

الجمعية الكويتية لرعاية الأطفال في المستشفى Kuwait Association for the Care of Children in Hospital

### 2018 Annual Report



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## **Message From the President**

### **Dear Friends**

From the humble beginnings of KACCH in 1989, when a group of enthusiastic and concerned mothers volunteered to decorate the paediatric wards and provide toys and play activities for children admitted to the hospital, the concept of Child Life in Kuwait has undergone dramatic developments. Most of the original volunteers remain as the Executive Committee, ensuring the development of KACCH stays true to its vision and mission, but the supportive care is now delivered by professionally trained Child Life Specialists who follow the standards set by the Association of Child Life Professionals. This year, 63,692 children including their siblings, parents or other family members/caregivers, received psychosocial and developmentally appropriate support across seven government hospitals in Kuwait. This involved not only KACCH Child Life Specialists and Play Leaders, but also BACCH Neurological Music Therapist who works one day per week with the children in Farwaniya Hospital.

Our teams, of highly trained, professionals of Child Life Specialists and Play Leaders, now provide psychosocial and emotional support to children and their families in all areas of the hospitals where children are treated, particularly those areas where there is significant risk of increased stress and anxiety, such as casualty, day case surgery, and imaging. With the rapid increase in new hospitals and extensions to existing hospitals, Directors and Heads of Paediatric programmes now frequently request Child Life services. Consequently at the request of the Director of NBK Children's Hospital, KÁCCH has expanded its program to include day case surgery and at the new Sheikh Jaber Al Ahmad Al Jaber Al Sabah Hospital, KACCH was asked to start a new programme in its out-patient department and a space has been allocated for a new KACCH playroom. To help make the paediatric wards more child-friendly, environmental changes have been made at Farwaniya Hospital, NBK Children's Hospital, the Physical Medicine and Rehabilitation Hospital and the new Sheikh Jaber Al Ahmad Al Jaber Al Sabah Hospital. Recognition of the work of KACCH Child Life Specialists and Play Leaders did not come easily, but over time not only the children and families receiving Child Life support but also the paediatricians and nurses who worked alongside the Child Life teams came to value their contribution to the care and wellbeing of the children and their families. Testament to the value of Child Life services in hospitals is also demonstrated by the increasing number of young Kuwaiti women who have been recruited by KACCH as Play Leaders and who came to love their work so much that they wish to continue their career pathways by studying to be a Child Life Specialist and to work to achieve their certification or a Master's degree in Child Life. Two young Kuwaiti women are embarking on a PhD degree in Child Life in the United States ensuring a sustainable cohort of home grown Child Life Specialists for future development.

However, evaluating the importance of Child Life in our hospitals today come not just from the number of children receiving care nor the numbers of interventions or coping strategies shared with children and the families, but most importantly from those receiving and those delivering the services themselves. This year we give you verbatim reports from the children, siblings, and mothers who are on the receiving end of Child Life, from the doctors and nurses and other members of the paediatric team who rely on the Child Life Specialists and Play Leaders to support them, and from volunteers who give up their precious time to play with children in the hospital playrooms. Their voices are powerful and their stories speak more eloquently than I could write about how their hospital experiences have been positively impacted by the KACCH Child Life team in each hospital. As you read this year's 2018 Annual Report, I am sure you will join me in congratulating those involved in its production, led by Deputy Director Banafsheh Azizi. The capture of the emotional journeys of the mothers and children, the sensitive and moving photography, and the beautiful overall design of the document is a worthy tribute to the 30 years of Child Life in Kuwait.

My sincerest thanks to our Child Life Sponsors without whom there would be no Child Life profession, to our generous donors who provide the means by which we can deliver our services, equip our playrooms, enhance children's lives and celebrate important occasions, and to all our invisible supporters who give of themselves and their talents to make a difference to the lives of children in our hospitals. Thank you.

Hiral Sam



## **KACCH MISSION**

### **Our Mission**

Kuwait Association for the Care of Children in Hospital (KACCH) advocates for the provision of optimal conditions for children and their families in hospital, in order to reduce the adverse effects of hospitalisation on their development and wellbeing.

### **Our Philosophy**

We believe in upholding the rights of the child as declared in the UN charter of 1989, to which Kuwait is a signatory that states that it is the right of every child to receive expert health care delivered, whenever possible, by paediatric trained physicians and nurses, within family-centred, child-friendly facilities. We also support the recent declaration of the WHO which states that palliative care is a basic human right for all children with life-limiting and life-threatening conditions, and the Rome Charter of 2016 which confirms the above rights and which is additionally supported by signatories representing the major religions of the world, including Islam.

### **Our Objectives**

- To minimise the stressful impact of hospitalisation and illness on the child and family in hospital.
- To facilitate optimal growth and development of the child.
- To prepare children and families for their health care experiences.
- To communicate effectively with other members of the health care team.
- To ensure the continuity and development of the Child Life programme within health care settings in Kuwait.
- To share expertise and co-operate with international and regional organisations.
- To recognise when hospital is not the optimum health care setting for the child and to advocate for the provision of paediatric palliative care at home, in a hospital, or in a children's hospice, so that parents can choose how and where their child with life-limiting or life-threatening conditions is treated.

## **KACCH VALUES**

### RESPECT

Acknowledging and responding to the rights and dignity of patients and their families and always, respecting them, yourself and colleagues.

Acting with honesty and transparency, maintaining truth in actions and interactions.

TRUST

### COMPASSION

Delivering care that goes beyond empathy and embraces "intelligent kindness".

### PROFESSIONALISM

Creating a positive working environment through team work and collaboration by supporting and respecting the efforts of every dedicated team member.

### INTEGRITY

Adhering to the highest ethical and moral principles and professional standards and being accountable for personal behaviour at all times.



