Raising funds for sarcoma

Cancers affecting young people have a disproportionate impact on society. The younger the patient, the greater their potential to contribute to society.

Although sarcoma is considered a rare cancer, it still affects about 700 people in NSW each year, and most of these are in their youth.

Sarcoma is a malignant tumour that is derived from cancerous bone and soft tissue and, while some cancers have a cure rate of around 80 per cent, the prognosis is significantly less optimistic for sarcoma patients.

Parramatta City Council Young Citizen of the Year and sarcoma patient, Gabriella Wehbe, is a shining example of someone who aims to beat the odds.

New and emerging treatments offer a glimmer of hope for young patients like Gabriella, and our aim is to bring this hope to life through our work.

The Lifehouse philosophy is to provide uncompromising care in a safe, comfortable, caring environment. Young Australians with sarcoma cancer deserve nothing less. Yet, we can only improve the existing treatment framework and outcomes with support from generous donors like yourselves.

Currently Chris O’Brien Lifehouse is a centre of excellence in New South Wales for sarcoma treatment. However, whilst we treat patients with radiation therapy and chemotherapy, we can still do a lot more. For example, we would love to commence sarcoma surgery at Lifehouse in the near future.

We place a high priority on providing comprehensive care, where all aspects of treatment are delivered under one roof by a cohesive, collaborative team. Our vision is to make this model of care available to our sarcoma patients, who are a particularly vulnerable young group.

With your help, we can create a future of promise for adolescents and young adults fighting for survival against sarcoma. Your donation via this newsletter will make this future a reality. So please donate now.

Steering a path through the storm

By Gabriella Wehbe

Imagine this, you’re on a boat, sailing along in fairly calm weather. You’ve been travelling in one direction for as long as you can remember and life is as good as it’s ever been. Then, without warning, a massive storm hits. Your boat thrashes around in the crashing waves, and you begin to question whether you’ll come out of this alive. Then, after what seems like an eternity, the storm clears, and you see someone in the distance holding a life jacket. Your boat has been damaged, nothing too severe, but then you realise you’re still a long way from home.

My name is Gabriella Wehbe and I am 18 years old and one of seven children. My father Jim is a builder and property developer who tirelessly works to provide for our family. As you can imagine with the demands of seven children, my mother Loretta is a full-time housewife. They have both been the rocks of our family and the anchor that keeps my boat stable.

2015 was an emotional year to say the least. I had planned to go to Cambodia with my school to visit an orphanage and build houses for the disadvantaged. Then in July we lost my maternal grandmother, which was a hard time for my family. At the time, I was completing an accelerated HSC mathematics course and I had to complete my trial examinations. I was also blessed to be elected assistant head girl at Our Lady of Mercy College in Parramatta by my peers. To say the least, I was very excited about my final year of high school.

I was participating in the City2Surf when I noticed a painful lump on my left foot. Numerous doctors’ visits and scans later, they deduced it was just a ganglion, nothing too serious and that it could be removed through a simple surgery.

I had the surgery on 18 September 2015 and the surgeon said it went perfectly and that the lump had been sent for routine testing. A couple of days later the doctor called and asked me to come back in for the results of the test. He then said: “I’ve done thousands of these surgeries and I’ve never seen this before. Unfortunately, you have alveolar (continued over page)
Open Letter
Eileen Hannagan
CEO Chris O'Brien Lifehouse

I hope 2016 was a wonderful year for you. It certainly was for us here at Chris O'Brien Lifehouse.

Last year we treated more than 17,000 patients and either ran or participated in more than 300 clinical trials and research projects. Some of these trials, such as the world’s biggest clinical trial of medical cannabis, sought to improve the quality of life for our patients. Others, such as for the drug, Keytruda, are saving lives right now.

Meanwhile, our da Vinci Xi Surgical System (the Robot) completed its 100th operation. As you might be aware, the Robot is one of the world’s most advanced pieces of medical hardware and allows our surgeons to conduct minimally invasive surgery as well as enabling our senior staff to teach robotics to the next generation.

