

Cottage Capers

The Newsletter for Bear Cottage families



Spring 2019



Welcome

Spring has sprung and we are looking forward to some beautiful warm days ahead here in Manly and finally saying goodbye to the endless winter season of colds and flu.

Our Family Support Programs continue over the next few months with an upcoming **Sibling Camp**, **Dad's Camp** and our **FITS (Footprint in the Sand) Camp** for bereaved families. If you would like to participate in any of these please contact me at narelle.martin@health.nsw.gov.au

The October school holidays are fully booked out for respite visits and the January school holiday bookings are now being finalised. There are still a few spots available so please register your interest now. Please remember that families cannot book for more than one week in school holidays and only every second holiday period.

One of our major yearly fundraisers,

A Bear Affair, was held on Saturday 24th August. It was great to see so many parents, staff and volunteers attend and support the wonderful place that Bear Cottage is.

A huge thank you must go to the organisers of this prestigious event which raises much needed funds for our Family Support Programs. Special thanks to Bear Cottage mum **Sara Spurr** who spoke so eloquently about her daughter Lucy and her family's experience of Bear Cottage.



Finally, many of you would be aware that we recently changed over to electronic medical management. This means that all children's medications need to be entered onto the electronic system. To do this in time for your child's next admission and ensure the process flows smoothly, please make sure your forms are returned for processing one week before your child's booking. Thank you for your co-operation with this.

We look forward to welcoming many of you to Bear Cottage over the next few months. 🐾

Narelle Martin, Nursing Unit Manager

Works of art

One of the things that you notice when you walk down the hallways of Bear Cottage are the bright and colourful artworks that line the walls.

As well as ensuring that Bear Cottage is a warm and inviting space for our children and their families, research has shown that an optimistic outlook reflected in art, can help improve a child's well-being and instil a sense of calm. Artworks are selected to provide comfort, delight and interest to patients, families and visitors.



Judge Judy selecting the winners

The Children's Hospital at Westmead (CHW) is a registered art gallery and we are fortunate to receive artworks from its collection to display on our walls. Many of the pieces on display are from the **Operation Art** collection. This is an initiative of CHW, in collaboration with the Department of Education, and involves school students from Kindergarten to Year 10 across NSW creating artworks for children in hospital with the aim of brightening their day and uplifting their spirits.

From an annual exhibition of over 700 artworks, 50 are chosen to go on a tour of regional galleries – these are then hung in the hospital (and Bear Cottage) as part of the permanent collection.

This year our Art Therapist **Judy King** was honoured to be selected as a judge at the exhibition. Judy was inspired by the range and talent shown within the exhibition and was moved by some of the children's artist statements, with some children describing their own long hospital admissions and their wish to brighten the walls and lives of children who have to spend time in hospital.

It was hard to choose only 50 pieces from the colourful and thought-provoking collection, but it is truly a celebration of creative expression and we look forward to seeing some of those artworks on our walls in the near future. 🐾



This Operation Art piece is currently on display at Bear Cottage



Dolly and the dragonflies

The wonder and power of nature are evident all around us. Often these present in the most ironic and surprising ways – for example, the MRI brain scan of a child with pontocerebellar hypoplasia, a rare congenital neurological disease, often looks like a dragonfly. Consider the magnitude of devastation and beauty in one life-changing image.

Dragonflies are particularly significant for one of our recently bereaved Bear Cottage families, facing the six-month anniversary of the death of their beloved **Dolly** – one of only a handful of children living with pontocerebellar hypoplasia in Australia.

Dolly was Alyssa at birth but nicknamed “China doll” then later “Dolly” by her adoring family because she looked like a little Dolly. Mum **Shanna** says “Dolly loved her nickname and would respond if you called her Dolly but not Alyssa.

“Dolly brought so much joy to her family, in particular to her protective band of five older brothers - **Corey**, 28, **Leeaf**, 18, **Seth**, 14, **Nathaniel**, 11, and **Noah**, 8. We all miss her dearly but have such fond memories of the short time we had with her.

“I rang Bear Cottage five years ago when we heard Dolly’s condition was life-limiting – she was only 8 months old. I knew then our family would need support and I didn’t know where else to access the specialised knowledge and especially the practical medical training and experienced palliative care that Bear Cottage offers. I didn’t know what else to do.