## **30 YEARS OF MAKING A DIFFERENCE**



KACCH services began at the new Stem Cell Therapy Unit of

> 2018 KACCH services began at the new Sheikh Jaber AlAhmad Hospital



This year we celebrate 30 years of making a difference in the lives of so many children and their families in hospitals across Kuwait. Our Child Life Specialists together with our Play Leaders provide a welcoming and safe environment for the children within the unfamiliarity of the hospital paediatric wards, a friendly welcome for siblings, a reassuring word for parents and sometimes a comforting shoulder for mothers to cry on.

To help you understand our impact, the following pages of the annual report are dedicated to providing you with a story from the perspective of a child, a mother, siblings, a volunteer, members of the medical team, and our KACCH staff.

These stories are just one of the thousands of narratives that are part of the 30 year history of making a difference.



## **A Child's Perspective**

My name is Farrah and I am 10 years old. My first hospitalisation experience was in Al Farwaniya Hospital in 2017, where I was admitted for paleness, fatigue and high fever. I was then taken to NBK Children's Hospital. I was scared, tired, in pain and very anxious. I wanted to know why I needed to be admitted to NBK Hospital. My mom was honest and direct with me from the very beginning and told me there was a problem with my blood cells. They later told me that what I had was Leukemia.

When I had first arrived at NBK Hospital, the Child Life Specialist came and introduced herself to us. As my parents were busy having discussions with the doctors, the CLS took me with her to the KACCH Playroom. She explained that she will be there during my stay at the hospital to support me. When my diagnosis was confirmed, the doctor and CLS sat down with us to explain to my parents and me what my diagnosis meant. The CLS described it to me in a way I could understand. She then stayed to listen to our worries and gave us more information.

When I am in the playroom, I forget my hospitalisation completely. I become lost in play and engaged with the Play Leaders. Playing helped me reduce the stress I was feeling from being sick and from being stuck in the hospital. I began making it a daily habit of visiting the playroom every morning, and it is the thing that helps me the most during my long stays at the hospital. The playroom is an escape for us children, and it gave us a break to laugh and be young and have fun. I still have to get chemotherapy every now and then, but it is not as scary anymore. During my time in the KACCH playroom, I made lots of new friends with children my age who also had to stay in the hospital. And I remember there were times where I felt too weak to go to the playroom, so the KACCH staff brought toys to my room and played with me there.

The experience I remember the most where I felt really thankful for the CLS was before I had to get a porta-cath insertion. I was so grateful to have the CLS there to explain the procedure to me and teach me some coping skills. The medical play she did with me was fun and informative. I believe it is really important to give children the chance to know what is happening. I think knowledge helps children reduce stress before any procedure. The CLS was also with me when I started losing my hair and she took the time to explain why this was happening. It was because of the chemotherapy treatment, but she assured me that when I finished my chemo course, my hair would grow back. She made me feel better about losing my hair by showing me all the cool hats I could wear, and by recommending I get my hair cut in stages and not cutting it all off at once.

I hope that all the children that have to be hospitalized get well soon and I would like to thank KACCH for their services to children who are not feeling well and their families.

Farrah Patient NBK Children's Hospital



## **A Mother's Perspective**

I was first introduced to KACCH when I saw a lady in the hallway wearing a colorful tabard, but she was definitely not a doctor or a nurse. She came in and introduced herself as the Child Life Specialist, and that she would be assisting me and my son in coping with his hospitalisation. When she mentioned the services KACCH offered, it was the first time I had heard of the Child Life field and I appreciated the great responsibility taken by this organisation to help children. I was so relieved and grateful to have such support, since I was expecting to stay with my son in the hospital for a long time. My son is very moody and difficult to deal with, so I knew I would need the help. Mentioning that there is a play room where my 7 year old son can play made us both feel happier and more relaxed.

My son likes to play and the hospital felt like a cage to him. To be honest, I was hesitant in the beginning to take him into the playroom, fearful that he might catch a bug from other children. But the playroom was clean, organised and colorful. Every toy was sterilized personally by the KACCH staff. It was a relief to find it so warm and welcoming. I was so pleased to see my child being provided with so many games suitable to his age. What surprised me the most was when the CLS involved my son in medical play. Seeing him play with the medical instruments and inserting an IV line into the doll, while he expressed his fears and pain to the CLS, made me better understand my child's hospitalisation experience and further encouraged me to be involved in his medical care.

The memory that stands out to me the most about how the CLS helped us was when doctors decided to insert a tracheostomy tube for my son. My husband and I were very worried and could not accept that my son needed it. Our biggest concern was convincing our child to go through the procedure. The CLS advocated for the doctor to spend time explaining the procedure to us in more detail, such as why it was important for our son to have the tracheostomy and the after-care process. When the decision was finally made to perform the tracheostomy, the CLS sat with my son to explain the procedure and she taught him some coping techniques. This made the whole process go smoothly. Now, when I see him every morning smiling and asking about the KACCH staff and if the playroom is open, and see the smiling faces of the KACCH team, I feel happy.

I believe that Child Life Specialists and Play Leaders have a big role in improving a child's mood, as well as his mother's, by caring about and engaging with the child. They assisted us in drawing up a care plan for our child while he stayed at the hospital. They helped us in understanding our child's needs and abilities. They helped my child express himself, and sometimes when he is not in a mood to play, they had a nice way of encouraging him to play and look forward to the next day. Because of KACCH, our hospital experience was a much more positive one.

Mother Al Farwaniya Hospital





## **A Siblings' Perspective**

My name is Sanad and I am 8 years old. My older brother, Fahad, was treated at Al Razi Hospital. I was scared because my brother had to have surgery and all my family were afraid and nervous. When I was at home, I was only thinking of my brother Fahad and my mom because my mom was sleeping in the hospital with him. And when I was at the hospital, I felt bad and bored all the time. But when KACCH playroom opened, I felt good and I enjoyed my time playing with other kids. The playroom was fun and made us happy and we made a lot of new friends. I made five friends in a week! My favorite game was the Play Station 4. I will not be scared of the hospital again because I know KACCH will be there.