Already 2017 is off to flying start. In line with our ethos of putting the patient at the heart of what we do, Lifehouse Director Gail O'Brien began her new role as Patient Advocate. In this position, Gail will bring to bear her enormous amount of experience with cancer as well as her unique perspective of being a carer.

We are also excited to announced that in May, we are bringing one of the world’s leading gynaecological oncologists to Lifehouse - Dr Marcelo Nascimento from Brazil. This position will allow Lifehouse to expand its tertiary ovarian cancer surgical capabilities and offer new hope to patients who have recently come out of remission.

And finally, I would like to thank everyone who took part in our 2017 Supporter Survey.

You sent us the strong message that you would like to hear more about our research and clinical trials. So I am delighted to let you know that we have just published our inaugural research report. If you would like a copy, please contact our fundraising team on 02 8514 0006. Alternatively, you can follow this link on our website: www.mylifehouse.org.au/researchreport2016

In future newsletters I look forward to updating you regarding new successes and innovations as 2017 progresses. Until that time may I wish you all the best on behalf of all the staff and patients at Chris O'Brien Lifehouse and thank you as always for your support.

“Steering a path through the storm” continued

rhabdomyosarcoma”. I didn’t know how to react because to be honest I didn’t know that a word could exist that could have that many syllables. But my only question for the doctor was whether I would still be able to go to Cambodia. To which he shook his head and said: “I’m sorry Gabby, I don’t think that’s going to happen”.

That’s when the tears started and I thought that the entire next year of my life would be spent in a hospital. I was referred to the Chris O'Brien Lifehouse, where I met with a team of people who were to become familiar faces over the next year. My oncologist, Dr Vivek Bhadri, explained to me what a sarcoma cancer was. To me however, it was much more than a simple definition.

A sarcoma involves several incredibly difficult conversations, bucket loads of tears from those around you, and it requires the most determination you could possibly channel. I was told I only had a 20% chance of long-term survival, but I was determined to be one of the 20%. I was given a 54-week treatment plan, involving both chemotherapy and radiotherapy.

I was worried about finding time for my role as assistant head girl. The elected leadership team was already a close network of girls and my diagnosis made us all communicate more and brought us closer. There was a real sense of camaraderie and teamwork which made it much easier for me to juggle my treatment with my role.

I was also concerned about not receiving my HSC through not having enough time at school. I decided to go ahead with my HSC because my teachers caught me up on what I’d missed and offered constant support.

As a result, I only missed three weeks of school.

After 93 chemotherapy sessions and 20 radiotherapy sessions, I’ve finished my treatment and the scans have come back clear. I’m truly looking forward to what the future holds for me. Next year I would like to further my studies at the University of Sydney in a Bachelor of Physiotherapy with a Masters of Teaching, a course that will enable me to pursue my dream of being either a physiotherapist or a PDHPE teacher. My number one ambition however, is to be completely happy, healthy and still have the same amount of determination and optimism that I currently have.

If it weren’t for those two qualities as well as the support of my family and my school and the hard work of the staff at the Chris O'Brien Lifehouse I would not be where I am today. I’m so grateful to this incredible cancer facility, that has saved not only my life, but also the lives of so many others. We cannot direct the wind, but we can adjust our sails.

Gabriella played a key role in helping us to raise over $400,000 for Chris O'Brien Lifehouse in 2016 and has been named the City of Parramatta Council Young Australian of the Year.
Opdivo immunotherapy drug approved for kidney cancer

After exciting results with skin and lung cancer, the government approved the marketing of immunotherapy drug Opdivo for kidney cancer. Professor Michael Boyer, Lifehouse's Chief Clinical Officer, says: “Tumours develop a way of evading our immune system and making themselves invisible. What these drugs do is allow the immune system to once again see.”

The drug is currently under review for listing under the pharmaceutical benefits scheme, making it affordable for patients.

Help create the change you want to see

At Chris O'Brien Lifehouse the importance of our work in transforming treatment and care for cancer patients cannot be underestimated. Knowing this, many people like to support our cause by leaving a gift in their Will. In doing so they are helping to enhance the work of our researchers, medical teams and other specialist staff in making a positive impact on the lives of cancer patients.

