

# Care & Community

KACCH & BACCH NEWSLETTER  
 Issue 1 - September 2023

## Editor's Note

Hello KACCH & BACCH Friends,

Welcome to the first edition of "Care & Community". In these pages, discover the latest from our clinical team and psychosocial team in hospice and in hospitals. Get to know our dedicated employees, volunteers, and community supporters for being the heart of our mission. Happy reading!

Warm regards,

Community Engagement &  
 Volunteering Department



## Superhero Health Squad

Read the latest news about our clinical team, their major highlights and activities



### A Grateful Tribute: Neuromuscular & Epidermolysis Bullosa Multidisciplinary Days March & June 2023

We extend our gratitude to the following esteemed doctors who volunteered their time and expertise to add value to our Neuromuscular and Epidermolysis Bullosa Multidisciplinary Days on March 6th & and June 22nd. Their dedication facilitated vital specialized consultations, offering invaluable support to our patients and their families:

- Dr Arti Nanda
- Dr Hisham Bu Rizk
- Dr Mansour Al Shimmery
- Dr Eman Bu-Hamra
- Dr Amal Bahbahani
- Dr Khaled Al Kandary



Neuromuscular dystrophies in pediatric patients are a group of genetic disorders that weaken muscles over time. These conditions affect a child's ability to move and can lead to progressive muscle loss. Common forms include Duchenne muscular dystrophy and Spinal Muscular Atrophy. Early diagnosis and ongoing medical care are crucial to manage symptoms and improve the quality of life for affected children.



Epidermolysis Bullosa (EB) is a rare skin condition where the skin is extremely fragile, causing blisters from even light touch. Children with severe EB might experience pain from everyday activities like walking or eating. They need special care to manage this delicate condition.

## Inspiring Tomorrow's Healers: Medical Students Explore Pediatric Palliative Care

Annually, Bayt Abdullah hosts Medical Students Day to raise awareness about pediatric palliative care and encourage students to consider this specialty. This year, we held two interactive lecture days in February and May, furthering our mission to build a cadre of local expertise.



## Empowering Awareness: Physiotherapists Embrace Pediatric Palliative Care

On May 2nd, 2023, we welcomed dedicated physiotherapists for an enlightening Physiotherapists Teaching Day at Bayt Abdullah. The day featured interactive lectures on various aspects of Paediatric Palliative Care, including our multidisciplinary approach and pain assessment. This expanded on their understanding of the holistic care we provide.

This day of learning strengthened our commitment to delivering top-tier care in collaboration with our community.

We're delighted to share our recognition as one of **Children's Palliative Care Providers of the Future by Imperial College London's Institute of Health Innovation.** This recognition reflects our dedication to top-quality care and support for young patients and their families. Our appreciation goes to our dedicated team, volunteers, supporters, and the inspiring young patients and families who drive our mission forward.



*Celebrating a Global Honour*

**KACCH & BACCH  
 RECOGNIZED**



We are thrilled to share a significant milestone!

As of this July, our reach extends to over 100 children in Kuwait. It brings us immense joy to say that our dedicated support and specialized pediatric palliative care & psychosocial services in Bayt Abdullah are now touching the lives of numerous children and families, significantly enhancing their quality of life.

**+100+  
 PATIENTS**



## Myths about pediatric palliative care

### Myth 1: Only for End-of-Life Care

**Correction:** Pediatric palliative care supports children throughout their entire illness journey, focusing on comfort, symptom management, and emotional support, regardless of the prognosis.

### Myth 2: Speeds up Death

**Correction:** Pediatric palliative care does not hasten death. It aims to improve the quality of life for children and their families by enhancing comfort and symptom management.

### Myth 3: Only for Cancer

**Correction:** Pediatric palliative care is for children with various life-limiting conditions, including neurological disorders, genetic syndromes, and congenital anomalies.

### Myth 4: Same as Hospice Care

**Correction:** Pediatric palliative care differs from hospice care; it can be provided alongside curative treatments, while hospice is typically for those with a prognosis of six months or less to live.

### Myth 5: Families Must Give Up Hope

**Correction:** Pediatric palliative care aligns with families' hopes and goals, offering hope in meaningful moments, comfort, and improved quality of life for the child. It does not require giving up hope.





## Heart & Mind Harmonies

Read about our psychosocial team and their latest in 9 different locations in Kuwait!