My name is Shahad and I am 10 years old. I love the KACCH playroom. I was nervous for my older brother to go to the hospital, and before the KACCH playroom opened, I had nothing to do and was worrying about my brother. The playroom was really fun and my younger brother Sanad and I made lots of friends. We played many games and my favorite games were Bingo and Jenga. I will be less scared coming to the hospital because I loved the KACCH playroom and the staff. KACCH helped me not to feel scared any more.



Sanad Sibling of Fahad Al Razi Hospital

Shahad Sibling of Fahad Al Razi Hospital





## **A Doctor's Perspective**

My name is Dr. Islam Eid and I am a paediatric orthopedic specialist at Al Razi Hospital. To me, KACCH is a breath of fresh air. Before KACCH, every activity with patients and families was really difficult and everyone would be extremely stressed. KACCH is the golden link between hospital staff and children and their families. The group of women working for KACCH are very kind and loving, and they are able to build a bond with mothers and children and create a strong sense of trust. I can remember hundreds of situations which were painful to children and the KACCH team were able to reduce the child's fears and anxieties, and at times, eliminate it totally. I believe KACCH services allows us better treatment outcomes, improved patient psychological well-being and a more positive hospital experience for families. I believe every medical facility will benefit from having KACCH present in their wards.

Dr. Islam Eid Paediatric Orthopedics Al Razi Hospital



## **A Nurse's Perspective**

My name is Jemimah and I was a nurse at the Chest Hospital for four years before moving to the new Jaber Al Ahmad Hospital. The first time I heard of KACCH was at Jaber Al Ahmad's Paediatric Outpatient Clinic where I was assigned. KACCH had a Play Service area complete with tables and toys. Someone explained to me that this corner is for children to play during their hospital visit. I liked everything about it. I loved the kitchen area and the colors and the toys. They made it look like a cozy play corner at home. When the news spread about the play area, we had nurses visit from other clinics and floors to see the new KACCH corner.

The KACCH play area and their staff provide a fun space for siblings to spend their time while they wait. They entertain infants, toddlers and older children by providing toys and diverting a child's attention from their anxieties, like when we take vital signs. They provide developmentally appropriate and cognitively supportive toys to support the children's development. The parent's feel stress free because the children will be happily playing and not upset about visiting the doctor, and this makes the parents happy. Because some children won't cooperate, especially during procedures, we are pleased when the Play Leader comes to explain things to the child and distract him or her with toys. We appreciate KACCH services and they leave a good impression on the families.

We have lovely staff members from KACCH working with us. They do a great job of therapeutically playing with the children according to age and needs. They keep things fun for the nurses sometimes as well! The KACCH staff are social, cheerful, hardworking, punctual and sincere. We consider KACCH staff to be part of our team and it feels like we have known them for a long time.



Jemimah Paediatric Nurse Jaber Al Ahmad Hospital





## **A Volunteer's Perspective**

I first heard of KACCH many years ago, as a member and on the board of the American Women's League. The League did a toy drive for KACCH. A small group of us delivered the toys to Al Amiri where the KACCH office was at the time and were given a tour of the paediatric ward.

Because of that visit to Al Amiri so many years ago, and the fact that some of the high school students where I worked did their community service hours with KACCH, it was always in the back of my mind to volunteer when I had the time. In 2015, after working 17 years in schools and with my own children graduating and heading off to college, I finally guit my job and that fall applied to volunteer.

My experience with KACCH has been a very positive one. I have always enjoyed interacting with children and I think that providing play opportunities, especially for young, or chronic and long term patients, is really beneficial to their well-being and healing.

What touches me about the services KACCH provides is knowing that we bring a bit of distraction and relief to the children and their families during their hospital visit and stay. We provide them with a safe, happy space, especially when their stay in hospital is for days, sometimes weeks.

My happiest memories with KACCH are all the times when children are being discharged and they actually want to stay in the playroom rather than go home, because that's when we know we've made a difference. It is also satisfying knowing that we've built trust and familiarity with chronic patients so that their time in the hospital is never something they dread, but they look forward to seeing us again and again. One of our patients was taught to crochet by her grandmother and since I'm a crocheter, we have that in common. She comes for treatment every 6 weeks and always has new crochet projects that she is excited to share. In that way, KACCH provides volunteers with opportunities to make real and meaningful connections and to be able to give back to society.

Being a volunteer is a very fulfilling experience that allows me to make a difference in other people's lives. I was a kindergarten teacher for 7 years, so I am able to bring some of that experience to the playroom when interacting with the children. My hope is that I provide moments of fun and laughter, care and support, and gentle guidance when needed to paediatric patients and their families in Kuwait.



Tammy **KACCH** Volunteer Al Amiri Hospital



## A Child Life Specialist's Perspective

An 8 year old girl was admitted to Ibn Sina Hospital, with a history of severe constipation and was scheduled for a rectal biopsy, botox injection procedure and regular enemas. Since the child was a school-aged patient, she was self-conscious and upset about getting the enemas. As the Child Life Specialist, I provided procedural support before and during the wash to help the child understand why she had to get the enemas and how to cope throughout the wash process.

The afternoon before her scheduled biopsy and botox injection, I planned a therapeutic activity with the child to help prepare her for the procedures. By using developmentally appropriate language to describe the procedures, the child had a clearer understanding of her diagnosis and treatment plan, while giving her strategies to assist her in coping. My aim was to reduce any fears and anxieties she had, as well as to make sure she cooperated with the medical staff.

I decided to create a felt puppet with the child, to provide her with a venue to share her feelings and concerns with myself and her parents and to clear any misconceptions she may have regarding the procedure. After spending 30 minutes happily decorating the puppet with her mother, which had a happy face on one side and an angry face on the other, she slipped her hand into the puppet. The side she showed us as she talked about the biopsy was the angry puppet face. I started talking to the child through the puppet, explaining the biopsy and letting her ask questions through the puppet. This allowed me to correct any misunderstandings the child had. She had some misconceptions such as whether the doctors were going to open her abdomen and if she would feel pain.