The Chris O'Brien Bequest Society recognises and honours those visionary people who have chosen to leave a gift in their Will to Lifehouse and have advised us of their intention to do so. Whether the bequest is large or small, Gail O'Brien, Bequest Society Patron, and herself a bequestor, says she is overwhelmed by the generosity of the Society's members.

“It is inspirational to know there are people who leave truly heartfelt gifts to Lifehouse with the aim of creating a better future for cancer patients. Chris would have been very touched to know people still strongly support his vision.”

Julian Hofer, a former cancer patient, is leaving a gift in his Will to Lifehouse to say thank you for the help and support he received during that difficult time. “Lifehouse gave me a second chance and, along with making an annual donation, leaving a bequest to help others just seemed like the right thing to do.”

To view Julian's personal story and/or for more information on leaving a gift in your Will visit: mylifehouse.org.au/bequests or contact Alison Muir, Major Giving Manager on 02 8514 0356, email: Alison.Muir@lh.org.au

YES, I WANT TO HELP
SAVE THE LIVES OF YOUNG AUSTRALIANS

Please complete, detach and return this form along with your donation, in the envelope provided.

CHRIS O'BRIEN LIFEHOUSE
PO Box M5, Missenden Road
Camperdown NSW 2050

Title: Supporter ID: __________________________
First name: _______________________________________
Surname: _______________________________________
Company: _______________________________________
Address: _______________________________________
____________________________________________________
Suburb: _______________________________________
State: _______________ Ph: __________________________
Email: _______________________________________

I WOULD LIKE TO MAKE A TAX-DEDUCTIBLE DONATION TO CHRIS O'BRIEN LIFEHOUSE

SINGLE DONATION - I would like to make a single donation to support Chris O'Brien Lifehouse.

☐ $25 ☐ $50 ☐ $100 ☐ $250 ☐ Other___________

Your tax deductible receipt will be mailed to you

MONTHLY DONATION - I would like to make monthly contributions to Chris O'Brien Lifehouse. Please debit monthly from my credit card (details below) until further notice.

☐ $25 ☐ $35 ☐ $50 ☐ $100 ☐ Other___________

One tax deductible receipt will be mailed to you at the end of each financial year.

CREDIT CARD PAYMENT

☐ Amex* ☐ Mastercard ☐ Visa

Card number: _______________________________________
Name on card: _______________________________________
Signature: _______________________________________
Expiry date: _______ / _______

☐ I would like to receive information about including Chris O'Brien Lifehouse in my Will.

☐ I would like to receive the Chris O'Brien Lifehouse e-newsletter.

☐ I would prefer not to receive further mailings from Chris O'Brien Lifehouse.

*As we pay a slightly higher commission on Amex cards, we recommend you make your donation with Visa or Mastercard. Thank you for your understanding to ensure as many donor dollars as possible are directed towards cancer care.

THANK YOU FOR YOUR SUPPORT, YOUR CONTRIBUTION WILL HAVE A DIRECT IMPACT ON THE LIVES OF PATIENTS LIKE GABRIELLA.
What is SARCOMA?
A sarcoma is a malignant tumour derived from cancerous bone, cartilage, fat, muscle, vascular or hematopoietic tissues.

Affects around 700 people in NSW alone each year

The absence of funding allocated to sarcomas, equates to less than 1% of total cancer funding and does not allow for new ground breaking research to be accomplished.

Survival rates have not changed significantly for 20 years

Sarcomas comprise between 10-20% of cancers occurring in teens and adolescents

“I was told I only had a 20% chance of long-term survival, but I was determined to be one of those 20%.”

Gabbie Wehbe, 18 year old sarcoma patient

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HOPE LIES IN RESEARCH
To make your donation, please visit www.mylifehouse.org.au/sarcoma or call (02) 8514 0006

Neurosurgery: Bernie McGuckin

Bernie McGuckin was one of the first patients to undergo neurosurgery at Lifehouse after the department was established in 2016, thanks to donations from our generous supporters. The 60-year-old from Sydney gained his understanding of anatomy by working as a PE teacher for 25 years. When he retired, he and his wife bought into two hospitality businesses which, in his words, crashed and burned as a result of the global financial crisis.

