness and coping with these challenges depend on care beyond a purely medical approach. We are, of course, a multi-disciplinary service model, but even more dedicated support is needed.

Our second objective is the area of palliative care — that's care upstream of hospice that does not require a terminal diagnosis or foregoing curative therapy. As healthcare moves toward a value-based model, palliative care is being ever more recognized as critical, and we need to be seen as a resource and partner within our community.

The work of Hospice & Palliative Care Buffalo is really a partnership between those of us who work here and members of our community. This effort arose from and belongs to this community. We are proud to play a part in helping others during times of challenge. Thank you — as a community — for helping us accomplish this.

Christopher Kerr, MD, PhD

Chief Executive Officer, Chief Medical Officer

#### **CONTINUED FROM COVER**

drop off a goodie bag. Callie knew Kathleen was thinking of her, even though they could not see one another.

Once home, Callie and Kathleen continued to communicate often via texts and phone calls. Kathleen has shared that they look up silly YouTube videos and laugh and laugh and laugh. Both are proud to talk about their friendship and affection for one another.

The special bond between Callie and Kathleen is a wonderful example of how volunteers impact the lives of those they meet for years to come. What started as a volunteer request turned into a meaningful friendship for both Callie and Kathleen. Thank goodness that our virtual world has allowed Callie and Kate to stay connected! They look forward to a face-to-face reunion in the near future.

In addition to our staff, many patients and families are eager to boast about the kindness, compassion and dedication demonstrated by the hundreds of volunteers assisting our patients and their families. Hospice & Palliative Care Buffalo volunteers are a vital part of our team and are often referred to as "angels." Our volunteers provide companionship to patients and their loved ones, help run errands and assist with household tasks. Others assist with events, fundraisers and administrative tasks.



The original developers of the hospice benefit were wise in recognizing and mandating the participation of volunteers. When the volunteer enters into a relationship with a patient, they have no other agenda other than to provide presence and assistance. The volunteer's objective is to be receptive and to connect. It's no wonder that unique bonds are formed, particularly for isolated older adults and ill children, whose lives are so often defined by medical processes. The friendship that developed between Kathleen and Callie is no less therapeutic than any medical intervention. There is no substitute for a true friend.

In 2019, prior to COVID-19, roughly 900 active volunteers provided over 29,500 hours assisting patients, families and staff. We are looking forward to the day when we can resume full volunteer activity so that all of those we serve can experience the same vital connection and support Callie did, provided by our cherished volunteers.

# Community Partner Announcement



Congratulations to Abigail Unger for her new appointment as board of directors member at BestSelf Behavioral Health.

**Abigail Unger,** LCAT, MT-BC, VP Psychosocial Services



When a child is suffering from a serious illness, everyone in the child's life is affected in some way. Parents, siblings,

extended family and others need support as they navigate the complexities of medical care and the challenges of daily living, along with their personal struggles.

For many parents, navigating their child's illness is a complex and daunting task. It's a journey without a map, and our system of healthcare falls short of meeting the totality of need. Our Essential Care program attempts to address this gap in care by providing a comprehensive, family-centered, home-based program. Care is provided by an interdisciplinary team and its focus on "comprehensive care" requires addressing

medical as well as psychosocial, spiritual and practical needs to improve quality of life for the child and his/her family. Specially trained nurses, social workers, spiritual care counselors and expressive therapists provide an added layer of support for the child and family while working closely with the child's medical team to improve symptom management, assist with goals of care discussions and provide vital linkage to support services and community resources. Our team is available to address needs on a 24/7 basis to help children thrive at home while avoiding unnecessary ER visits and hospitalizations. In 2020, we served nearly 150 children dealing with serious illness. Our program exists only because of the generous support from our community — a wonderful testament to the generosity of Western New York.

## Staff — Who We Are

#### **DURABLE MEDICAL EQUIPMENT EXPERTS**



Once patients begin hospice care, our highly trained durable medical equipment (DME) technicians are part of the team of experts that surround you and your loved ones during the most difficult of times. They are ready, willing and able to deliver equipment and supplies to your home any time, day or night, and anywhere in Erie County, at no cost.

The DME concept was created to personalize and deliver high-quality care to patients and families in their own homes so they could have peace of mind, knowing that their daily medical equipment needs are met.

The process works seamlessly as your hospice nurse develops an individualized care plan, specific to your loved one's needs, and then enters the order. The DME team takes it from there to coordinate delivery and setup, ensuring that all equipment is in good working condition once in the home. Available medical equipment includes electric hospital beds, oxygen, bedside commodes, shower chairs, wheelchairs and more that are all vital resources to assist with safety and comfort.

You and your loved ones will be educated about home safety and the effective use of equipment, with any special instructions, by the DME team and your hospice nurse. They will cover what to do if you have a concern as well. Our trained associates gladly provide support and answer questions 24 hours a day, seven days a week as they understand that time is of the essence when there is a concern. The DME team works to provide the necessary home medical equipment to lessen your worry. Patients and family members alike have shared with us their gratitude for the proper equipment that allows for greater dignity, comfort and safety, right in their own home.