I made it clear to her that the doctor will not be making any openings in her abdomen, and that the procedure was going to help her feel better. Also, I explained how the anesthesia process, a mask that had a special sleepy medicine, will help her sleep during the procedure, so she will not feel any pain. I also explained that once the procedure was done, she would wake up, and her parents will be waiting for her to bring her back to her room. After hearing my explanations, the child turned the puppet to the smiling side. The child life intervention was a success and the child took the puppet with her to main theatre.

The morning after the surgery, the child was the first one to come to the playroom and she had a big smile on her face. I asked her about the procedure, and she said she was no longer scared and was now in very little pain.



KACCH Child Life Specialist Ibn Sina Hospital



## **A Play Leader's Perspective**

I first met 10 year old Fahad when I joined the KACCH programme at NBK Children's Hospital. Our Child Life Specialist Hadia informed me that Fahad was diagnosed with Osteosarcoma. She told me about his habits, such as his preference to say up all night and sleep all day.

When he does wake up early enough to come into the playroom, Fahad will only play on the PlayStation or Uno. True enough, Fahad spent most of his time during the day asleep, and on the afternoons that he did wake up, he would only play on the PS4 or Uno.

One day, I had designed a large and colorful umbrella and hung it on the board in the room. On the tables, I had placed smaller, white umbrellas with coloring pens and decorative items, like glitter and beads. I asked every child that came into the playroom to take an umbrella, decorate it however they liked, and to write their names on them. I then hung them up on the board with the big umbrella. This was the first time a project captured Fahad's interest, and he decided to contribute to the playroom art project.

As he worked on his umbrella, Fahad stated he never enjoyed coloring before. I thought he did a wonderful job, and when I complimented him on his umbrella art, he looked at me in surprise. He then told me that he never thought of himself as being any good in arts and crafts or coloring, and I assured him he was doing guite a lovely job. I asked him if he would like to start a bigger art project with me. He nodded excitedly and agreed. We spent an enjoyable afternoon together coloring, cutting and pasting.

At the end of the day, Fahad asked me if I could go to his room every morning to wake him up, as soon as we opened the KACCH playroom. I was so happy to hear that. And from then on, that was my routine. I would go to his room every morning, and find him waiting for me and we would head to the playroom together. Fahad spent his time between the hospital and home, coming in for his treatments.

Whenever he was at the hospital, we worked together on new projects and beautiful artwork to decorate the playroom. He was always eager to start a new project, and was always happy and proud to see the final work hung on the wall.

On the 20th of January 2019, Fahad finished his last round of chemotherapy. He also finished his final project that day, then he collected all his projects that he had done before. Fahad left NBK Hospital as a young burgeoning artist. When he left, Fahad took all his beautiful art projects with him, and said he would start his journey into becoming an artist in his little room at home.



**KACCH Play Leader** NBK Children's Hospital



## **MAKING A DIFFERENCE IN** 2018

ŝ Total number of patients, siblings, and parents/ caregivers received Child Life interventions, therapeutic play services, and neurological music therapy services by KACCH Child Life Specialists, Play Leaders, and BACCH Neurological Music Therapist across all 7 KACCH Child Life Programmes in 2018.



## **Al Amiri Hospital**

The KACCH Team at Al Amiri Hospital is led by 1 Child Life Specialist and is supported by 2 Play Leaders. Child Life Services are provided in Paediatric Wards 14 and 15, Outpatients Department, and Casualty.

### **Child Life Specialist Interventions**

3,777 patients, siblings, and parents/caregivers received Child Life interventions by the Child Life Specialist I at AI Amiri Hospital in 2018.



5,096 patients, siblings, and parents/caregivers received therapeutic play services by the Play Leaders at Al Amiri Hospital in 2018.

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Total number of patients, siblings, and parents/ caregivers who received Child Life interventions and therapeutic play services by Child Life Specialist I and Play Leaders at Al Amiri Hospital in 2018.

### **Play Leader Services**





## **NBK Children's Hospital**

The KACCH Team at NBK Children's Hospital is led by 1 Child Life Specialist and is supported by 3 Play Leaders. Child Life Services are provided in: Paediatric Wards 1,2,3, Outpatients Department, Stem Cell Transplant Unit, Day Case, and referrals from Intensive Care Unit.



### **Child Life Specialist Interventions**

3,220 patients, siblings, and parents/caregivers received Child Life interventions by the Child Life Specialist II at NBK Children's Hospital in 2018.







Total number of patients, siblings, and parents/ caregivers who received Child Life interventions and therapeutic play services by Child Life Specialist II and Play Leaders at NBK Children's Hospital in 2018.

### **Play Leader Services**

9,717 patients, siblings, and parents/caregivers received therapeutic play services by the Play Leaders at NBK Children's Hospital in 2018.



## **Al Jahra Hospital**

The KACCH Team at Al Jahra Hospital is led by 1 Certified Child Life Specialist and is supported by 2 Play Leaders. Services are provided in: Ward 6,7,8,28, and 31 as well as Paediatric Intensive Care Unit.

### **Child Life Specialist Interventions**

4,820 patients, siblings, and parents/caregivers received Child Life interventions by the Child Life Specialist I at Al Jahra Hospital in 2018.



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Total number of patients, siblings, and parents/ caregivers who received Child Life interventions and therapeutic play services by Child Life Specialist I and Play Leaders at Al Jahra Hospital in 2018.

### **Play Leader Services**

3,690 patients, siblings, and parents/caregivers received therapeutic play services by the Play Leaders at Al Jahra Hospital in 2018.





### **Al Farwaniya Hospital**

The KACCH Team at Al Farwaniya Hospital is led by 1 Child Life Specialist and is supported by 2 Play Leaders. Services are provided in the following areas: Wards 5,6,7 and 8, Outpatients Department, and Paediatric Intensive Care Unit. Music therapy services are provided to patients and their families once a week by the BACCH Music Therapist.

### **Child Life Specialist Interventions**

4,364 patients, siblings, and parents/caregivers received Child Life interventions by the Child Life Specialist II at Al Farwaniya Hospital in 2018.



\*\* During the months of August and September, Child Life Services in Al Farwaniya Hospital were supported by KACCH Play Leaders.

