**November 2015**

With the weather warming up, we start to think about the Christmas break and the holidays. The January school holidays are traditionally a very busy time for Bear Cottage. We have been waiting for quite some time to start on much needed renovations at Bear Cottage and unfortunately, it looks as if this will impact summer and the school holiday period. We will try to accommodate as many families as possible, but as always is the case, emergency admissions will take precedent.

Bear Cottage has a wonderful Facebook page where we are able to spread the news on what’s been happening. It is a great way of communicating with our many families both past and present. Please note that it is a NSW Health policy that staff and volunteers do not form friendships with families on personal social media sites. We appreciate your understanding with this.

We hope to see many of our families at our much anticipated Family Christmas Party which will take place on **Sunday 13th December**. This should be a lovely day when we welcome back all of our Bear Cottage families both past and present. The staff and volunteers look forward to the opportunity to catch up with many familiar faces, celebrate the holidays and share memories.

*Narelle Martin, Nursing Unit Manager*

“Maybe Christmas,” the Grinch thought, “doesn’t come from a store. What if Christmas, perhaps, meant a little bit more?”

-Dr. Seuss
Our family story

About ten years ago I was teaching at a primary school in Western Sydney. The students were asked to make a gold coin donation to a little place called, “Bear Cottage”. I asked myself, “What is Bear Cottage? Where is this cottage and why do they need donations?” I was so perplexed as to what the link was between our school and Bear Cottage.

Little did I know ten years ago that this Cottage would become the oasis that welcomes families like mine into its warm embrace in the time when it’s needed most.

Three years ago, we eagerly awaited the arrival of our first child. Like many parents, we went about our day to day activities, thinking we still had several months to go until our baby arrived. We were wrong. The day came when the path we were on took a whole different direction and we arrived in a foreign destination to where we had planned. Emily Perl Kingsley described it best in her story “Welcome to Holland” http://www.our-kids.org/archives/Holland.html where she spoke about her experience of raising a child with a disability.

Daniel was delivered at 27 weeks gestation weighing 595 grams. His name seemed to be appropriately chosen as 18 days later, weighing 450 grams, Daniel fought with the lions on the surgical table. He had developed an infection in his small intestines that meant 80% of necrotized tissue was removed. He didn’t have enough intestines remaining to survive on oral feeds alone. Since that day, Daniel has received the nutrition he needs to survive, a pharmacy made formula Total Parenteral Nutrition (TPN), through an IV central line.

“But . . . if you spend your life mourning the fact that you didn’t get to Italy, you may never be free to enjoy the very special, the very lovely things . . . about Holland.”

Emily Perl Kingsley

It took a long time, but after 15 months in hospital we were able to take our baby home for the first time on TPN. The elation of being at home soon changed when we started to adjust to all the responsibilities of a child with complex medical needs. Days and weeks filled with appointments, multiple ED visits and re-admissions. When was I going to actually stop and start to learn to love being in Holland?

It was the day that I arrived at Bear Cottage. From that moment on, I have never felt so much a part of a very special community. A group of people, parents and carers, nurses, doctors, social workers, play therapists, administration staff, maintenance, chefs, housekeeping, the multitude of amazing volunteers and the best four-legged fur friend. Each and everyone welcomed us into that community. I didn’t feel so alone any more in my new destination. I found new friends that understood our thoughts, fears and feelings, without the need for words.

I finally got to stop being the carer and became the parent. I was able to enjoy the company of my child. I also had the opportunity to really reflect on who I now was. First and foremost, I am a mother to a very special boy that I am so proud to call my son. Second, although I’ll always be a teacher at heart, I’ve recently decided to change career paths to enrol in TAFE and become a florist. It is because of Bear Cottage and participating in the Mum’s Boot Camp that I took this step.

I did question if I could do this with a child with special medical needs, but I am very lucky to have an amazingly supportive family.