### Child Life Month Celebration: Open House Invite!

On March 4th, we marked Child Life Month with an engaging open house event. It was a chance to spotlight our dedicated child life specialists and their vital work.

**Community Engagement:** Community members joined us to learn about the role of child life specialists.

**Interactive Tools:** Each hospital set up a vibrant table to showcase the interactive DIY tools used to engage and comfort children during their hospital stays. From distraction tools to age-appropriate activities, our team demonstrated their ingenuity and dedication to making hospital visits a little brighter.



### Representing Kuwait and KACCH & BACCH at the Annual Child Life Conference

We are thrilled to share our presence at this year's Annual Child Life Conference held in June in Texas, USA. In the photo, you can see our certified Child Life Specialist, Jayti Sud, and Child Life PhD Student, Nadia Al-Nassar, proudly representing Kuwait and KACCH & BACCH.

### It is all about Play !

In the world of pediatric psychosocial care, one element shines as a universal language: PLAY. It's not just a pastime; it's an essential tool that helps children facing illness, pain, and the unfamiliar hospital environment. At our core, we understand that play is more than just fun—it's a powerful means of healing and coping.

**The Familiar Comfort of Play:** Regardless of their circumstances, children are inherently familiar with play. It's a natural part of their lives, and even when faced with health challenges, it remains a constant source of comfort.

**The Multifaceted Benefits of Play for Children in Medical Settings**

- **Emotional Outlet:** Play offers a safe way for children to express emotions, helping them navigate their feelings and fears.
- **Pain Reduction:** Scientifically proven to reduce pain perception, play complements medical interventions by keeping children engaged.
- **Normalization:** Amid clinical hospital settings, play provides a sense of normalcy, maintaining routines and fostering peer connections.
- **Social Bonds:** Play encourages social interaction, enabling children to form friendships and share experiences.
- **Creative Escape:** Through play, children unleash their creativity, offering cognitive development and a respite from medical challenges.



### Did you know?

Our Child Life Specialists and Play Leaders provide an average of

523 Child Life Services &

1023 Therapeutic play services to

children every MONTH across

8 government hospitals and hospice.

Ref: Koukourikos K, Tzaha L, Pantelidou P, Tsaloglidou A. THE IMPORTANCE OF PLAY DURING HOSPITALIZATION OF CHILDREN. Mater Sociomed. 2015 Dec;27(6):438-41. doi: 10.5455/msm.2015.27.438-441. PMID: 26889107; PMCID: PMC4733554.





# 3 Children Highlights



Meet **Maryam**, one of our remarkable patients with a passion for fashion. Maryam's creative spirit shines brightly, and she's brimming with wonderful design ideas. Recently, we had the privilege of collaborating with a talented local fashion designer to bring two of Maryam's unique designs to life. The joy on Maryam's and her sister Bayan's faces as they donned these one-of-a-kind pieces was truly heartwarming. We eagerly anticipate many more fabulous outfits and moments of creativity with Maryam in the future. Her vibrant spirit inspires us all.



Introducing **Sheryas**, our young patient who is bursting with a passion for video-making. With unshakable enthusiasm, he launched his very own YouTube channel, alongside his loving mother. Sheryas' zest for life is truly infectious, as he radiates joy in every moment, despite the challenges his illness brings. His determination to continue creating videos that capture his daily adventures is a testament to his vibrant spirit. Sheryas reminds us all to embrace life's wonders and seize each moment with a smile. We eagerly await the incredible stories he will share on his journey.



Introducing **Houriya**, a young patient whose journey has been marked by courage and resilience. Despite her extended stay in the hospital, Houriya channeled her strength into creating a vision board with the guidance of our dedicated play leader. On her vision board, Houriya beautifully captured her feelings towards her beloved parents, siblings, and cousins. She shared her dreams of traveling to far-off places when she regains her health and showcased her many talents and hobbies. Houriya's vision board is a testament to her persistent spirit and her determination to embrace life's possibilities, no matter the circumstances. Her story of hope and resilience inspires us all.



Meet the talented **Hanan**, a young patient with an extraordinary passion for art. Hanan approaches every art activity with boundless enthusiasm and creativity. Her vibrant spirit and dedication to her craft are truly inspiring. Whether it's painting, drawing, or any form of artistic expression, Hanan's love for art shines through in every stroke. Her unwavering passion reminds us all of the beauty that creativity can bring, even in the face of challenges. We celebrate Hanan's artistic journey and look forward to witnessing her continued growth as an artist.