Essential Care for Children

Our three-year-old son Logan is the light of our lives. Born with a severely compromised pulmonary system, Logan was in the hospital for the first 15 months of his life. As you can imagine, his medical needs were and continue to be complex. His care requires many specialists and extensive monitoring. In addition to a long list of medications, Logan has a trach, ventilator and feeding tube.

When it was finally time to come up with a plan to take Logan home from the hospital, we were both elated and nervous. The hospital team recommended Essential Care for Children. Described as a home-based palliative (symptom control) care program, providing coordination of medical services and emotional and spiritual support, we immediately became concerned. To us the words "palliative care" suggested that Logan was near end of life and we knew this was not the case. Thank goodness an Essential Care nurse visited us in the hospital to explain that palliative care offers additional support for children and families struggling with illness, but that the illness does not have to be life limiting and can be provided alongside curative treatment. After discussion, we decided to accept the help.

The Essential Care nurse and social worker routinely visit our home to answer questions, coordinate care and services and help us advocate for Logan. They are available 24/7 by

phone or to visit if symptoms or concerns arise. We often need assistance securing authorizations for equipment, services or therapy and the team manages absolutely everything for us. Having a medically complex child comes with challenges of care coordination. Who do we call and when? Our Essential Care nurse and social worker cut through the red tape and guide us every step of the way, relieving a lot of stress.

One of the primary goals of Essential Care is to minimize emergency room visits. Keeping Logan home is always our preference, but at times, after collaboration with his medical team, a visit to the hospital is recommended. On such occasions, the Essential Care team calls ahead to prepare the hospital so that all goes smoothly.

We are happy to share that our son is growing stronger every day. Though he still has a trach and feeding tube, he is slowly being weaned off his ventilator. He is becoming a very active three-year-old. Soon Logan will be going to preschool a few times a week for additional socialization and therapy.

We are sincerely grateful that we have the support of Essential Care. If you have a child or adolescent with serious illness, there are experts in our community ready to help relieve stress, find answers, and are on call when you need them most.

— Brenda and Gary Lee Proud Parents of Logan



From left to right: Steve Sommers, Dr. Chris Kerr and Scott Bieler

# Scott Bieler

President and CEO of West Herr New York

### **Donation:**

Essential Care for Children
Office Space in Orchard Park

# From Passion to Paying It *Forward*

### An Essential Gift for Essential Care

What is it that moves people to give to causes, organizations and others? This question has no right or wrong answer, but there seems to be one common denominator that people, when asked, cite as a reason — personal passion. That's what moves Scott Bieler, President and CEO, West Herr New York.

Scott recently donated a fully furnished office building, located in Orchard Park, as a most generous gift to Hospice & Palliative Care Buffalo. The gift specifically

benefits Essential Care for Children, a home-based palliative (symptom control) care program that provides coordination of medical services, as well as psychosocial, emotional and spiritual support to seriously ill children and their families. Essential Care is a resource for infants through adolescents.

Scott was motivated to give back to our organization after he and his family experienced firsthand the care, comfort and strength that the hospice team afforded them when his 91-year-old mom and 92-year-old dad were in need of the services before they both passed in 2020.

"Your compassion shows in so many ways, especially in the little things that the nurses say and do — like stroking mom's hair or paying attention to the animals

in the home," fondly recalls Scott. "Every single person I encountered from Hospice had true, natural empathy." He wanted to express his gratitude for the comfort and care his family received, yet he wasn't exactly sure how his actions and sentiments could measure up to the priceless gift they were given.

Scott expressed his desire to provide a meaningful donation, when the time was right, in memory of his dearly beloved parents, Robert and Sally Bieler. He kept in contact with Hospice Foundation Executive Vice President Elizabeth Siderakis and other leadership members to learn more about the goals, opportunities and needs of the organization.

Sommers, Vice President of Recycled Alternative Solutions, MidCity Office Furniture. "We were happy to step in to help an organization that provides such compassionate care and navigation to children and their families."

"The majority of services offered through Essential Care, such as nurses and social workers, are funded through charity support, so Scott's extraordinary gift helps to offset administrative costs and stretches charity dollars for vital services even further," shared Dr. Kerr. "Our children are thriving as a result of the incredible generosity from people like Scott Bieler and Steve Sommers."



When the right time came, Scott called our CEO Christopher Kerr, MD, PhD and asked if purchasing an office building in Orchard Park would fit within the organization's strategy. Dr. Kerr said that the location could help with spatial challenges, as the Essential Care team has grown exponentially. Moving them to Orchard Park would assist in efforts to expand awareness and reach in the community. "It's amazing how things come together for a greater cause," commented Scott.

Scott went to work immediately to remodel and furnish, with the gracious assistance of MidCity Office Furniture, which donated conference and education room tables. "Essential Care touched my heart because my son was born with a hole in his heart, and we went through a lot of fear of the unknown and needing help to navigate options," expressed Steve

"The spirit of this organization is rooted in people like Scott who, in the midst of grief, are compelled to give back and to help others," he added. "It's this wonderful notion of filling the void of loss with meaning. This is what Scott did after losing his parents in our program." Scott simply reached out and said, "I don't know what or how, but I am going to contribute to this organization."

Hospice & Palliative Care Buffalo salutes Scott Bieler and Steve Sommers for their recent donations and for all their passionate efforts in making our community a better place to live and work. When asked where his overall philanthropic passion comes from, Scott humbly said that he is overwhelmed by the support and loyalty the community gives him every single day when purchasing cars. He is beyond happy to give back.

