

Light up little lives

Do you love the Christmas spirit, spreading joy and making Christmas extra special for your family and friends?

Do you want to know how you can enjoy Christmas to the fullest and help to save precious young lives at the same time?

Then we'd love to hear from you!

By joining the Christmas Lights Appeal, your fantastic Christmas lights display at your home, school or business will help raise much-needed funds for The Children's Hospital at Westmead.

Do more than spread the joy of Christmas this year – change the lives of sick children and their families.

Our annual Christmas Lights Appeal is much more than a fundraiser. You'll get lots of support and it's also a chance to meet new friends, swap ideas and

have lots of fun.

Join the Christmas Lights Appeal this year and show your neighbourhood just how much you care.

For more information, please phone Andrew on (02) 9845 3367, email andrew.bohlken@health.nsw.gov.au 🐾



2011 Christmas Lights supporting The Children's Hospital at Westmead

In Memoriam

We gratefully acknowledge gifts recently received, in lieu of flowers, in memory of:

Adam Pleri	Greg Walton	Nick Danger	Estate Keith Henry Line
Alice Aida Richardson	Gwendoline Fay Melrose	Norman Lin	Estate Emma Georgina Norton
Alicia Maria Tantala	Hamish Martyr	Peter Barnes	Estate Lionel Ernest Fredrick Dege
Andrew Robert Bensley	Hap Hung Dang	Peter Mackie	Estate Mollie Adele Moffat
Anil Kulkarni	Haralambos Vlahakis	Phil Gosling	Estate Alice Victoria Mason
Anna Lyon	Heidi Brook	Philippa Sutcliffe (Rowntre) Crossley	Estate Lydia Davidson
Anna Szasz	Jack Ajlin	Prisha Patel	Estate Patricia Marea Hirst
Antonella Bester	James Patrick Nolan	Robert Grainger	Estate Eileen Theresa Mariner
Arthur Frederick Loveday	Jane Cordin	Roy Wagland	Estate Violet Falls
Barbara Elliott	Jarrold Evans	S Spasojevic	Estate Henry Friend
Barry Arthur Edward Coyle	Jennifer Morrow	Sebastian Trovato	Estate Ronald Strike
Barry Coyle	Jesse Hattersley	Stephen Robertson	Estate Florence Rogers
Barry Demeder	John Littlehales	Terini Crumlin	Estate Thelma Chippendale
Benjamin Slaney	Joshua Abreu Gjorevski	Van Trung Tran	Estate Jill Patricia Marsh
Betty Gill	Kam Ying Kwong	Vassiliki Simos	Estate Nola Caroline Tranter
Betty Jones	Kim Fook Chin	Verna Parker	Estate John Colvin Evans
Bob Miller	Larry Lok Wai Chan	Victor Francis Arnold	Estate Arthur Brown
Caitlin Armytage	Laurie Miller	William Feng	Estate S.M. Kimber
Caterina Lavezzaro	Leslie Reynold Nicholls	Xavier Andrew Dimitri	Estate Lilianti Sutedja
Charles Arthur Headley Spencer	Lincoln Fletcher	Yvonne Madge Salmon	Estate Margaret D'altry Carter Sherwin
Damien Roberts	Long Huynh		Estate Roderick Robson Kelly
Edward Fryar	Luke Hedge	Bequests	Estate Joan Wilson
Esther Wilson	Maria Catena Spina	Estate Hilda Dorothy Catherine Barnett	Sir Robert & Lady Askin Charities Trust
Felicia Marchione	Marise Vella	Estate Pauli Salomon Hakkio	The Bernard David Rothbury Trust
Florence Newman	Meg Davies	Estate William John Ford	K & G Gluck Trust
Francesco Paolo Cannali	Mr Dawson	Estate Noela Eileen Thearle	H & R Israel Fund
Gillian Fairfax	Mrs G Fong	Estate Mabel Kohler	
Giovanna Greco	Nick Baldas	Estate Arthur William Byrne	

'the bandaged bear'



Newsletter July 2012 www.chw.edu.au

Message from the Chief Executive



Reflecting back over the past 12 months, so much has been achieved at The Children's Hospital at Westmead. From the opening of innovative services to enhance patient care, to ground-breaking research projects and establishing new support services for families, there has been much to celebrate.

