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Care & Community

KACCH & BACCH NEWSLETTER Issue 3 - June 2024

Editor's Note

As we step into the warmth of summer, we're excited to bring you the latest edition of "Care & Community." In these pages, you'll discover updates and stories from our dedicated clinical and psychosocial teams working in hospices and hospitals. Our mission to provide exceptional care to children in hospitals and those with life-limiting and life-threatening illnesses continues to inspire and drive us forward.

Join us as we highlight our incredible employees, volunteers, community supporters, and inspiring children. We are grateful for your continued support and partnership in making a difference in the lives of these children and their families.

We wish everyone a wonderful summer, filled with joy and positivity. Enjoy this edition, and stay tuned for our next release in December! Happy reading!

With regards,

The Community Engagement & Volunteering Department







Superhero Health Squad

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

EB & NMD MDT Series - February/June 2024

We again extend our heartfelt gratitude to the esteemed doctors who volunteered their time and expertise during our EB & Neuromuscular Multidisciplinary Days in Bayt Abdullah. Their ongoing consultations and advocacy are valuable to our patients and their families.

Dr Arti Nanda Dr Hisham Bu Rizk Dr Mansour Al Shimmary Dr Eman Bu-Hamra Dr Amal Bahbahani Dr Khaled Al Kandary Dr. Aseel Al Awady Dr. Mohamed Lotfy Dr. Ahmed Ibrahim

Dr. Islam Sayed Dr. Mohamed Lotfy





We would like to shine a bright spotlight on the amazing pediatric palliative nurses at Bayt Abdullah Children's Hospice (BACCH) on the occasion of International Nurses Day! They are the superheroes who provide top-notch care, advocacy, and wisdom to children facing life-limiting illnesses and their families.



We are pleased to announce that Dr Ahmad Jaafar MBBCh, FRCPC, FAAP, Pediatric Complex and Palliative Care Specialist joined us as a Senior Pediatric Registrar in April. Dr Ahmad brings with him many experience in Pediatric Complex and Palliative Care.





Another successful Medical Students' Day was held at Bayt Abdullah in collaboration with the College of medicine at Kuwait University in February. The initiative continued to educate future doctors about the significance of pediatric care and the profound impact it has on a child's healthcare journey.



Presenting Key Study on "Parental Experiences of their Child Declining Food Intake as a Disease Progression Occurs" at EAPC Congress

Dr Tala Al Dabbous presented in May an important study at the World Research Congress of the European Society of Palliative Care (EAPC) in Barcelona, focusing on the delicate ways parents address their children's diminishing appetite during illnesses. This profound research was documented in the esteemed Journal of Palliative Medicine.





positioning & providence of adaptive equipment



Foot print to assess abnormalities



Orthotic & Gait clinic





Ankle-foot orthosis for patients



Daily Physiotherapy Clinic



Educational Interdisciplinary Collabs





From our Pharmacy: Does Aromatherapy Really Help?



Aromatherapy is a form of Complementary and Alternative Medicine (CAM). It uses essential oils to manage symptoms or boost your well-being. It's a holistic therapy, meaning it supports your whole self — mind, body and spirit. Aromatherapy involves inhaling essential oils or applying them (diluted) to your skin

People around the world have used aromatherapy for centuries. In the U.S., aromatherapy often complements other treatments for people with conditions like anxiety. People also use aromatherapy to maintain wellness and feel better in general.

How does aromatherapy work?

When inhaled, aromatherapy stimulates your nervous system (brain, spinal cord and nerves). This means aromatherapy starts a chain reaction of signals to your brain and chemical responses throughout your body. This activity begins once you start smelling an essential oil.

Essential oils (like all substances that smell) release tiny molecules into the air. When you inhale an essential oil, those molecules move into your nose. Special cells in your nose called olfactory receptors send messages to your brain which stimulate activity in your hypothalamus and your brain's limbic system. that help control your emotions and store your memories. Your brain then releases hormones like:

- Serotonin
- Endorphins
- Dopamine

like:

These hormones help regulate many body functions like mood, sleep and digestion which can help you in various ways, like lowering anxiety and reducing your perception of pain.