# Perspectives Corner

JOCK MITCHELL, EMERITUS CHAIR, HOSPICE & PALLIATIVE CARE BUFFALO, BOARD OF DIRECTORS



Jock Mitchell, Emeritus Chair

# Thank You, Bob!

Nearly forty years ago, I joined M&T Bank as vice president of marketing and public relations. Also relatively new to the bank at the time was Robert G. Wilmers, president and CEO. Mr. Wilmers had recruited a management team consisting of many "out of towners" and as a lifelong Buffalo boy, I was called upon more than once for my advice on local matters. Soon after my arrival at the bank, word came down from the top floor that Mr. Wilmers would like my suggestions on a worthy not-for-profit for him to support philanthropically.

Coincidently, my father-in-law had recently been diagnosed with acute leukemia and been admitted to Hospice Buffalo. I remember having no idea what hospice was. I had mistakenly assumed it was a place for families to stay while their family member was being cared for in a local hospital, similar to the Ronald MacDonald house. I decided to learn more about hospice and contacted Dr. Robert Milch, hospice medical director, who arranged for me to meet with him and Charlotte Shedd, Hospice Buffalo executive director. These two, who led the establishment of our hospice, are among the most remarkable people I have ever known. Little did I know at the time that this meeting would be one of the most consequential of my life.

Hearing Bob and Charlotte explain the hospice mission was both fascinating and profoundly emotional. Allowing patients and their families to spend their last days in comfort and at peace made all the sense in the world. "They had me at hello." I was sold. As the meeting ended I remarked that I had some marketing and fundraising experience and that I would be interested in joining the board of directors of Hospice Buffalo should they have an opening. I am pretty sure my phone rang the very next day and I began a 30-plus-year experience as a Hospice volunteer, friend and ambassador.

I used the word "remarkable" to describe Bob Milch and Charlotte Shedd. They are both typical of the people I have met and worked with over the years at Hospice Buffalo. Words like "caring" and "compassionate" are perhaps overused, but they only begin to characterize hospice people. As Hospice board president, I requested that we start every board meeting with a "mission moment." Each month we invited a hospice patient, family member or caregiver to tell us their hospice story. Their words were always heartfelt and emotional. Years later I saw the hospice miracle firsthand as my own mom spent her last days in the program.

66

Words like "caring" and "compassionate" are perhaps overused, but they only begin to characterize hospice people.

I will always cherish my days as a hospice volunteer. Frankly, they made me a better person. I am filled with both gratitude and wonder as I think about the tremendous impact Hospice Buffalo has had on our community. And I will always be grateful to Bob Wilmers, who made a generous donation those many years ago and indirectly opened a door for me that changed my life.

Thank you, Bob!

# **Volunteer Spotlight**

Hospice & Palliative Care Buffalo is fortunate to have hundreds of volunteers who give of their time and talents in so many different ways. Whether assisting in the in-patient unit, providing companionship to patients at home or working one of the many annual signature events, our organization could never accomplish all we do without the hard work and commitment of our volunteers. In this issue of Journeys, our Volunteer Spotlight is on one of our leadership volunteers — a treasured board member — to share what drives her to give of herself. Our patients, their loved ones and our staff thank you for the impact you make on the Hospice & Palliative Care Buffalo community every day.

# Compassion Turned Into Action

Nora McGuire, senior VP marketing, chief marketing officer at Independent Health, is no stranger to Hospice & Palliative Care Buffalo (HPCB) — she happens to be the Chair of our Board of Directors. She will tell you that although she has always had a passion for what the people of HPCB do every day, she did not always know what she knows today.

Nora's story is unique. She is a nurse by trade and started her career taking care of patients in an intensive care unit. Nora often found herself helping families faced with serious illness or loss of loved ones. She developed a special place in her heart for people who made a career out of helping others through their most vulnerable times. Early in Nora's career, she transitioned from the clinical to the administrative side of health care. "I moved on to different roles, yet I always remained compassionate to people's stories and felt a calling to still stay connected in that realm," recalled Nora. "My passion for helping people in their most vulnerable time never left me. It's the most important thing in this world to help bring the patient and family together and feel the support around them."

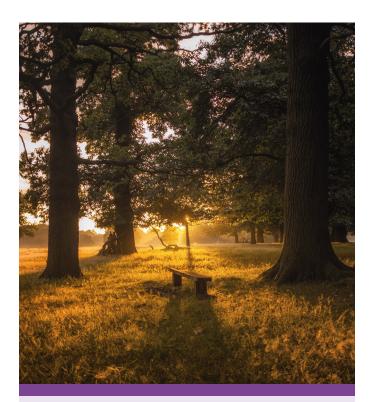
Nora felt this passion grow even stronger after the unfortunate loss of two brothers in one year. She remembers the very difficult grieving process. It was then that she was drawn to Hospice & Palliative Care Buffalo because of all the great work she had been hearing about. She was inspired to volunteer, and a board member position was open. Nora was ecstatic to be a part of HPCB and has since become board



Nora McGuire

chair. Nora's parents-in-law went through the hospice experience after she became involved, and she and her family witnessed firsthand how the hospice team helps everyone through the end-of-life process. "I was in awe of the level of giving that the team of nurses, doctors, bereavement specialists and spiritual guides provided," said Nora. "They provide care and comfort, but they also help patients and family members to accept and transition after passing. I saw it all happening." Nora added that Dr. Kerr, CEO, epitomizes everything she ever expected, hoped and dreamed of in someone leading the charge. He is an incredible inspiration to her. Nora feels it takes a very special person to be a hospice worker, especially during the COVID-19 pandemic, when no one knows what they might walk into at someone's home. "They help people at their toughest times," exclaimed Nora. "Knowing this energizes me and makes me feel proud to be a part of such a wonderful, meaningful resource in our community."