### The Power of Music Therapy

Music Therapy interventions are provided once a week at Al Farwaniya Hospital. 200 patients and their families received Music Therapy services by the BACCH Neurological Music Therapist in 2018.



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Total number of patients, siblings, and parents/ caregivers who received Child Life interventions and therapeutic play services by Child Life Specialist II and Play Leaders at Al Farwaniya Hospital in 2018.

### **Play Leader Services**

6,158 patients, siblings, and parents/caregivers received therapeutic play services by the Play Leaders at Al Farwaniya Hospital in 2018.





## Al Razi Hospital

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The KACCH Team at Al Razi Hospital is led by 1 Child Life Specialist and is supported by 2 Play Leaders. Services are provided in: Ward 1 and 2, Outpatients Department and Day Case Surgical Department.

### Child Life Specialist Interventions

5,067 patients, siblings, and parents/caregivers received Child Life interventions by the Child Life Specialist II at AI Razi Hospital in 2018.



\*\* During the months of August and October, Child Life Services in AL Razi Hospital were supported by KACCH Play Leaders.



Total number of patients, siblings, and parents/ caregivers who received Child Life interventions and therapeutic play services by Child Life Specialist II and Play Leaders at Al Razi Hospital in 2018.

### **Play Leader Services**

7,920 patients, siblings, and parents/caregivers received therapeutic play services by the Play Leaders at Al Razi Hospital in 2018.



## Ibn Sina Hospital

The KACCH Team at Ibn Sina Hospital is led by 1 Child Life Specialist and is supported by 2 Play Leaders. Services are provided in the following areas: Wards 1 and 6, Al-Babtain Burns Centre and Paediatric Day-Case Surgery.

### **Child Life Specialist Interventions**

4,889 patients, siblings, and parents/caregivers received Child Life interventions by the Child Life Specialist I at Ibn Sina Hospital in 2018.



\*\* During the month of December, Child Life Services in Ibn Sina Hospital were supported by KACCH Play Leaders.

.



Total number of patients, siblings, and parents/ caregivers who received Child Life interventions and therapeutic play services by Child Life Specialist I and Play Leaders at Ibn Sina Hospital in 2018.

### **Play Leader Services**

4,699 patients, siblings, and parents/caregivers received therapeutic play services by the Play Leaders at Ibn Sina Hospital in 2018.





## Sheikh Jaber Al Ahmad Al Jaber **Al Sabah Hospital**

The KACCH Team at Sheikh Jaber Al Ahmad Hospital is led by 1 Play Leader. Therapeutic play services are provided in the Out Patients Department and In-Patient Ward.

## 75 patients, siblings, and parents/caregivers received therapeutic play services by a Play Leader at Sheikh Jaber Al Ahmad Hospital in 2018.







## **KACCH VOLUNTEER PROGRAMME**

In 2018, KACCH volunteers, long term, new and returning, continued to impact and make a difference in the lives of so many children and their families. They continued to be a great support to our relatively small Child Life teams in the hospitals.

This year, KACCH recruited 32 new volunteers and continued its ongoing collaboration with the United States military forces in Kuwait who provided weekly volunteer rotations to two hospitals. Each of our volunteers continued adding value and dedicating quality time and effort in creating a better and more positive hospital experience not only for the patients but for their siblings as well. KACCH volunteers were essential contributors to our efforts in normalizing children's time in the hospital through engaging them in one to one activities that made their time in the playroom unforgettable, much more fun and extra special!

A SPECIAL THANKS to our long-term volunteers for always being there:

- Abha Suri
- Anju Matthew
- Beth Al-Mutawa
- Tammy Asaad
- Bibi Al-Andaleeb
- Clara Olivos
- Ali Reza
- Mona Al-Haffar
- The United States Military Volunteers from Ahmad Al-Jaber Air Base, Ali Al-Salem Base, Camp Arfijan







## **KACCH AND BACCH EVENTS**

Events held throughout the year by organisations or individuals helped connect the community to children and their families. These events created lasting memories for everyone.

### **KACCH EVENTS**

2018 Girgiaan events at KACCH Hospital Programmes, Sponsored by:

- Al Ahli Bank of Kuwait
- Burgan Bank
- Gulf Bank
- HSBC
- Kuwait International Bank
- Kuwait Finance House
- Ooredoo
- Zain
- McDonald's Kuwait
- Spread the Passion

Al Tijaria (The Commercial Real Estate Co.) event at Ibn Sina Hospital, Al Razi Hospital, and NBK Children's Hospital American University Middle East event at Ibn Sina Hospital

American University Middle East event at Ibn Sina Hospital Australian College Kuwait event at Ibn Sina Hospital Bloomingdales "Big Bear" visits to KACCH Hospital Programmes Bloomingdales "Big Bear" visits to KACCH Hospital Programmes for Eid A-Fitr Bloomingdales event at Al Farwaniya Hospital and Al Amiri Hospital Burgan Bank event at Al Razi Hospital Diabetes Day at Al Jahra Hospital FedEx Kuwait visits to KACCH Hospital Programmes JW Marriott Hotel event at Al Amiri Hospital Kuwait Finance House Eid Celebration at Al Jahra Hospital McDonald's Screening of Peter Rabbit for Children and their Families in Hospitals Ooredoo Riders Group event at Al Razi Hospital SaveCo event at NBK Children's Hospital The English School "Shoe Box Drive for Children in the Hospitals" Warba Bank event at Al Amiri Hospital World Diabetes Day at Al Jahra Hospital Zain visit to KACCH Hospital Programmes

### **BACCH EVENTS**

Activity Day Workshop-Build a Bear organised by BACCH Christmas Party organised by BACCH Eid Al Adha Event organised by BACCH Graish Lunch organised by BACCH Guirgian Event sponsored by Kuwait Graduate Society Halloween Event-Phoenician Riders sponsored by Al-Ghanim Engineering Hats on Palliative Care organised by BACCH Joss Stone Visit (UK singer) organised by BACCH Mother>s Day Celebration sponsered by Habshi & Chalhoub NBK Carnival Teddy Bears Clinic sponsored by UFM Teen Group (5Weeks) organised by BACCH World Hospice Day organised by BACCH World Music Therapy Day organised by BACCH





## **CHANGING PAEDIATRIC ENVIRONMENTS**

As part of KACCH's commitment to patient and family centred care, KACCH supports hospitals across Kuwait to make child and family friendly environmental changes. The organisation supports hospitals in creating environments that can help alleviate fear and anxiety, fostering a healing and calm environment for children and their families.

