

Cottage Capers

The Newsletter for Bear Cottage families



Spring 2018

A Bear Affair to remember

On the 25th August many of us enjoyed a wonderful night at our annual Gala Ball – **A Bear Affair**.

A Bear Affair is our biggest fundraising event of the year and enables us to continue the valuable programs we run at Bear Cottage. This year it was fabulous to see a large number of past and present families in attendance, along with staff and volunteers.

You may not know that the inspiration and visionary insight for Bear Cottage came from one man, Paediatric Oncologist **Dr Michael Stevens**. Michael worked tirelessly in the 1990s to ensure that the dream of building a children's hospice became a reality. Michael and his wife **Margaret** chose the site and along with strong community support, raised the \$10 million needed to build it. We were delighted to have Michael and Margaret attend A Bear Affair this year for the first time. After 17 years of operation they were delighted to see that so many children and families continue to reap the benefits of Bear Cottage.

Also joining us on the night was the **Spence family**. **Jenny, David** and their adult triplet sons, **Will** and **Tom**, were our guests and we were privileged to have Tom and Will speak of their experiences as eight year old siblings at Bear Cottage. Their sister **Mattie** stayed at Bear Cottage for a number of years before she died in 2007. It was touching and inspiring to hear about the impact Bear Cottage had on their family. Tom kindly shares his story later in the newsletter and we thank the Spence family for making the evening so memorable for our guests.

Thanks must also go to the A Bear Affair Committee, for ensuring it was such a fabulous night. ■

Narelle Martin, Nursing Unit Manager



Dr Michael Stevens, with his wife Margaret, receiving a standing ovation at A Bear Affair

Comfort, support and empathy

Bear Cottage siblings are amazing human beings and constantly surprise us with their maturity, patience and thoughtfulness.

For the staff who are fortunate to have the privilege of running a Sibling Camp, we get to see and hear first hand how these camps benefit them.

Recently we had a **Destination Camp** to Cairns and the first of two **Junior Sibling Camps** at the **ATYP** (Australian Theatre for Young People).

While these camps provide amazing opportunities for the siblings, we see the real benefits of the camps when the siblings come together at the end of each day. Whilst the siblings are sharing a meal together, recapping their experience or just hanging out, they also share individual stories about living with a terminally ill sibling with their peers. We hear them encouraging each other and providing words of comfort, support and empathy.

As well as providing fantastic experiences, these camps provide a safe space for siblings so that they feel comfortable just being themselves.

At our most recent Junior Sibling Camp at the ATYP, during their final stage performance, the siblings took us on a journey through their eyes of their experiences at Bear Cottage and gave us insight into their school lives and their hopes and wishes for the future.

We would like to thank each of the Bear Cottage siblings for their extraordinary strength, courage and resilience. ■

Gy Ho, Bear Cottage Child Life Therapist





Tom and his brother Will made a heartfelt speech at our recent A Bear Affair Ball, sharing memories of their sister Mattie and their stays at Bear Cottage

A gentle and loving spirit

Mattie, Will and I were born on April 16, 1994, late at night. We were born prematurely at 28 weeks gestation. As Mum and Dad often recall, when we were born, Will was the colour red like the Coca-Cola logo, I was as small as a one litre carton of milk and then came Mattie. From the moment Mattie was born, her struggle began with intensive care and an abundance of medical professionals looking after her, yet with the most loving, caring and thoughtful parents anyone could wish for by her side.

As a primary school aged child, I would often describe Mattie's illness as 'she can't talk, walk and she has a tube in her stomach', however she suffered a host of medical problems, that as a kid I guess I really couldn't comprehend. Despite her illness, Mattie's wide ecstatic smile could light up a room, she was always very happy to see familiar faces. Growing up, Mattie often had to undergo countless late night medical interventions at the Children's Hospital, yet Mattie's perseverance and courage for the unknown is remarkable, something I cannot really put into words, she battled for so long.

However, Will and I are not here to tell you about the tough times, we want to talk to you about the good times. Mattie was a very happy little girl, even the simplest things such as chasing a butterfly around the room with her eyes, would call for a sudden outburst of laughter and body movement. Mattie's sudden outbursts of sheer delight and excitement, waving her arms and feet around, with a huge smile on her face, always occurred when she arrived at Bear Cottage. When driving up the hill along Darley Road, Mattie's face would start to light up and upon entering the lift at Bear Cottage, Mattie's excitement was uncontainable. For Mattie, Mum, Dad, Will and I, Bear Cottage was/is a very special place.

It's hard to pinpoint exact memories, moments or experiences at Bear Cottage, as many have been so wonderful. I think for me, some of the happiest experiences at Bear Cottage were being able to play and make friends with the other siblings staying there. Certainly, playing Xbox on the large screen TV in the lounge room was always a highlight of our stay. Will and I would always look forward to having a meal cooked for us by the chef, which we always appreciated. Scooter, the therapy dog was very friendly and I would often enjoy giving him a pat.

