

Cottage Capers

The Newsletter for Bear Cottage families



Winter 2018



What matters most

'What Matters Most' was the theme of **National Palliative Care Week** which ran from the 20-25th May and Bear Cottage celebrated this important week in a number of ways. As the only children's hospice in NSW and one of only three in Australia, it was an opportunity to showcase the need and the work these fabulous facilities do in supporting children and their families.

We started our week of activities on Sunday 20th of May with our **Remembering Day Service** which is held each year to remember and celebrate the lives of the many children who have lost their individual battles. Many old and new faces attended the service and light lunch. Friendships were rekindled and the day was filled with both sadness and joy.

Throughout the rest of the week we took a 'high-vis' approach and celebrated the work of our Allied Health team, our volunteers and our staff. 'Palliative' and 'hospice' are two words that no one wants to hear, but we believe Bear Cottage can bring these two words together and bring happiness and hope to the children and families that we connect with.

The week finished off with an afternoon tea and visit from former **Premier Mike Baird**, our local member for Parliament, **James Griffin**, a Bear Cottage bereaved family, staff and volunteers who marked the spot in our garden where we hope to erect a permanent statue to remember all of the children who have passed through our doors.

As always, we look forward to seeing you in the upcoming months for what we know, is a much needed break. ■

Narelle Martin, Nursing Unit Manager

A chance to feel special

Bear Cottage's **Mum's Camp** provides an opportunity for our mums to take some time out just for them. They are able to stay at Bear Cottage with their sick child, safe in the knowledge that all medical needs will be taken care of and that it is OK for them to rest, relax, make friends and enjoy experiences that they may not otherwise be able to. To quote our mums, it gives them the chance to "*feel pampered and special*" and provides them with the space to be "*more than mum to a high needs kid*".

Recently six of our mums did just that and they enjoyed a variety of activities co-ordinated by nursing staff **Fiona** and **Megan**. The week started by getting back to nature with the mums enjoying a 'Flower Crown Workshop' and then designing and creating their own terrariums. It was then time for some pampering with facials, reflexology and 'Yoga Under the Stars'.

The Mums also had a chance to kick up their heels. Looking glamorous after their hair and make-up 'make-overs', they were then collected by limo and taken to dinner at the Glass Brasserie. This was then followed by a night at the theatre where they enjoyed the musical *Priscilla*.

Our Bear Cottage camps would not be possible without a number of generous donors and our Mums were incredibly grateful saying "*you further realise and appreciate the kindness of so many other people who are so happy to give their time and expertise to make us feel special.*"

Thank you to **Channel 9**, **Jill Cogan** from **The Natural Spa Therapist**, **Michelle Simpson** from **SugarArt** for her "Handbag Cake", Bear Cottage volunteers **Anne** and **Ann** for reflexology, **Yoga Under The Stars**, **Ivy Styling**, **The Boathouse Shelly Beach** and **Capitol Theatre**. ■





This July we will be once again celebrating Superhero Week. Each child and family that we care for show courage and bravery and are true superheroes. We thank the Brown family for sharing their story . . .

Family connections

Asking for and accepting help has never been something we've been comfortable with.

When our daughter, Erin (now 10) was born we knew eventually we'd need a bit of help. Erin suffered a fetal-maternal transfusion within the final hours of pregnancy, this means that most of her blood drained out of her body before birth.

Erin had a number of blood transfusions at birth but her brain was badly damaged as a result. Erin has cerebral palsy and we were told that with the amount of damage to her brain, it would be unlikely if she survived past her first birthday.

We first heard about Bear Cottage in the early days of Erin's life. Unfortunately our stubbornness prevented us from visiting or having any contact.

When Erin was 7 years old, her airways started collapsing and we were again given the heartbreaking diagnosis that Erin's condition would more than likely be fatal. After spending a long, hard and emotional 7 months locked up inside our house, to keep Erin at a stable air temperature we were at breaking point. We needed to open up and allow someone else to help us to care for Erin and to give us the opportunity to have a break and spend some much needed time with our son Denver (now 12).

I arranged for Erin, Denver and myself to spend a week at Bear Cottage and for my husband Darin to join us at the weekend. I didn't really know what to expect. I was amazed at how relaxed, comfortable and welcome we felt.

Denver enjoyed meeting other siblings, being involved with the music therapy, visiting the beach and spending quality time together. He was made to feel very welcome by all of the staff and volunteers and loved the attention he was receiving from everyone.

After the first few days, my husband asked me "Does it really feel like a break?" Yes it really did, so much more than expected. I was able to sleep in, go for walks, relax, do yoga and enjoy the good parts with Erin like cuddling and not having to worry about the day to day care of feeding, bathing etc. Darin joined us on the weekend and was able to relax and see for himself what I'd been telling him all week. At the end of our first week, honestly we didn't want to leave.

