

My husband's legacy – having crossed the black line from doctor to patient

This is an edited speech given by Gail O'Brien at the launch of Stage One of our neurosurgical services at Chris O'Brien Lifehouse.

Eight years ago, my husband Chris O'Brien, a surgeon and humanitarian, succumbed to the brain cancer that he had been diagnosed with two and a half years earlier.

Support from generous donors like you has allowed us to begin neurosurgery and it gives me pleasure to commemorate the launch of neurosurgical services at Chris O'Brien Lifehouse.

It has been an arduous journey, bringing together an enormous number of dedicated and passionate people from all walks of life, working together for a noble cause. What a rare privilege to be part of this creative process and to continue to shape its future.

Chris O'Brien Lifehouse is my husband's legacy, born as much as anything out of his own personal experience, having crossed the black line from doctor to patient. The day of his diagnosis is still crystal clear in my mind. I recall his escalating crippling headache, nausea, vomiting, confusion, visual impairment... and panic.

After a CT scan late that afternoon, a young neurosurgical registrar named Dr Brindha Shivalingam came with Chris's great friend, Prof Michael Besser, to deliver the news to us.

Although 10 years ago, I can still feel the unspoken pleading in my eyes as they connected to hers: "We can treat it, but it is not curable" she said.

Despite my own health background, I could not absorb what she was saying.

And here we are eight years later. Although not overtly, we are still recovering from his illness and death. That is how it is with brain cancer.

Neurosurgery marks a significant turning point in the treatment and care of people with brain cancer at Lifehouse. We have come full circle.



The brilliant medical care that Chris received gave him precious time which he used to live, love and to leverage support for his dream of an easy-to-navigate comprehensive cancer centre to support patients through their treatment. It would be focused on holistic, compassionate care and underpinned by research and complementary therapies.

Chris knew this would be the key to unlocking better outcomes for the cancer he had - and for all cancers.

In my role as Patient Advocate I am privileged to just be with our patients and families as they receive the same news that Chris and I did. We provide a safe haven.

I would like to thank you, our generous donors, for your courage and determination to take the tide at the flood and take the current as it serves so that we may achieve our venture.

Thanks to friends like you, our neurosurgical team is meeting a vital need. But for Stage Two of our service development, we still need to raise more than \$395,340 for additional equipment such as the Jackson Table with 360° axis rotational capability, allowing our surgeons to best position patients for complicated neurosurgery. To ensure that we continue to provide the best possible care to patients, we invite you to make a gift today.

Glycomics cancer research

In May, we launched a joint project between a research team based at Lifehouse and the Glycomics Institute at Griffith University in Queensland. Patients at Lifehouse are providing tissue samples that will be sent to the Glycomics Institute.

Glycomics is the study of the carbohydrates that appear on the surface of both healthy and diseased cells. These so-called "sugar" signatures play a pivotal role in the life

of a cell, not the least being their part in determining cancer growth and development. We will identify the link between these carbohydrate ("sugar") patterns and cancer progression in order to develop new biomarkers of outcome and new drugs aimed at these molecules.

This collaboration has attracted \$2.5 million in philanthropic funding.



Open Letter

Eileen Hannagan
CEO Chris O'Brien Lifehouse

As I walk around our hospital, I feel great pride at what we've achieved. Chris O'Brien's vision of a comprehensive cancer centre has been realised as a thriving centre of excellence, caring for patients from many backgrounds, with a range of complex and rare cancers.

In these moments of reflection, I am thankful and full of admiration for those who have contributed to the Chris O'Brien Lifehouse family – people like you.

Over this past year, surgical services, supportive care and integrative medicine have continued to develop. In

particular, we are excited to bring one of the world's leading gynaecological oncologists to Lifehouse – Dr Marcelo Nascimento. In this issue, you can read more about his work which will allow Lifehouse to expand its tertiary ovarian cancer surgical capabilities and offer new hope to patients who have recently come out of remission.

In the same vein, I'm delighted to share our LivingRoom@Home program which allows our rural patients to access crucial follow-up support they may not otherwise have access to.