“I needed help, my daughter needed help and my family also needed counselling and guidance to help us anticipate and manage expectations of Dolly’s limited lifespan. At the time, I don’t think I ever fully appreciated the level of support we would all go on to receive at Bear Cottage.

“During Dolly’s life I was able to access Bear Cottage as a respite care facility – a home away from home that was a step down from a hospital stay. In the early days, when the whole family would visit, the nursing staff helped me develop my nursing skills and understanding of Dolly’s extensive care needs. This was all new to me. When I needed to undertake some short-term study, or if I was exhausted from the relentless responsibility of 24-hour care, I could leave Dolly at Bear Cottage for respite and remain reassured she would receive high quality care.

“Whenever Dolly was at Bear Cottage I had peace of mind that she was well cared for and more than that, she was loved. I am forever grateful for the love and care Dolly received in her short lifetime from the staff, volunteers and other parents and siblings.

“Experiencing Dolly’s first sunrise on the beach at Manly is my most precious memory of Bear Cottage. It was something that we were able to do together.

“Dolly’s brothers were also able to participate in Sibling Camps and other family events such as the Christmas party. It was of great benefit for my children as life can become very challenging for siblings of medically complex children. Camps gave the boys a break from those daily challenges and created a safe space for them to make friends and to enjoy a shared experience with other Bear Cottage children. The boys would always come home with stories to tell of their adventures, the activities they participated in, the siblings they had met and the funny things the staff and volunteers had done to ensure each camp was memorable and fun.



“I have so many fond memories of our time at Bear Cottage like playing in the large spa with all my children, including Dolly. Before Beau arrived, there was Frankie, such a beautiful therapy dog; I loved lying on the floor with her and talking with her! I also enjoyed laughing with other mums and being free to share our worries, joys and fears.



“We were supported so well during our Bear Cottage stays, by staff and volunteers who worked tirelessly but joyfully to help our whole family, especially Dolly. We know Dolly was so loved and adored during her stays - she had books read to her, had her nails painted, she watched Frozen and had sing-alongs, she was taken into the sensory room and she made friends of her own.

“It’s nice to know that support is always there, for as long as we need to access it.”

“Without Bear Cottage, I visualise a much harder time for my family! With Dolly’s diagnosis, life became harder all round, for all of us. I have made life-long friends who understand the challenges, heartaches and joys of parenting a medically complex child. My children enjoyed well-deserved moments of happiness on a difficult path and Dolly, our beautiful girl, was loved and spoilt so we know she always enjoyed staying at Bear Cottage. She was so excited when she came home and told me all about her adventures.

“Our Dolly died at the age of five in the ICU at The Children’s Hospital at Westmead.” said Shanna. “We were so grateful we were able to then bring Dolly to Bear Cottage, where we spent three sad but precious days beside her.

“That gift of time is hard to describe. Our family is a mix of Chinese and Aboriginal ancestry and over these five years we had the support of many relatives and friends. Dolly’s father and I were community workers before Dolly’s birth and we were used to assisting others during difficult times, so it was wonderful to be on the receiving end, being nurtured and looked after by the staff and volunteers at Bear Cottage in those last few difficult days.

“Despite her passing, our association with Bear Cottage continues. We have received the most caring bereavement support and continue to be invited to events. It’s nice to know that support is always there, for as long as we need to access it. We remain joined together by that ‘Invisible String’.

“Bear Cottage remains so special to my family. There are other Mums I maintain regular contact with - we support each other still. I speak with some of them often and with others on Facebook. We hope to catch up with them again when we attend the upcoming Bereavement support events.

“I am most grateful we live in a country that supports children and their families facing the most difficult circumstances. And I am grateful every time one of us notices a dragonfly hovering over us – we know our Dolly remains close to us all and we will love her forevermore!” 🐾

We thank Dolly’s mum Shanna and family for so kindly sharing their story.



Camps at the Cottage

Our Camps are an important part of our care at Bear Cottage and are available for Siblings, Parents and Grandparents. We recently held Camps for our Dads and Junior Siblings and it was great to receive feedback from two people who participated in different ways.



Dad's Camp by Dad Willie

I recently took part in another memorable **Dad's Camp** which was an opportunity for fathers to take some time out and enjoy 'dad-activities' together. There were a few regulars and a few new dads – and together we got to share some cool experiences.

