

# Cottage Capers

The newsletter for Bear Cottage families



Spring 2020

## Welcome

It has been a busy few months for Bear Cottage as we get accustomed to the changes and challenges that 2020 has brought with it.

Fortunately Bear Cottage is now available for booked respite and that much needed family break.

Due to COVID-19 restrictions, we have had to make some changes in the number of people staying at the Cottage at any time and only immediate family members will be permitted to stay or visit.

We have also had to reduce the number of children staying in the interests of everyone's health and safety.

Sadly, most **Family Support** programs are still on hold and we will let you know when this changes.

We have had some great news with the completion and opening of our long-awaited pathway to the beach.

A chairlift has also been installed on the back stairs to make access to the path possible.

You will read more about the pathway in this newsletter and I would like to acknowledge and thank the many people who have made this possible.

We are looking forward to warmer weather, loads of sunshine and of course, catching up with our Bear Cottage families soon.

**Narelle Martin**  
Acting Nurse Manager

## Pathway to the beach

It has been 18 years in the making but our pathway to the beach has finally been completed. It has been a long-held dream of many to be able to provide a wheelchair-accessible path that would allow children and families easy access to the beach nearby.

It was back in 2002 when the **Tony McCullough Foundation** first donated funds to be used for a wheelchair ramp to be built in the back garden of Bear Cottage. As long-time supporters, the Foundation has championed this project from the start and contributed substantial funds to ensure it would become a reality.

Unfortunately, building the ramp did not prove an easy prospect and it could not be built as first planned.

Over many years, Bear Cottage (with our two previous Business Managers **Matt** and **Roy** leading the charge) and a determined group of supporters, have endeavoured to find alternate routes and navigated many obstacles to try to get the project approved and completed.

Working with the Sydney Catholic Archdiocese and local architect **Vivianne Marston** (wife of one of our Bear Cottage volunteers), an alternate pathway through the St Patrick's Estate was designed. There was further opposition and approvals needed from the Heritage Council, Lands and Environment Court and Local Council and finally – just as consent for the pathway was granted in February 2020 – we were hit by a global pandemic. A minor hitch in comparison to all that had gone before!

With the project now much bigger than first anticipated, our friends from **John Holland Group CPB Ghella** offered their expertise and took over the project management and construction –



calling on a number of their contractors and suppliers to also donate their services. Whilst our pathway is small in comparison to many other John Holland projects, this one has certainly been closest to their hearts!

On the 17th of September we were delighted to finally be able to hold our path 'Opening Ceremony', which was a wonderful opportunity to thank the many donors and supporters who have been involved along the way.

It was also a chance for Bear Cottage mum **Jennifer Brankin** to share her heartfelt words about what this pathway will mean to our children and families and the importance of equity of access.

Our pathway will be affectionately known as **"McCullough Way"** and we look forward to our children and their families being able to enjoy the freedom that this path will provide. 🐾

*Former Business Managers Matt and Roy (who was unable to join us from Adelaide but was there in spirit and on Facetime) with Narelle.*



*Kerrie McCullough cutting the ribbon, accompanied by Jennifer and Alexander Brankin.*







## Online reflections

At Bear Cottage we are always trying to find new and creative ways to stay connected with our Bear Cottage children and families and surprisingly, COVID-19 has provided the impetus we needed to fully embrace technology!

In April this year, not long after the shock of home schooling and increased lockdown measures were in place, we invited families to sign up for some virtual volunteer support. We thought, if families couldn't come to Bear Cottage, our volunteers would take Bear Cottage to them – offering a little extra help keeping children entertained or on task with their home schooling schedules.

Whilst this has tapered off in recent weeks, we still have a few volunteers working with families. Bear Cottage volunteer **Sarah** has been supporting patient **Ashleigh** – a sociable 14 year old who really enjoys interacting with other people. Due to COVID-19 restrictions, Ashleigh's regular Saturday program was put on hold, leaving a real hole in her social life.

Sarah shared her experience working with Ashleigh and Ashleigh's mum **Jo-Anne** spoke about the positive and beneficial experience that this has provided.



**Sarah:** "Smiles and stories are two words that capture my recent experiences providing virtual volunteer support with Bear Cottage. After the traditional "getting to know you" via Zoom and the eHealth conferencing platform, I have been enjoying regular fortnightly online 'visits' with Ashleigh and her mother Jo-Anne since April. The share-screen features enable me to connect with Ashleigh by showing her related videos, music or

pictures to our focus story, the childhood classic, "Five On A Treasure Island" by Enid Blyton. Ashleigh has loved the adventurous antics and the book's superhero dog, Tim. The sound of the boats on the water has also been a relaxing element for her."



