

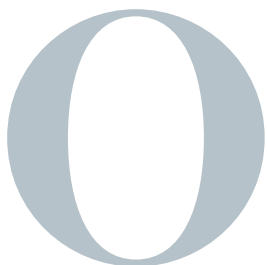


Just days after her 50th birthday, **Julie Randall's** world was turned upside down. This is how she **fought her way** onto a trial cancer treatment – that **saved her life**

BY JULIE RANDALL FROM THE BOOK *PATIENT 71*

*At home in Sydney
with the family
dog, Roxy*





On Thursday 21 June, 2012 I was on top of the world. It was the last day of my working week at the marine rescue organisation in Sydney, and my colleague Delfina and I were being taken to lunch by one of the directors. Life was good. I'd just celebrated my 50th birthday and was thanking the universe for my wonderful life, my beautiful husband, daughters, sisters, brother and dad.

After lunch I suddenly didn't feel right. I sat at my desk and the next thing I remember was lying on the floor and someone was shouting my name. When I opened my eyes I saw two paramedics hooking me up to a device. The nausea was intense. I can't remember ever feeling so sick.

I was taken to St Vincent's Hospital where I had an MRI scan and was told I had a brain tumour. At best, it was benign and I would require brain surgery. At worst, it was malignant which meant I had cancer. They needed to do a CT scan to check the rest of my body.

The next afternoon a doctor walked into my hospital room with the results of the CT scan. "You have tumours in your brain, liver, lungs, pancreas and lymph nodes. Basically, you have advanced cancer. It's not good news."

I was stunned, shocked, in disbelief. I was told I'd need further tests to find out what type of cancer it was, but for now I could go home.

"This can't be real," I murmured to

my husband, Scott. But it was. We had to go home and tell our two daughters, Morgan, 19 and Remy, 16. When I delivered the news they were distraught, so I promised them I would live.

We were facing an uncertain, terrifying future. Instead of overseas travel we would be travelling to doctors' appointments, scans, cancer treatments and blood tests. There would be sickness and hair loss. I knew what I was in for because both my



"I think I can get this out without too much damage. Go home, pack your bags and be at the hospital in two hours"

mother and sister had been through it. My sister survived breast cancer twice, but my mother, Beryl, died when I was 39.

The following Thursday I had an appointment with an oncologist: my third medical appointment since the seizure seven days before. "You have melanoma," he said and referred me to a melanoma professor, who told me I had stage four advanced metastatic melanoma and there was no cure. "I'm very sorry," she said.

I needed to have the brain tumour removed urgently, and she made us an appointment with the brain surgeon for the next day.

Dr Brian Miller put my X-rays on the lightbox. "I think I can get this out without too much damage. But there is always a risk of complications," he said. "Go home, pack your bags and be at the hospital in two hours. I will operate in the morning."

After the surgery I made an appointment for radiation treatment to the site where the tumour had been removed.

In a little over two weeks I had turned 50, had a seizure, been told I had stage four advanced cancer with no cure, had a brain tumour removed and was lying in intensive care with 16 staples in my head. My face was bloodied, bruised and a bandage was wrapped around my head. Dried blood was everywhere. I looked like a front-row rugby player.



Julie at her first chemotherapy treatment in Sydney

THE 35 PER CENT CLUB

The only treatment available for my cancer was a chemotherapy drug called Dacarbazine, which had a ten per cent chance of response. It was not a cure and had many side effects. I didn't want chemo, but I had to do something to slow down this thing until I could work out a plan for survival.

It was now almost a month since the seizure, yet it felt like ten years.

At my next appointment with my oncologist, he told me about a chemo combination therapy he'd heard about in the USA, which uses Abraxane (a breast cancer drug) and Pazo-



Julie, wearing a hairpiece and scarf, with her daughters Morgan and Remy

panib (a kidney cancer drug). It had been tested in a small clinical trial of 40 melanoma patients in Germany and around 35 per cent of patients responded. Some had even had extensive shrinkage of their tumours. The drugs weren't readily available in Australia, but he could order them in and I could get started with treatment – which would mean total hair loss and all the usual chemo side effects.

We went home with a tiny bit of hope in our hearts ... until we got a call from the melanoma professor. She called and said she was happy for me to take the combination therapy prescribed by the oncologist, but “it wouldn't change my life expectancy”.