In addition to this challenge, Bernie was also coping with cancer. In 1997 a fibrous sarcoma was discovered in Bernie’s head which was surgically removed. However, the cancer had metastasised to his left lung, meaning another surgical procedure to remove it. Late in 2014, the cancer returned, this time in his skull. Three surgeons worked on Bernie for 14 hours but they were not able to remove all of the cancer.

After radiation therapy Bernie had an MRI every three months. However in March 2016 the scans showed the tumour was growing again. Moreover it was exerting pressure on the brain and Bernie was having seizures which were weakening his left side. Because of the risks involved,

Bernie with his family at Lifehouse

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Meet regular giver
Jolita Benjamin

Jolita Benjamin has been involved in staging for some of the biggest acts touring Australia including the Bee Gees, U2, Jimmy Barnes, Pink Floyd, Fleetwood Mac, the Commodores, Shirley Bassey and Dionne Warwick.

Her diagnosis of brain cancer, however, seemed an insurmountable challenge.

Jolita was diagnosed with lung cancer in 2015 and was treated with chemotherapy and radiation therapy. However, one small cell escaped from her lung tumour and made its way to her brain. She says: “Having cancer is a shock. I was shattered and I didn’t know how to tell my family, it made me crumple for two days.”

But then she realised she needed to look for positives and she feels that Lifehouse and the team looking after her most definitely fall into that category.

Jolita has been fortunate enough to be placed on a trial of immunotherapy drug Opdivo which has worked to reduce her tumours. She says: “Not everybody has been lucky enough to respond as well as I have.”

So in response, she became a regular giver to Chris O’Brien Lifehouse.

As a pensioner, Jolita says: “I’m giving just a small amount but I plan to up it a little bit and hit up all my friends for donations as well. If I felt better, I’d go and raise some money but I still experience a lot of fatigue.”

Her working life was full of energy. She worked as a display artist painting commercial display items like mannequins, Christmas trees, wreaths and Easter decorations. She then went on to form a business supplying crews and staging for huge music events.

After retiring, she now paints for enjoyment. She is also looking forward to the birth of her new granddaughter, her daughter’s wedding and seeing her other granddaughter off to high school.

If you’d like to make a regular gift to Lifehouse, why not call Amelia Davis on 02 8514 0113 or email Amelia.Davis@lh.org.au

World’s first cannabis trial

Lifehouse launched the world’s largest trial of medicinal cannabis for the treatment of nausea and vomiting induced by chemotherapy treatment. The first patient was recruited to the trial in January and more than 300 will be recruited across New South Wales. Chemotherapy side effects can cause these patients significant nausea and unfortunately, they do not respond to the usual anti-nausea medication.

Lead Researcher, Associate Professor Peter Grimison, said: “The role of cannabis medicines in alleviating chemotherapy-induced nausea and vomiting is still unclear, and this study aims to provide a definitive answer to this question.”

The trial builds on a Spanish study which found that a spray form of cannabis medicine seemed to dramatically reduce nausea and vomiting in cancer patients receiving chemotherapy. The trial aims to replicate these results in a rigorous clinical setting using a capsule imported from Canada.

Gail O’Brien

Lifehouse welcomed Gail O’Brien to its staff as the new Patient Advocate. Gail brings her personal experience with her husband Chris O’Brien’s illness and the subsequent illnesses of her two children to the role and hopes to harness those experiences for the benefit of patients.

Gail says: “It’s a wonderful privilege for me to have been offered this opportunity and I look forward to bringing my passion and experiences to the role, to contribute to the exceptional care that our patients receive. I am hopeful that by visiting patients with a “listening heart”, they will find it valuable and beneficial.”

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As a medical oncologist, I’ve seen hundreds of patients with prostate cancer. As a researcher, my aim is to resolve the unanswered questions that we have in the clinic so that we can improve our decision making and help our prostate cancer patients live better and longer.

Over the past decade we’ve seen the introduction of several new drugs for prostate cancer, which have certainly helped patients live better and longer. However, these drugs don’t work for all patients. Most of them are effective on only half to two-thirds of cases and we don’t have any way of knowing which patients will respond to them ahead of time.

