

# Cottage Capers

The Newsletter for Bear Cottage families



September 2016

Thank you to the Superhero Week participants from all over NSW who supported our special event!



Staff and family from IMC Financial raising funds on the Manly Ferry



Fiona Reid from Reid Family Lawyers



Yeppoon Kindergarten



One of our very special Bear Cottage Superheroes



Bendigo Bank, Port Macquarie



The Parmy Army, Greystanes Hotel

## House news

It is great to see the days becoming longer and warmer and an end in sight to the capital works. Bear Cottage is now open to full occupancy despite finishing touches to the inside and work continuing on the outside. The September/October school holidays will see the Cottage at capacity but there is still respite available from mid October. If you would like to come along and have a much needed break, please call on **02 99768301** or email **narelle.martin@health.nsw.gov.au**

Bear Cottage will be closed for booked respite admissions from the 23rd December and will reopen on the 28th December.

Our **Family Support Team** have been very busy organising activities for all in the upcoming months. Two **Junior Sibling Camps** will be held at Bear Cottage for our 8-12 year old group whilst some of our older siblings will be off to the Gold Coast. There is a **Back to Bear Cottage BBQ** for our Bereaved families and the first of our wellbeing programs for dads, **PitStop**, will get underway in October. If you, or someone in your family would like to be involved in these activities in the future, please do not hesitate to contact us.

Bookings are now open for the **Dad's Camp** being held from 10-14 November. If you haven't been before, it is a great opportunity to meet others in similar circumstances whilst enjoying some fabulous activities.

Congratulations to our Clinical Nurse Specialist **Philly** who was a finalist in the **NSW Health Excellence in Nursing Awards**. Philly was nominated in the Consumer Appreciation category for her passion and dedication to the children and families who visit Bear Cottage. We are all very proud of what she has achieved.



As summer approaches we look forward to catching up with you soon. ■





# My family story by Ethan Hannay

Our journey to Bear Cottage began 15 years ago when my partner Lynne and I received the news that we were soon to become parents. The news was unexpected, but we were very excited and optimistic as to what the future would hold for our new family.

After a somewhat problematic pregnancy, our daughter was born with minimal complications, and was deemed by the attending paediatrician to be "small but perfect", we named her Isabella.

Unfortunately, all too soon it became obvious that this was not the case. By the age of one Isabella could be described as suffering from a global developmental delay, but the magnitude of her disability was still unknown. By two, it was becoming apparent just how profound her intellectual and physical disability was, and the implications this would have for her in the future. The realisation of the severity of Isabella's disability coincided with the birth of our son Caius. The next few years saw Isabella also develop a multitude of chronic illnesses that compromised her health extensively. After all the available testing had been exhausted, with little to no result, we were told that it was unlikely that they would ever find a unifying diagnosis. There would be no name to give to Isabella's disability, nothing to help explain her many conditions, but she could be considered to have a life limiting illness and it would be unlikely that Isabella would live into adulthood.

**"We felt like we were in paradise."**

Although this prognosis was distressing, after years spent in and out of hospitals with illnesses, it would be this prognosis that would ultimately enable us to access services that were previously unavailable to us. One of these services was Bear Cottage.

When we were first told about Bear Cottage my initial response was pessimistic. I thought, do we really want to spend our family time in a hospice for sick children? After all the time we had spent in hospital wards the thought of more of the same was less than appealing. We had been offered respite options before, but they all involved relinquishing the care of your child and leaving them to be cared for by strangers – something neither Lynne nor I were comfortable with. That Bear Cottage offered the option for all of us to stay with Isabella, whilst having the freedom to catch up on some much needed rest and family time, was certainly more appealing.

Ultimately I have my beautiful partner Lynne to thank for not allowing my pessimism to get in the way of what would turn out to be a fantastic opportunity. Lynne wanted to give it a try, and after six years of her tirelessly caring for Isabella, I knew it would be the very least I could do to support her.

