

# Cottage Capers

The Newsletter for Bear Cottage families



Winter 2019

## Welcome

Welcome to the Winter edition of **Cottage Capers**. We have had a very busy few months and a number of important days on our Bear Cottage calendar.

On Sunday 19th May, the annual **Bear Cottage Remembering Day Service** was held. Many families joined staff and volunteers at the **International College of Management Sydney** to remember the children who have visited Bear Cottage and since died over our 18 years of operation. The sun shone on this very special day and amongst the tears, there were also laughter and smiles as we remembered each unique baby, child and adolescent who has touched our lives. It was also a day to catch up with friends past and present members of the Bear Cottage family.



May 19th was also the first day of **Palliative Care Week** – a week to remember why we are all here and a week to highlight to the broader community, the need for paediatric palliative care. We took the opportunity to unveil our new **Garden of Remembrance**, with the centrepiece being a beautiful bronze sculpture. This is a wonderful tribute to all the children who have come through our doors over the past 18 years and all the children who will come in the future.

For two and a half years the **Bear Cottage Family Consumer Advisory Group**, consisting of parents (bereaved and non-bereaved) and staff, has been meeting quarterly to provide feedback which ensures that Bear Cottage is responsive to patient and carer needs and experiences. We value the input we receive from all Bear Cottage patients and families – our 'consumers' – because without it, we cannot possibly know if we are getting it right.

The Group has made valuable contributions such as the addition of physiotherapy support. We would love to have additional input from our present families and if you would like to get involved, please call me on 02 99768301 or email [narelle.martin@health.nsw.gov.au](mailto:narelle.martin@health.nsw.gov.au) for further information.

On behalf of the staff at Bear Cottage, we look forward to seeing you soon. ■

**Narelle Martin, Nursing Unit Manager**

## Garden of Remembrance

As our families, staff and volunteers joined together to celebrate the opening of our **Garden of Remembrance**, Bear Cottage mum, Shelly Clarkin spoke about the importance of having a place available for families to remember and reflect. We thank Shelly for her beautiful words . . .



*The Murchison family who kindly donated funds for the sculpture in memory of their daughter Mia*

*It is wonderful to be here today for the opening of the "Garden of Remembrance" and unveiling of the bronze statue.*

*I was lucky enough to be present for the pouring of the bronze a couple of months ago. I remember it had been raining for days and there had been a lift in the weather for that afternoon. I like to think it was holding off just for us.*

*The sunset was beautiful, but it wasn't until night filled the sky, that we could truly see the glow and vibrance of the bronze coming to life. It was remarkable – watching this boiling metal being (cautiously) poured into the casts – soon to be our statues. It reminded me of our Bear Cottage children – precious, pure and unique. Now in the darkness they shine brightly.*

*And here we are with this extraordinary gift for our extended Bear Cottage family. Initially, I wondered if these statues truly represented the children that are in, or have passed through these doors – and then I had another thought. They do! They symbolise the spirit within all our children – our babies, toddlers, tweens and young adults. The able-bodied and the disabled.*

*Many of our children were unable to stand tall – but their spirits do. This is a beautiful acknowledgment of their spirit and uniqueness.*

*Nature has the quality – more like a gift – of being able to ground, inspire, delight and heal when we connect with it. I hope that the Garden of Remembrance will be a special place for families in-house to have quiet time, get some fresh air and take in the beauty that surrounds us. And for bereaved families, to feel their angels are acknowledged.*

*As a parent who has lived grief and loss, Bear Cottage has become a place that holds our memories, some positive, some heartbreaking.*

*I know this area will be cherished and used and as a parent I thank you for not forgetting. Memories are like a bookmark to connect to our children.*

*Thank you for those who have donated money, contributed and looked after our children. With the opening of the Garden of Remembrance you have once again reminded us that we are family and will always be remembered. ■*



*Shelly Clarkin*

**We send our heartfelt thanks to the donors who made our Garden of Remembrance possible.**



## What matters most

**Lucy and her family have stayed at Bear Cottage for respite many times since their first visit in 2002. With 18 years of palliative care for Lucy to look back on and four other children keeping them busy, her parents Sara and Luke have kindly shared with us what really matters.**

Sara and Luke say it was devastating when their daughter Lucy was diagnosed with Aicardi seizure disorder at five months and given a life expectancy of a few years, but they decided Lucy's care would be their life's work. They were also compelled to have another child as soon as possible, to provide their firstborn, two-year-old Rose, with another playmate.