It's the simple things which Will and I always appreciated, being able to watch the Simpsons on Foxtel on a Saturday morning for hours on end, as we didn't have Foxtel at home. Or being able to go for a surf at Manly Beach so easily. But as I think back to our stays, I appreciate that Mum and Dad were able to get a decent night's sleep without having to worry about Mattie, as she was always in loving and caring hands – again it's the simple things.



However, Bear Cottage's tremendous support extends beyond just providing a home away from home for sick children and their families. Will and I have been lucky enough to have been given an opportunity to attend a few sibling camps, where street hummers, Harley Davidson motorcycle rides and Master Chef cooking challenges were all commonplace. Whilst these activities were fantastic, the thing I really appreciate is the friendships both Will and I made, it's as if all the siblings shared an unspoken bond, a common thread, as if we could share our emotions without being judged.

Will and I always look forward to seeing the friendly faces of the many volunteers. I seem to remember that there was a roster, which Will and I would scope out, shortly after arriving. We both greatly appreciated each volunteer who spent time with us, as we would plan out activities based on which volunteer was rostered on. The volunteers are a vital part of Bear Cottage and I'm sure without them our stays would just not be the same. I am sure Mattie always loved spending time with the volunteers. Whilst she couldn't say so, I'm sure she had her favourites. In particular, Mattie was always delighted to hear Moira playing the piano, it would always bring a huge smile to Mattie's face.

As Will and I have grown up and after Mattie's passing, it has been increasingly important to remember Mattie. On our dining room table is Mattie's picture sitting next to a candle. We often light the candle in memory of Mattie. Mattie's spirit and legacy live on throughout our daily lives. Whenever I sat an exam at Uni, Mum and Dad would assure me that Mattie was always with me by my side and more recently during job interviews, Mattie was always there. I always think of Mattie in times of pressure, her spirit always calms me down.

There have been many challenging moments throughout my life, however Mattie will always be with me by my side. My darling sister will always guide me through life and will always look over my shoulder. I love Mattie and I will always remember her gentle and loving spirit.

■ **Tom Spence**



Dads' day out

Five of our wonderful Bear Cottage Dads recently stepped outside their comfort zones and came to Bear Cottage for a weekend of fun and connection.

It was an action-packed weekend – taking part in a whale watching power boat ride, a 'barber shop experience' with **M Barber**, a welcome dinner at the **Hotel Steyne** and tickets to see **The Book of Mormon**. If that wasn't exciting enough, they got to cheer on the Blues at the State of Origin!

There was also some down time which was spent with our Bear Cottage Art Therapist **Judy** and our Business Manager **Roy** (AKA the BBQ King) who hosted a gourmet BBQ.



The feedback from the Dads has been overwhelmingly positive, with the State of Origin and trip to the theatre the highlights. But what was equally beneficial was the opportunity to make new friends or re-connect with old ones.

The Dads spoke of the benefits of having the chance to share their experiences and learn from each other, whilst getting the chance to relax and have a break from everyday stresses.

Our Dads encourage other Bear Cottage fathers to attend Dads' Camp if they have the opportunity and we look forward to hearing



from you if you are interested. Our next Camp will be held in November, so please contact **Narelle** on **9976 8301** to check availability.

These Camps would not be possible without the wonderful contribution of our supporters. We'd like to thank **Channel 9**, **M Barber** in Manly and the **Hotel Steyne** for the ongoing generosity. ■

Parent's corner

Technology update

Being part of the **Sydney Children's Hospitals Network** has meant that Bear Cottage has benefited from recent upgrades that the Network has made to IT infrastructure and the electronic medical records management system. On your next visit to Bear Cottage, you should notice increased internet speeds when accessing our Wi-Fi system and future enhancements will enable us to streamline our referral, admission and documentation processes. We will keep you updated with new developments. ■

Bookings information

Spring is here and as it gets warmer it's a great time to organise a stay at Bear Cottage. Please give us a call on **99768301** to see what is available.

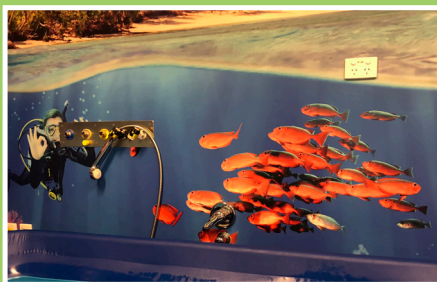
Another date to keep handy is the **Bear Cottage Family Christmas Party** which will be held on **Sunday 9th December 2018**. More information will follow but jot it down in your diary now. ■

Housekeeping help

Please remember to label all of your child's belongings when they come for a stay at Bear Cottage. It is sometimes difficult for our housekeepers and nurses to know who belongs to what and items do go missing. If something is mislaid please check the lost property on your next visit. ■

Bath bliss

On your next visit to Bear Cottage take time to check out our new bathroom design. Thanks to **Merlin Entertainment**, our children can now feel like they are surrounded by the sea and swimming with fish whilst they relax in the bath. ■



Remembering our children

Owen Fizzell
19/09/17 – 25/06/18

Jarrold St James
31/05/05 – 28/06/18

Wendy Gomes-Black
19/03/17 – 8/03/18

Angelina Kovacevic
18/02/05 – 27/05/18

Gabriel (Gabe) Smith
1/11/04 – 2/07/18

Sam Smith
14/11/10 – 15/07/18

Lili Khoury
24/03/14 – 27/07/18

Stella Bawalan
14/12/13 – 1/08/18

Mia Murchison
27/07/09 – 17/08/18

Evelyn (Evie) Lee
8/06/18 – 24/08/18



Have you ever wondered . . .

what FITS stands for?