For this reason, my research is focused on the search for “markers”, preferably in the blood, as that involves a very simple test that will show me which patients I can give the drugs to and how I should sequence the treatment to best provide personalised cancer therapy.

The exciting news is that we have new technology which allows us to measure which of the DNA in the blood has come from the prostate cancer cells. This gives us a fantastic indication of how those cells are changing in response to treatment as well as whether they will even respond to treatment in the first place.

This technology is now available in Australia and we are using it to test these genes in our patients to see if we can marry them up with markers that we’ve already found. This will allow us to find a signature to tell us which patients will respond to which treatments.

So, that’s my research in a nutshell; the quest to find a simple blood test to guide prostate cancer treatment so that we can give each individual patient the best chance possible.

Virtual Reality distraction therapy

Start VR began trialling Virtual Reality as a distraction therapy for patients undergoing chemotherapy at Lifehouse. In conjunction with Samsung, the trial uses mobile virtual reality to allow patients to don a headset and escape their surroundings to exotic destinations.

Using the viewing headset, patients can be transported out of the chemo chair or waiting room to a tropical island, the Sydney harbour, deep in the jungle or even to the perspective of someone who is skydiving and looking down at the earth.

Talking about the virtual reality goggles, Day Therapy Nurse, Kiara Montuoro, says: “From a utilisation perspective they are quick to put on, you don’t need a prescription for it, they’re effective and the patients love them so I can see them definitely being a part of our practice in the future.”

Volunteering

Volunteering is a time to learn, to experience and to share

Medical student Joey Michael was at Lifehouse on the very first day it opened, volunteering as a wayfinder. Three years later, he is still here.

“I’ve always loved volunteering and this is an amazing opportunity for me. I want to be a doctor one day so I thought, why not immerse myself in the environment now?”

His typical day at Lifehouse involves wandering around the hospital, talking to patients, making cups of tea and coffee, restocking supplies and doing whatever else he can to help.

Joey says: “The strength of the patients never ceases to inspire me! Many patients are positive and they seem to lend strength to each other. And the staff are wonderful, there’s a smile around every corner.”

Joey also volunteers elsewhere. He spent eight months last year as a volunteer in villages in Armenia through Birthright Armenia, a journey that led him to speak at a gala event for the Children of Armenia Fund in New York.

For Joey, “volunteering is more than just giving back, it’s also a time to learn, experience and share. Each time I walk out the door I take a new lesson with me.”

If you’d like to find out more about volunteering at Lifehouse, please contact our friendly Volunteer Services Manager at volunteers@lh.org.au or phone 1300 852 500 and ask for Lorainne Brecard.
Neurosurgery: Dale and Doone
In the last edition of Open House we shared the story of Central Coast family Dale, Doone and their young son Jai. Jai was just five weeks old when Dale had a seizure early one morning. In hospital, Dale was diagnosed with a brain tumour. He underwent surgery, chemotherapy and radiation therapy, meaning long stays in Sydney away from home. We checked back in with Doone to see how they were getting on.

How are you and the family?
We are all going well. Jai is loving pre-kindy although he comes home with his pockets full of rocks and gravel from the nature walks they go on each morning. Maybe we’ve got a future geologist in the house! Dale is well and staying very positive. We are slowly moving forward with our lives in a positive direction.

We’re thrilled to let you know that we opened our neurosurgery department at Lifehouse last year.
That’s fantastic news, this is a strong testament to the power that is created when individuals come together for a common cause. Many lives will be positively impacted by this development.

We feel that our experience would have been eased if Dale had been able to access neurosurgery at Lifehouse. The people at Lifehouse are part of our extended family and the atmosphere contributes to less stress and therefore a more positive experience and outcome. And having facilities and equipment in one establishment would have made a vast difference to us.

What would you say to patients who are facing surgery for brain tumours?
Stay positive, take each moment as it comes, you cannot deal with any more than the moment in front of you. Keep an open mind and an open heart. It’s possible that you may not return to the ‘normal’ life that you had - you will have a new normal that may take some time to adjust to. Be gentle with yourself.