# Insights From the Bereaved



We belong to the largest company in all the world — the company of those who have known suffering.

- Helen Keller



**Abigail Unger,** LCAT, MT-BC, VP Psychosocial Services

Abigail Unger, vice president of psychosocial services, had the pleasure of speaking with Irving Sellers as he generously offered reflection on his experiences with Hospice Bereavement services upon the deaths of his wife 18 months ago and his mother three years ago.

What would you like to share about your wife, Doris, and your mother, Betty?

My mother was my lifeblood while we were growing up — because my father was working on the road quite a bit. She had a way about her. She was a good soul and I miss her dearly. She was, of course, a huge part of my life all those years. I miss her. I miss her an awful lot.

Doris was truly a special human being. From the day I met her, which was on a blind date, I knew that this was somebody I was going to potentially spend the rest of my life with. She was the most caring, understanding and tolerant person that I ever met in my life. She is truly my soulmate; I put that on her gravestone. She molded me into who I am today. I miss her every minute of the day. Every minute. I could talk for hours about her, I really could.

# How has Hospice's grief counseling helped and supported you?

First of all, I think most people know and maybe understand what Hospice is here for. I thought I did, but not anywhere near as much as what you can expect to gather and understand once you lose someone. Losing a loved one is one thing. Losing a soulmate is completely different. I've lost my mother, my father, aunts and uncles — but losing my wife Doris was very, very sad and it really took over. It took a part of my heart, it truly did. I honestly didn't know what to expect moving forward until I got started with the bereavement support.

I remember the first day I went to go see my grief counselor, Danielle. Honestly, right from the very beginning, she had a way of settling me and putting me at ease. I was nervous — not about talking to her but about what would come out of our discussions. Being in management as long as I have been, I've learned how to communicate with people — but when you are on the receiving end, trying to get help, it is very hard when you are normally the one in command of the conversation.

10 | HOSPICE & PALLIATIVE CARE BUFFALO

It was very, very hard and something that I had to grapple with, but I did, and it didn't take long because Danielle knew what buttons to push and she was good at getting me there.

Our weekly conversations were very comforting. One thing that happened was incredible: I started to talk with her about things I'd completely forgotten about, going back many, many years. And these were important things. She was very good at bringing all this out of me, and I did most of the talking! There were times it brought tears to both of our eyes. It's very emotional. I think the grief counselors try to keep everything in check by giving you a good perspective on your life before and after the death, if that makes sense. It sure does to me now.



One thing that happened was incredible: I started to talk with her about things I'd completely forgotten about, going back many, many years.



# What has been the most challenging aspect of your grief experience?

My personal emotions. At times they are very hard to control as the emotional side is very difficult for me. I'm a very emotional person. I'll cry at Flipper! I look at everything in my house and there's so much here that Doris and I created ourselves. Dealing with all that was not easy. Putting to use the good perspective and impactful

information that I got from everybody at Hospice on how to deal with things to help me in the days after Doris passed was challenging. I tried to listen very attentively and I asked a whole boatload of questions, but it was not easy to put everything to practical use on a daily basis while initially going through the grieving process.

# What has been the most impactful aspect of Hospice's bereavement support?

Having someone there to talk to. Talking and sharing helped me put together missing pieces of mourning after death that were necessary to have in place. I could have cried morning, noon and night every day, but I learned to stress the positives too. As hard as it is, I think accentuating the positive helps with the difficult emotions of grieving. You can think about all the years you had. You can look at pictures, movies, all your memories, and you can think on all the positive times you had with your loved one. This has helped me immensely.

There is a learning process in this that is extremely important and extremely beneficial. The counseling helped me better understand my own feelings. I talked about the six years I took care of Doris — about all the caregiving and all the different things I did for her at home. I can honestly say, from my heart, that I did everything humanly possible to help her and to give her every opportunity to live a quality life. As her advocate, I always made it a point to everyone all those years: Doris needs to be treated with the utmost dignity and compassion. Everyone at that time of life needs to be treated with that dignity and compassion. And when we came on to Hospice, they provided that. I know that's part of their job and I know it's not easy, I am sure it's not easy but everyone who was there knew this was their job and they knew how to provide this for their patients and how to provide for their families.