It has been the best decision as now I am both literally and metaphorically surrounded by the most beautiful flowers you can imagine. The people I have met at Bear Cottage are like the sweet smell of lilies, the softness of peony rose petals, the bright colours of gerberas and the warmth that sunflowers need to grow. All unique yet full of their own special qualities sitting in one vase together.

And so, on our last visit to Bear Cottage a mum asked me what my favourite flower was? I didn’t know at first and thought about it long and hard because I love all flowers, but you know what I finally did answer her?

A tulip.

Ann-Marie (Daniel’s mum)

If you would like to share your family’s story for use in our newsletter or other marketing material, we would love to hear from you. Please contact: bronwen.simmons@health.nsw.gov.au

Staff news

We are fortunate to be able to offer Assistant in Nursing positions to Undergraduate Nursing students. Recently, Alana and Anna joined our team and bring with them enthusiasm and an eagerness to learn and meet our families.

Vanessa has joined our team as Music Therapist whilst Phoebe is enjoying the new addition to her family, baby Charlie.

Sadly after 13 years of nursing, Lucy has said goodbye to spend more time with her family and Tryphyna, our very talented Art Therapist, has set off for a tree change on the north coast.
Sail away

Seven of our older siblings recently took a trip out on the harbour on the John Louis - the last sail-rigged working craft built in Australia specifically for pearling.

The trip was organised for us by The Australian National Maritime Museum and our four hosts ensured everyone had a magical morning on Sydney Harbour.

The morning was complete with a historical commentary, a beautiful morning tea and ample time to chat, whilst sitting in perfect, albeit cloudy, weather.

The siblings absolutely loved the experience and left requesting more frequent catch ups!

A big thank you to the parents for helping things run so smoothly and to the amazing staff at The Australian National Maritime Museum who are always so generous and creative when donating their services.

Parent’s corner

Transition from Bear Cottage

Gaby is one of our former Bear Cottage patients and she has recently turned 20. She and her family have come to Bear Cottage since she was a little girl after being diagnosed as a baby with her complex life threatening metabolic condition. Once Gaby turned 19 she was no longer able to access our hospice and Gaby is currently living in a high level support unit staffed by Registered Nurses and run by Ageing, Disability and Home Care. Her mum Seanne is happy to share her experience to help other young people (YP) and their families navigate the Health System.

Mum Seanne says that as a parent she was worried and anxious as the time approached that Gaby would no longer be able to access Paediatric Specialists and services.

The thought of transitioning from these long-term relationships to a new team of strangers was daunting. She wondered how anyone else would understand her daughter and her family’s commitment to care, the same way the paediatric team had done. She also worried about the ‘safety net’ of Bear Cottage no longer being available.

Looking back now, Seanne says that it was as much about ‘letting go’ and moving forward as it was about the processes involved.

Seanne’s first tip is to find a good GP who takes a holistic approach and is willing to care for a young person with a complex medical condition. Many families become very comfortable and reliant under the umbrella of their paediatric teams who are nurturing and co-ordinate many aspects of care. There is usually not an equivalent service in the adult world.

Gaby was also referred to the Agency of Clinical Innovation’s (ACI) transition service. They have co-ordinators who specialise in the process of transition. The family found that the ACI co-ordinator’s wealth of experience was invaluable. They were able to discuss the options available e.g. independent physio with disability expertise; different Specialists with interests in YP and disability. They also needed to access some private clinics as there were no equivalent eye or dental clinics in the adult system. They made sure that they did not miss anything e.g. who would now change Gaby’s gastrostomy.

Seanne is a great advocate for Gaby and they can be seen on the recently launched Trapeze Website discussing transition in a short video (http://www.trapeze.org.au/stories/gaby-and-her-mum-seanne).

Trapeze is the SCHN Transition Service and they help facilitate young people with chronic illness transition to the adult health system. Trapeze work closely with ACI by gathering information from paediatric services and remain in contact with the YP and family until they turn 25. Trapeze will also help find a good GP.