Aromatherapy has several benefits in palliative care, which include:

- 1. Pain Management: Essential oils like lavender, chamomile, and peppermint have analgesic properties that can help in managing pain. They can be used in massages or baths to provide relief.
- 2. Stress and Anxiety Reduction: Aromatherapy can help to reduce stress and anxiety, Essential oils like lavender and bergamot, known for their calming effects.
- 3. Improved Sleep: Aromatherapy can also help to improve sleep quality. Oils like lavender and chamomile are popular for promoting relaxation and sleep.
- 4. Enhanced Mood: Certain essential oils can help to uplift mood and promote a sense of well-being. Citrus oils like orange and lemon, as well as floral oils like rose and jasmine, are known for their mood-enhancing effects.
- 5. Nausea and Vomiting: Some essential oils like ginger, peppermint, and lemon can help to alleviate symptoms of nausea and vomiting, which are common side effects of some treatments in palliative care.
- 6. Improved Digestion: Aromatherapy can also aid digestion. Oils like ginger, peppermint, and fennel are known for their digestive benefits.
- 7. Respiratory Support: Essential oils like eucalyptus, peppermint, and rosemary can help to support respiratory health.



2

Heart & Mind Harmonies

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







Remarkable achievements within our psychosocial team!
Congratulations to Noor for earning certification as a Certified Child Life Specialist. Your dedication to supporting our young patients and their families is truly commendable. We're also proud to recognize Nuria for completing a course in Palliative Care education and practice. Your commitment to enhancing our palliative care services is invaluable. Your accomplishments inspire us all and reinforce our commitment to providing the highest quality care to our children and families. Well done!

Creating Lasting Memories By Badriya Al-Mekhled, Play Leader

Children with life-threatening illnesses often miss out on the joys of the outside world, and their families can feel overwhelmed. That's why we, at KACCH & BACCH, always advocate for experiences that allow our children and families to create lasting memories together, free from everyday stressors.

Inspired by the efforts of my colleagues, I planned a special outing for our patient, Junaid. Usually quiet and reserved, Junaid's excitement was palpable as he explored the Abdullah Al Salem Cultural Center with his family, turning the day into a grand adventure.

I was very happy to share this special time with Junaid and his family. Special outings and experiences for our children are a vital part of our holistic care, thereby enhancing their overall emotional well-being and quality of life.





We are thrilled to announce the launch of our Child Life Internship Program, supervised by Certified Child Life Specialists and adhering to the rigorous standards of the Association of Child Life Professionals (ACLP). This initiative is designed to train and develop the next generation of Child Life Specialists, ensuring the continuation of exceptional care for our pediatric patients.

In addition, we are actively working towards making Bayt Abdullah and our hospital playrooms a premier training site for international child specialists. This exciting project is set to launch in 2024, marking a significant milestone in our commitment to global excellence in child life services. Stay tuned for more updates!





Innovation and Healing

Nuria, our Play Leader, recently participated in the Palliative Care Educational Practice (PCEP) course in Boston, where she developed a robot designed to enhance the well-being of pediatric palliative patients. Nuria explained that her innovative robot aims to promote interactive, therapeutic play with children with features like LED lights, a sensory board, game drawers, and an AI tablet for engagement. She chose the green color as it symbolizes health and inclusivity. This initiative aims to revolutionize Child Life services at KACCH & BACCH, offering groundbreaking support for our young patients.



Transforming Fear into Joy

By Hanadi Al-Moubayed, Child Life Specialist

Meet our 2-year-old patient, who's undergoing surgery at al-Razi Hospital. Initially, her laughter filled the room as she interacted with dolls and medical props. However, a complication led to her transfer to the ICU, where she experienced fear and distress, often crying and struggling to sleep.

As her Child Life Specialist, I had the privilege of enhancing her hospital care experience. Introducing activities like playing with oobleck (corn starch & water), she found solace in its soothing texture, bringing back her smiles amidst the worry. Encouraged by her mother's participation, her comfort expanded, easing tensions and fostering relaxation.

As days passed, she engaged in various play activities with Play Leader Sahar and myself, from free play to playing with play dough to blowing bubbles, gradually alleviating her anxiety and fear. With a personalized child life support plan, we played a pivotal role in her emotional well-being and recovery.



After five transformative days, she confidently explored beyond her hospital room, embracing playtime with other children and even sharing hugs and smiles with the medical team upon discharge. This hospital journey highlights the essential role of Child Life and psychosocial interventions in providing care and normalization to children within the hospital environment.



The impact child life specialists have on the emotional well-being of children and families in healthcare settings is unparalleled.

To highlight and celebrate the invaluable contributions of child life specialists, we dedicated the month of March every year to engaging with our patients, their families, and healthcare teams across our eight child life programs in Kuwait.

Learn more about the Child Life Profession through our website and childlife.org



In hospital halls where whispers stay, Children find joy in moments of play. Amidst the beeps and sterile light, Their laughter turns the dark to bright.