### Is there any other aspect of the grief support you received that you would like to share?

When we talk about grief support, we need to talk about the full support system that Hospice has beyond the grief counselor. I am sure there are people who do not even understand all the support that is available when Hospice is caring for your loved one. After Doris' death I had a chance to speak with a rabbi as well as a nurse they arranged a meeting with. These interactions gave me a completely different perspective. I asked questions — anything I wondered about and this brought out a lot of very important pieces related to what happened prior to and right at the time of her passing. I had a lot of unanswered questions in my mind. These conversations gave me a great bit of knowledge that was extremely beneficial at that time and has continued to be beneficial in processing everything that has taken place since.

Another piece I want to mention is the winter solstice remembrance event. Even though it was all virtual, it was very, very good. I thought it was very well done and it was very meaningful to hear everybody from Hospice talk. It was just Hospice showing that they are very caring and that they don't forget. Even though your loved ones are gone, they are never forgotten — and this is something that Hospice does a very good job of.

### Do you have any wisdom or advice you would like to pass along to the newly bereaved?

Yes. There's no question in my mind: seek support. It is very important to seek support. You may not think you need it, but believe me, as time goes by, I have found it extremely beneficial in my life. You have got to talk to somebody who knows the business. The support system of Hospice is there for you. Communicate it and talk about it. That's the thing — you've got to talk. There may be fear on someone's part to go somewhere and

talk about all this, but if they know that counselors will talk to them without obligation and that this is a service that Hospice provides to give support in one's life, give it a chance. They will put things in perspective for you, and if you want to continue, they will help you do it together. It's especially important if someone doesn't have a good support system. If you are alone and do not have anybody, it can be that much more challenging. I think person-to-person contact and communication during this time is critical. I have my family and they are very supportive. I have also talked to my daughter every day since Doris passed — and it's very important for me to be able to talk to her because I have cried with her and in front of her. I am not afraid to show my emotion because it's not healthy to keep it in. Even though some of it may hurt, in the long run it pays great dividends. It truly does.

# What would you say to an individual who is hesitant to take advantage of bereavement services?

It helped me a great deal. For anyone who gets involved with the grief counseling, it can be very rewarding to give it a fair chance and put their heart and soul into trying to help themselves. If they do, it will be very beneficial in their grieving process. I truly believe this and would tell it to anyone.

I can only hope, and I mean this from the bottom of my heart, that my words will make sense to somebody and they will take advantage of these bereavement services. It's an incredibly valuable service that needs to be sought out by people. I would have been a lost cause if I didn't have it. I'm hoping that some of the things I've tried to share here will be meaningful to somebody and if it helps them get through their crises and their mourning process, then we've done our job.

 Irving Sellers, Hospice Bereavement Client, Husband of Doris, Son of Betty

# How Holding on to Hurt Affects the Bereavement Experience

### **Hurt and Forgiveness**

Throughout our lives, we have been told to always be the bigger person and to forgive people who have wronged us. Young children are often trained to automatically say, "I forgive you" after a someone apologizes to conclude a conflict. However, many of us can attest that it's not as simple and straightforward. In fact, the process of forgiving someone who has hurt you can be quite complicated. It's much easier to hold on to a hurt than to forgive.

Unfortunately, holding on to hurt can have negative repercussions. Over time, hurt individuals may become resentful, vengeful and bitter. They can also experience shame, guilt and embarrassment and may intentionally distance themselves from others. Harboring hurt can lead to poorer health and chronic health conditions. Conversely, forgiveness has several significant benefits, such as a decrease in anger, hostility, depression, anxiety and distress. Forgiveness also can help individuals better cope, increase self-esteem, compassion and generosity and improve overall well-being.

### Hurt and the Impact on Grief

At the end of life, situations can arise that are emotionally charged and may result in people getting hurt. These hurts can occur at the time of diagnosis, during the disease progression or at death. For family caregivers, if the hurt is not resolved, it can affect their grieving process.

In a recent study published by Hospice & Palliative Care Buffalo, 42% of bereaved family caregivers indicated that they had experienced some form of interpersonal hurt. Most commonly, caregivers were hurt by a family member (40%). Likewise, clinical staff surveyed agreed that interpersonal hurt does impact caregiver well-being and bereavement.

The main finding of this study demonstrated that, while not all bereaved individuals experienced interpersonal hurt, those who did had poorer bereavement outcomes compared with those who did not. The magnitude of hurt also played a role in the bereavement experience, often manifesting itself psychosomatically and/or with frequent recall or rumination of the offending event. In this study, nearly half of those hurt indicated that they have not forgiven the offender and felt that they could benefit from forgiveness and forgiveness-based support services. Research has demonstrated the great benefits to forgiveness. Forgiveness can potentially be a salve to help soothe their soul and help them with their grief. Future research should assess the feasibility and usefulness of this type of support for caregivers and the bereaved, as it seems that forgiveness is as much for the forgiver as it is for the forgiven.



— **Pei C. Grant,** PhD, Director of Research, *Emeritus* 

#### **EXPRESSIVE THERAPIES SPOTLIGHT**

# Art Therapy

66-

"Art is an irreplaceable way of understanding and expressing the world... It addresses us in the fullness of our being... It educates our emotions, and it remembers."