The day we first walked into Bear Cottage it didn't take me long to realise that this place was very different to what I had been expecting. My preconceptions quickly dissolved as we were warmly welcomed upon arrival and shown to a lovely bedroom where Isabella would be staying. The rooms for the children are fully equipped with all the facilities you would find in a hospital, but that is where the similarity ends.

We were told that three meals a day were provided, but at dinner that night we were amazed to find ourselves seated at a large communal table sharing a home cooked meal with other families

and staff. It felt more like we had been welcomed into a large extended family than to a respite hospice. Anyone who has ever eaten a hospital meal will appreciate how stark the contrast is. We felt like we were in paradise.

The nursing staff at Bear Cottage are some of the most dedicated professionals you are ever likely to find. It has been my experience that continuity of care is paramount,

particularly where children are concerned, and after eight years of attending the facility we have formed such strong bonds with long term staff that there is nowhere else we could ever feel more comfortable to have Isabella cared for. The significance of this familiarity is more than evident in Isabella's response to staff



members and in the cheeky smiles she gives them.

One aspect that particularly impresses me is that very few of these facilities are exclusively for the use of the patients, the ethos of Bear Cottage being inclusiveness for the whole family.

For our son Caius, who had spent much of his early life in hospital wards and waiting rooms and as the sibling of a sick child he rarely found himself the focus of attention. I believe that this inclusiveness has been life changing.

I strongly believe that Caius's experience of having a sibling with a life limiting illness has contributed to him becoming the amazingly compassionate, thoughtful and humble young man he is today. I also believe that his experiences at Bear Cottage have helped to alleviate much of the inequity he would otherwise have suffered growing up in the shadow of his sister's illness.

Special weekend camps for siblings are hosted by Bear Cottage. The friendships forged at these events are truly unique given the obvious, mostly unspoken camaraderie between the siblings. They are deservedly pampered and spoilt and generally have a whole lot of fun.

There are also events timed around Father's Day and Mother's Day, to give mums and dads the opportunity to meet and network with other people with similar circumstances. The activities that are provided could be anything from diving with sharks, a meal at a restaurant, a show at a comedy club, or even synchronised swimming. I've attended seven of these dads' camps and the friends I have made and the memories of these events will stay with me for the rest of my life.

Bear Cottage has offered support to our family through several traumatic events in Isabella's life, such as supplying an alternative to long term hospitalisation after episodes of severe illness and a place of transition between hospital and home after undergoing orthopaedic surgery.



**"The passing of any child is an undeniable tragedy, but every other moment is a gift."**

Accessing Bear Cottage for respite helped to improve our circumstances so dramatically that we found ourselves able to make the formidable decision to have a third child. Our second son Owynn has known little of the adversity we suffered as a family during Isabella and Caius's early childhood. For Owynn, Bear Cottage is a bonus, a place full of fun and friendly faces, that has been to him a home away from home for his whole life.

My greatest fear in our early days of attending Bear Cottage was that I would be incapable of coping emotionally when the children we had got to know whilst staying would pass away. The first time this occurred, although indescribably sad, allowed me a remarkable insight. I realised that within the amazing place that is Bear Cottage the focus is never death, but instead a celebration of life. There is no greater privilege than to share in and celebrate the life of any one of the many inspirational children and families that I have encountered there. The passing of any child is an undeniable tragedy, but every other moment is a gift. ■



## A grand time

*Bear Cottage recently held its very first camp for Grandparents. Grandparents play a special and significant part in their grandchild's life and they are deeply affected by the impact that a sick grandchild has on their entire family. We wanted to provide the opportunity for this special group to form friendships and gain support from others who have shared this experience. Gail and Pat Rafferty were kind enough to share their experience of the camp.*

We first became involved with Bear Cottage through our grandson Aidan, who was diagnosed with a rare mitochondrial disease.