With dolls and blocks, they build and dream, A hopeful heart in each small gleam. Play's magic weaves a healing thread, Bringing smiles to every bed.

Through games and crafts, they find their way,
To forget the pain, if just for a day.
For in those moments, pure and true,
A child's spirit finds strength anew.



Offering a sense of Normalcy through cooking By Alaa Nasr, Child Life Intern

Who likes hospital admissions? Let alone repeated, long ones? No one! Meet our patient, a 10-year-old who has experienced long hospitalizations since her diagnosis at age 5. This time, she was not happy and made it very clear. During a conversation, she said, "I want pasta! I want to cook and eat it fresh! It doesn't taste the same if someone cooks it at home and brings it to me. I want to go home and cook it myself." Unfortunately, that wasn't possible.

That's when the idea came to me. The child loves cooking and tasting food, so why not make it happen in the hospital? With the support of the child life team and our volunteers, Younis and later Samah, we brought a kitchen to the playroom. She started cooking, eating fresh meals, and learning about new cuisines. This not only helped her regain her appetite but also gave her a purpose to look forward to in the hospital. It transformed her from not wanting to get out of bed to having the energy to walk and practice what she loves most: cooking!

Such activities significantly improve the well-being of children, offering them a sense of normalcy and joy in a hospital setting. The advocacy of the child life team and volunteers is crucial in creating these positive experiences, making a lasting impact on their emotional and physical health.





3 Children Highlights

We want to shine a spotlight on **Maryam**, who has a strong passion for fashion and has been previously featured in our newsletter. Maryam now actively participates in fashion design classes led by

Yousif Abdulsaid at Bayt Abdullah. This is how we support her in showcasing her creativity and acknowledging her accomplishments as she navigates her health journey. We are eager to see her latest sketches and designs, bringing the magic of fashion to life!

Through similar collaborations with our community, we are dedicated to nurturing each child's interests and talents, providing a supportive environment for them to flourish and feel fantastic.





Big shoutout to **Melo Bakery @melo.kw** for sweetening up the lives of our BACCH children with their scrumptious cakes every month of the year since 2021!



Our Child Life team at NBKCH Hospital has kicked off a heartwarming initiative to cheer on kids completing their chemotherapy marathons. After their last treatment, these young champions get to ring a magical bell, symbolizing the end of a tough journey and the start of new adventures.

To make this occasion even more special, **Al Shaya Group** has been contributing special gift vouchers and tickets for KidZania and Tech Zone for the children. This collaboration serves to amplify the joy and celebration surrounding these memorable milestones.

Special thanks to
Mr Ayman Barakat for his
continues support to our initiatives!

Spreading Joy and Laughter at Bayt Abdullah

Meet Hamza, one of our delightful BACCH patients who never fails to brighten everyone's day. With his charming personality, Hamza makes sure to gather everyone around as soon as he arrives at Bayt Abdullah, greeting everyone as he moves from one spot to another.

Recently, Hamza has discovered a new hobby: pranking the community engagement team! His playful antics and good-natured scares have everyone laughing and on their toes. Hamza's joyful spirit and mischievous sense of humor bring so much fun and energy to everyone around Bayt Abdullah. We're always excited to see what he'll come up with next!





In a wonderful collaboration between the School Team and the Community Engagement and Volunteering Department, we are thrilled to share the success of our annual summer camp for the children of the schooling program. This cherished event, a highlight since the schooling program's inception at Bayt Abdullah, offers a delightful mix of fun, learning, and memorable experiences for our young participants and their family members.

This year's camp was packed with engaging activities. The children dove exciting science experiments, unleashed their creativity through art projects, and explored their culinary skills with cooking and baking sessions. Each activity was thoughtfully planned to provide educational value and foster a sense of joy and achievement among the children. Adding to the magic of the camp, local artist Shoji made a surprise appearance, interacting with the children capturing moments of joy creativity in photos.

The camp wrapped up with an exciting trip to Kidzania, where the children experienced a world of imagination and role-play, adding an extra layer of excitement to their summer adventures.



Blockat and @shooj
Real Sciences
Shaikha Al Habshi
Nour AlMejadi
Al Shaya Group
Burger King Kuwait
and all our
wonderful Volunteers

for your contribution to our summer camp experiences.







section highlights a few of our events that

took place over the past few months

Phoenician Riders: A Decade of Joy!

For over 10 years, the Phoenician Riders have brought smiles to our children's faces with their annual visit to Bayt Abdullah. Their thrilling show and generous donation support our cause, spreading joy and making a real difference in our community.