# 4 Events

This section highlights a few of our events that took place over the past few months

## Bayt Abdullah celebrating 10 years Anniversary



In partnership with NBK, we joyfully marked a remarkable milestone - Bayt Abdullah's 10th anniversary! Together with our patients and their families, our dedicated staff and their loved ones, our incredible volunteers, and our community supporters, we embarked on a celebratory carnival on 10 March 2023.

The carnival buzzed with a delightful array of activities, ensuring a fantastic time for all. As we reflect on a decade of steadfast commitment to providing palliative care for children, our hearts are filled with gratitude.

We are immensely proud to have served our young patients and their families for ten years, and we are resolute in our commitment to continuing to offer our vital services, always striving to enhance the quality of life for these remarkable children. The journey continues, and together, we create brighter tomorrows.

## HAPPY Father's Day

On June 17, 2023, we celebrated Father's Day at Bayt Abdullah, a day dedicated to honoring the essential role of parents, particularly fathers, in the lives of our patients and their families. It was a heartwarming occasion, fostering sweet moments of connection and bonding within our Bayt Abdullah family.



THANKS

We extend our heartfelt gratitude to the extraordinary community supporters, generous donors, dedicated vendors, and diligent organizers whose great efforts make these events a reality for our patients and their families. Your commitment to bringing joy and creating memorable moments is deeply appreciated.

## Annual Remembrance

On May 6th, we observed our cherished tradition - the **Annual Remembrance Ceremony**. This solemn event pays tribute to the lives of our children that we've lost to illness and fosters a sense of connection, reflection, and healing.



Seven bereaved families joined us, reaffirming our commitment to nurturing the bonds we share with them.

During the ceremony, families planted memorial plants at Bayt Abdullah, each adorned with a personalized memento bearing their child's name - a poignant symbol of remembrance and love.



## EID AL ADHA CELEBRATION



In the spirit of Eid Al Adha, on June 30th, we came together with our children and their families for a festive celebration. At Bayt Abdullah, we believe in seizing every opportunity to bring joy and create cherished moments for our patients and their loved ones. The event was filled with a multitude of fun activities and sheep-themed arts and crafts, ensuring that the joy of the occasion radiated through every smile and shared experience.





# 5 Volunteer Spotlights



## Mid Year Gathering

In June, we came together for a heartwarming and delicious occasion - our **Volunteer Potluck Gathering**. This mid-year event held great significance as it provided an invaluable opportunity for our dedicated volunteers, spread across various locations, to connect, share stories, and build stronger bonds. As they brought dishes representing their unique backgrounds, the warmth and camaraderie that filled the room mirrored the spirit of our volunteers' ongoing support. It was a joyous celebration of their collective efforts and a heartfelt "thank you" for the positive impact they've been making. This gathering exemplified the strength of our community and the power of collaboration, reminding us that even across distances, we are united in our mission of making a difference.



Our dedicated volunteers are the essence of KACCH & BACCH, now supporting all our **9 locations**. Their invaluable bonds with our patients and valuable assistance to our small teams across hospitals are the heart of our organization.



8,000 Books+

**A monumental achievement by our dedicated volunteers:** cataloging **7,850** English and Arabic books in Bayt Abdullah's Library. Their dedication has created an organized treasure trove of knowledge for our children, families and employees. Thank you!

## Testimonials

I truly feel blessed to be a volunteer at KACCH & BACCH. Making a difference, however small, in the lives of others is a great blessing to me. I'm grateful for KACCH & BACCH for giving me the opportunity to offer support to the children and their families here.

Another great thing about KACCH & BACCH is their staff, who are very professional, yet very kind and warm. They are 100% invested in providing the best for these families and they are a great help to us as volunteers. Simply put, I wouldn't trade my time volunteering at KACCH and BACCH for anything!

Samah Kalakh, Volunteer Since 2017



**HELLO  
 MY NAME IS**

**Diana Shahada,  
 Sr Play Leader  
 NBKCH Hospital**



**PLEASE DESCRIBE YOUR ROLE AND RESPONSIBILITIES WITHIN THE ORGANIZATION.**

I am a Senior Play Leader within the psychosocial team, appointed to support patients and families. My responsibilities involve facilitating developmentally appropriate play and therapeutic activities at the playroom, bedside, and clinics. An integral part of my role is to normalize the hospital experience, aiding patients and families in coping with stress and anxiety reduction.