Aidan loved to go to Bear Cottage, he loved the staff, the games and music they played – he fancied himself as a musician and dancer. We went to Bear Cottage on one of Aidan's earlier visits but it was not until Aidan's final day that we realised what a unique place the Cottage was. The staff are very caring people, without them our final goodbye to Aidan would not have been so special. THANK YOU!

After Aidan's passing we struggled so much. Aidan is never far from our minds and little things, like his favourite song or a word he would have used would trigger an emotional downer. For the six years of Aidan's life, we were on this roller coaster of up and downs and then there was an emptiness that nothing will ever fill.

When we were invited to go to a grandparents' camp we were unsure about going but we found the experience not only enjoyable but very helpful.



**“ . . . talking won't fix your pain but it helps.”**

On Friday night we were met by the wonderful staff from Bear Cottage who made us feel so welcome right from the start. After settling into our wonderful accommodation we all met for dinner where the staff mixed with us to help break the ice with the other grandparents.

The next morning they had arranged breakfast for us but allowed us to work it between ourselves which helped us to mix with the other grandparents. After breakfast we got together as a group for a therapy session. At all times over the weekend there was never any pressure to get involved, you could say as little or as much as you wanted and the staff made you feel at ease. After the group session we went on a tour of the Quarantine Station, which is where we were staying, then had a foot massage.

That night, only the grandparents went to dinner and by this stage we were feeling very comfortable with each other. On Sunday morning we had a drum lesson which was a lot of fun, followed by some more discussions and group photos.

After we got home, we discussed what a wonderful weekend it was but it wasn't until a few days had passed when we both agreed that somehow we felt an inner peace and a little better.

The thing about meeting and talking with other grandparents is that you have someone to talk to who is going through, or has gone through, the same thing as you are and understands your pain and feelings. Talking won't fix your pain but it helps. ■

***We would like to thank the Q Station for their generous support providing beautiful accommodation, facilities and extraordinary meals for our grandparents.***

## Remembering our Children

**Murray Cunningham**

10.11.10 – 5.06.16

**Anthony Portelli**

15.03.05 – 12.06.16

**Jai Robertson**

16.01.12- 13.06.16

**Massimo Mencio**

28.07.14 – 22.06.16

**Elizabeth Payne**

28.10.99 – 9.07.16

**Malakye Davison**

21.08.04 – 16.08.16

**Martin Hillawi**

21.05.08 – 17.08.16

**Amok Mawein**

29.09.06 – 22.08.16

**Charles Petersen**

28.07.16 – 22.08.16

**Abdul San**

8.06.15 – 23.08.16

## Parents' corner

### Brainwave

At Bear Cottage, we support many children who have neurological conditions and we are always keen to share information about resources and services that may help to reduce the impact of paediatric neurological conditions on children and their families that we care for.

Brainwave aims to provide practical assistance and emotional support to children with neurological conditions as well as their families and carers to positively impact their quality of life. Brainwave also provides financial assistance for funerals.

Registration is simple and online: <https://brainwave.org.au/brainwave-registration/>.

Once registered you will receive invitations to all free family events, a monthly newsletter and you are eligible for the Brainwave funding program for equipment and therapies. All information provided is treated as confidential.

For more information contact <https://brainwave.org.au/> ■



### Wi-Fi at Bear Cottage!

To access Wi-Fi internet at Bear Cottage, simply go to settings, select Wi-Fi and choose NSW-Health-Guest-CHW from the networks available. You will then be asked to register as either a 'first time user' or 'existing user'.

First time users will need to enter their city, postcode, email address, password and mobile number.

You will initially get a 15 minutes free access period.

This can be extended to 90 days by going to your email and activating your account through the link that has been sent. ■





## Lasting friendships

*For many of our young adult siblings, the friendships they have formed with other siblings through attending Camps and other activities, continue to flourish. Many keep in touch and enjoy the opportunity to catch up when they can. **Renee** is one such sibling for whom these friendships have been invaluable.*

Since its inaugural year, I have participated in Sibling Camps. As a short weekend away, these camps have provided the opportunity for me to engage in a number of activities and share stories with other young people. They have included visits to places such as the Opera House, Centre Point Tower, Shark Island and the Q Station. Each camp was always well organized by Bear Cottage staff and assisted by a supportive group of volunteers.