Our children are already looking forward to the PHR's visit next year.











This February we celebrated the National Holiday with Kuwaiti Student Club in Jordan through a special event filled with activities, games, crafts, and art, bringing joy to families and children. It was heartwarming to see our community come together and create lasting memories in celebration of the national holidays.

Special thanks to Basta, Zainab Alkandari, Nawar Bashir, M'oishi, Dar Alsaad Catering, and Kuwait Pharmacy Student Association (KUPSA)





We extend our heartfelt thanks to **Qout Market** for graciously hosting us and providing a free booth in April. This opportunity allowed us to engage with the public and raise awareness about our charity's mission. We look forward to future collaborations and continuing our partnership to support our cause.





We were honored to be invited to the AmCham Annual Iftar event, celebrating our efforts to enhance children's hospital wards across Kuwait among other local charities.

We took this opportunity to express our heartfelt thanks to AmCham for their continued support of KACCH & BACCH. We are proud to be named one of their charities of choice for the third consecutive year.

















Celebrating the Festivities of the holy month of Ramadan

As we welcomed the holy month of Ramadan, we shared joyful moments with our children and their families through a series of celebrations. We began with Guraish, a pre-Ramadan festivity that brought everyone together in anticipation of the month ahead. Mid-Ramadan, we enjoyed the vibrant Girgaan celebration, filled with traditional activities and candies & sweets. Finally, we wrapped up the month with a joyous Eid Al Fitr celebration, marking the end of fasting with laughter and togetherness. These events brought immense joy and strengthened our sense of community during this special time.

We extend a very big THANK YOU to FroYo, The Graduates Society, and Asnan Tower for making these wonderful 3 celebrations possible in Bayt Abdullah.

A huge thank you to all individuals, groups, and entities who work with us to arrange visits to KACCH & BACCH playrooms in hospitals to bring joy to our children.







Hollywood star Tyrese Gibson brought smiles to our children during a special visit to Kuwait in May!

Special Thanks to Four Seasons Kuwait!



We have launched the Learning Calendar that aims to provide educational opportunities on diverse subjects to our community. Through partnerships with renowned community resources, we deliver expert-led sessions to encourage ongoing learning and skill enhancement for all involved. So far, we have successfully conducted four learning sessions, some exclusively for our staff and volunteers, while others welcomed public

Eng Fatma Al Zalzallah, Food Waste Management TDB, Destigmatizing & Understanding palliative Care in Kuwait Dr Mohamed Al Suwaidan, Finding Meaning - A Path to Inner Peace LOYAC & KIPCO, 7 Habits By Highly Effective People









We bid a heartfelt goodbye to our volunteer, Sachin, who has dedicated over a year and a half of his time to KACCH & BACCH. During his stay, Sachin formed special bonds with two of our patients, Shreyaz and Junaid, creating lasting memories and making a significant impact on their time.

Now returning to the United States, Sachin reflects on his time in Kuwait, highlighting his volunteer work at KACCH & BACCH and his fishing trips on Jaber Bridge as the most valuable experiences. Sachin's kindness and dedication have left a bid mark on on all of us at KACCH & BACCH. Thank you, Sachin, and best of luck in your future endeavors!

Full Circle of Joy

We've got a heartwarming tale to share about our superstar volunteer, Zakia. Back in 1998, Zakia experienced firsthand the positive impact of our play services during her hospital stay. The joyful moments and support she received from our hospital team then left a lasting impression on her. Fast forward to today, Zakia is back in action as a dedicated volunteer with her drawing that she created in our playroom many years ago, spreading joy wherever she goes. From being patient to rocking the volunteer scene, Zakia's dedication and high spirits are top-notch. She's always on time and ready to dive in - Zakia, you're a rockstar!







Our volunteers have a remarkable ability to connect with our teenage patients in ways that truly stand out. Whether it's through engaging in video games, having meaningful conversations, or simply being present, their interactions are always impressive. It's especially heartwarming to witness these connections with patients who are typically reserved and less interactive. The dedication and empathy of our volunteers create a supportive environment where our teenage patients feel understood and valued.











HELLO MY NAME IS

Azza Abdalaty Chief Pharmaceutics' Specialist



PLEASE DESCRIBE YOUR ROLE AND RESPONSIBILITIES WITHIN THE ORGANIZATION.