It felt like she'd put her fist through the phone and ripped out my insides!

Besides the radiation treatment to my brain, we also made an appointment with a doctor to talk about radiation to my internal organs. I'd promised myself I would explore every option, only to be told by the doctor: “There's not much point in you having radiation at this stage ... I don't know how long you've got.”

What the hell. Why would she say that? With those words, determination and the will to live manifested deep inside me.

My first chemotherapy infusion was in August – seven weeks after my diagnosis.

That night, I felt a lump on my back. It might sound trivial, but it was a big deal for me. It was the first time this ‘thing’ was a total reality. This thing that was moving around inside my body had now become visible. I was inconsolable.

I was to have chemo every week for



I felt a lump on my back. This ‘thing’ that was moving around inside my body had become visible. I was inconsolable



Left to right: A total of 16 staples were put in Julie's head after the tumour was removed; undergoing radiation therapy

... well, who knew? I would start losing my hair in about the third week of treatment, and I would have a PET (positron emission tomography) scan in six weeks to tell me if I was responding to the therapy.

Fortunately, the scan results six weeks later were good. My tumours were shrinking and some had even disappeared. I had responded! I was in the 35 per cent group that I so desperately wanted to join.

TREATMENT

My oncologist was happy about my results and I was coping well with the chemo. I didn't feel nauseous and I'd managed to keep up my yoga, walking, running and singing. However, after eight weeks of weekly chemo,

I started feeling numbness in my fingers and toes. It meant that my nerves were being damaged by the chemicals.

As the nerve tingling became more distressing, I decided to self-diagnose and change my chemo infusions to fortnightly. I knew the numbness was from the chemicals going into my bloodstream, and if my nerves were being affected, then what else was being damaged?

By late October I had a burning question for my oncologist. "How long will this treatment work for me?"

"Put it this way," he replied, "it won't be working in March."

I felt sick. All those morbid feelings came bubbling to the surface again. We knew this treatment

wasn't a long-term answer. We had been told my condition was a death sentence. Chemo was only a stop-gap, not a cure.

Scott asked him if there were trials anywhere in the world experimenting with drugs for melanoma. He told us there were a few clinical trials overseas and that they had around a 38 per cent response rate but they didn't like taking overseas patients. If we were to go down this path, we would have to do it ourselves.

The second I got home I headed straight for the computer. I googled until I couldn't google any more. It was an absolute minefield. There were so many clinical trials and experimental drugs and treatments. But there was one therapy that stood out. It was called immunotherapy, working with an experimental drug called PD-1 (programmed cell death 1).

A PD-1 trial working specifically with advanced melanoma patients was being carried out in the US. The next day we swung into action and called the nurse coordinating the clinical trial – Daniel Jackson. Disappointingly, the call went through to an answering machine.

Forty-eight hours later I called again and left another message. Finally, one November morning the phone rang. It was Daniel Jackson. He was positive about the trial but confirmed that only a third of patients responded. The study was only in stage one and there would be three stages, so too early

to predict long-term future results.

"How do we get into this trial, Daniel?" I blurted out.

"Well, it's an unusual situation. We have never had anyone applying from Australia before. I'll get back to you." A couple of days later we received an email from Daniel.

Hi Julie,

I spoke to my team and they think there would be a lot of red tape and complications for you to take part in the clinical trial here in Portland.

We have totally different health cover and if you were to have any complications from the treatment you wouldn't be covered under our system. Sorry we couldn't help.

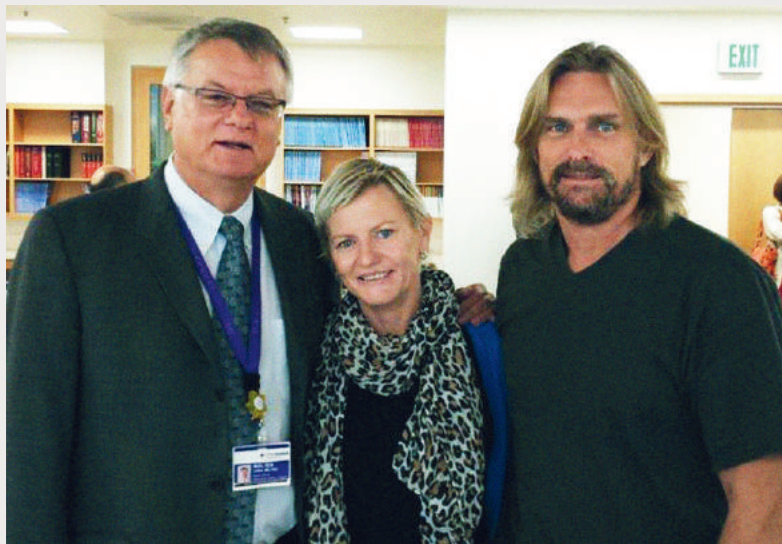
I was gutted. But my determination kicked in. I was going to get into this clinical trial in Portland, no matter what. I fired off another email.