Lucy recently celebrated her 18th birthday - it's a bittersweet milestone for her and her parents, for Rose, now 20, and for the three children Sara and Luke had in quick succession - Sophie is 16, Jack, 14, and Max, 12.

*"We didn't know how long Lucy would survive, we really just wanted to make sure she had the best life possible," said Luke. "What really matters is that we surrounded Lucy with a noisy bunch of brothers and sisters and we all care for her with such compassion and love."*

*"I cannot describe the gratitude we feel towards Bear Cottage and the staff and volunteers who have supported us so kindly all these years," said Sara. "And I thank our ADAC case worker, Jenny who literally dragged me along because at the time I was deluded in thinking I could cope without any external support. However this is why I have managed to remain sane despite the physical and emotional toll of caring full-time for Lucy and our family."*

### Therapy matters

*"The palliative care we received at the beginning of Lucy's diagnosis focused on improving the quality of her life and relieving distressing symptoms. As the years went by, it was fabulous for Lucy to have access to the other therapies such as play and art and music that Bear Cottage offers, and for our other children to attend specially developed sibling camps. I've been to the Mum's Camps which are so blissfully pampering and memorable as we all shared such personal stories of pain and growth."*

Luke says the Dads' Camp he attended was fantastic. *"It began with an Art Therapy session that got everyone talking about similar issues and we could all relax. I know how much effort the staff put into organising these camps. The nurses at Bear Cottage always look after Lucy so well but they also take the time to keep an eye on how I'm getting on. Their care and concern for our whole family is priceless."*



### Support matters

*"In those early years, an impending visit to Bear Cottage really sustained me through the difficult hours, especially when Luke, a police officer, was working away from home. Bear Cottage had only just*

*opened and wasn't as busy as it is now, so I think we could visit up to six times a year for respite. It was such a relief to hand over the medical care of Lucy to the nurses and just have a family holiday. It was one of those things we thought we would never be able to enjoy because we can't cater for all of Lucy's needs anywhere else but Bear Cottage."*

As Luke says, *"The nurses don't wear uniforms so it creates a sort of resort feel. The stresses of cooking and housekeeping are removed so we don't have to think about what to have or make for each meal – we can all relax and spend quality time together."*

### Pragmatism matters

In addition to her positive thinking, Sara remains pragmatic to her core. She had neck surgery to repair several discs following a fall at work before starting her family, which she now describes as a bonus because it made her stronger and better equipped to handle all the heavy lifting required since Lucy was born. Likewise, she describes dark episodes questioning her life's path as lasting only seconds because that's – literally – all the time she had to waste before Lucy's next seizure would snap her out of the doldrums.

### Family ties matter

When Rose was two and Lucy about three months, Sara moved in with her parents as Luke was working hours away in Bourke.

Her mum and dad were both in their 70s and still working full-time. *"One afternoon the five o'clock feeding routine just overwhelmed me and I called mum to ask if she could leave work early to come and help me,"*

*said Sara. "Mum stayed home the next day and never went back to work, saying she had no idea what I had to do all day every day – the constant suctioning to clear her airways, the hours spent trying to get some food into her with a spoon before we were informed she had lost her ability to swallow and needed gastro feeds – it was such a relief to have mum helping me and I will be forever grateful."*



### Adaptability matters

Over a decade later, as their health declined, Sara and Luke invited her parents to live with them and so the Spurr home housed a family of nine! *"Dad had multiple myeloma and dementia and mum was riddled with crippling arthritis, and both needed a lot of care and attention," said Sara, "but they stayed with us until the end. Because we couldn't leave them to visit Bear Cottage, we adapted our routines – I'd visit Bear Cottage with Lucy and one or two of the children for three days of respite, then Luke stayed for a few days. It meant we could all have a break without unsettling mum and dad."*

The Spurr family's most recent stay with four of their five children has just come to an end. It has been a week of visits to the beach, morning walks and a chance to take in the ocean views and sea breezes. Lucy enjoyed art and music and the older children enjoyed activities with the other siblings staying at the Cottage and had some one on one time with their parents. All of them leave with their batteries re-charged and ready to face their busy lives with new energy.

It's no surprise to hear that eldest daughter Rose is now studying for a Bachelor of Science and Masters of Nursing. *"We are thrilled," said Luke and Sara. "Thrilled and proud and looking forward to seeing what the future holds for Lucy and for Sophie, Jack and Max! Now that Lucy is 18, our days at Bear Cottage are numbered as Lucy approaches her graduation, but we are thrilled that an adult version will be built on the old Manly Hospital site and we look forward to settling Lucy in to that new home away from home some time soon. Her future care, stability and comfort – that's what really matters!"* ■



## A work in progress

If you have visited Bear Cottage recently, you may have noticed some changes – not only with the installation of our new **Garden of Remembrance**, but also in the nearby soft play area. We now have the beginnings of a vibrant and interactive mural where all children, patients and siblings are invited to create something that will become a permanent part of Bear Cottage.