Music, craft and visiting a coffee roastery made sure that everyone was relaxed enough at the start, before picking up the pace. Even the non-coffee drinkers tantalised their taste buds on the specialty coffees and experienced the wonderful world of caffeination. As the Camp was held in June, there was of course 'footy' and the dads made their way to the SCG to watch the Swans game on a Friday evening and ended the weekend by watching State of Origin on television at Bear Cottage.

We also attended an American BBQ cooking class and got to learn about the intricate techniques of smoking meats – this was followed by dinner where we could taste the results of hours of smoking. Sunday was packed with a trip to **MBarber** in the morning, with some of us

wishing they could add some hair instead of taking it away!

This was followed by an informative, perhaps even haunting, tour of **Q Station**, before a well-deserved delicious dinner at the **Hotel Steyne** restaurant.

But Dad's Camp is more than just the great activities we get to enjoy. It is an opportunity to spend time with other Dads who know what you are going through. Dads who are able to share from their own experience, knowing there will always be a group of guys you can reach out to who 'get it' – this truly is what Dad's Camp is all about. 🐾

Sibling Camp by Volunteer Alex

After hearing about the partnership between Bear Cottage and my employer **John Holland**, I felt inspired to look further into the wonderful work Bear Cottage does and to see if there was a way I could contribute.

After my training, I started my first volunteer shifts in June, initially planning to do some housekeeping, dish washing and any odd jobs around the grounds, however Rachel our Volunteer Manager suggested I keep an open mind and try some shifts assisting the extremely talented and inspiring Child Life Therapists.

I am very grateful for the challenge from Rachel to step out of my comfort zone and in a short time I have gained much perspective and meaning, witnessing the truly selfless and beautiful work Bear Cottage does for families and children going through the hardest of times.

I recently volunteered at the **Junior Sibling Camp** and the weather turned on a gorgeous day at Manly Beach.

Our task was to oversee a scavenger hunt and after splitting the group into two teams with myself and fellow volunteer Rosie as team leaders, we set off to Manly Corso with a tricky list of clues. It was interesting to watch this really clever group of youngsters assign roles amongst themselves, with a couple in charge of the clue list, another two leading the search party and others taking it in turns to take photos as the clues were found.

There were loads of laughs, plenty of excitement, home-made pizza (thanks **Owen**) and some heartfelt moments as a few members of my team shared some of their family history.

I know I echo the sentiment of all the siblings who attended when I say that **Gy, Philly** and other Bear Cottage staff did a fantastic job organising this Camp and made it a day to remember for myself and most importantly, for the kids. 🐾



Staff profile

My name is **Aaron** and I will have been an AIN at Bear Cottage for a year on 24th September – it has been an amazing year!

Before I came to Bear Cottage, I worked for five years in adult acute care at St Vincent's Hospital. My experience has largely been in mental health, detox and psychogeriatrics and I was regularly allocated to the high risk, unstable and challenging patients who require individual nursing. Needing a career change, I applied for the job at Bear Cottage – and here I am!

When I tell people where I work now, their first response is universally one of concern about how sad it must be to be working with life-limited children but I tell them Bear Cottage is undoubtedly one of the most joyful places I know.

The real eye-opener for me is how positive and uplifting Bear Cottage is. Whether it is with the staff or many volunteers, even Beau our therapy dog. We see families and children who are going through a uniquely difficult time and when that long-lost smile returns to their faces during your



shift, it is the best feeling ever.

After nursing in a big hospital, what I most appreciate about working here is the time and energy I am able to commit to each child – it is almost a fluid environment, where we are not pressured to "get through" our tasks, where one-on-one time is valued, and every child is a priority. Their cares are complicated at times, but in between feeding, cleaning or dressing the kids, there's always time for a little play, some craft time, or a cuddle with a baby if you're lucky!

I've been a lot of things in my life; I'm a youth counsellor, a rugby player, a beekeeper, and now I'm proud I can say, I am a paediatric nurse at Bear Cottage. 🐾

Remembering our children

Caspian Aurova 11.04.19–14.06.19

Joshua Davis 7.12.10–21.06.19

Madeline Gladen 9.05.05–2.07.19

Jaxon Hands 7.06.13–2.07.19

Aiyana Cabanero 18.10.03–26.07.19

Jasmine Borg 25.06.05–26.07.19

Lacey McDaid 22.09.18–3.08.19

Zuha Tariq 19.11.07–3.08.19

Ellis Layfield 16.06.18–5.08.19

Adam Al Masri 24.01.06–12.08.19

Alisha Kapoor 5.03.13–8.08.19

Jai Bruynius-Greene 2.02.08–21.08.19

Rumaysa Syed 7.06.11–20.08.19

Ivar Nurcholis 18.09.17–29.08.19

Archer Robertson 26.08.16–1.09.19

House news



Superhero Week

Superhero Week has come and gone for another year with schools, pre-schools, individuals and organisations taking part – once again the event has grown, raising almost \$350,000 this year.