My role as a Chief Pharmaceutics' Specialist is like safety valve for the clinical team in the organization, it is a critical role in ensuring patients receive appropriate medications management tailored to their needs, managing symptoms effectively, addressing medications adverse effects and Drugdrug interactions also provide support and education to patients/families and IDT members.

WHAT'S THE MOST REWARDING PART OF YOUR JOB?

The most rewarding aspect is often the opportunity to make a meaningful difference in the lives of children and their families during incredibly challenging times by offering comfort, support during different stages of their disease.

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

- The most challenging aspect of my role is managing the emotional toll of witnessing the suffering of children and their families.
- Dealing with complex medication regimens, addressing medication shortages or access issues.
- Maintaining emotional resilience, empathy and professional boundaries during dealing with children and families at end of life.

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

Reading and watching comic movies to maintain emotional wellbeing.

SHARE SOMETHING WITH US THAT NOT SO MANY PEOPLE KNOW ABOUT YOU.

Getting stressed easily, and I am an overthinker.

SHARE A FAVORITE QUOTE OR MOTTO THAT YOU

Quality is not an act, it is a habit.





HELLO MY NAME IS

Mohammad Azazmeh Nurses Team Leader



PLEASE DESCRIBE YOUR ROLE AND RESPONSIBILITIES WITHIN THE ORGANIZATION.

I lead a team of nurses at KACCH BACCH, ensuring topquality pediatric palliative care through best practices and collaboration. I also directly care for patients, participate in quality improvement, and advocate for nurse education. Effectively managing resources optimizes patient care and unit operations.

WHAT'S THE MOST REWARDING PART OF YOUR JOB?

Supporting families of seriously ill children and working with a compassionate team like KACCH & BACCH.

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

The most challenging part of my role as a nurse team leader in pediatric palliative hospice is managing the emotional toll of working with seriously ill children and their families. Witnessing their pain and struggles can be heart-wrenching. To overcome this, I focus on self-care and emotional resilience, ensuring I have the support of my team and professional resources. Regular debriefings, counseling, Regular discussions with my colleagues and leaning on the KACCH BACCH team help me stay strong and continue to provide compassionate care.

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

-When I'm not at work, my favorite hobbies and activities revolve around spending quality time with my family. I Love family gatherings, including meals, games, and catching up. And taking my kids outdoors, for parks or the beach.

SHARE SOMETHING WITH US THAT NOT SO MANY PEOPLE KNOW ABOUT YOU.

Something not many people know about me is that I genuinely enjoy my work and have a deep passion for helping others. I value clarity and directness in everything I do and prefer people to treat me the same way. I always speak openly and honestly, whether in my professional role or personal interactions.

SHARE A FAVORITE QUOTE OR MOTTO THAT YOU LIVE BY.

"When you ask, ask Allah; and when you seek help, seek help from Allah. And know that if the entire nation were to gather together to benefit you with something, they would not benefit you except with what Allah has already prescribed for you. And if they were to gather together to harm you with something, they would not harm you except with what Allah has already prescribed against you. The pens have been lifted, and the pages have dried".









Ru De Abeletonio Ana

hat is the worst that can happen—I die? That is a very normal thing! These were the courageous words of my late father. Dr. Ridha Alkhayyat, amidst the most harrowing moments of my life. Diagnosed with late-stage lung cancer at the height of the pandemic, while I was immedical school, frequent hospital visits became our new normal. Yet, in those moments, my father would often remind me of the ordinarioses of dath.

His perspective on mortality profoundly influenced my understanding of death and underscores the critical role of palliative care. Palliative care is defined as holistic care of people with health-reated suffering as a result of severe medical conditions, especially, but not only, those nearing the end of life (Radbruch et al., 2020). Its aim is to improve the quality of life of both patients and their families, espetie its importance, misconceptions and stigmafiten lead to its understification of the

To bridge this gap, my team at The Doctor's Brew partnered with the Kuwait Association for the Care of Children in Hospital (KACCH) and Bayt Abdullah Children's Hospice (BACCH), organizing the 'TDB Cares: Palliative Care' event in honor of my father Dr Rotha Alchayvat. This initiative, through expert-leed panels and lectures, highlighted palliative care practice in Kuwait, the vital work of KACCH & BACCH, and the role of junior decleres in easily and the role of the rol

Through this article, I aim to share the transformative insights from our event, hoping to challenge perceptions and encourage wider embrace of palliative care. In practice, palliative care is underutilized and misunderstood. For example, a study exploring













hey do ... the new salms

Trep a wrote on Faceback on Aug.

synist, "is not interested in clearsy dm system" the said.







7 Join Our Mission: Wake 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.