In the years following, we have been able to visit Bear Cottage as a family numerous times. I've attended a mum's camp where I was pampered, spoilt but most importantly I was able to meet some amazing mums and connect with them in a relaxed and fun way.

Denver has really embraced being a part of the Bear Cottage family. He has attended sibling camps where he was able to meet and bond with other siblings who 'just get it'.



Denver was inspired to approach his school and nominate Bear Cottage to raise awareness and funds. With the help of his teachers and the school community, the school held a Superhero Day where all the teachers and students dressed up as superheroes, had a teddy bear's picnic and held a raffle. Denver even contacted Arnott's Biscuits to see if they could donate Tiny Teddy Biscuits for the students to enjoy as part of their day. He was beyond excited when they agreed. The day went well and the school was able to raise almost \$2,000 to present to Bear Cottage.

Denver loved telling his friends and fellow students about Bear Cottage, what it is and why it is such an important place for families. As parents, we are so proud and happy that he has been able to fulfil his dream to give a little back to this place that has made him feel like he was a part of it.

Bear Cottage is an amazing place for families like ours. We've met many great people that we've been able to bond with, share stories and experiences with on our own terms knowing that we have all been through so much and all understand the feelings that we have experienced with our children's diagnosis.

Bear Cottage is not only caring and beneficial for the sick child, it is special to the entire family, and I can now see how important that is for all of us. ■ **Belinda, Bear Cottage Mum**



Time to get your cape on

Superhero Week will be held from **29th July until 4th of August** and there are lots of ways you can get involved. Bear Cottage will hold its annual **Superhero Launch Party** at Bear Cottage on **Sunday 29th July** and your invitation is enclosed with this newsletter.

You can also get your schools, friends, family and workplaces involved by registering to hold your own fundraising event. Details are on **www.superheroweek.com**

For the second year, we will also be holding an "adults-only" **Superhero Party** at the **Hotel Steyne** hosted by **Better Homes & Gardens Chef 'Fast Ed' Halmagyi**. Tickets are on sale at Eventbrite (just search Superhero Corporate Party). We hope you can join us! ■



All roads have led me to Bear Cottage

Our nursing staff have a variety of backgrounds and experience but their warmth and compassion is something they all have in common. Nurse Megan is one of our nurses who has had a very interesting career path.

My name is **Megan** I am proud to say I am a Registered Nurse here at Bear Cottage. I have been nursing for over 20 years, and in contrast to most of the Registered Nurses here, I came from the adult care setting having worked at RPA for most of my career as a Kidney Transplant Nurse Specialist.

For five years I had a break from hospital nursing and had an unbelievable opportunity working as a private nurse caring for only one patient in their home/home environment which took me on private jets, to country estates and bobbing around on super yachts all over the world (wow did I really do that!?). The experience I gained whilst doing this, in combination with my experience in the hospital caring for people with chronic and complex care needs (many who had transitioned from paediatric care), has helped me enormously working with the families at Bear Cottage.

As with renal nursing, what I love the most about my role here at Bear Cottage is really getting to know each child and their family. The 'home-like' environment, being able to chat to families over lunch and dinner, removes some of those barriers that exist in hospital and helps me to better understand the family's experiences, frustrations and triumphs.

Working with our Mum's **Boot Camp** and Dad's **Pit Stop** program has definitely been a highlight for me. Being witness to some of our parents having the opportunity to focus on themselves, even if just for a moment, and make positive changes for their own physical and mental wellbeing has been really wonderful. By caring for our parents and carers we are indirectly caring for our children and siblings.

Whilst we try as much as possible to meet the needs of our children and their families it can be challenging at times. The amazing



teamwork here at Bear Cottage, and when I say team, I mean staff, volunteers and most importantly our families themselves working together is what (I think) makes Bear Cottage shine. It is such a privilege to work here. ■



“The amazing teamwork here at Bear Cottage . . . is what makes Bear Cottage shine”.