**Jo-Anne:** "Sarah is wonderful, entertaining Ashleigh with activities to accompany the story. One week while reading "The Famous Five" by Enid Blyton, Sarah and Ashleigh went on a scavenger hunt in their respective houses, just like the characters in the book. It has been lovely getting to know Sarah through these visits. She has also shared in an important time in our family's life, the arrival of our new puppy, Frankie. Listening in

the background, I often hear Frankie's name mentioned when a dog features in a story. It has been wonderful for Ashleigh, and for me, as it provides me with a little respite. I will often use the time to do something I need to do, without having to worry about Ashleigh being entertained for that time."

**Thank you to our wonderful volunteers for their incredible compassion and enthusiasm, to find and develop connections with children and families to explore their interests and passions during a time of real challenge. If you are interested in volunteer virtual support for your family, please contact: [rachel.simpson1@health.nsw.gov.au](mailto:rachel.simpson1@health.nsw.gov.au) 🐾**

## Biography project

Every child who comes to Bear Cottage is unique and has an individual story to tell. Family members often want to share stories and qualities of their child and it is important to record and celebrate these. With this in mind, we have started to develop a project to help families do just that.

The Volunteer Managers of **Bear Cottage** and **SCHN Palliative Care Family Support Volunteer Program** have been working to introduce a Volunteer Biography pilot project.

There has been much planning, testing and training and we want to ensure that it meets each family's needs and that the finished product will reflect the special qualities and personality of each child. We know family members and friends may each have stories they would like to contribute to help weave a tapestry of stories around the child. They will choose which stories to include and the role of the volunteer is simply to record the spoken memories and reflect the stories of each child from their own family's perspective.

The process involves organising a volunteer to visit the family in their own home, hospital or Bear Cottage – they will document the story using a recording device. The biography may include artwork, photography, poems or song lyrics. At the end of the interview process, a storybook will be written and produced for the child and family to keep, both as a hard copy and on a data stick.

We also consulted with our Bear Cottage **Family Advisory Group** and they suggested the option of video biographies as an alternative and this will be explored once we have launched the initial stages of the project.

We hope to trial this by the end of the year and have a fantastic small group of volunteers who have been training with us and are very keen to meet with families. If you would like further information on being involved, please contact: [rachel.simpson1@health.nsw.gov.au](mailto:rachel.simpson1@health.nsw.gov.au) 🐾





## There's more to the story



It goes without saying that reading with your child on a regular basis has well-known benefits. It can provide a space for conversations to be had and big emotions to be explored.

Spending this time together can help develop stronger relationships, increase cognitive development and expand language

skills. It offers a way for children to spend quality time with parents, siblings or other caregivers and form special connections.

If children are worried or having a difficult time, reading a book can be a great way to distract their minds from difficult emotions and focus instead on more positive imaginary worlds. Stories about how people feel, may help children to better understand themselves and the people around them and explain why they may feel or act in a certain way. By reading about a character who shares similar emotions, children may realise they are not alone.

The benefits of story reading or '*bibliotherapy*' also holds an important place in the area of paediatric palliative care. Bibliotherapy is defined as the application of specific literature within a therapeutic context.

Bibliotherapy is often used at Bear Cottage. By using story books with patients, siblings and families – through the end-of-life stage and into bereavement – we have found it to be a beneficial tool to identify and support individual grief processes, help teach coping skills and identify the perspectives of other family members. It may also be used as a way to normalise feelings, to help children realise they are not alone in their experience, and to provide information and guidance.

If you would like to find out more about how bibliotherapy could benefit your family, please make contact with our Social Workers, **Lauren** and **Claire**.

Some of the books that we have in our Bear Cottage library and can recommend are:

- ♥ ***The Invisible String*** by Patrice Karst
- ♥ ***The Goodbye Book*** by Todd Parr
- ♥ ***The Next Place*** by Warren Hanson
- ♥ ***The Memory Tree*** by Britta Teckentrup
- ♥ ***Gentle Willow*** – A Story for Children About Dying by Joyce C. Mills
- ♥ ***Life is Like the Wind*** by Shona Innes
- ♥ ***When Dinosaurs Die*** – A Guide to Understanding Death by Laurie Kransy Brown
- ♥ ***In My Heart – A Book of Feelings*** by Jo Witek
- ♥ ***Let's Talk About When Someone Dies*** by Molly Potter 🐾



## Superhero Week update



Despite the challenges, Superhero Week has been a huge success, raising over \$310,000. Schools, pre-schools and organisations really embrace this event and despite many activities having to go online, they were as enthusiastic as ever to take part.

There are many people to thank and we have some stand-out fundraisers we would like to mention. Our very own **Nurse Vikki** raised over \$30,000 with the help of her family and local community, while **Manly Village Public School** raised twice as much as they did last year, donating over \$10,000!

We would also like to thank **Moustafa** and the entire **Ali family** for so generously sharing their story to help us promote Superhero Week.

Sadly, our Superhero Party could not go ahead this year, but we did try to ensure the week was SUPER fun for the children and families staying with us.

The always generous, **Tonya** from **Bricks4Kids - Northern Beaches**, brought her workshop in-house and the children enjoyed a wonderful morning learning more about Lego – but with a Superhero twist.