I became involved with Bear Cottage in 2008 when my brother Adam first started to receive respite. Prior to the camps commencing I used to relax in the chill out spaces such as the games room and quiet room. Bear Cottage has always provided a number of great services to support families and the Sibling Camps were an extension of this. I am incredibly thankful for the encouragement, care and generosity the staff at Bear Cottage have given me, and continue to offer. I would highly recommend these camps to other young people. In 2014 I graduated from High School and attended my last camp, however, the support did not end there. Moving on from the Sibling Camp program, Bear Cottage have organised annual dinners for young adults who are over the age of 18. These dinners enable our small network of friends to keep in touch as we undertake new and exciting endeavours.

I would like to extend my appreciation to all the staff and volunteers who make these occasions possible. I have thoroughly enjoyed each and every experience and look forward to seeing what the future holds. ■

**Siblings that are over 18 years of age are welcome to join the Young Adults Group. For more information visit Bear Cottage Siblings on Facebook.**

## Fundraising news

### A Bear Affair



Our **A Bear Affair Gala Ball** was held at the Four Points on Sheraton, Darling Harbour with over 400 guests

attending. This sparkling night was a huge success and we are on track to raise over \$500,000. The generosity of all who attended, sponsored and donated was greatly appreciated.

We were also honoured to be joined at this event by Bear Cottage parents **Ethan** and **Lynne**. Ethan was kind enough to share his family's experience of Bear Cottage with their beloved daughter, Isabella and you can read his speech from the night on page 2 of the newsletter. ■

### Superhero Week

We also celebrated our 5th annual Superhero Week and we have been thrilled with the result. With funds still coming in, this event will raise over \$200,000. It has been inspiring to hear how so many people have taken this event to heart. Special thanks to **IMC Financial**, **Westpac Group Tech**, **Tim Parmenter** and the **Greystanes Hotel** team and **Krystell McCardell** for their outstanding efforts. Thank you also to **ICMS** and everyone who donated their time and resources for our Superhero Week Launch Party. It was wonderful seeing so many of you (in costume) at this event! ■



### A Bloody Long Walk!

Congratulations to **Karen** and **Craig Crawley** who participated in **"The Bloody Long Walk"** to raise funds for Bear Cottage. This 35km walk from Palm Beach to Manly is no small feat but it was made more difficult by the fact that they were wearing Winnie the Pooh onesies!! In their words, the effort was worth it as they felt that Bear Cottage had allowed them to take a well deserved break for the first time in nine years from the "nightmare of an illness" suffered by their daughter Kara. Thank you Karen and Craig for this wonderful effort! ■



## Staff news



Recently our lovely nurse **Helen** retired after 12 years of nursing service to Bear Cottage. Aside from being a very passionate nurse, Helen has

been instrumental in organising our beautiful photo wall along with our Remembering Day Service over the years. Helen won't be a stranger as she plans to return as a very valuable volunteer.

Other nursing changes will see nurse **Emma** leaving us to welcome the arrival of baby number two, whilst **Naomi** is returning after



the birth of Caleb. We will also be welcoming **Hayley** to the nursing ranks in the next few weeks.



Bear Cottage is a hard place to leave and we are very happy to have **Claire** return to us as our Fundraising Manager. Claire was in this role

previously for 12 months as a maternity leave position and was also a volunteer for a number of years. Claire will be joined in the office space by a new face. **Jane** is taking on the role of Administration Assistant. A very much needed and long-awaited role for Bear Cottage.

Welcome to the team Hayley, Claire and Jane! ■



## Calendar

Wed 19th October  
**Bereavement morning tea**

October 30

**Mini-Golf Day** (see details enclosed)

November 5-6

**Junior Sibling Camp**

November 10-14

**Dads' Camp**

December 11th

**Christmas Party**