#### — Dana Gioia

Children do not have relatable language, developmental capacity or resource, available to process illness, limitation and challenge. They also do not have the capacity or experience to process profound sadness, grief and loss. Whether drawing, painting or sculpting, designing an object of symbolism or creating a token of tribute and remembrance — engaging in and experiencing the physiological influence of art offers an innate opportunity to channel and process feelings and thoughts within a nonverbal and nonthreatening expressive language. These experiences often offer our children and families opportunities for meaningful communication, creativity and exploration, accomplishment and success, release and outlet, as well as opportunities for enhanced self-expression and a means of connection that can be seen and felt.

In what follows, art therapist Kris Crosson offers a reflection on her engagement with both our Essential Care for Children team and Bereavement Services. Kris has been with Hospice & Palliative Care Buffalo's Expressive Therapies team since 2015. Kris earned her master's degree at Buffalo State College; she has been practicing throughout Western New York for 25 years.



— **Abigail Unger**, LCAT, MT-BC, VP Psychosocial Services



Art leaves a tangible product — a lasting mark on the world. The resulting image becomes important, not only in communicating feelings and experiences but by acting as a visible and external record of one's self. When children draw or color, words are not needed. Art making helps children put their inner emotions outside so they can see their experience from a different perspective, making things clearer and giving them distance. Through art, children can let go and make sense of their experiences, which becomes an important coping skill that can serve them for the rest of their lives.

Pediatric patients' psychosocial needs are paramount in treatment and are the major focus when using art expressions as therapy. In art therapy, the patient and therapist work together to understand visual and verbal messages. The patient becomes actively involved through the process of making art and the active qualities of this engagement are effective in alleviating feelings of helplessness and lack of control. The patient develops trust and a relationship with their art and with the art process. It is a safe way to express these strong emotions.

Art interventions can effectively support the grieving process. Therapeutic approaches are designed to strengthen children's social and emotional skills, allowing them a safe place to navigate feelings such as grief, loss, anxiety or fear. Because children do not usually have the words to express their grief, it tends to show up in their mood, play and behavior. Art therapy offers

a safe and comforting way for them to ask difficult questions and release concerns. Art making creates order from chaos and allows the child to exercise choice and control, create something new and connect to memories. Through memory art making, children have opportunity to create ritual, an activity that can represent the feelings they have for someone they miss. This provides a tangible way to channel feelings and activate healing.

I am grateful and humbled every day when I work in this way with children and families. The trust, connection and courage they demonstrate as well as their willingness to share their journey are very powerful. Their connection to the artwork and with one another within the therapeutic relationship is something I truly enjoy. I have captured this in my own art making of a colorful magnificent sunset. I am very grateful to catch a glimpse of these meaningful and beautiful lives.



— Kris Crosson, LCAT, ATR-BC, **Art Therapist** 



# death is dream Finding Hope and Meaning at Life's End Christopher Kerr, MD, PhD with Carine Mardorossian, PhD

# An Exciting Research Year in Review

It's been quite a year-plus for our CEO, Dr. Christopher Kerr, MD, PhD, and his research team! In February 2020, the release of Dr. Kerr's co-authored book, Death Is But a Dream, received international acclaim for its extensive and poignant focus on the connections between hospice patients, their families, and the powerful dreams and visions often experienced at end of life. Since the release, Dr. Kerr and the research have been featured worldwide through forums such as the annual End Well conference, a Netflix docuseries (Surviving Death, episode 5), a national public television documentary (Death Is But a Dream), and ongoing conversation with journalists worldwide.

As Dr. Kerr and his team continue this important work, more exciting updates are planned.

Visit drchristopherkerr.com and join the conversation on social media for the latest news.











# Meaningful Moments Essential Care for Children's Perinatal Program

Life is sprinkled with meaningful moments. Some of these — like a first birthday party, an engagement proposal or a wedding day — are carefully planned out and orchestrated. Others just spontaneously occur. These unexpected, memorable occasions strike us as highly unusual, as exceptions to the ordinary, and maybe, at times, as supernatural in origin. They are often recalled as flashes in time that cannot be replicated regardless of how hard one tries. Meaningful moments can even be understood as instances of hope. That's how I came to understand a beautiful and very meaningful moment for myself and approximately 20 medical workers who were present in the Oishei Children's Hospital delivery room as we supported a family's wishes, asking God to bless the naming and spirit of a child who wasn't long to be with us.

The scene was surreal, as if it were occurring on a celestial landscape in another dimension. As a spiritual care counselor with the Essential Care for Children team at Hospice & Palliative Care of Buffalo, I stood outside the delivery room clad in a white medical jumpsuit, surgical mask, goggles, a blue hair net and booties. My task was to baptize

the infant who was about to be born.
Unfortunately, the expected infant's likelihood of surviving her first breaths, hours or days was limited due to a congenital chromosomal deficiency detected at a prenatal appointment. Throughout this pregnancy, members of the Essential Care team accompanied this mother to her doctor visits and provided a variety of supports. As part of the birth plan, the parents requested a baptism to care spiritually for themselves and their baby.

In my role, the opportunity to support families during unique meaningful moments such as these comes often. In this instance, I stepped into a very large room that was dazzling with energy and bright light. The C-section had just taken place, and the mother smiled as I offered my congratulations. The baby's father stood close by, cradling his new daughter. The nurse gently placed her on the warming table, and our team nurse manager draped the newborn with a whitelaced christening gown donated by the Western New York Perinatal Bereavement Network. With a radiance of her own, she looked like an angel. "She is doing much better than we expected," the doctor said as he encouraged me to proceed with the baptism.