Our friends from **Ben & Jerry's Manly** provided an incredible Superhero ice cream cake for us all to enjoy and **Mrs Jones the Baker** provided Superhero-themed cakes.

**Merlin Entertainment** got in on the act as well – hosting Superhero-themed online visits from **Madame Tussauds**, **SEA LIFE Sydney Aquarium** and **WILD LIFE Sydney Zoo**.

**Art Therapist Judy** organised a morning of cape-making. Judy encouraged the children and siblings to identify their strengths and hero-like abilities and then create their own personalised capes (made by our crafty volunteers from bed sheets). The children were then able to wrap themselves with all their 'hero' qualities.



There were invisible cloaks and kind, super and amazingly brave capes to hang from the backs of wheelchairs and from siblings' shoulders helping them to fly.

And every Superhero, no matter how high they fly, appreciates a furry companion like Beau to navigate the corridors of Bear Cottage. 🐾





## House news

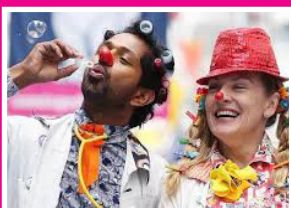


### A Bear Affair

Thank you to everyone who supported our **A Virtual Bear Affair** for 2020, which raised over \$243,019. This included an incredibly generous donation from **Kay van Norton Poche** of \$100,000. This is the fifth year in a row that Kay has donated this amount at A Bear Affair and we are incredibly grateful to her for her extremely generous ongoing support.

We are now looking forward to next year's A Bear Affair when we will celebrate our 20th anniversary. 🐾

### Clown doctors on call



We all love a visit from the **Clown Doctors** and now Bear Cottage families will also be able to enjoy a fun visit in the comfort of their own home.

**Clown Doctors on Call** is a **free** virtual visiting service for patients and families and is available by booking online: [humourfoundation.org.au/clown-doctors-on-call](http://humourfoundation.org.au/clown-doctors-on-call) 🐾

### Play on at Bear Cottage

Our registered music therapist **Belle**, has made over two dozen recordings of songs she regularly sings to the children when they come to Bear Cottage. A CD has been created and is kept in the lounge room along with three boxes of puppets and instruments which have been chosen especially to accompany the songs.



Now, when families come to Bear Cottage, it will be possible for them to enjoy music sessions together at any time. The CD may be played for receptive music enjoyment or it may be used interactively.

For each song, a user-friendly guide sheet has been created with suggestions for the use of puppets and small percussion instruments.

Look for these materials in the instrument cupboard in the lounge room (beside the television set) and you will find boxes clearly marked **'Play On'**. Our CD player is easy to locate as it is kept on the craft table in our messy play area.

In fact, you don't even need to come to Bear Cottage in order to listen to our new Play On recordings. All 28 songs are freely available to Bear Cottage families and if you would like your own personal copy of the songs and guide sheets, just email Belle on [Annabelle.Keevers@health.nsw.gov.au](mailto:Annabelle.Keevers@health.nsw.gov.au) and she will send you digital copies. 🐾



## Remembering our children

**Dekkard Maynard** 7/09/08-20/06/20

**Murray Rodgers** 5/10/17-26/06/20

**Fatima Zahra** 25/11/18-27/06/20

**Adam Taylor** 7/09/13-8/07/20

**Zane West** 3/03/11-8/08/20

**Agamjot Singh** 16/02/12-24/08/20

**Eliza Resch** 22/05/20-3/09/20

**Mia Pantaleo** 4/12/06-13/09/20

## Staff news

We will soon be joined by **Margot, Felicity** and **Ella**. They are joining our casual pool of Registered Nurses and will bring much experience, knowledge and enthusiasm.



Margot



Ella

Sadly, we have said goodbye to Child Life Therapist **Wendy** who has taken up a full time role at CHW. We have also farewelled our physiotherapist **Amy** who is taking on a management role. Amy will be a big loss for Bear Cottage, as the physiotherapist role has become an important part of every child's stay. We will endeavour to replace Amy as soon as possible.

Meanwhile, **Erin** is commencing shortly as our Child Life Therapist on a Sunday and Monday and we look forward to having her on our team. 🐾



Erin

## Farewell Frankie



We have some sad news to share. Our much loved Assistance Dog **Frankie** sadly passed away in mid August. Living to the ripe old age of 12, Frankie had retired from Bear Cottage two years ago and had been enjoying a very busy retirement with our **Nurse Annie**.

Frankie spent many days with Annie visiting the pet café at Wollstonecraft station for a two course meal! In the evenings she visited the nearby Italian restaurant for a pork and fennel sausage. As sociable as ever, Frankie continued to make friends with everybody she met.

Sadly, in early August she became very unwell with her arthritis affecting her spine. This came as a great shock to Annie, as Frankie had been very active until a few days before she died.

Frankie had been a wonderful companion to so many children, families, staff and volunteers at Bear Cottage and she will be fondly remembered by us all. 🐾



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