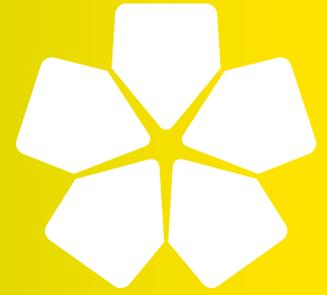


2011

Winter Update



The Chris O'Brien Lifehouse at RPA



James, Chloe and Kara Conry.

Kids make a difference for their mum

TINA Conry began each day with the energy and determination of a seasoned runner. Sadly, Tina's race to beat stage 4 melanoma ended in May this year.

Mother of James, 11 and twins Chloe and Kara, 10, Tina always encouraged her children to participate in a vast array of sporting activities. "She managed the kids' soccer team and was so involved with school events that new teachers assumed Tina was on staff," says Gemma Hawkins, a close friend of Tina's.

While undergoing chemotherapy treatment last year, with husband Craig by her side, Tina noticed a number of fellow patients on their own, without even a book to pass the time. "An avid reader herself, Tina wanted to raise money to purchase books and other practical items for the chemotherapy suite patients and their families," says Craig. "She was always thinking about other people, even while undergoing cancer treatment herself.

"When the person you love most in this world passes away it can be easy to feel let down but I want Tina's medical team at Sydney Cancer Centre to know how much we appreciated all they did for her. We know that they never stopped trying."

James, Chloe and Kara have proudly established Team Tina – a group of family, friends and students who participate in sporting events to raise funds for cancer care and research. The children are looking forward to participating in the Sun-Herald *City2Surf* for the first time on August 14.

"Team Tina is great because I want to raise money to get rid of

this disease," says James. Chloe agrees. "It is good to support Lifehouse so one day other families don't have to go through what we are going through."

"And Team Tina is really fun," adds Kara. "We get to raise lots of money to help people who have cancer."

The children continue to receive counselling through the Sydney Cancer Centre and are being supported by Craig and a close group of family and friends. "It's good for them to be involved in these fundraising events," says Craig. "It allows them to have some control, raise awareness of melanoma at school and provides an outlet to talk about their mum."

Team Tina expects to have 70 people take part in the *City2Surf* this year and has a fundraising goal of \$14,000. "Tina wanted the money raised to go to The Chris O'Brien Lifehouse at RPA," says Craig. "She read his book, *Never Say Die*, and loved watching Chris on Channel 9's RPA program."

The Conry family and Team Tina will support Lifehouse further by wearing branded running shirts on the day, to raise awareness of the new facility. We wish all team members the best of luck – thank you for your fabulous support.

Unique charitable project takes off

OVER the last 12 months The Chris O'Brien Lifehouse at RPA and ACP Magazines have collaborated on **LifeSupport**, an everyday guide to living with cancer.



The magazine is a pro bono project for ACP and covers not just medical issues but financial matters, dietary advice, relationship support, ideas on how to manage side effects, information for carers, thoughts on the challenges of survivorship and much more. **LifeSupport** involved the support of cancer groups nationally and the participation of dozens of healthcare professionals, together with patients, their families and carers. The publication features many inspiring real life stories from cancer patients all around Australia.

Lifehouse is incredibly proud to have initiated this project. **LifeSupport** is available in newsagents for \$7.95 or visit www.lifesupportmagazine.com.au

CEO Message Timothy Dugan



HELLO, and welcome to our Winter newsletter and supporter update.

Work on The Chris O'Brien Lifehouse site has really taken off since I last wrote to you. A new section of tunnel between RPA and the Radiation Oncology Facility has been completed and excavation should be completed by the end of July.

We are about to sign a contract for the main construction works, which are due to commence in August. This is a major milestone in the project and we expect to see the new building out of the ground by the end of this year.

With the new facility works now tendered and underway, there will be an increased focus on the organisational design of Lifehouse and its culture. As I have said previously these aspects of Lifehouse are every bit as, if not more, important than the physical facility. We will have up to 400 staff working at Lifehouse and we want to make sure that they feel passionate about the organisation and proud to be part of it.