We do a lot of special things at Lifehouse. The most important of all though, is to say, "Thank you" to people like you who make it all possible.

A shared passion

Antonia Korsanos and Leanne Enright met when Antonia came to Lifehouse for her first chemotherapy treatment. They recognised a shared passionate nature in each other along with a love of art and coffee.

Antonia Korsanos, Chris O'Brien Lifehouse patient

Meeting Leanne was comforting. She walked into the room and I could tell she was very experienced and she had a friendly, comforting demeanour. Leanne cares about the work she does. It comes across strongly in the way she relates to patients. One day I was walking down the street and I was feeling a bit down. I saw Leanne and she brightened my day just by saying hello. Leanne is sincere in her care and support of patients.

I admire her for the work that she does, this is not just a job for Leanne and that's obvious. I'm a very passionate person and when I believe in something I'm completely committed. I see the same in Leanne. I love it, I love seeing people execute their work without it being a chore, or just a job. That is especially key in this field of work, it matters. I wish we had more people like Leanne.

Like me, Leanne is interested in art, loves great food and is very particular about her coffee. We've only known each other for the 18 weeks I've been coming for treatment but we can talk about anything and everything. As long as Leanne's here in the ward, I feel good. Chemo is not a battle when Leanne is around.

Leanne's encouraged me on my journey

down the path to fitness. When I first came here I had a lot of questions. I was looking to understand how the treatment would affect me and how combining fitness and nutrition could make a difference. Despite being 18 weeks into chemotherapy treatment, I feel better and healthier today than I have in a long time. I have improved energy levels and fitness and I feel mentally and physically stronger.



You do the things under your control and you hang on to the things that give you comfort. Being active gives me comfort, time alone with my music gives me comfort and seeing Leanne gives me comfort.

Leanne Enright, Clinical Nurse Specialist, Chris O'Brien Lifehouse

The first time I met Antonia was when she came for her first chemotherapy treatment. I remember that day very clearly, feeling this was the opportunity to do what I feel like I do best. I could

give Antonia the attention she needed and walk her through the steps. I felt like we clicked that day.

Antonia has a very open personality. It's easy to gauge where she is sitting emotionally and how she's feeling on the day. She's happy to share this with me which is lovely. She's very intelligent and I enjoy our conversations for that reason.

I agree with Antonia; I think we do see passion in each other. One of the first conversations we had was about scientific research on the importance of exercise in improving treatment outcomes. Antonia took this on and has been doing her walking and working out before chemotherapy treatment. She's thrown herself into it. And she is showing us that what the science is telling us is correct because her outcomes are so good. She has less side effects and she is in a good place psychologically.

For me this is more than just a job, I believe it is a vocation. If I can just make a tiny difference each day in our patients' lives, then I feel happy about that and I tell myself: "I've had a good day." It's a very special job.

I think Antonia and I could be friends outside of this which is wonderful. It's genuinely been a pleasure to look after her.

You may remember Leanne from our most recent appeal. Thanks to generous supporters like you we have been able to fund two specialist nurses in the coming year. Your generosity has brightened the day of many more patients just like Antonia.

LivingRoom@Home telehealth program

Being based in rural, regional and remote areas can mean country patients miss out on crucial follow-up support after treatment for cancer.

In June 2016, the Lifehouse LivingRoom began a pilot program, LivingRoom@Home, to remedy this situation.

LivingRoom@Home ensures patients who would otherwise be isolated from ongoing support by their remote addresses, are not disadvantaged by distance and can receive the best post-cancer treatment care and support.

The LivingRoom team develops and works through a personalised rehabilitation plan which is delivered via this innovative program.

Using an e-Health platform - accessed on tablet or computer - patients can now enter a virtual room for their consultations

with physiotherapists, dieticians, exercise physiologists and other Allied Health practitioners. By being able to view the patient on screen the doctor or practitioner can also see the patient in person.

Additionally, LivingRoom@Home allows patients to receive their rehabilitation and supportive care services in their own homes with the knowledge of their own GPs and carers.