In 2018, KACCH completed the following projects:

- Design change of the Paediatric Ward and bathroom/shower area for the Physical Medicine and Rehabilitation Hospital
- Design change of the Sleep Study Room at Al Farwaniya Hospital Design and Development of the Outpatients Department of Sheikh Jaber Al Ahmad . Al Jaber Al Sabah Hospital
- Design and Development of the Outpatients and Day Case area of NBK Children's Hospital

The successful completion of these projects would not have been possible without the guidance, commitment and support of KACCH Executive Committee Member, Mrs. Kim Al-Yousifi.







## **KACCH SPONSORS**

Our gracious thanks to the following individuals and companies for sponsoring the Child Life Profession in 2018.

Abdulla Al Hamad Al Sagar & Brothers Company Advanced Technology Company Al Ahli Bank of Kuwait Ali Alghanim & Sons Automotive Co. W.L.L. Al Mojil Drug Company Bader Sultan & Brothers Co. W.L.L. Burgan Bank Gulf Bank Kuwait Financial Centre 'Markaz' Kuwait Finance House Kuwait National Cinema Company Mohammed Bin Yousef Al Nisf & Partners Company Mr Adnan Al Bahar Mr Hamad Al Sagar Mr and Mrs Anwar Al Mulla Mr Issam Mohamed Abdulrahman Al Bahar Mr Marzouk Abdulwahab Al Marzouk Mrs Adlah Mohamed Abdulrahman Al Bahar Mrs Afaf Al Bahar Mrs Shorouq Al Ghanim, In Memory of Mr Lutfi Al Mulla National Bank of Kuwait Sheikha Intisar Salem Al Ali Al Sabah Thilth Abdulaziz Al Sagar Thilth Yacoub Yousef Behbehani



## **KACCH DONORS**

Our gracious thanks to the following individuals and organisations for supporting KACCH in 2018.

Abdullah Al Sayer Abrar Al Omar Adel Easa Husain Al Yousifi, Easa Husain Al Yousifi & Sons for Contracting & General Trading Advanced Technology Company Ahmed Roan Aibanco Company Al Ahli Bank of Kuwait Al Kharafi Family Al Mulla Group Al Tayer Group, Bloomingdales Kuwait Alaa Al Bahar Ali Abdulwahab Al Mutawa Commercial Co. American University Middle East American Women's League Kuwait Ann Bhola Australian College Kuwait Bader Al Mulla Holding Company Banafsheh Azizi Barbara Sandhaus Burgan Bank Dalal Al Omar Dalal Al Zabin Dasman Bilingual School Dhuha Al Ajmi & Friends Donna Burábee Dr Nawal - Al Jahra Hospital Dr Rawan Al Fouzan Duha Mohammed Abdul Wahab Ramadan Fahad Al Nasrallah Farah Khajah FedEx Kuwait Fouz Tifouni Ghada Faraj Ghalia Al Kharafi Gholamali Dareshkaft Gulf Bank Gulf Insurance Group Hassan Al Jarallah HSBC Huda IKEA In Memory of Mrs Fatima Abdullah Al Majid In Memory of Nabil Hassan Basma International British School Jumana Al Bahar Khaled Al Otaibi and Dahlia Al Otaibi Khatib Al Ami Kim Al Yousifi **Kuwait American School** 

Kuwait Finance House Kuwait International Bank Laliit Agarwal Lulu Hyper Market Máha Al Bahar Maha Al Jallal and Zainab Al Naki Mai Al Farhan Maryam Al Bahar McDonald's Kuwait Mohammed Musaed Yahya Al Shayaa Nasser Bader Omniaty Ooredoo **Ooredoo Riders Group** Partake Camp Rabia Al Issa **Rajeev Meethal Veedu** Rawan Al Fozan Rawia Al Saeed **Renee Bester** Retai **Riva Fashion** Saba Al Bahar Sara Al Zabin SaveCo Shafiqa Al Mutawa Shaikha Al Zabin Shiraz Basma Shroug Al Asfour Spread the Passion Spring Flows Market Students and Parents of The English School The English School Um Athal United States Air Force, Ahmed Al Jaber Air Base United States Air Force, Ali Al Salem Air Base United States Army, Camp Arifian and Camp Buehring Vivek Shah Warba Bank Zain Zainab Al Naki Zainab Murtadha ...and many anonymous donors...



## **BACCH DONORS**

Our gracious thanks to the following individuals and organisations for supporting BACCH in 2018.

Abdullah Saleem Mohammad AlAdasani Aisha Mohammad Saleh Abdulwahab AlAdasani Al Jazeera For Real Estate Development Company Al Jeel Al Jadeed Alghanim Industries & Yusuf A. Alghanim & Sons, W.Ľ.L Ali Salem American Baccalaureate school Australian College of Kuwait Balvest Holding Limit Jersey LTD Barakat Food For Foodstuff **BUILD-A-BEAR Charles Aguilar** College of Technology Studies Dahan General Trading & Contracting co Danah Sabeeh Ahmad Ameen Dr Fajer Al Barrak Dr Nayef Falah Al Hajraf Dr Qais Al Duwairi Edward Brown Elite Fitness **English school Fahaheel** Fajer Tareq Jaafar Alwazzan Farah & Fay Mohammad Karam Fatema Abdulaziz Faisal Al Thuaini Fatima Abdullah Hamad Abu Rabee Fatmah Abdullatif AlShaya Fawziya Al Nafisi Food Master-Babak Grill House Ghalia Al Fulaij Ghalia Saud Al Fulaij Ghalia Saud Al Fulaij & Najat Al Marzouq Habshi and Chalhoub Hadeel Hamed Khalifah Al Fadalah Hassan Salem Yaacoub Al Tarafi Heirs of The Late Ezzat Mohammad Jaafar Helal Meshari Helal Al Mutairi Helen Asfour Ibtissam Al Bassam Jessica Klein Kuwait Engineering Office - International Consultants Kuwait Finance House Kuwait Foundation For The Advancement Of Science Kuwait Pearls Catering Co Kuwait Petroleum Corporation Kuwait Red Crescent Society Laila Youssef Lamya Mohammed Ahmed Al Roumi Loav Al Amer Loulwa Khaled AlZayed Al Khaled

