I firmly believe a clinical trial saved my life

Juliet De Nittis is a 53-year mother of one from Victoria. In early 2019, Juliet discovered she had a tumour big enough to cover her entire left kidney.



When were you diagnosed?

I was diagnosed in February 2019, which was the day before my daughter's 16th birthday. I had to pretend I didn't know.

What symptoms did you have?

Initially a lot of back pain. My period was really heavy and painful, which was unusual as I never had this problem in the past. This was due to the tumour growing so large.

How did you feel when you received your diagnosis?

Initially I wasn't surprised and I thought to myself it will be alright. What I didn't know was that it was actually a rare cancer and that it was aggressive.

My first thought was that they would just take the kidney out. I also wasn't aware that it had spread to my lungs. At this stage I didn't receive a lot of information as there was a big rush to get me started on the clinical trial.

My biggest fear was as a parent, I wanted to be there for my daughter. Especially when they said if the treatment didn't work, I would have a year or two.

Luckily I have well and truly exceeded my expiry date.

What treatment have you had?

I was placed on the UNISoN trial and given a new immune treatment to see if it helped me. My cancer was a rare kidney cancer (non clear cell cancer).

Non-clear-cell kidney cancers occur in about 25% of people with kidney cancer; and because it is rare there are no treatments currently reimbursed in Australia.

When I discussed my options with my specialist Associate Professor David (Dave) Pook he said because of the type of cancer I had, if we had nothing to treat me with, I would be dead.

The medical staff, all of them; doctors, study coordinators and incredible, competent, endlessly patient, fabulous nurses and auxiliary staff at Monash Clayton Clinical Trials Centre are brilliant, kind and professional – vitally important and have helped myself and fellow patients every step of the way through our trial experience.

I firmly believe that the UNISoN trial saved my life.

How did your friends and family help you during treatment?

My friends and family were my absolute support and coping mechanism, although my husband at the time was the opposite, so I left him.

My friend Helen Smith was an incredible support. Not only is she my employer but she has helped in so many ways.

The house that we are actually renting now is all thanks to a work colleague, as it was a house they bought. This is because real estate agents don't like terminal patients signing leases.

As my daughter and family remind me (especially at every birthday since my diagnosis), I may not be important to many people but I am everything to a few people – as we all are!

How are you feeling now?

I'm scared some days, then other days I get really excited and think oh it's all good. Then at the back of my brain there is that fear because it seems and feels too good to be true.

There are still a lot of side effects, which has impacted me not being able to work at the moment. Then I think things could be worse, don't take anything for granted, which is a good thing.

You said you firmly believed the trial saved your life. Can you elaborate on this?

Absolutely, as there was no treatment for rare cancers and for this particular cancer.

The cancer I have is renal cell carcinoma (RCC) with sarcomatoid and extensive rhabdoid differentiation (which is clear and non-clear) which is a highly aggressive form of RCC.

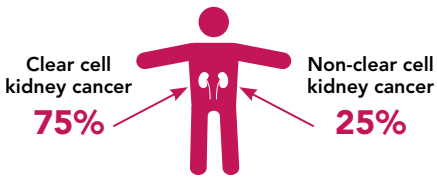
Due to the sarcomatoid being so aggressive and spreading so rapidly, there wasn't anything to combat that. Previous trials looked at normal renal cell carcinoma but not the rare ones.

Ironically it seems to be the actual sarcomatoid is what made the treatment a success. So once the immune system teams are trained they can actually spot it out. Dave has said to me, that I've had a greater success rate than others because of the aggressiveness of it.

So what was the worst-case scenario part and response part of my cancer is actually what saved me. Interestingly, I didn't actually have to have the combination of drugs because the nivolumab was successful on its own, which was originally for melanomas. They discovered that the melanomas didn't come back. Even as I was getting treated, I must have had a melanoma on my hand that disappeared. The connection is incredible.

Is there anything else you would like to mention?

For patients, carers and community to support these clinical trials.



I joined the trial not just with the hope the treatment may help me in some way but also to contribute to research for future cancer patients, and with enormous gratitude for previous cancer patients who have participated in trials that have led to my current treatment, including much loved family and extended family members.

I was completely surprised by the success I have had. You definitely wish for it but you cannot allow yourself to truly believe it! I have been incredibly lucky in that my tumours responded to the experimental drug and they have been stable since December 2019.