66

With a radiance of her own, she looked like an angel.

"She is doing much better than we expected," the doctor said as he encouraged me to proceed with the baptism.

The in-breaking of hope then emerged. She opened her eyes as I crossed her forehead with water and spoke the ritualistic baptismal words,



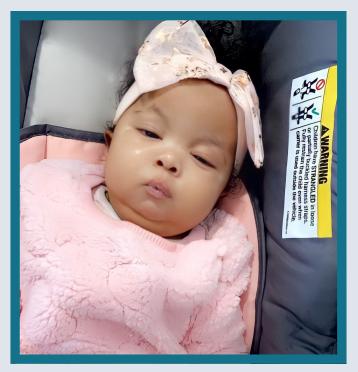
Raven at the Moment of Christening

asking God to seal her in the book of eternal life. And then, earnestly and unaware that anyone aside from her parents was paying attention, I said, "...and hear us as we pray together." Suddenly, I heard the clear, familiar words of others in the room saying the Lord's Prayer with me, together, in unison: "Our Father, who art in heaven..." I was awestruck as all these voices came together in hope for this little newborn. Upon reflection, that meaningful moment was an unexpected instance of hope that sprang forth for that beautiful newborn and yet offered so much more.

Hope sometimes emerges in big ways and sometimes in small and more precious ways. Regardless, hope is a spiritual construct that manifests in a multitude of unexpected ways. A common prayer offered in unison in a delivery room for a newborn clinging to life was yet another sprinkling of a beautiful and meaningful moment of hope.



— **Rev. Becky Naber,** M.S., M.Div., Spiritual Care Counselor



Raven at Seven Months Old

For additional perinatal resources, contact the WNY Perinatal Bereavement Network:



# Western New York Perinatal Bereavement Network, Inc.

#### HELPING FAMILIES, HONORING LIVES

WNYPBN assists the community in meeting the needs of people facing perinatal death, the death of a baby due to miscarriage, ectopic pregnancy, stillbirth or early infant death.

Support services and activities include:

- Peer group support: Tiniest Angels Support Group
- Peer telephone support
- Resources including the Forget-Me-Not Newsletter
- Community awareness and remembrance events

(716) 626-6363 | wnypbn.org



### Thank You, Coordinators!

Thank you to everyone who joined us for the Hospice Spring Bouquet Sale 2021! It looked a little different this year but the WNY community once again demonstrated why Buffalo is the City of Good Neighbors by purchasing over 20,600 bouquets from our volunteer coordinators, florists and our flower trucks!

# Save the Date

Hospice Spring Bouquet Sale 2022:

February 28 - March 5



For the past six years, Lancaster High School employees have helped to bring a touch of spring to our halls when these beautiful flowers! Each year, we challenge ourselves to break our record and this year we raised over \$2,400 from sales at our high school alone!

Terri Mazur,

Lancaster Schools (Top Sales)



Hospice flowers out for delivery today at Heritage Heights Elementary School! This was my first year as coordinator at Heritage Heights Elementary School! Our previous coordinator was working remotely from home and she is retiring this year. I plan on keeping this job!

Margaret Desiderio, Sweet Home Schools



I am a bouquet coordinator for Glendale Elementary School. Fifteen years ago, I took over this job from a colleague and I've kept it since! I am thrilled to support Hospice and so are my colleagues!

Joelle Loughrey, Sweet Home Schools



Michele Kennedy, Cloverbank Elementary First Year as Coordinator

Jessica, Athenex Pharma Solutions First Year as Coordinator

Kathleen McMahon-Wahler Coordinator for Four Years



Lisa Santasiero First Year as Coordinator Volunteer for 10 Years



Kim, Casey Middle School Coordinator for 15 Years



Theresa Chabot, Ferguson Electric Coordinator for Eight Years



### Wheelbarrow of Booze & **Summer Fun Raffle Tickets**

\$15 for one ticket \$40 for three tickets

Enjoy a wheelbarrow full of your favorite local and national brands. Yes, you can keep the wheelbarrow!



# Summer Affair — July 20–22

Purchase your party package online and pick it up at 55 Chicago Street, Buffalo, NY 14204, outside Resurgence Brewing Company and Hartman's Distillery, the week of July 20. Enjoy a cold one as we celebrate summer and Hospice!

For details visit HospiceSummerAffair.com



# Spring Appeal — Thank You

We are so grateful to the many donors who generously gave to our Spring Appeal featuring precious Grace Korba. Monies raised in this year's spring appeal provide critical dollars in support of our Essential Care for Children program. Hospice & Palliative Care Buffalo (HPCB) touches many of us at some point in our lives, but our efforts reach audiences one would not traditionally think of that need hospice and palliative care.

Our Essential Care for Children program serves more than 110 pediatric patients daily in our community. Because of your generosity, more than \$90,000 will benefit the care and compassion our youngest patients receive. For more information on HPCB's Essential Care for Children program, please visit HospiceBuffalo.com



### What Will Your Legacy Be?

Fulfill your financial and philanthropic goals by making a difference for patients and families in our community. Include a charitable gift to Hospice & Palliative Care Buffalo in your estate plans. It's the gift others will never forget.