LOYAK Maali Hmood AlNusif Maha Al Ghanim Mariam & Sharifa Al Sayer Mohammad Hajjaj Al Mutairi Muneera Hamad Mohammad Al Nafisi Nada Zaben Yousef AlZaben Nadia Mohamed Abdulrahman Al Bahar Najat Sayed Redha Behbehani National Bank of Kuwait Nawal Shamlan Noora Sulaiman Salem Al Fassam Nora Al Ghanim Nour Bader Nour Bader Philippa Huxtable Philippa Huxtable Phoenician Riders Prime Retail Trading Co Ramadhan Karrout Rasha Al hamad Rasha Mishary Khaled Al Zaid Al Khalid Rawafid Food Stuff Catering Co Roofaida Boodai Sahar Abdulmohsen Yousuf Al Abdul Razzak Saleh Al Shalfan SH:Naser Mohammad Al Ahmed Al Sabah Sheraton Hotel Kuwait Shoug Al Omran Shuwaiheena Shaher Baddah Al Mutairi Stephanie Hopkinson Suad Al Mufarrej Taiba Al Khaled Taiba Hamad Mohammad Al Nefisi Tayba Anas AlSaleh The Graduates Society The Kuwait Company for Process Plant Construction & Contracting The Light House Academy The Tides Foundation-USÁ Thilth Abdulaziz Hamad Al Sagar Tracy Andrade United Facilities Management United Facilities Mangement Vigor Entreprises Volunteers Wasmeyah Hajjaj Al Mutairi Youssef Al Ansari Youssef Saleh Al Othman Zahoor Hussein - Al Ahli Bank Zouzou Nabil



## **BAYT ABDULLAH CHILDREN'S HOSPICE**

Bayt Abdullah Children's Hospice continues in its efforts to expand its services to better support our children and families by recruiting a qualified Play Therapist to add to our growing Family Support Team. This addresses an identified need of our children's psychosocial requirements as play therapy is a form of counseling and psychotherapy using play as the medium. This will support the aim of improving quality of life for children, young people and their families.

This year we have expanded our sessional work in Day Care to include siblings' specific needs by offering targeted age appropriate sessions with afternoon and weekend sessions to take into account families' wishes and scheduling wants. We also continue to expand our referral base for those children with life limiting and life threatening conditions coming in from various nationalities, ages, religions and with different disease groups to cover as much of the need as possible within Kuwait.

Once more we would like to present a case study of one of our children for a better understanding of how our services impact children and families on our caseload. This is done in partnership with our families to help improve their quality of life and support them through their journey.



### Jamila's Story:

(Name of the child has been changed to provide anonymity but consent has been gained from parent to share their story).

Jamila is a 2 year old girl diagnosed with microcephaly and global brain atrophy. This means that she has an abnormal smallness of her head and incomplete brain development. She also has a loss of her brain cells which causes limited life expectancy.

Jamila was referred to BACCH in November 2017. She is an only child of young Syrian parents who had already lost one child with a similar condition. They are from a very challenged socio economic background. This young family is part of a wider extended family that all live in very close proximity to one another. Mum has 10 younger siblings (under the age of 18 years) who are all very close to Jamila. Jamila's grandparents are also very supportive and heavily involved in her care. All of the extended family lives in a very rundown apartment complex with intermittent air conditioning. There are financial challenges for this family which are exacerbated by their low educational attainment which subsequently affects the types of lower paid employment that dad and granddad are able to obtain.

### How did BACCH support this family?

When Jamila and her parents came to BACCH for an introductory tour and assessment, they were surprised by the services that were on offer to them free of charge and were very keen to receive the support available. Through the different assessment tools we utilized, Jamila's and her family's priorities of needs were identified to be able to address the type of support needed by them.

Her clinical needs were seen as paramount with an epilepsy review being a first priority. Therefore, with the cooperation of her primary physician at Al Farwaniya Hospital an Epilepsy Symptom Management Plan was implemented, in addition to, advocating on behalf of the mother to better support, educate and inform her regarding Jamila's diagnosis, prognosis and care.

The BACCH Interdisciplinary Team consisting of our doctors, nurses, pharmacist, allied health professionals and Family Support Team set up a comprehensive review of her care including her medications, as Jamila was on a cocktail of different medications for her condition.

A written plan was completed for administering all the different medications in both English and Arabic with instructions on how and when to give the medications; this was taught to mum by the BACCH nurses. The training was also extended to Grandmother and mum's younger sister as they also supported mum in caring for Jamila.

Daycare at BACCH became an integral part of the family's schedule with a huge positive impact. The sessions were an opportunity for mum to become more confident in delivering all of the daily care needs for Jamila with nursing support. The Child Life Specialist spent time engaging mum, grandmother and aunt in learning how to play with Jamila and the Family Support Team helped engage the younger members of the family in play and communication. Our Music Therapist was able to plan weekly music therapy sessions with mum and Jamila to develop and nurture better communication between them. Our Physiotherapist had weekly sessions on postural drainage and taught mum and grandmother how to continue to do this at home to alleviate Jamila's breathing symptoms. Catering was prepared with an array of meal choices and snacks for the family as a whole. Many weeks these sessions were themed and at times the children were able to make their own pizzas and decorate their own muffins and then take them home. It was also an opportunity for the family to build relations with other BACCH families during different activities and Respites at BACCH.