I oversee the playroom and manage toys, activities, and events within my designated hospital. Additionally, I am the key-worker role for paediatric palliative patients and their families, providing support to enhance their quality of life.

**WHAT'S THE MOST REWARDING PART OF YOUR JOB?**

The most rewarding aspect of my job is the satisfaction derived from supporting sick children and their mothers during their most challenging moments. Despite their concerns, witnessing their smiles as they momentarily set aside their worries to engage in play or arts and crafts brings immense gratification. Seeing their anticipation for the playroom to open and observing their active participation in activities also fills me with joy.

Furthermore, I feel a sense of reward when I enrich my knowledge and skills, continually learning and evolving within my role.

**WHAT DO YOU FIND MOST CHALLENGING IN YOUR ROLE, AND HOW DO YOU OVERCOME IT?**

Navigating challenges is a common aspect of my role, especially when working with children during their most vulnerable moments. Factors like mood swings, disease progression, and demanding treatment plans impact their stay significantly. Drawing from years of experience, I've established a routine of self-care and professional boundaries to address these challenges. Each experience, whether positive or challenging, contributes to my skill growth. Customized plans for individual patients and teamwork often prove effective.

**WHEN YOU'RE NOT AT WORK, WHAT ARE YOUR FAVORITE HOBBIES OR ACTIVITIES?**

Outside of work, I cherish my role as a family-oriented individual. Much of my solace comes from sharing moments and tending to the well-being of my family members. Quality time spent together and watching television provides a sense of comfort.

Additionally, I have a fervent interest in drawing, dedicating my free time to creating artwork for personal enjoyment. Cooking is another passion of mine, as I derive immense satisfaction from preparing meals for my family. Experimenting with diverse cuisines.

Share a favorite quote or motto that you live by.  
 The good you do comes back to you.



**Inside the Action**  
 Meet our team

**HELLO  
 MY NAME IS**

**Nelda Defensor  
 Family Support  
 Services Coordinator**



**PLEASE DESCRIBE YOUR ROLE AND RESPONSIBILITIES WITHIN THE ORGANIZATION.**

I am responsible for coordinating with various departments to support our families. This involves maintaining daily communication with families to address transportation requests, send out event invitations, and distribute necessary supplies. I collaborate with the psychosocial team to oversee patient and family information, documents, and meetings. I also partner with different departments to ensure that our families have enriching respite weekends at Bayt Abdullah. Furthermore, I am in charge of managing the in-kind donations we receive, ensuring their effective distribution to the various playrooms.

**WHAT'S THE MOST REWARDING PART OF YOUR JOB?**

Engaging with diverse families, listening to their life stories, and bringing smiles to all our children when providing toys and essential items. That is in addition to establishing rapport with my colleagues.

**WHAT DO YOU FIND MOST CHALLENGING IN YOUR ROLE, AND HOW DO YOU OVERCOME IT?**

One of the most challenging aspects of my role is organizing and tracking bulk donation deliveries. Having said that, collaborating with volunteers proves to be a significant support in overcoming this challenge.

**WHEN YOU'RE NOT AT WORK, WHAT ARE YOUR FAVORITE HOBBIES OR ACTIVITIES?**

Meeting up with friends, walking, listening to my favorite playlist, and connecting with family and friends.

**SHARE A FAVORITE QUOTE OR MOTTO THAT YOU LIVE BY.**

The best and most beautiful things in the world cannot be seen or even touched – they must be felt with the heart". – Helen Keller





# Join Our Mission: Make a Difference Today!

At KACCH & BACCH, we believe in the power of community and compassion. Together, we can make a lasting impact on the lives of children and families facing challenging medical journeys. We invite you to join our mission by supporting our organization.

## Here are a few ways you can get involved:

**Donate:** Your generous contributions help us provide essential care and support to our children. Every donation, no matter the size, makes a difference.

**Volunteer:** Join our dedicated team of volunteers and directly impact the lives of children and their families. Your time and skills are a precious gift.

**Spread Awareness:** Share our mission and stories on social media. By raising awareness, you help us reach more families in need.

Together, we can make a difference in the healthcare experience for our children in Kuwait.




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