For more information, call (716) 989-2261.

HospiceBuffalo.com/Giving







# Annual Report Now Available Online

Thank you for your kind and generous support of Hospice & Palliative Care Buffalo. The 2020 Annual Report is now available online at bit.ly/Annual-Report20. Please take a moment to review the report.

If you would like a hard copy, please contact the Hospice Foundation Office at (716) 686-8090. We will be happy to mail one to you.



#### **HONORS**

We are pleased to announce that, for the fifth consecutive year, Hospice

Buffalo has been named a Hospice Honors award recipient. The Hospice Honors award is a landmark given to hospices providing the best patient and caregiver experience. The prestigious annual review recognizes hospices that continuously provide the highest level of quality as measured from caregivers' point of view.

Hospice Honors acknowledges high-performing agencies by analyzing performance with respect to family satisfaction survey quality measures. The awards are an exclusive recognition for hospices that have selected HEALTHCAREfirst as their hospice survey partner. This is a true testament to our staff's compassion, expertise and commitment to providing the highest-quality care and support to patients and families. We are grateful for all they do.

# Honor Your Loved One

Create a permanent legacy to honor and remember that special person in your life. Memorial bricks available starting at \$250.

Please call the Hospice Foundation to learn more (716) 686-8090.





**COMMUNITY EVENTS UPDATE** 

We are so grateful for our Hospice Helpers, who continue to help us with our fundraising efforts. Thank you to the following community groups and individuals who organized events to benefit HPCB. Recent events raising over \$250 are listed below.

Event	Organizers	Total Raised
12 Days of Giving	GEICO	\$1,200
Buffalo 60 Strong Calendar Sales	Senior Care Advantage One and Buffalo Medical Group	\$2,292
Derby for a Cause	Michael Donovan	\$1,400



# THANK YOU TO OUR FACEBOOK FUNDRAISERS FROM JANUARY 2021 – APRIL 2021 WHO RAISED OVER \$250!

Amy Augustyn Susan Forbes Dorothy O'Shei
Caitlin Cupples-Wolff Amy Kirsch Brenda Thurman

Cathy Donovan Holt Bob McDonnell Cruise

### Thank You, Paula's Donuts!

Thank you for the Cannoli & Nutella Chocolate Chip Specialty Doughnut created just for Hospice! Since 2017, Paula's has been creating a specialty doughnut for sale and donating half the proceeds raised to support patient care programs and services. We are extremely grateful for your continuous support throughout the community.







### Thank You, Walkers and Sponsors!

Thank you to all 460 walkers, 48 teams and sponsors that participated in the 25th Annual Virtual Hospice Memorial Walk on Saturday, May 15 & Sunday, May 16. Thank you, Absolute Care at Aurora Park, Buffalo PBA, Independent Health, Rigidized Metals Corporation, the Zemsky Family Foundation and all our 2021 sponsors.

Presented by Wegmans





### Did You Know?

Many couples are choosing to make a donation to Hospice Buffalo in lieu of traditional wedding favors.

Remember a loved one who may be with you only in spirit on your special day. Give the gift of compassionate care and use your celebration to support Hospice Buffalo's mission while thoughtfully remembering your loved one(s) on your wedding day. For more information and options available, please contact the Hospice Foundation Special Events team at (716) 989-2010.

Save the Date!

HARVEST FEST

# A Gathering of Giving

Friday, October 15, 2021









The Light-A-Life bell is a cherished community tradition for family and friends who have lost a loved one. With your gift of \$55 or more, you will receive this year's commemorative bell inscribed with the name of your loved

one. A tag and bow with your loved one's name will placed on the Light-A-Life trees on the Hospice Mitchell Campus. 2021 bells go on sale in October 2021.

## Save the Date:

Light-A-Life Memorial Tree Lighting Ceremony

Saturday, December 4, 2021

Hospice Mitchell Campus

For more details and information, visit HospiceLightALife.com



POSTMASTER: DATED MATERIAL **REQUESTED IN-HOME DELIVERY** JUNE 25-28, 2021



225 Como Park Boulevard Buffalo, New York 14227-1480

HospiceBuffalo.com

### Save the Date! **HOSPICE & PALLIATIVE CARE BUFFALO 2021 EVENTS**

- Summer Affair .....July 20–22
- Chiavetta's Chicken Pick-Up Dinner .....Thursday, September 16
- Harvest Fest ......Friday, October 15
- Light-A-Life Memorial Tree Lighting ......Saturday, December 4

### Mail / Email Update

- To receive the Journeys newsletter electronically, email info@palliativecare.org
- To receive community and event updates, email info@palliativecare.org
- For volunteer opportunities, email volunteer@palliativecare.org or call (716) 989-2014
- To be removed from the mailing list, email info@palliativecare.org or call (716) 686-8090

# Make a Change That Will Change You — Become a Hospice Nurse

We are always looking for exceptional healthcare providers and talented professionals. Explore Hospice Buffalo careers and apply today.

HospiceBuffalo.com/Careers



### **66** The doctors here trust you and rely on you.

They rely on you for assessment and they are always available for you to talk to. You have 24/7 professional resources no matter what situation you're in.

- Drusilla, Hospice Nurse, 3 years