I am also proud to be able to announce the launch of a new magazine for cancer patients, carers and supporters. **LifeSupport** is an initiative of Lifehouse at RPA and is a magazine for the cancer community of Australia generally. This unique publication would not have been possible without the support and contribution of many organisations and individuals, including ACP, who got behind the idea from the outset. ACP kindly provided their time and resources on a pro bono basis and we are very grateful to all involved.

Staff at Sydney Cancer Centre, including Radiation Oncology, continue to devote their time to all aspects of planning the new Lifehouse organisation and culture, and we are extremely appreciative of their magnanimity.

Kind regards,

Timothy Dugan

Chief Executive Officer, The Chris O'Brien Lifehouse at RPA



Second anniversary Chris O'Brien memorial luncheon



Her Excellency Professor Marie Bashir AC CVO, Governor of New South Wales with Mrs Gail O'Brien and emcee Peter Overton.



Supporters Harry, Rod and Diana Mitchell.

WE would like to extend our deep appreciation to Guillaume Brahimi, who graciously offered his restaurant *Guillaume at Bennelong* for a commemorative lunch to mark the second anniversary of the passing of Professor Chris O'Brien AO.

It was an honour to have The Hon. Gillian Skinner MP, Minister for Health and Minister for Medical Research provide the keynote address at the event. Lifehouse is very grateful to have the NSW Government's support for this important project. We were also honoured to have our Patron, Her Excellency Professor Marie Bashir AC CVO Governor of New South Wales, speak at the luncheon.

Thank you to our wonderful sponsors for their support, in particular Drs Sansom, Air Mauritius, Grand Mauritian, Neil Perry, Matt Moran, Peter Griffen, Trimex, Flavours From Afar, Laurent Perrier and Winestock for their generosity. We appreciate the efforts of the SHNCI Committee. Finally, our deep gratitude to all the guests who attended the lunch which raised over \$140,000. We so appreciate the opportunity to engage you in the genesis of something truly innovative for the benefit of all Australians.

A clarion call from across the Nullabor

VINCE Paparo, an environment and planning lawyer now living in Perth, was first treated at Sydney Cancer Centre for nasopharyngeal cancer in 2004. Six years after his recovery Vince noticed concerning symptoms and unfortunately recently received a diagnosis of a recurrent tumour.

“I initially started down the path of having treatment in Perth but at the urging of my children sent my MRI results to Dr Tin, radiation oncologist at Sydney Cancer Centre who had treated me back in 2004 when I lived in Sydney. Dr Tin rang me on my mobile as soon as she saw the scans.”

Vince says he was immediately taken by Dr Tin’s approach, her humanity, sense of hope as well as her undoubted expertise and experience.

“She told me that my tumour was in a dangerous position but that we could come up with a good plan for treatment. She said let’s go for broke, I had nothing to lose. There was something in her voice which was so compelling, like a clear call across the Nullabor telling me I needed to go back to Sydney for treatment.”

It all then happened quickly, with Dr Tin arranging scans and consultations. Within 2 weeks Vince had relocated and started treatment in Sydney. He says he feels like he has come back to a family for his treatment.

“I just feel that they are on my side. I have total trust and confidence in (radiation oncologist) Dr Tin and (medical oncologist) Professor Boyer and their wonderful teams. When I saw Keith Cox, the chemotherapy nurse practitioner again after all these years, he said ‘We haven’t changed a bit, have we Vince?’ “

Now living in Perth, Vince wasn’t aware of the plans for The Chris O’Brien Lifehouse at RPA before his current visit. When he first arrived, he says he noticed the excavation underway and hoarding around the site. “When I saw the statement about Lifehouse on the hoardings, ‘We treat one type of cancer – yours’ I couldn’t help but point it out to my family; it is such an accurate reflection of my experience here.”

Vince has noticed considerable advances in cancer treatment



this time round. “The scanning techniques are more advanced, the focus of radiation therapy is more targeted and precise and I’ve noticed nausea is more controlled with the chemotherapy drugs now used. But having cancer treatment is just like the legal profession – the law makes up only half of it and the rest is about people.”

Vince says he has been able to focus on his spirit and soul, and his medical team on his treatment. But he notes that his medical team has also provided him with great comfort and support on his emotional journey too.

In July, Vince and his wife Chris will travel to London for the wedding of their eldest son Joshua – the first of their five children to be married. Vince’s medical team is focused on the best possible outcome for him in preparation of this special event.