Robot’s first birthday
The Lifehouse da Vinci Xi Surgical System robot marked its first birthday in December with two kidney cancer operations carried out by urologist Dr Scott Leslie. Dr Leslie is an authority on robotic surgery and mentors and trains urologists throughout Australia.

The dual-console robot is one of the world’s most advanced pieces of surgical hardware and allows our specialists to carry out advanced onco-surgery with minimal invasion.

This was the first surgical robot of its type operating in the Southern Hemisphere and it has been used at Lifehouse in over 100 surgical procedures. The purchase was possible thanks to the kind generosity of our donors. It started with a pledge of $1 million by former Lifehouse Chairman, Robin Crawford AM. His friend and former Chairman of the Lifehouse Building Committee, Lang Walker, then made a matching donation.

These two incredible acts of generosity acted as the catalyst for some of our most generous supporters, including Mr Wai Kong Lo and The Star, Sydney amongst others, to donate the remaining funds, allowing us to purchase the robot in December 2015.
World Cancer Day

On Saturday 4 February, World Cancer Day, nine brave souls took the challenge of a lifetime and skydived for Lifehouse. Among them were mother-daughter team Jackie Butler and her daughter Kristy, jumping in support of their son/brother Dylan who is being treated at Lifehouse. Jackie and Kristy smashed their fundraising targets in just 24 hours.

And if that wasn’t enough, NRL legend Paul Langmack and his partner Amanda Lee jumped for the very first time. Paul is a Lifehouse Ambassador and has supported us in the past by running City2Surf. Paul has thankfully beaten his cancer and says: “We want to make a difference. As a former NSW and premiership winning Bulldogs NRL player, I faced some tough opponents, but nothing like my battle with cancer in 2016. I am so inspired by and grateful for the work of the not-for-profit cancer hospital, Chris O’Brien Lifehouse, not only for myself, but for the thousands of others they have helped, including my sister Diane Langmack.”

Lifehouse staff member Leanne Hodgkiss also jumped. Leanne said: “I have the privilege of working for this incredible organisation, and every single day at work I am inspired, amazed, proud and thankful. Lifehouse was looking for people to take up the challenge to raise vital funds, be brave and do something a little crazy – skydive. And I thought, I’ll do it. I’ll be brave for Lifehouse and all those people who are facing cancer.”

Eleni Prineas was diagnosed with a rare and inoperable cancer two months after her first child was born in 2016. She received the green light from her oncologist just 24hrs before the jump. Eleni has raised over $6,200. She says: “Chris O’Brien Lifehouse has been such an amazing support during a very tough year. The staff and facilities have made our time easier and helped us cope with the stresses, especially as we have a small child.”

Julia, Zoe and Miki are friends who work at Nova Entertainment, they drove down to the Wollongong site together in the hope that they could help calm each other’s nerves.

If you would like to be brave and join Team Lifehouse, please contact Sara Walker on 02 8514 0300 or Sara.Walker@lh.org.au or head to www.mylifehouse.org.au/teamlifehouse for inspiration.

What challenge will you choose?

**Australian Running Festival**
Choose your run in our nation’s capital
Date: 8 - 9 April

**SMH Half Marathon**
21ks through Sydney’s most iconic sights
Date: 21 May

**The Sydney Harbour 10k & 5k**
Run, jog or walk around Sydney’s spectacular Harbour
Date: 9 July

**Stadium Stomp**
Epic stair climb of the SCG and Allianz Stadiums
Date: 16 July
[www.stadiumstomp.com/Locations/SCG](http://www.stadiumstomp.com/Locations/SCG)

**The Sun-Herald City2Surf**
Australia largest fun run is back
Date: 13 August

**Blackmores Sydney Running Festival**
The run that’s fun for everyone – from 4ks to a marathon
Date: 17 September

If you would like to know more about our events or Team Lifehouse, please contact Sara Walker on 02 8514 0300 or Sara.Walker@lh.org.au or head to www.mylifehouse.org.au/teamlifehouse for inspiration.

Are you ready to challenge yourself and help create a future free from cancer?

Join our Team Lifehouse and help us challenge cancer together to make a real difference.