The initial pilot program was funded entirely by two private foundations and today, with committed ongoing support, LivingRoom@Home will continue as part of the package of supportive care offered at Lifehouse.

Lifehouse sincerely thanks the Curtis Foundation and the Mostyn Family Foundation for their generosity, vision and commitment to ensuring equitable access to the Living Room's innovative support services.

Ring in the next step on the road to recovery

Sarah was the 600th patient to ring the celebration end-of-treatment bell in Chris O'Brien Lifehouse's radiation therapy department. But she had bells of different kind - wedding bells - on her mind when she was diagnosed with breast cancer earlier this year.

Sarah was only weeks away from her wedding when she found the lump. "I definitely didn't think it was breast cancer. I had no family history, I was young, I'd run marathons, and I loved kale."

Her fiancé, Alistair, suggested she visit the GP for peace of mind. "My GP told me that lots of young women get small lumps that are usually nothing to worry about, but that I should get an ultrasound just in case."

When the call came confirming that it was breast cancer, Sarah did not initially understand. "We were in Melbourne when my GP called to give me the results. It was all quite surreal - I was sitting on a tram being told it was invasive ductal carcinoma with positive receptors. I had no idea what a 'ductal carcinoma' was! At the end of the call, I asked: 'so, does this mean it's bad?' She said: 'Yes, it means it's cancer'."

Sarah underwent surgery five days after her diagnosis and healed in time for her wedding which went ahead as planned six weeks later.

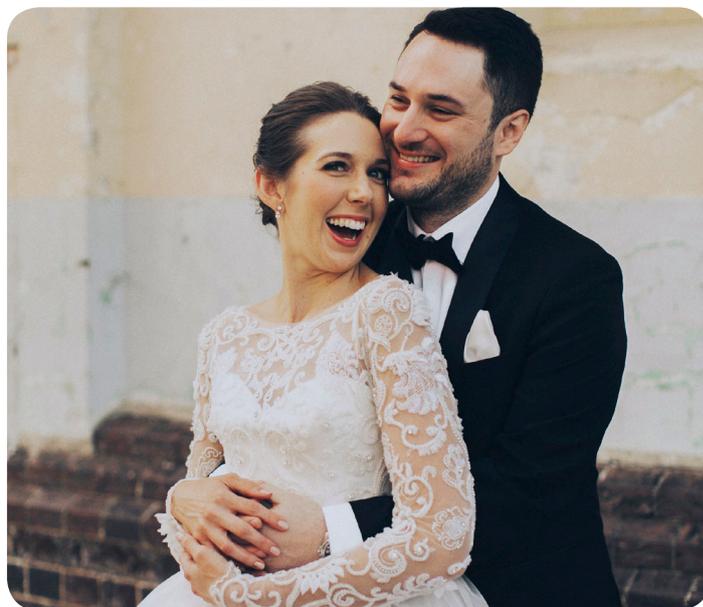
Only days before the wedding she received an unexpected test result which meant that the benefits of chemotherapy would not outweigh the side effects. And so, instead of jetting off on honeymoon, she plunged straight in to six weeks of radiation therapy.

And at the end of May, Sarah rang the bell heralding the end of her treatment.

Ring in a bell at the end of radiation therapy treatment is a wide-spread tradition around the world. The bell is rung to mark the end of a treatment for a cancer patient and the beginning of a new life.

She now has journeys of another kind on her mind. She recently started a new job as a Government lawyer, and is looking forward to a belated honeymoon to California and New York later in the year.

Today Sarah is as comfortable talking about breasts as she is about brunch and hopes that sharing her experience will serve as a reminder of the importance of self-checks. "Don't think you're too young, you're too fit, your genes are too good, or you're too busy."



Wedding Photography by Dan O'Day



Scott Reading

A marathon effort to give back to Lifehouse

We're thrilled to welcome the first-ever marathon runner to support Lifehouse. Self-proclaimed Hip Hop Scholar Scott is 43 and will be joining thousands of runners on the Sydney Harbour Bridge for the Blackmores Sydney Running Festival on 17 September.