“They are constantly referring to the wedding, speaking to one another with this goal in mind, suggesting the best way to deal with side effects of the treatment and manage symptoms in the lead up to the flight. They keep telling me I should upgrade to premium economy,” he laughs. “They are just thinking of my future and want to be involved – it’s a privilege to feel that.”

Vince quotes a line from the Bob Dylan song Mississippi. “‘You can come back, but you can’t come back all the way’. I’m no longer sure Bob was right on that one,” he says. “Maybe, sometimes, you can come back even further.”

We wish Vince and Chris all the best and congratulate Joshua and his wife-to-be Louisa on their upcoming nuptials.



Transport now in operation for patients

KIA Motors has kindly donated a *Grand Carnival* to transport patients of the Sydney Cancer Centre to and from their treatment sessions. The transport service is manned by volunteers and operates each weekday for patients undergoing radiotherapy or chemotherapy.

Celine Crowther, volunteer coordinator at Sydney Cancer Centre says, “The service provides convenient, complimentary transfers for patients who have no other means of attending their appointments.”

There are also plans underway to operate a service to nearby Central Railway Station if there is enough demand, connecting patients from regional NSW. This Lifehouse at RPA initiative enhances and extends the patient care offered by the Sydney Cancer Centre. We are very grateful to Kia Motors for their generous support.

Medical Director's Message Professor Michael Boyer AM



THERE is a palpable sense of excitement amongst Sydney Cancer Centre staff about the new Lifehouse development and what it will mean for the patients of tomorrow. Despite this, we remain firmly focused on today's patients and continue to work hard to provide them with the very best possible care. Our job is made easier as a result of the backing that we receive from those of you who so generously donate to The Chris O'Brien Lifehouse at RPA. Some of these funds are provided to the Sydney Cancer Centre each year in the form of grants, which support numerous important ongoing programs.

One such program is the psycho-oncology program, which provides counselling and support services to our patients and their families. This program is partially funded by the NSW Cancer Institute, but a substantial increase in the funding provided by Lifehouse will see it become the major funder of

this valuable service. Over the past 12 months almost 1,000 patients have benefitted from sessions provided by two psychologists and a social worker. As a result of your support, an additional psychologist and a psychiatrist will join the team later this year, allowing even more patients to benefit.

The psycho-oncology program incorporates the Information and Support Centre and the Volunteer Program, which are wholly funded by grants from Lifehouse (and of course also rely on the tremendous contribution made by our team of 70+ volunteers). Each year, literally thousands of patients benefit in a range of ways including: access to a library of cancer related material; internet access and assistance with searching for information; the provision of volunteer transport; a tea and coffee service in our waiting rooms; and a range of workshops.

These are just some examples of how your support helps us to make the cancer journey for our patients just a little bit easier. I'd like to thank you for your past support and encourage you to continue to partner with us to allow us to help even more people in the future.

Michael

Professor Michael Boyer AM

Director, Sydney Cancer Centre and The Chris O'Brien Lifehouse at RPA

Friends unite for Sydney Half Marathon fundraiser

GEMMA Wald and Amy Nixon were training up to four times a week in the lead up to the Sydney Half Marathon held on 15th May. It was Gemma's first ever half marathon and she chose to raise funds for The Chris O'Brien Lifehouse at RPA in honour of her late father Neal Wald, who was a patient of the Sydney Cancer Centre.

"Dad's doctors did such an incredible job – Professor Boyer, Dr Milross and Dr Clarke – and they were so good to my family as well. This was a way to thank them, give back a bit, and raise money for future cancer care. It was also good to challenge ourselves, and of course training with a friend is inspiring. It's easy to stay motivated when you believe in a good cause."

Gemma works for the Westfield Group and was overwhelmed by the incredible support she received from her colleagues. "Amy and I created an online fundraising page and sent the link to everyone we knew, asking them to support us," she says. "A large majority of donations made came from co-workers at Westfield. It was just fantastic."

The pair entered under the name 'The Waddlers' and were the second-highest online fundraisers for the event. More than \$7,000 was raised by the duo for the Lifehouse project. The money will also contribute to cancer patient care, research programs and equipment purchases for the Sydney Cancer Centre.