Parent's corner

Music to remember

You may recognise **Jenny McGregor** as one of our regular Clown Doctor visitors however in her other life Jenny is a talented singer and songwriter. Jenny is also a bereaved parent and has recently released her first album entitled **Love and Let Go**. This album is specifically for bereaved parents and their families who have lost a child and whilst proceeds from the sale of the album will go to the Red Nose Charity, the album is free to all parents who have lost a child. There is more information about how to download the album on her website www.jennymcgregor.com.au ■



Time for a break

From time to time we are contacted by generous organisations wanting to donate to Bear Cottage. Recently we have had some family accommodation in the Byron Bay hinterland offered to Bear Cottage families for short stays. Visits would only be possible when there are vacancies and during times deemed suitable by the owners of the property. All arrangements would need to be made directly with the owners and all travel expenses would need to be incurred by the family. If you are interested in finding out more, please contact bronwen.simmons@health.nsw.gov.au ■

Remembering our children

Kai Boele
6/11/2000- 4/03/18

Zack Perram
5/01/16 – 6/03/18

Lucas Handwerker
7/11/18 – 12/03/18

Natasha Sljokic
8/11/08 – 21/03/18

Carys Bradshaw
4/02/10 – 6/04/18

Lucy Sargent
01/03/02- 10/04/18

Archie Bateman
27/11/15 – 2/05/18

Michael Murnane
13/10 2000 – 24/05/18

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

Isaac Bird
4/04/09 – 31/05/18

House news

Well deserved

We are all very proud of our Clinical Nurse Educator, **Fiona Niven**, who was recently



awarded the **Pride of Workmanship Community Award**. Fiona was nominated for the dedication she has shown to Bear Cottage since she began in 2002 as a Clinical Nurse Specialist in paediatric Palliative care.

In 2015 Fiona became our very first Clinical Nurse Educator and has been responsible for ensuring all staff have the confidence and expertise required to work in this specialised field. Her enthusiasm is immeasurable and she is a wonderful mentor and role model and works tirelessly to ensure Bear Cottage is a safe and caring workplace. Congratulations Fiona! ■

Remembering garden

One of our bereaved families – **Ryan and Karen Fowler** have set up a foundation in memory their son **Rio**. **Rio's Legacy** made their first donation of \$10,000 to Bear Cottage during Palliative Care Week. These

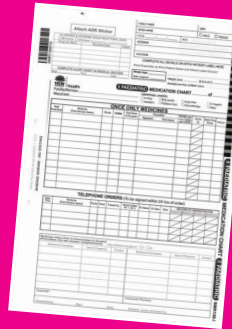


funds have been used to purchase a much needed state-of-the-art, fully automatic cot. In addition, part of the donation will also go towards the building of a bronze statue which will be placed in our Remembering Garden. This will provide a place where Bear Cottage can acknowledge the many children who have been in our care and provide a space for families to reflect and remember their child. ■



Admission paperwork

Several weeks prior to your stay at Bear Cottage, you will be mailed the admission paperwork relevant to your stay. This will include a Medication Chart.



The Medication Chart is a legal document and needs to be completed by either your Paediatrician or a GP who knows your child. Nursing staff cannot give medications that are not legally charted.

It is essential that we receive the completed paperwork either prior to your arrival or that you bring it with you on arrival. Please note that faxed Medication Charts will NOT be accepted. ■

Research news

As we mentioned in our previous newsletter. **Social Worker Liz** and **Nurse Philly** have recently been undertaking some research evaluating the use of Clifton Gardens, our special room. They would sincerely like to thank all the families that have been interviewed and watch this space for the results.

Additionally, the **Sydney Children's Hospitals Network** are undertaking a research study looking at the experience and adjustment of siblings of children with a life-limiting condition. Liz and Philly will be contacting you to see if you would like to participate but please feel free to contact us on 9976 8300 if you would like further information. ■



Winter woes

Bear Cottage provides a place of warmth, comfort and care during the colder months of winter. Unfortunately with the cold, comes coughs and runny noses. When we are healthy many of these bugs can be warded off, but for many of the children that stay, they are very harmful.

If you have a booking and your child or any family member is sick, please call the Nursing staff for advice about your stay. Thank you for your consideration. ■

Staff news

At Bear Cottage we try to ensure that every day is a fun day for the children staying. Our Allied Health team has welcomed **Emma** this month into the fold as our new **Child Life Therapist**.



Emma

Emma brings with her much enthusiasm and passion and is looking forward to meeting many new faces every Sunday and Monday.



Wendy

After many years at Bear Cottage we have said goodbye to **Wendy** and **Nicole**. Both have provided a high standard of nursing care to the children and been wonderful work colleagues. We wish them well in retirement and new work ventures.



Nicole

We have also farewelled our wonderful Housekeeper **Julie** and wish her all the best in her new role.



Julie

Many of you may know that our lovely **Social Worker Liz** is expecting her first baby at the beginning of September. Liz will commence her maternity leave in early August and we look forward to sharing her baby news in the next newsletter. ■



Liz



Calendar

Superhero Week

29 Jul-4 Aug

FITS Back to Bear Cottage BBQ

Sat 11 August

Junior Sibling Camp

11-12 August

Mum's Camp 2

9-13 September

Junior Sibling Camp

27-28 October