"I've completed two half-marathons before but never a full one. When I found out that I would be the first marathon runner to represent Lifehouse, I had to do it, nothing was going to stop me.

"Choosing Lifehouse was the easy part. In July 2002, I was diagnosed with testicular cancer. After surgery, I was referred to Prof Michael Boyer. Three months later, I was diagnosed with lung cancer. I went through nine weeks of chemotherapy and thankfully, was cancer free by December 2002.

"I had regular check-ups for the first 10 years afterwards and can gladly say I've been cancer-free for 14 years. I owe everything to Prof Boyer and the team at Lifehouse.

"By running for Lifehouse, I hope to bring attention to the wonderful work it does every day to save lives like mine."

You don't have to be a marathon runner to join the running festival. Options start with a fun, family run of 3.5km. There's something for every type of runner.

Join Scott here:

<https://donate.grassrootz.com/blackmores-sydney-running-festival-2017/chrisobrienlh>

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.



Walk with Lifehouse 14 October 2017

Walk With Lifehouse is a one-day, 28km coastal trek from Otford Lookout to Bundeena through the stunning Royal National Park. We are delighted to have Gail O'Brien as our walk ambassador. Gail will be leading a team in this first-ever coastal walk challenge for Lifehouse on Saturday 14 October.

"Having grown up in that area, I know how beautiful and unspoiled the coastline is – I often take my 90-year-old father there, to smell the sea, look at the horizon and have the chance to put his feet in the sand.

"I know from my event participation in the past and now in my role as Patient Advocate, the camaraderie between supporters is extraordinary with everyone doing it for their own reasons. I have learned that every person has their own story, each of them so powerful, and I look forward to hearing them and meeting new friends on this trek."

If you and three of your friends would like to join Gail on Walk With Lifehouse on Saturday 14 October, contact our Community Fundraising team on 8514 0006 or email fundraising@lh.org.au for more info - we look forward to hearing from you.

www.mylifehouse.org.au/team-lifehouse/walk-with-lifehouse

Blackmores Sydney Running Festival 17 September 2017

The 2017 Blackmores Sydney Running Festival is an iconic event with a spectacular course that includes a run over the Sydney Harbour Bridge and a finish at the Opera House.

www.sydneyrunningfestival.com.au/

Bowral Classic 22 October 2017

A one-day Gran Fondo Cyclo-Sportif held in the pristine Southern Highlands, centred around Bowral.

www.bowralclassic.com.au/

Outback Trek 2018 7 – 13 May 2018

Imagine a journey that takes you right into the heart of Australia, across the ochre-coloured landscapes of the Red Centre. The Challenge Lifehouse Outback Trek is your chance to see the real Australia, and raise funds for Chris O'Brien Lifehouse.

inspiredadventures.com.au/events/challenge-lifehouse-outback-trek/

I tell everybody now, get checked regularly

Music lover Arthur St Clair loves bringing his old rock 'n roll records out for a spin. He notes that they are getting popular again, as a result of younger people getting into rockabilly.

Lifehouse monthly donor Arthur is a 72-year-old retiree. He went for a routine medical check-up in 2014 and received some irregular blood test results. A few more tests confirmed prostate cancer.

Arthur is grateful that the cancer was discovered early. "I had a positive outlook. If you've got it, you've got it and you just get through it." He thinks this is what made him popular with the staff in radiation therapy.

"I tell everybody now, go and get checked! You can be walking around thinking that you are healthy. The bloke next door asked me a few questions and he went and had a check. He's on prostate treatment now. Like me, they got him in time."

Arthur is grateful for the treatment he received and that he now only comes to Lifehouse for check-ups. "Most of my family has had cancer. I can't give much but I want to give something in return for all the care."