In addition, Gemma's family is making plans to provide a



Lifehouse fundraisers Gemma Wald and Amy Nixon.

fellowship grant for research into parotid gland cancer, which Neal was diagnosed with in 2007.

"Amy and I want to say a big thank you to our families, friends and colleagues for supporting us, and in turn supporting the Lifehouse project," said Gemma, who is off to Africa in a few months to climb Mt Kilimanjaro.

We wish her all the best for her upcoming trek.

Determination and a trial drug works for lung cancer patient



Caroline, husband Simon, and daughters Ava and Claudia.

A FEW weeks before Christmas in 2008, Mosman marketing executive and mother of two Caroline Bernardi was diagnosed with lung cancer.

“It was surreal,” says Caroline, who was 44 at the time. “I recall delivering Christmas presents to my clients in the morning and then at 3.00pm finding out I had inoperable cancer. The following day I was told I had a less than 5% chance of surviving more than 12 months. During the course of one day our lives changed forever.

“I hadn’t had any physical symptoms, however, for months I’d had this feeling that something wasn’t right and kept returning to my GP’s office for check-ups, insisting I had cancer somewhere in my chest or head area. I just had this overwhelming instinct that I had cancer. My GP continued to ask about symptoms but I never had any. She finally agreed to refer me to an ear, nose and throat specialist but made me promise I’d accept the findings and not dwell on a hypothetical illness anymore.

“And eventually, after a CT scan and biopsy I was told, ‘Actually Caroline, you are right’.

“Our lives were devastated. My friends told me I was going to be alright but I didn’t believe them. I wasn’t an especially positive person and I wondered how I could possibly fight this and live.”

Caroline’s primary tumour was in her right lung but by the time she was diagnosed it had spread to both lungs and into her bronchus and neck. She was told her prognosis was very poor.

Caroline and her husband Simon decided to tell their daughters, aged six and 10 at the time, only as much as they thought the girls could handle. Their eldest daughter Claudia had recently finished a school project about the effects of smoking. Caroline says she was determined to make sure they knew that her illness wasn’t from smoking.

“I was immobilised by fear,” says Caroline. “I was terrified to go to sleep at night because waking up to face the nightmare

again was unbearable. It was the emotional torture of leaving my children and husband alone that I found so difficult. I was consumed by thoughts like, ‘Who’s going to do the girls’ hair for ballet?’”

Working for a hotel group at the time, Caroline says she went from giving presentations to large groups of people at conferences, to not being able to go to the supermarket to buy milk. “I was just a shell of myself. Some days I had to physically force myself to get out of bed. It took several months to even start to comprehend the diagnosis.”

At a friend’s urging, Caroline went to see Professor Michael Boyer at the Sydney Cancer Centre. Over the next few months, Caroline underwent several rounds of chemotherapy, began to eat an organic diet, started learning about meditation and tried Chinese medicine. “But I felt the missing piece of my personal puzzle was to participate in a clinical trial,” she says. Previously Caroline had been told there was not a suitable trial underway for her particular type of cancer.

“Unfortunately I didn’t respond to the chemo,” Caroline says. “Professor Boyer admitted it hadn’t done the job he’d wanted it to, but he did find a suitable trial drug for my type of cancer. I was immediately convinced this was the right path.”

The drug was taken in tablet form three times a day and resulted in many side effects, including diarrhoea, mouth blisters and an acne-like rash. But Caroline said she could feel the tumours in her neck starting to soften after just 5 days of treatment.

“I’ll never forget going to see Professor Boyer at the eight week mark, after I’d had another CT scan. He began flicking through the results very quickly, pointing and saying ‘it’s gone, it’s gone’.

“Simon and I were both floored. We were staring at him in disbelief for a long time. I asked him what my reply should be if someone asked me if I had lung cancer. He said that I could say I had it, but I don’t have it anymore. The cancer had completely disappeared!

“The impact hit during the night when I realised I didn’t have to worry about when I was going to die anymore. Now I could think about making the kids’ lunches and taking the car in for a service and deciding what to cook for dinner. The worries of day-to-day life are so beautiful.

“It was the trial drug of course, but also my determination. My life and my outlook are completely different now. This will sound bizarre,” says Caroline finally, “but if I had my time again I would still want to have gone through all this because it’s changed me as a woman, a mother, and a wife. I have a new respect for myself and I want to help others feel the same way.”