Once Jamila started to deteriorate, home visits were introduced as Jamila was too unwell to travel to BACCH. Our Outreach hospital visits around symptom management and play continued whenever she was admitted to Al Farwaniya Hospital for any acute episode. Towards the end of her life, symptom management, relaxation techniques and play continued to be offered.

Conversations between the family, her primary doctor and BACCH physicians continued around what Jamila and her parent's wants and wishes were going to be towards the end. Peace and pain free were

the paramount concerns and these were the areas that BACCH continued to advocate. On the day that she passed away as per the family's request in hospital, Jamila was surrounded by not only her family but as the family so succinctly put it 'her extended BACCH family too'. The BACCH physicians were there to ensure she was pain free, our Music Therapist was there with Jamila's favorite selection of musical instruments to ensure peace and tranquility and our Child Life Specialist was there to support the family in the very difficult time ahead. Jamila died in October 2018 surrounded by those she loved.

Jamila's family continue to receive bereavement support in their own home but also with visits to BACCH supported by our Family Support Team. This is a family that embraced the care that BACCH was able to give them. They were initially reluctant to try new things that did not necessarily fit in with their perception of what was culturally appropriate for them such as music therapy. But by attending events and Day Care they saw what the benefits were for other children, which encouraged and supported them in making different choices. We continue to support Jamila's family in remembering and embracing the precious memories that were made with this wonderful family.

This family's journey illustrates the work we do at Bayt Abdullah and how your continued support and generosity helps these children and their families.

Lastly, I would like to thank you, our donors and supporters and extend our sincerest appreciation, for without your generosity and support we could not have achieved our objectives to support those children and families in need, and we thank our many sponsors who support us by funding wonderful activities at Bayt Abdullah throughout the year. This collaboration is what our families see as the community's willing engagement to be a part of Bayt Abdullah and the life of our children and families.

Rasha A. Al-Hamad CEO

## **BACCH MISSION**

To provide the highest standards of multi-professional, specialist, paediatric palliative care and support to children with life limiting or life threatening illnesses who are resident in Kuwait, and their families.

We aim to improve the quality of life for children and their families from diagnosis and beyond by offering these services, tailored to the individual family's needs, in the location of their choice, whether at home, in Bayt Abdullah or through our outreach programme in their local hospital.

We offer specialist symptom management, medically supported 'respite' care, home care, rehabilitation services and play activities as well as psychological and practical support for the whole family.

We believe the **protection and safety** of every child at **BACCH** is paramount.

We deliver child friendly, responsive and individualised care, advocating for the child.

We are passionate about promoting **quality of life** in general and **quality at the end of life** in particular.

We ensure **compassion**; **respect**, **dignity** and **confidentiality** are always a top priority.

We com

We embrace and support change, flexing and adapting to changing needs.

We work **effectively** and **efficiently** as a team, **adapting** to need and the **voices of children** and families.

We promote **continuous learning** and value the **skills and commitment** of our employees and volunteers.

We work with **integrity**, **collaborating** with our community to **provide excellent**, **holistic care**.



### **BACCH Operational data for 2018**

From January 2018 to December 2018, we have had **36 patients** on our case load offering our services to **142 family members** (parents and siblings) and **supporting 72 siblings**.

BACCH

### The following is a summary of BACCH's Patient Data for the year 2018:



### Association for Children's Palliative Care (ACT) Categories of Life Limiting and Life Threatening Conditions

Category 1 Life-threatening conditions for which curative treatment may be feasible but can fail.

Category 2 Conditions where premature death is inevitable.

- Category 3 Progressive conditions without curative treatment options.
- Category 4 Irreversible but non-progressive conditions causing sever disability, leading to susceptibility to health complications and likelihood of premature death.









## **FINANCIAL REPORTS**

### Statement of Income and Expenditure - KACCH

	Year Ended Dec 31, 2018	Year Ended Dec 31, 2017
Income		
Sponsorship	464,000	403,144
Donations	6,480	8,814
Interest and Investment Income	4,498	1,563
Total	474,978	413,521

Expenditure		
Salaries and Related Costs	279,474	290,406
Miscellaneous	10,868	14,497
Total	290,342	304,903
Net Income	184,636	108,618
Surplus at the Beginning of the year	133,342	24,724
	317,978	133,342

### Statement of Income and Expenditure - BACCH

	Year Ended Dec 31, 2018	Year Ended Dec 31, 2017
Income		
Donations	1,009,097	980,746
From Sales of Pins	293	655
Interest and Investment Income	37,676	30,157
Total	1,047,066	1,011,558

Expenditure		
Salaries and Related Costs	606,493	548,621
Operating Costs	286,983	236,340
Equipment Costs	40,453	109,265
Total	933,926	894,226
Net Income	113,140	117,332
Surplus at the Beginning of the year	3,724,323	3,606,991
Surplus at the end of the year	3,837,463	3,724,323

### Balance Sheet for KACCH & BACCH

	Year Ended Dec 31, 2018	Year Ended Dec 31, 2017
Assets		
Cash and Bank Balances	1,332,124	1,236,095
Fixed Deposits	552,401	350,000
Investment in Managed Funds	2,634,673	2,603,027
Total Assets	4,519,198	4,189,122
Provision End of Service Indemnity	228,082	196,771
Provision End of Service Indemnity Other Payables	228,082 24,676	196,771 23,683

Represented by		
Capital	111,000	111,000
Retained Surplus	4,155,440	3,857,668
Total	4,266,440	3,968,668







### KACCH is especially grateful to

Mr Souham El Harati for his legal counsel and expertise for KACCH and Bayt Abdullah.

Mr Anwar Y Al Qatami and Grant Thornton, Al Qatami, Al Aiban & Partners for their annual auditing of KACCH and Bayt Abdullah's accounts.



Mr Khaled H Al Mutairi and Al Jarida for publishing the KACCH Annual Report every year.







الجمعية الكويتية لرعاية الأطفال في المستشفى Kuwait Association for the Care of Children in Hospital