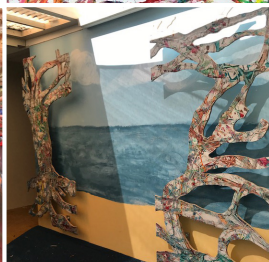
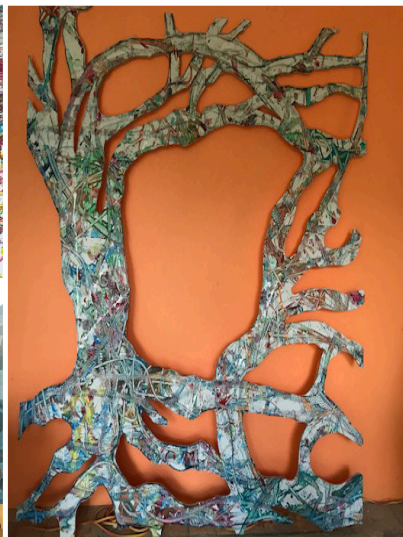
Art Therapist **Judy** started the process by holding a wheelchair art session which provides all children the opportunity to make their mark. Syringes were filled with brightly coloured paint which was then squirted across the patchwork of paper and marine ply timber placed on the garage floor.

The mixture of tyre tracks, trolley trails, footprints (and paw prints!) made for a colourful, tactile, sensory experience for all involved.

### The opportunity for all children to make their mark

Our Maintenance Manager **Brendon**, then took the timber and fashioned it into a tree which he hung from the wall. This formed the centrepiece of the mural and allows for other artworks to be clipped or hung from its branches.

Once the tree trunk and branches were in place, taking inspiration from Bear Cottage's beautiful seaside location, the children who



were staying with us at the time decided that the sky, ocean and sand would form the background of the mural. From there, the children used their creativity to add various sea creatures and beach-themed objects to the wall.

Although the mural looks amazing, it is by

no means finished and will continue to be a work in progress – collecting ideas, images and stories from the many children who will visit in the future.

Thank you to the **Dulux Trade Centre Chippendale** who very kindly donated the paint for our mural. ■

## Always remembered



**Footprints in the Sand** is Bear Cottage's Bereavement Programme and included in this is our annual **Remembering Day Service**. A day to formally remember the lives of the children who have died.

All those children whose lives we remember have left their mark and their legacy. This year our theme was 'stars', a fitting theme as every star is as individual and distinct as the children we care for.

Bear Cottag staff produced a video using starfish to represent the uniqueness of each child, the many things they teach us and the difference they make to the care we continue to provide – part of the amazing legacy that each and every one of your children has contributed to.

We invited families to write a message on a star and add it to the Bear Cottage constellation, demonstrating the way that our families are connected, not only in their grief, but also in the knowledge that their

children are continuing to make a difference for those who follow.

Two incredibly strong family members shared their stories and for this we are grateful. We acknowledge that it cannot be easy for them to share their story so honestly and openly, but other families have described these as very powerful and compassionate shared experiences.

Observing the way that families connect and support each other in this environment is beautiful to watch and is another demonstration of the connections that are made within the Bear Cottage family. Once you are part of our extended family, you remain connected as long as you wish. ■



**Footprints in the Sand**  
Bear Cottage's Bereavement Service

### The Star

**A light went out on earth for me**

**The day we said goodbye**

**And on that day a star was born**

**the brightest in the sky**

**Reaching through the darkness,**

**with its rays of purest white**

**Lighting up the Heavens,**

**as it once lit up my life**

**With beams of love to heal**

**The broken heart you left behind**

**Where always in my memory**

**Your lovely star will shine**

### Remembering our children

**Vincent Axel Gile**  
**29/03/08 – 24/03/19**

**Harmonie Martini**  
**22/01/05 – 8/04/19**

**Amelia Reichert**  
**23/02/16 – 2/05/19**

**Rabih Elarja**  
**13/07/12 – 19/04/19**

**Quinn Boyce**  
**19/09/18 – 9/04/19**



# House news

## Congratulations



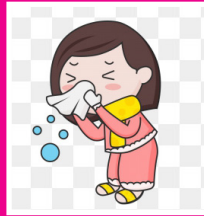
Many of you would be familiar with our very special volunteer, **Moya Martin**. Moya was recently awarded an OAM at Government House for her commitment

and dedication to Bear Cottage. Moya has been filling the halls with music every Wednesday afternoon for more than 15 years. Moya is quiet and unassuming and clearly loves coming along and entertaining the children. She has formed friendships with many over the years. We are fortunate that Moya and her husband Dr Frank Martin, have been long term supporters of Bear Cottage. Congratulations Moya! ■

## Winter woes

As winter is now upon us, we often find ourselves and our children, battling colds and the many different viruses that spread through our community at this time of year.