I'm really proud of all that has been achieved by staff and volunteers at The Children's Hospital at Westmead. But I am equally proud of the involvement of donors in almost every one of our achievements. It's a true testament to how much we rely on your support and a clear indication that we simply could not provide our world-class life-saving care without you.

One of our very exciting recent highlights is the establishment of an Australian-first clinical trial using gene therapy to treat childhood cancer, as reported in this newsletter. Researchers here at the Hospital are understandably thrilled to be commencing this trial after investing 14 years into the ground-work and preparation, strongly supported by over \$3 million in donated funds.

The potential for this to completely change the way childhood cancer is treated is enormous. It's incredible to have committed donors who see the long-term value in funding research and are as excited about the future possibilities of our research program as we are.

I am enjoying the opportunity to work closely with our new Sydney Children's Hospitals Network Board, headed by the new Chair, Dr Christine Bennett. Dr Bennett has over 25 years of health industry experience in clinical care, strategic planning and senior management that will benefit us significantly as we move forward.

Thank you very much for your continued support and for partnering with us to fulfil our important mission of improving the health and wellbeing of children through clinical care, research, education and advocacy.

Warm regards,

Elizabeth Koff
Chief Executive
Sydney Children's Hospitals Network

Bandaged Bear's Big Day Out!

In 2012, our traditional Teddy Bears' Picnic will be transformed into something bigger and better - Bandaged Bear's Big Day Out!

Bandaged Bear's exciting new adventure will take place at Luna Park, Sydney on Sunday 9 September and promises to be an action-packed day for the whole family.

This very special day, in support of The Children's Hospital at Westmead, will be filled with excitement and laughter as kids of all ages ride the Mighty Mouse, explore Cony Island, bump into each other on the dodgems or have their Teddy Bear's checked out at our famous Bear Clinic.

Also included in your ticket price are live performances from some of your favourite stars who will be announced in the coming weeks.

Bandaged Bear's Big Day Out has something for everyone, so bring your family and friends and enjoy an amazing day out while showing your support for sick children and their families.

Tickets to Bandaged Bear's Big Day Out will sell quickly, so make sure you check out www.bandagedbear.org.au for prices and on-sale dates.

If you are unable to join us on the day, why not purchase a ticket

for a disadvantaged child or family to enjoy Bandaged Bear's Big Day Out? Your purchase of charity tickets will have double the impact, supporting

disadvantaged families and The Children's Hospital at Westmead at the same time. To purchase a charity ticket, please visit www.bandagedbear.com.au. 🐾

**BANDAGED BEAR'S
BIG DAY OUT**
Sunday 9 September
Luna Park, Sydney



How to support Bandaged Bear's Big Day Out

- Come along to Luna Park on Sunday 9 September and enjoy Bandaged Bear's Big Day Out!
- Purchase a charity ticket for a disadvantaged child and family to attend Bandaged Bear's Big Day Out

For more information visit www.bandagedbear.com.au

For more information on sponsorship and partnership opportunities please email Nicole Jervis at nicole.jervis@health.nsw.gov.au or phone (02) 9845 3473

a patient's journey

Operation first a huge success for baby Harrison



Harrison and his family

"He loves books," says mum, Lisa. "Even on Sunday, he'll sit down with us and 'read' the newspaper. I'm not sure if it's because of what he went through, but people are drawn to him, he's a very loveable little boy – I look at him and think he's my special little boy. He's really beautiful."

Harrison Moses is your typical cheeky two-year old. He loves getting up to mischief, tormenting his big sister, Ava, and is always full of beans. You'd never know that, at just two days old, Harrison was the first baby to be operated on at The Children's Hospital at Westmead using specialised diaphragmatic keyhole surgery.

You may remember Harrison's story from our 2011 Christmas Appeal. Born with a very rare condition, known as a 'congenital diaphragmatic hernia', a large part of Harrison's intestines were sitting up in his chest, which affected his ability to breathe.

His mum, Lisa, vividly remembers the trauma of Harrison being whisked away to be put on life support just

moments after he was born.

"It was a nightmare," she recalls. "It all happened so quickly. You've only just met your baby, you haven't even hugged him and they want to take him away. I honestly thought we were going to lose him."