Dear Daniel,

Thank you for your response, but I'm



I was gutted. But my determination kicked in. I was going to get into this clinical trial in Portland, no matter what



Julie and Scott with Dr Walter Urba (left), who was instrumental in starting up the immunotherapy trial

sorry I can't accept your team's decision based on the reasons you gave.

Apart from the melanoma I am fit and healthy. I walk and sometimes run on a daily basis. As for the financial side, if you work out a figure that would cover me for any perceived complications, I would be happy to transfer the money...

PESTER POWER

I told Scott we needed to keep sending emails to show our commitment. I knew I was being annoying and pushy, but I didn't care.

More emails were exchanged without the desired result. Then I had an idea. I would remind them of the

Hippocratic Oath, an oath taken by medical professionals that states (in a nutshell), if there is treatment that may help a person stay alive, then any doctor with access to that medicine is obliged to do so.

A couple of days after Christmas, we got the email we'd been hoping for. The doctor leading the trial, Dr Urba, had agreed to look at my case file to see if I was eligible to take part in the study. They were seriously considering me!

We sent my medical files, and some weeks later the phone rang. It was the Providence Cancer Center in Portland asking which date I would like my appointment with Dr Urba.



Julie having her first infusion of the immunotherapy drug in Sydney

They were taking me! They were giving me a chance at life! We were going to Oregon!

PORTLAND

Scott and I arrived in Portland on 1 March, 2013, ready for my appointment on the fourth. I signed up to the trial for two years, if I made it that far. That was the deal. Two years away from my family and friends.

At the Providence Cancer Center we met Daniel Jackson, the man who had worked tirelessly for me to overcome all the objections and get the all-clear for us to come over.

Daniel looked like he was in his 30s. He chatted about the trial and told me I'd need CT and MRI scans

and a liver biopsy. The thought sickened me; if I had any lesions on my brain I would be going back home.

Next we met Dr Urba, the man who was instrumental in getting this immunotherapy trial off the ground. Dr Urba was about 60 and super friendly. He congratulated us on our tenacity and determination to get ourselves to the US. Something about him made us both fall in love with him immediately.

Three days later Daniel called with the test results. "Your brain is clear. We think you have plenty to work with. We biopsied one of your liver tumours and got the information we needed. We will start you on the drug on Monday."

I went to my room and cried tears of happiness.

The next Monday we were at the cancer centre by 8am. I was first there and last to leave. It was quite the marathon: nine solid hours in the chair. I felt like a lab rat by the end of it. But this was research. I was just a number. I would become known as Patient 71. The trial should have been cut off at 70 patients, but because of all our begging and pleading, they made room for one more. For the first time in my life I was happy to be 'just a number'.

I went to the hospital every day for the first week to have my blood taken and analysed. After the first week I would only have an infusion of PD-1 every fortnight and go in for a check-up once a week. It felt bizarre being so far from home when I only needed to be at the hospital around five hours a fortnight.

By the end of March, Scott had to go back to Australia for the girls. I had an ache in my stomach. The feeling of loneliness was a double whammy: the big hole I felt from a life-threatening illness and the physical loneliness.

Some weeks later Dr Urba asked if I would like to get involved in a project to raise funds for the Providence Cancer Center. I enthusiastically agreed. Feeling useful is so uplifting: I'd spent far too long being focused on myself. The volunteer work involved making videos for the Providence website. They wanted

Scott to be in the videos, too. Scott was excited when I told him over the phone; we were both passionate about giving back.

Scott returned to Portland 14 days' later for my next round of scans. The results would determine if I lived or died.