Please keep this in mind if you have a booking at Bear Cottage. We endeavour to keep Bear Cottage free from nasty bugs and the children in our care, safe. If any member of your family is unwell, please give us a call prior to your admission. Staff can clarify if it is suitable to go ahead with the admission or reschedule another booking. ■



# Staff news

Our team continues to grow at Bear Cottage and this month we have welcomed a number of new staff.

**Sharnie** and **Emma** have joined our Nursing team and bring with them different skills and experience, but most importantly, a passion to provide optimum care to the children they care for.

**Toby** has recently taken on the Business Manager role with gusto and is looking forward to ensuring Bear Cottage continues to flourish into the future.

Our Allied Health team has been joined by **Wendy** on a Sunday and Monday as Child Life Therapist and we are very happy to announce that **Amy** has taken on the role of Physiotherapist. Amy is at Bear Cottage two afternoons a week. We look forward to offering this new service to our Bear Cottage families whilst they are in residence.

We have also seen some changes in the office area with **Laura** moving in to Fundraising and **Wendy M** taking on the Administration Officer role.

It is very exciting seeing our team come together and we are very fortunate to have so much skill and expertise in each person's specific field.

Sadly, it has also been a time to say goodbye to a few wonderful people. **Kirsty**, one of our Housekeepers is taking a much needed rest and our Social Worker **Bianka** will also be moving on in her career in July.

Finally, **Dr Ksenia**, who has been our Paediatrician/Consultant for four years has decided to take some time out to spend with her young family. All three have contributed so much to Bear Cottage in their time here and will be greatly missed. ■



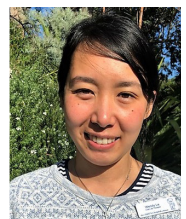
Sharnie



Emma



Toby



Wendy –  
Child Life Therapist



Amy



Laura



Ksenia

## A Bear Affair

**A Bear Affair** is our annual Gala Ball and will be held on **Saturday 24th of August** at the Hyatt Regency Sydney. Since the inaugural event in 2002, when volunteers and staff raised \$25,000, A Bear Affair has raised



more than \$5 million to support patients and families in our care. Tickets are on sale now and if you are interested in attending or donating a prize, please contact [laura.giles@bearcottage.org.au](mailto:laura.giles@bearcottage.org.au) or visit [www.abearaffair.org.au](http://www.abearaffair.org.au) ■



## It's time to 'get your cape on'

**Superhero Week** will be held from **28th July** until **3th of August** and there are lots of ways to get involved. Bear Cottage will hold it's annual **Superhero Launch Party** at Bear Cottage on **Sunday 28th July** and your invitation is enclosed with this newsletter.

We are asking you to get your schools, friends, families and workplace involved by holding a fundraising event. For more details on how to register, visit

[www.superheroweek.com](http://www.superheroweek.com) ■

## Local Superheroes

Huge thanks to **Martin** and his fantastic team from **MBarber** who are located in Darley Road, Manly. Not only are they longtime supporters of Bear Cottage – many of you may have had a "barber shop experience" whilst staying at Bear Cottage – but in true Superhero-style, MBarber have taken up the challenge and will be raising awareness and funds for Superhero Week. We would love to hear how you will be celebrating and please let us know if your schools or workplaces are taking part so that we can acknowledge them. ■



Bear Cottage Superheroes – the Garafalo family



The team from MBarber, Manly



2 Fairy Bower Road Manly NSW 2095  
PO BOX 2500 Manly NSW 1655  
Tel: (02) 9976 8300 Bookings: (02) 9976 8301 Fax: (02) 9976 8303  
[bearcottage.org.au](http://bearcottage.org.au)



The Sydney  
children's  
Hospitals Network  
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## Dates for the diary

**Superhero Week: 28 Jul-3 Aug**

**Junior Sibling Camp: 17-18 July**

**Mum's Camp: 1-5 September**

**Back to Bear Cottage BBQ: 7 September**