Lisa and her husband were told that their little boy needed an operation if he was going to make it.

"We were told about a new keyhole surgery that could save Harrison's life. It was a huge decision, but at the same time, you just do what has to be done. Being at The Children's Hospital at Westmead, we knew he was in the best hands."

For Harrison's family, initial despair and anxiety were replaced by elation. His operation was a success. Through three

tiny incisions, surgeons managed to fix Harrison's breathing muscle and return his intestines to his abdomen.

Their story touched the hearts of wonderful supporters like you, who responded with overwhelming generosity to our Christmas appeal, donating \$300,000. That money means we can buy more state-of-the-art equipment like that used on Harrison – helping save the lives of more children.

Today Harrison is a happy, thriving toddler who loves spending time with his family, including his brand-new baby sister, Isla, who is just a few months old. And the family treasures every minute with the little son and brother they came so close to losing. 🐾

research news

New research to fight lethal brain tumours

An Australian first clinical trial recently commenced at The Children's Hospital at Westmead, which aims to protect children's bone marrow while they are having chemotherapy to treat brain tumours.

After 14 years of research, gene therapy will be used in childhood cancer to allow for the protection of bone marrow while using higher doses of chemotherapy to fight brain tumours.

This innovative research will allow for better treatment for children fighting some of the most serious and life threatening tumours.

Brain tumours in children have been historically very difficult to treat because temezolomide, the chemotherapy drug that is used, has very toxic side effects and can destroy healthy bone marrow

cells, leaving the child susceptible to dangerous infections.

Higher doses could be more effective in treating these lethal tumours, but the drugs have previously been too toxic for young patients, making it difficult to eradicate tumours.

Under the gene therapy to be used in this clinical trial, the aim will be to increase the level of Methylguanine Methyltransferase (MGMT) contained in bone marrow by inserting a specific gene into the patient's cells. MGMT is a natural occurring substance which protects cells from the chemotherapy drugs. This will mean doctors can then safely administer a higher chemotherapy dose, dramatically increasing the chances of successfully eradicating the cancer cells.

Children taking part in the trial have a very poor prognosis and have exhausted all other conventional treatment options.

"We are optimistic, but cautious, and this is the first step along a difficult road," the Head of the Gene Therapy Unit Ian Alexander said.

"This is a phase one trial, where we aim to establish the long term feasibility of the gene therapy and its potential long term benefits for other paediatric conditions involving bone marrow."

The research has been undertaken by the Children's Cancer Research Unit at the Kids Research Institute, the Hospital's research arm. The Kids' Cancer Project (formerly Oncology Children's Foundation) has contributed over \$3 million to this program. 🐾



L-R Dr Ian Alexander, Head of Gene Therapy Research (CHW), Belinda Kramer, Senior Scientist (CHW), A/Prof Jennifer Byrne, Head Children's Cancer Research Unit (CHW), Peter Neilson, The Kids Cancer Project, Majella Clifton, Radpharm, Dr Geoff McCowage, Senior Staff Specialist, Oncology (CHW)



Harrison as a newborn in intensive care with Nurse Emily



Harrison with his older sister Ava today

Double the care

A recently completed unit at The Children's Hospital at Westmead is expected to dramatically improve the lives of children who suffer from debilitating epileptic seizures.

The expanded \$1.1 million Epilepsy Monitoring Unit monitors children during epileptic seizures to pinpoint the location within the brain where their epilepsy originates. It is expected to double the number of children each year who undergo brain surgery to treat epilepsy and to improve the success rate of this operation, designed to lead to a seizure-free life.

There are more people with epilepsy in Australia than there are with Autism, Cerebral Palsy, Multiple Sclerosis and Parkinson's Disease combined. Approximately 14,000 children have epilepsy in NSW, and for almost 30 per cent, medication poorly controls their disease.

Historically in NSW, access to specialists and appropriate tests for children with this severe brain disease has been very limited.

The expanded Epilepsy Monitoring Unit, with four state-of-the-art beds and a laboratory was recently opened at The Children's Hospital at Westmead by the Member for Parramatta, Dr Geoff Lee.

The unit was funded by the State and Federal Governments and through donations from the George Gregan Foundation.