FITS stands for **Footprints In The Sand** which is the name of our Bear Cottage Bereavement program. This includes our Camp for bereaved families, our **Back to Bear Cottage BBQs** and our annual **Remembering Day**. For more information about our **Footprints in the Sand** program, please contact **9976 8300**.



Footprints in the Sand
Bear Cottage's Bereavement Service

The pink army

If you are a regular visitor to Bear Cottage you will often see our 'pink t-shirted' volunteers helping at the craft table, reading stories in the lounge, helping in the kitchen and joining in with music therapy sessions.

We have a pool of roughly 140 volunteers who regularly give their time to ensure support is available seven days a week, 9.30am-7pm each and every day. But what you won't see is the army of volunteers who are often working behind the scenes at fundraising and community events so that we continue to raise awareness and funds and have a public face in the community. This can involve selling raffle tickets, speaking at events, collecting donations or wearing the Bandaged Bear suit!

We recently held our annual A Bear Affair Gala Ball and this really typified the collective support our 'vollies' provide. Throughout the year we have had a dedicated volunteer committee planning and sourcing auction prizes and designing the event. Other volunteers willingly tap into their community connections to secure donations of gifts, vouchers and silent auction prizes. On the day of A Bear Affair, we had a total of 43 volunteers who gave up their day and evening to set up for the event, act as table hosts, sell raffle tickets and help in the Bear Cave. Many volunteers stayed until the early hours of the morning helping with the packing up at the conclusion of the event.

It's hard to quantify the impact the volunteers make however their connections with the wider community mean they are able to advocate and shine the light on the wonderful place that Bear Cottage is, enabling more families to get to experience and benefit from a stay here.

As a staffing group we certainly wouldn't have the reach and connections that our volunteers have. Instead we complement each other, ensuring Bear Cottage is recognised as a valuable resource for children and their families when they need us. ■



Staff news

It would be difficult to find a more dedicated and passionate group of people than those who come to work each day at Bear Cottage.

One group is our **Assistant in Nursing** undergraduates who often begin their nursing career at Bear Cottage. Each year we take on three new recruits and these positions are highly sought after and regarded. As is always the case it is highly competitive and we are lucky to attract some outstanding students. Commencing in this role over the next couple of months will be **Bryarna, Olivia** and **Aaron**. Watch out for their enthusiastic faces.

Whilst our Social Worker **Liz** is off on baby duties after the birth of her daughter **Charlize**, we will be joined by **Bianka**. **Bianka** is thrilled to be taking up this role where Liz left off and we are excited to have her on our team.

Pam has now stepped out of her Volunteer role and joined the Housekeeping staff. Where would we be without this small team who ensure Bear Cottage is sparkling every day?



Pam

Lastly, but definitely not least, is **Laura** who has slotted into the Administration Assistant role. Laura replaces **Jane** who is now on our Casual pool. After working in a busy hospital I am sure Laura will enjoy the ambience of Bear Cottage.



Jane

Keep an eye out on your next visit for these wonderful new members of our team. ■



Laura

Fundraising news

A Bear Affair

Our recent **A Bear Affair Gala Ball** was a sell-out event with 500 guests and raised over \$500,000!

It was wonderful to see so many friends of Bear Cottage gathered to support the patients and families in our care. All auction prizes were generously donated, with our major prize this year being a fabulous boat trip on **True North** in the Kimberleys valued at \$40,000. We also had support from **AHG** who once again donated a car as first prize for our raffle and we were thrilled to announce the winner as our very own long-serving volunteer – **Judy Lavery!**

We thank our friends and donors, volunteers and families for the richness you bring to Bear Cottage and for supporting this special night. ■



Superhero Week

We have had another successful year with our Superhero Week event. With funds still coming in, the event will once again raise almost \$300,000. Whilst we have participants all over NSW, it has been particularly heartening having our Bear Cottage families getting their schools, workplaces and friends involved. Thank you all for taking time out of your busy lives and helping raise awareness and funds.

We would like to make particular mention of Bear Cottage mum, **Sara Khoury**, who has raised close to \$40,000 through her Superhero fundraising efforts. Friends and family have been inspired to donate to the fundraising page in memory of Sara's precious daughter **Lili**. ■



Calendar

- World Hospice Day**
13 October
- Junior Sibling Camp (ATYP)**
27-28 October
- Dads' Camp**
15-19 November
- Family Christmas Party**
9th December
- Closed for respite**
21 December
- Open for respite**
27 December