If you would like to learn more about our monthly giving program, please contact Goldia Shum on (02) 85 14 0626 or goldia.shum@lh.org.au

A new first for Simone

We are so delighted for proud mother Simone Georgiou who has announced the arrival of Zoe, her baby girl. We met Simone back in 2015 when she was our first ever ICU patient, following surgery for bowel cancer. Simone overcame considerable obstacles placed in her path by bowel cancer treatment as she moved towards having her own family. She is now a crusader for raising awareness around bowel cancer and the importance of early diagnosis.



Giving hope to patients with advanced gynaecological cancers

Marcelo Nascimento, Lifehouse's newest Professor of Gynaecological Oncology, is eager to deliver on the trust placed in him by you, our supporters. "I'm very grateful for your support. I see myself as an instrument to come back to the community with new treatment options so that we can give patients more hope," he says.

Marcelo's position is made possible through two matching major gifts. He and his family are from Porto Alegre in southern Brazil and have moved to Sydney from Queensland. "We like cold weather so we were happy to come to Sydney."

One of the attractions of Chris O'Brien Lifehouse was to work with the newly formed Peritonectomy team and after having the access to an extensive database and the ability to dedicate time to research and teaching. "We are treating women with advanced disease and following them closely to see if we are heading towards the right answers."

Marcelo is especially interested in a treatment that combines surgery to remove cancer implanted on the peritoneum, an internal lining in the abdominal cavity, like ovarian cancer, with chemotherapy delivered to the patient during the operation. Known as heated intraoperative chemotherapy, or HIPEC, this technique has the potential to achieve better outcomes for cancer patients. Further chemotherapy may be delivered post-operatively as part of a treatment plan, but it is thought that this one crucial shot delivered during the operation is the one that may make a difference to a patient's survival.

"There is a lot of research underway and we don't have all the answers yet but this technique has the potential to be a huge development in cancer treatment," says Marcelo. "This is why I came here, it's an exciting time."

"I'm very grateful to be part of a multidisciplinary team made up of medical oncologists, specialist nurses and allied health that is able to give hope to patients who otherwise may not have any."



Marcelo Nascimento



What will your legacy be?

Your Will is your opportunity to leave a lasting legacy. Not only does it allow you to ensure that your loved ones are taken care of, it also gives you the chance to make a difference to the lives of others.

Did you know that if you don't have a valid Will your estate may not be distributed in the way you hope? This can result in extra costs in finalising your estate and can potentially cause family conflict.

To help answer your questions about planning your estate, we have partnered with Thomson Geer Lawyers and Perpetual Trustees Estate Planners to host a free Wills and Bequests Seminar.

Lifeshouse CEO Eileen Hannagan says, "Deciding how you want your estate to be distributed brings great peace of mind and I'm delighted to draw on the expertise of our legal partners to answer questions people may have about Wills and bequests."

The free seminar will cover a range of topics including different types of Wills, estates and tax law, the role of an executor and how to leave a charitable legacy. It will be held at Lifeshouse on Friday 15 September from 3:00pm – 5:00pm.

To book your place or find out more, contact Alison Muir on (02) 8514 0356.

www.mylifeshouse.org.au/bequests/

Keeping one nurse's passion for education alive

An In Memoriam gift is a thoughtful way to remember someone and a way to ensure their legacy lives on to help others. Some choose to set up a Memorial Fund as a tribute to their loved one.

One such fund is the Anne Marie Griffin Fund. Anne Marie Griffin was a dedicated chemotherapy nurse who was passionate about nurse education. Sadly, she died from breast cancer in 2010. The Griffin Family created the fund to honour her life and her passion.

This fund provides scholarships to support ongoing education of cancer care nurses at Chris O'Brien Lifeshouse. Enhancing the knowledge and experience of our nurses helps us to provide a better experience for our patients and continually raise the standard of care within our hospital.

Anne Marie would be so proud to know that her legacy lives on to support nurse education.

To learn more, contact Stacy Barnard on (02) 8514 0621.

www.mylifeshouse.org.au/in-memoriam

YES, I WANT TO HELP

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 Lifeshouse.

\$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 Lifeshouse. 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 Lifeshouse in my Will.

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

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

*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 WITH BRAIN TUMOURS.