Dr Deepak Gill, the Department Head of Neurology and Neurosurgery, says the expanded Epilepsy Monitoring Unit allows doctors at The Children's Hospital at Westmead to "be able to test children with severe epilepsy, allow appropriate treatment plans to be made and to find small areas within the brain from where the disease is arising from that can be removed by specialised surgery."

It is estimated that this initiative will double the number of children undergoing epilepsy surgery from ten to 20 per year. 🐾



Epilepsy patient, Bethany Anne McFadden, in the Epilepsy Monitoring Unit



George Gregan officially opens the Unit



Member for Parramatta, Dr Geoff Lee, and CHW Head of Neurology and Neurosurgery, Dr Deepak Gill

Bandaged Bear Appeal

The 2012 Bandaged Bear Appeal was a great success in March, filled with exciting events and opportunities for the community to get involved and support The Children's Hospital at Westmead.

Gorgeous seven-year-old Holly Sultana was our ambassador for this year's Appeal and is a star in the making after featuring throughout the Appeal in all our promotion materials, including our TV ad.

Bandaged Bear was extremely busy during March visiting schools, businesses and community groups who were holding Bandaged Bear Breakfasts and selling our wonderful range of merchandise.

The Appeal culminated in over 200 volunteers hitting the streets, train stations and shopping centres across Sydney on 30 March for Bandaged Bear Day. At Martin Place, supporters were lucky enough to meet the Bulldogs Cheerleaders and listen to the Waubonsie Valley High School Choir, all the way from the USA,



Volunteers and Bandaged Bear selling merchandise on Bandaged Bear Day

who performed especially for us.

The 2012 Bandaged Bear Appeal raised over \$530,000. A big thank you to everyone involved in this year's Appeal,

including our merchandise outlets - St George Bank, HCF, Starbucks, Best and Less and Blooms the Chemist. 🐾

Simulation Saves Lives

Clinical Education, with an emphasis on simulation training, is being expanded at The Children's Hospital at Westmead, with the assistance of valued supporters.

Treating a critically ill child requires a skill set that can only come from hands-on, real time experience. This kind of experience can come from exposure to critical care situations in simulated patients and situations that mimic real life and provide an opportunity for healthcare teams to fine-tune their skills and performance. The stakes are too high and the patients too precious not to practice before the real event comes around.

The Paediatric Simulation Centre, at The Children's Hospital at Westmead, is a unique facility designed to keep staff skilled in the most cutting-edge

treatments for sick children, especially in emergency scenarios.

Simulation provides priceless training opportunities using advanced technology which replicates real life scenarios and allows for learning, educational innovation, collaboration and research.

All types of scenarios, including rare or adverse events, are used by the Paediatric Simulation Centre to train staff, not only to learn technical skills, but also to learn and develop vital communication skills that can mean the difference between life and death in the Hospital environment.

One Emergency Registrar sums up the benefit of simulation training well.

"The benefit of simulation training was brought home to me only two weeks after attending the course. At 4am on a

night shift in Emergency I was asked by another registrar to help with an incoming baby in cardiac arrest. The experience I had gained from the simulation course gave me the confidence to take on the team leader role. I was much better equipped to plan for the situation and organise the team of staff available. I felt more calm and in control of the situation."

In today's cutting-edge world of health care, having the best staff means continually investing in them to keep their skills current and to build upon their talent. Investing in training to build upon the talent and capabilities of doctors, nurses and other health professionals is vitally important for a healthy future for generations to come. 🐾

Art for Healing

Art is a fun and relaxing way to express thoughts and feelings. For sick kids, art is especially important as it gives them a chance to escape from feeling sick, in pain and unsure what the future will bring.

The Art Therapy Program at Bear Cottage gives seriously ill children a chance to experience art, despite their illness or disability. Even children who can't move their arms and legs can create artworks by oozing paint through their fingers. This program brings smiles to the faces of sick kids and makes them feel proud to create something special and unique.

Since the start of 2012, our Volunteer Art Therapist, Megan, has been working with Cottage kids, families, staff and community members on a range of arty projects, enabling everyone to exercise

their creative capacity.

The scissors have been snipping, paint dripping and glue-sticks sticking, as everyone has worked together to create a number of eye-catching murals on our art wall in the centre of the house.