Both agencies will help ensure that there is an Emergency Patient Management Plan in place at the local hospital so that if she presents to the Emergency Department her complex care needs and wishes are clear. All children who have ever accessed Bear Cottage are able to be referred to Trapeze.
Makeover magic

For those of you who have visited recently, you will have noticed that we have had our ‘Games Room’ renovated. This space was given a bright and colourful facelift by our generous supporters from Accor Hotels.

General Managers from a number of the Sydney hotels, as well as other Accor staff, spent the day sanding, painting and decorating the room. We are thrilled with the result, as were our kids who quickly made themselves at home.

The Accor team have also provided accommodation at various times for some of our parents and our Sibling Camps – no request is ever too much – and this incredible generosity is sincerely appreciated by all of us. ■

A Bear Affair

This year’s A Bear Affair ball was our biggest fundraiser ever with $535,000 being raised. It was a wonderful evening with “Fast Ed” Halmagyi once again hosting and one of our dads, Richard Martyr speaking on behalf of our families. Planning has now started for ABA 2016. ■

Superhero Week

This event has also gone from strength to strength raising $180,000 this year! Once again pre-schools and schools from around Australia have taken part, as well as a number of corporate groups such as IMC and MediaCorp. Next year we hope to grow this event in the corporate sector. If your workplace would like to be involved, stay tuned for more information. ■

Making music

Whilst our wonderful Phoebe is off on maternity leave, we are very lucky to have the talented Vanessa taking over for the next 12 months. Vanessa studied at the Sydney Conservatorium where she completed a Bachelor of Music (Honours) and a Masters of Music (Performance) and most recently, a Masters of Music Therapy at the University of Melbourne.

She has toured extensively as Principal Flautist and Piccolo with numerous orchestras throughout China, Germany, the Czech Republic, Italy and The Netherlands. Vanessa has also toured and performed nationally with chamber ensembles and the Sydney Symphony Orchestra.

In 2013 whilst Vanessa was studying music therapy, she completed a clinical at Bear Cottage where she met Phoebe. It was then that Vanessa’s interest in paediatric palliative care took off and she later went on to complete a thesis focussing on paediatric palliative care in which she received first class honours.

Vanessa’s music therapy experiences include working with children in special school settings, adolescent mental health and children in hospital, as well as currently being head of the music therapy program at the Central Coast Conservatorium.

Vanessa feels very lucky to be working as the music therapist at Bear Cottage and thoroughly enjoys working with children, their siblings and families in such a supportive and nurturing environment. ■

Volunteer success

We all think our volunteers are irreplaceable but it is lovely when others recognise their achievements.

Joe Staniuch was recently awarded the ‘Palliative Care NSW Volunteers Supporting Palliative Care Award 2015’ which was presented to him at Parliament house by the Hon. Jillian Skinner.

In her speech Minister Skinner recognised the talented, generous and selfless work he has done for Bear Cottage. Joe has donated thousands of hours of service and is irreplaceable to Bear Cottage.

Judy Lavery has also been recognised for two volunteer awards. She was finalist in the NSW Volunteer of the Year Award (North) and was the winner of the Volunteer of the Year Award for Sydney Children’s Hospital Network.

Judy has worked tirelessly both at Bear Cottage and also represents us at fundraising events, sells raffle tickets, helps out at our annual Bear Affair gala and has even stomped grapes!

Marieke Jongerius was recently presented with an award for ‘Outstanding Volunteer 2015 Manly Council’ by Mayor Jean Hay.

Marieke, a talented photographer, volunteers her time to help families with memory making. Her stunning photos are treasured by our families. We are grateful to Marieke for helping families cope with their grief by creating such precious memories. ■

Christmas cards for sale

Our Bear Cottage Christmas cards are once again for sale. To order, please contact emma.pike@health.nsw.gov.au ■