HOMESICK

"It's a good result but it's not great ... yet. You have had a small reduction in most of your tumours, so we just need to keep going with the treatment," said Dr Urba.

Then I blurted out, "I want to go home, Dr Urba. How can I get this drug back in Australia? I miss my girls, my family and friends." I thought he'd reply with, "Are you kidding?" but he didn't.

He calmly said, "For now you need to stay. But I will do anything I can to try and find a way to get you home."



I felt like a lab rat. I was just a number, 'Patient 71'. For the first time in my life I was happy to be 'just a number'

All too soon it was time for Scott to go back to Australia. My body responded with all those feelings of despair. Then I had an idea. *I will go with him! I'll go after my treatment that week, see my girls and come back for the next infusion two weeks later.*

"Darl," Scott replied when I told him. "We worked hard to get you here, you don't want to stuff it up now."

"I'm aware of that, but what if I don't get to six months? And I am spending all this time away from my family?" Scott didn't have an answer to that.

I called Dr Urba to ask if I could go home and that I'd be back in two weeks. "The drug company won't like it, but you are fit and healthy, besides the obvious..." I hung up and started dancing around the room. I would be home for Mother's Day in May.

That first week at home felt like a day. I squeezed in everyone and everything I could. After two weeks in Australia I returned to Portland and was ready for more of the PD-1 drug,

only to be told I couldn't have it because my thyroid was out of balance.

I was devastated. I had left my husband and children to stay on schedule to get my drug, and I couldn't have it. I could have stayed home!

Later that day Dr Urba called to tell me that the drug had revved up my immune system and "unfortunately it sometimes attacks your thyroid, but this usually means the drug is working. So I think it's a positive sign." Two weeks later, my thyroid levels were good and I had my infusion.

The following week my sisters Michelle and Nicole arrived so they could be with me for my birthday. It was 8 June, 2013. That night we hit the city to celebrate: I had made it to 51!

A couple of weeks later Scott arrived for the next round of scans and the filming of the cancer centre fundraising video. Telling my story was harder than I'd anticipated. Reliving my feelings of my prognosis was traumatic and exacerbated my sense of isolation from my daughters. I decided in that

Update



"I am still having infusions at the Mater as a kind of insurance policy, even though two doctors have said I am cancer free. Immunotherapy drugs are creating hope for cancer patients and I am proud I was part of the science behind it." Julie recently sold film rights to Sunstar Entertainment, makers of *Lion*. She is also an international motivational speaker. For more information visit: www.julierandall.com.au

moment I would sneak home again with Scott after my next treatment.

Along with heartache, this journey had cost us financially. It had become clear that we could no longer afford to keep flying back and forth between Sydney and Portland. This luxury had to come to an end. But, not before I attended Remy's Year 12 graduation and Morgan's 21st birthday party.

I'd been in Sydney for two weeks when Scott announced he'd book my flight to Portland that day.

"You'll have to leave on Wednesday, Darl."

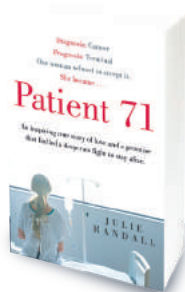
"I'm not going back. I can't. I want to be at home." I knew I was behaving irrationally. Like a spoilt brat. I knew I had to go back. Then something compelled me to turn on the

computer. I noticed an email from the Mater Hospital in Sydney.

Dear Julie,

Your next infusion of Nivolumab (PD-1) will be administered at the Patricia Ritchie Centre at the Mater Hospital in Sydney. Please call to set up an appointment.

I would be staying home with my precious family, for good! **R**



This is an edited extract from *Patient 71* by Julie Randall © 2017. Published by Hachette Australia, RRP \$32.99.



COFFEE NOT ESSENTIAL FOR LIFE

Swiss coffee importers are required by law to store bags of the raw beans. The system of emergency reserves, which includes sugar, rice and edible oils, was established between WWI and WWII as Switzerland prepared for potential shortages in case of war, natural disaster or epidemics.

According to a plan released for public comment, coffee stockpiling obligations would expire by the end of 2022, as "The Federal Office for National Economic Supply has concluded coffee...is not essential for life," the government said. A final decision on scrapping coffee stockpiles is expected in November. Switzerland's mandatory coffee reserves amount to about 15,300 tonnes, enough to cover three months of the alpine state's domestic coffee consumption. **REUTERS**