We have loved hearing from everyone who has taken part and it has been wonderful to see our Bear Cottage families getting their schools and workplaces involved.



Mackenzie Bennett, sister of Bear Cottage patient **Holly**, inspired her fellow schoolmates from **Rouse Hill Public School** to take part and raise \$2041.

Wakehurst Public School held a special Superhero event in memory of Bear Cottage patient and student **Joshua Davis** and raised \$4396. Our Bear Cottage volunteer reflexologist **Ann Jooste-Jacobs** organised for the residents at her mother's retirement village – **The Cotswolds** in Turrumurra – to get involved and together they raised \$1000. Finally huge thanks to parent **Krystell McArdle** who once again supported the event by getting Baker's Delight stores in Port Macquarie involved.

We also had tremendous support from long-time corporate supporters **John Holland** and **IMC** and for the eighth year in a row, our friends from **MCN** produced our TV commercial free of charge. This support is invaluable!

Thank you to all those Superheroes out there for really making a difference and to the **Garafalo** family who so generously agreed to help us promote the event. 🐾

Volunteer recognition

We all know how devoted our Bear Cottage volunteers are and we appreciate the outstanding contribution they make every day, but it is wonderful to see them receive acknowledgement in the wider community.

This year, all 133 of our Bear Cottage volunteers were entered into the Northern



Beaches NSW Volunteer of the Year Awards and to our delight, won in the category **"Volunteer Team – Northern Beaches"**. This award is testament to the dedication and commitment of all our volunteers who contribute in so many different ways.

As **James Griffin MP**, Member for Manly said, "volunteers form the fabric of our society" and this is certainly true of our volunteers without whom Bear Cottage would not be the warm and welcoming home away from home that it is. Congratulations! 🐾

Going to the ball

Our **A Bear Affair** Gala Ball was held in August and once again was a very successful night. We had 430 guests in attendance and this year's event raised over \$500,000.

Bear Cottage Goodwill Ambassador **Mike Baird** was our MC for the night and he did a wonderful job ensuring that everything ran smoothly. Mike has been a long-time supporter of Bear Cottage and tireless advocate for paediatric Palliative Care.

A Bear Affair takes months of planning and sourcing of prizes and we are extremely grateful to **Lesley Montgomery** and the other **A Bear Affair Committee** members for their tireless efforts.

We also send a huge thanks to our **Bear Cottage volunteers**. These volunteers already contribute so much in-house but they also sourced prizes for the event and volunteered on the night with setting up, packing down and hosting tables.

This event is certainly a team effort and we are so grateful to everyone who contributed to the evening's success! 🐾



Staff news

We have been very fortunate in the last few months to have **Dr Nicole Armitage** as our Staff Specialist. Nicole has worked at both Sydney Children's Hospital and The Children's Hospital at Westmead in Paediatric Palliative Care and brings with her a wealth of knowledge. Nicole is presently at Bear Cottage on Tuesdays and Thursdays.

Our Undergraduate AIN team has grown to include **Jess** and **Eleanor**. Both are studying Nursing at UTS and are very enthusiastic to take on these new roles and learn from those around them.

Nicola has joined our team of Housekeepers so look out for her on your next visit.

We welcome back **Liz** to the role of part-time Social Worker after the birth of her beautiful baby. Liz will be back at Bear Cottage on Thursdays and Fridays. 🐾



Nicole



Jess



Eleanor



Nicola



Liz

Calendar

Friday 11th October
Hats On for CPC Day

Saturday 12th October
World Hospice Day

Saturday 26-Sunday 27 October
Junior Sibling Camp

Friday 15-Sunday 17 November
Footprints in the Sand Camp

Sunday 8 December
Family Christmas Party

Sunday 22 December
Closed for Respite

Friday 27th December
Open for Respite