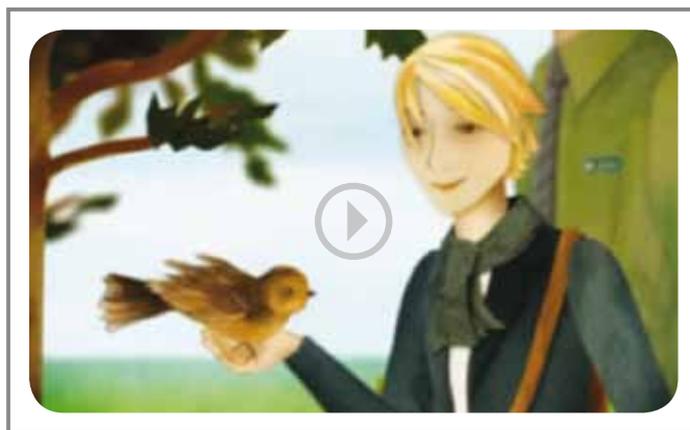
Caroline now teaches meditation and talks to people who have been diagnosed with cancer. She will participate in The Sun-Herald *City2Surf* in August, raising valuable funds for Lifehouse for the second consecutive year. We wish Caroline well and thank her for sharing her story.

Lifehouse launches new animation

A TWO and a half minute animation depicting the future experience of cancer patients at The Chris O'Brien Lifehouse at RPA has been created and launched on YouTube. It highlights some of the challenges in today's healthcare environment and contrasts how the delivery of cancer care will look tomorrow.

Dealing with a cancer diagnosis is shocking, confronting and all too often confusing. We want to make things easier for people with cancer – and for their friends, families and carers – by advancing the understanding, diagnosis, treatment, care, cure and prevention of cancer.

Internationally, integrated cancer centres are recognised as the ideal delivery model for optimal cancer care. They provide the best possible outcomes and support for survivors, along with hope, empowerment and medical advances through research and education. Lifehouse aims to achieve lasting change in the way we treat and prevent cancer in Australia. By bringing cancer research, treatment, care and support into one centre,



we can offer truly uncompromising care.

This animation has been created to visually reveal what that uncompromising care will look like. Visit our Lifehouse at RPA YouTube channel and take a look.

Thank you How you are helping

LIFEHOUSE wishes to thank the following generous supporters for their fundraising efforts and recent donations*:

- Nuttalex Food Products \$95,000
- Maple-Brown Family Charitable Foundation Ltd \$50,000
- Mr John Thame \$36,000
- Carinya Manufacturing Co. Pty Ltd \$25,000
- Mrs Wendy Pratten \$25,000
- Mrs Helena Waters \$13,000
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- Nedigi Pty Ltd \$10,000
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- Abey Family Foundation \$10,000
- Mr Anthony Cripps \$10,000
- ANZIIF NSW Annual Charity Luncheon \$7,233
- The Manildra Foundation \$5,000
- Mrs Mary Birchill \$5,000
- The Berg Family Foundation \$5,000
- Mr Kenneth Gyde \$4,000
- Canterbury BMW Annual Golf Day \$3,800

We are also grateful for numerous contributions made In Memory of:

- Mr Adam O'Brien
- Mr David Clarke AO
- Mr Dennis Buckland
- Mr Ronald Kitchen
- Mrs Maria Calabrese
- Mrs Helen Sirakas
- Mr George Toohey
- Dr Patrick Twomey
- Ms Judith Irene Quinlan
- Ms Josie Danckert
- Mr Mark Tankey

Thank you for donations received In Celebration of:

- Nick Murray's 50th birthday
- Gail Barnes' birthday

*as at date of going to print



A big thank you to Zena Sutton, owner of the *Have To Shop* boutique in Gladesville, who arranged a fashion parade and Latino dance party fundraiser in March with \$9,000 in proceeds donated to the Sydney Head and Neck Cancer Institute. The event was generously supported by Linda Sharp, Brian Geach and The Elite Cruise Company.

We look forward to keeping you updated on the progress of Lifehouse.

If you would like to receive our quarterly newsletters by email rather than mail (and help us save on administration costs) please sign up to our e-newsletter at www.lifehouserpa.org.au or phone us on **1300 852 500**.

Thank you for your continued support.