To emphasise my point, I found out some really bad news that my step dad has just been diagnosed with cancer. I was upset but at the same time my first thought there may be a clinical trial for him? It gives you hope. When there's no hope it really does give you hope.

Juliet's doctor was Associate Professor David Pook

A/Prof David Pook specialises in the treatment of prostate, kidney, bladder and testicular cancers. He is the principal investigator on multiple international clinical trials treating urological cancers with experimental drugs including novel combinations of immunotherapy.

He is a clinical research fellow in the Prostate Cancer Research Group at Monash University where he helps develop prostate cancer models which can be used to test novel treatments. He is also the Deputy Chair of the Kidney Cancer Subcommittee of the Australia and New Zealand Urological and Prostate Cancer Trials Group.

What is happening with kidney cancer rates in Australia? Both people diagnosed and survival rates?

Kidney cancer has become increasingly more commonly diagnosed and survival rates continue to improve. Kidney cancer is the 7th most diagnosed cancer in Australia.

How many people every year are diagnosed with kidney cancer?

In 2020 it was estimated there were 4,193 new cases of kidney cancer diagnosed (2,755 males and 1,438 females). Kidney cancer is rare in people under 40 but risk does increase with age. Also, men are almost twice as likely to be diagnosed with kidney cancer as women.

What symptoms should people look out for?

Most people with kidney cancer have no symptoms. Many are diagnosed with the disease when they see a doctor for a different reason.

Symptoms may include:

- blood in the urine (haematuria);
- pain or a dull ache in the side of lower back that is not due to an injury;
- a lump in the abdomen;
- rapid, unexplained weight loss;
- constant tiredness;
- fever not caused by a cold or flu.

What are some of the clinical trials that you are working on at the moment?

I am testing a drug called cabozantinib in rarer types of kidney cancer (non clear-cell) which are no longer responding to immunotherapy. This is important as there are no funded treatments for these types of kidney cancer in Australia. I am also involved in testing immunotherapy as a preventer of cancer returning after surgery. This is exciting as a recent trial has shown that this is effective.

What are you most excited by with regards to kidney cancer treatments?

It is exciting to be able to say kidney cancer treatment is now at a transition point. For a while, treatment options for kidney cancer included surgery alone. We now have more to offer as a standalone treatment or in combination. Targeted therapies are now being used and target specific molecules in cells to block cell growth. We are now also well aware of the role immunotherapy plays in cancer treatment and are excited to be part of clinical trials of immunotherapy in kidney cancer. Current trials will allow us to understand how this form of treatment will benefit patients with kidney cancer – both the rare and common forms of the disease.

Immunotherapy works to enhance the immune system of your body. Antibodies can now be given to take "the handbrake" off the immune system by blocking so-called checkpoints. This allows the immune system to attack kidney cancer and for the first time we have seen kidney cancer disappear in some patients.

We are eager to explore how immunotherapy can be integrated with existing therapies and current treatment combinations. Clinical trials in immunotherapy allow us to test various combinations of this type of treatment to try to increase the number of patients who respond well to treatment.

Developments have been happening in other cancer areas. Better understanding of biology has allowed the use of precision medicine which is now filtering through to kidney cancers. This is taking time as kidney cancer does not exhibit a lot of DNA mutations which can be targeted by medicines. Clinical trials and ongoing research will enable us to search for more alterations in cell function which may be targeted by future medicines.

All the research being undertaken suggests we will witness a rapid increase in the number of available kidney cancer treatments in the next year or two, leading to some people having very positive outcomes from their kidney cancer treatment. At the same time, it is likely that more targeted immunotherapy treatments that are now being tested in other cancers will be modified for use in kidney cancer and enter clinical trials, further improving outcomes in the years to come.

What advice would you give to people with regards to preventing kidney cancer?

Not smoking or quitting smoking. Up to one third of kidney cancers are thought to be due to smoking. Not ignoring symptoms such as pain, weight loss or blood in the urine may enable cancers to be discovered early and cured with surgery.

What treatment plan did you put in place for Juliet?

Juliet has a type of kidney cancer called non clear-cell kidney cancer (clear-cell is the more common type). In Australia there are no treatment options for this type of cancer funded by the PBS. Juliet agreed to take part in an ANZUP trial testing the immunotherapy drug, nivolumab in her cancer type.

In doing this, she is helping future patients who develop this disease by allowing us to test how well this drug works in this situation.