The ever-changing art display has already featured many things from sea creatures, to pirate ships, ferry races and firework displays, leafy trees, magical mushrooms and wise watchful owls. This really adds to the healing environment of Bear Cottage and brightens the day of patients and families.

It is easy to see why Art Therapist, Megan, believes that creative activities can give people an opportunity to share their experiences and start a different kind of conversation.

"Sometimes people can use images to express thoughts and feelings that

they can't express using words. Other times, using our creative strengths helps us to relax, play and focus on something a little different for a while. It is important that we can continue to find ways to share our stories, have fun, support each other, build positive memories and start creative conversations," she said. 🐾



Kids enjoy the Art Therapy Program

Our Bear Cottage Superheroes

When most children are thinking about school, playing and fun, some kids have other things on their minds – their serious illness. It's difficult to imagine how isolating it is for children to be faced by an uncertain future, so Bear Cottage regularly organises camps to bring these vulnerable children together.

We recently held our Junior Boys Camp for boys suffering from Muscular Dystrophy - a muscle-wasting disease that means they rarely live past their late-twenties. These boys truly come alive when matched with others in the same situation, knowing that there is shared understanding and support and especially knowing that they are not facing their difficult battle alone.

The theme of the camp was 'Be a Superhero' and the boys enjoyed making Superhero costumes and turning their wheelchairs into awesome Superhero characters. They then spent the rest of

the afternoon racing their 'hotted-up' wheelchairs up and down the corridors.

The following night they enjoyed making home-made pizzas and roasting marshmallows while watching their favourite Superhero movie.

Camps like these show that when there is strength in numbers, these boys can really feel on top of the world. 🐾



Bear Cottage Superheroes

Supporting a beary good cause

The staff and students of Pennant Hills High School went above the call of duty to celebrate Bandaged Bear Week in March. The Year 8 Leadership members organised a range of fundraising events in support of sick kids at The Children's Hospital at Westmead.

On Friday 23 March, the Year 8 students ran a staff Bandaged Bear Breakfast before school. This event was prepared and hosted by the students. The group split in two, having one group cook (dressed in their chef whites) and the other serve (dressed in smart waiter uniforms).

On the menu was muesli trifle, buttermilk pancakes with maple syrup, cereal, coffee, tea and juice. These had to be pre-ordered during the week to ensure the group had enough food to go around. The students had so much fun working together to raise money for The Children's Hospital at Westmead and learnt some valuable skills along the way.

After the morning breakfast was such a success, four students started setting up the cake stall. By the end of recess, students had sold everything except for two plates of cakes which were quickly sold off to teachers and office staff, raising a total of \$300.

Not content with the great success so far, the Year 8 students still wanted to raise even more money for The Children's Hospital at Westmead, so they sold chocolates at recess and lunchtime for a whole week.

Pennant Hills High School and their generous students believe it's very important to help others who are in need in their local community. Through their

ingenuity and dedication, they raised a total of \$1360 towards the Bandaged Bear Appeal and The Children's Hospital at Westmead.

Thanks to everyone involved in this fantastic series of events. We really appreciate this tremendous support and this money will make a real difference to the services we provide for sick children and their families. 🐾



Pennant Hills High School celebrating Bandaged Bear Day

Sweet treats for sick kids

A parent of one of the Hospital's patients was the driving force behind an innovative fundraiser, a collaboration between Kindikids Early Learning Centres and My Sweet Boutique.

A Gourmet Tea and Waffle fundraiser proved to be a big hit with kids and adults alike. Families and educators enjoyed fresh waffles and delicious organic teas and then the fun was taken into the classrooms where kids participated in a cooking lesson with the team from My Sweet Boutique.

Kindikids is no stranger to supporting

The Children's Hospital at Westmead, after recently contributing towards the purchase of a breathing machine through the Mums on a Mission Charity.

My Sweet Boutique has a 'Random Acts of Sweetness' program where the community is invited to work with them to create sweet treats while contributing to worthy charities.

On behalf of The Children's Hospital at Westmead, thanks to Kindikids and My Sweet Boutique for so passionately supporting us. Sounds like a lot of sweet fun! 🐾



Elisabeth and Maria from Kindikids