OCRF Case Studies for State of the Nation

Case Studies

Kel Pittman

- Kel lives with her family in Adelaide
- She was diagnosed with Stage 3 Ovarian Cancer in 2014
- She relapsed in 2017 and is managing the disease for life

Kel first presented with symptoms in 2013. Originally misdiagnosed with IBS, she describes how her symptoms could be attributed to other, more common conditions. Kel was 43 years old when she was finally diagnosed with Stage 3 ovarian cancer in 2014. After undergoing immediate treatment and being declared in remission, Kel unfortunately suffered a relapse in September 2017.

Kel is now a committed advocate for women living with ovarian cancer and is a part of the OCRF's Consumer Representative Panel. She is a strong voice for women advocating for their own health and frequently presents at year 11 and 12 classrooms to speak about her experience.

Her focus is on managing the disease for life and supporting the research that will ensure her daughter and her friends have access to an early detection test that may have been a "game changer" for her when she first experienced symptoms.

"Early detection is a game changer. We keep losing too many beautiful women to this disease and we don't have to," Kel says.

"There needs to be information gained and awareness raised. We know about everything else – you have your pap smear, you have your breast check – but because you can't see it and because there is no test it becomes this hidden disease."

Jordan Turner

- Jordan lives in Melbourne
- She was diagnosed with ovarian cancer in December 2019
- Completed treatment in March 2020

Jordan's story is best told in her own words: "I'd had shingles in September, and all of the painkillers and medications I was on had left me bloated. All the symptoms I was having made sense and were in line with the shingles and codeine I was taking for it, which is why we didn't pay it further attention," she says.

"These symptoms are not uncommon. Bloating or weight loss are not uncommon. It's not something you would even think about as cancer. After two months, the bloating hadn't gotten any better, and I was starting to lose a lot of weight because I felt full all the time, so my doctor sent me in for a CT scan.

"They found a 16cm tumour on my left ovary, and once my specialist Dr Peter Grant had looked at the scans and my blood tests, he diagnosed me with dysgerminoma*. He estimated the tumour to weigh about 2kg. I was diagnosed the day before my 28th birthday, December 5, and my surgery was scheduled in for December 11. I had two weeks to recover from the surgery, and then chemotherapy commenced on December 30."

Jordan feels that an early detection test would be a lifesaver. "To be diagnosed when it's too late shouldn't be the only option," she says. "An early detection test is critical so they can treat it early and improve survival rates. One of the reasons the death rate is so high is that very often, by the time you're diagnosed it's too late to do anything about it.

Jordan decided to fundraise for the OCRF because she had been given so many beautiful gifts and flowers before and after her surgery and knew that there would be people who'd want to do something for her during her treatment.

"So, I set up the fundraising page with the view that if somebody wanted to drop in a bunch of flowers for me, they could contribute to cancer research funding instead. I never imagined I'd raise so much money so quickly."

Additional info:

*Dysgerminoma is another name for Germ Cell ovarian cancer. This type is most common in women under 30 and usually responds well to treatment.

Jordan completed her treatment in March 2020 and returned to work. Jordan also managed to fundraise in support of the OCRF, despite being very ill, and raised more than $26,000. See link to Jordan's fundraising page: https://www.ocrf.com.au/my-fundraising/151/jt-is-putting-the-fun-in-fundraising

Vali Creus

- Vali lives in Melbourne
- She is a 42-year-old mother of 6-year-old twin girls
- Vali was diagnosed with ovarian cancer at the age of 19 – she had had many recurrences since but is currently free of the disease

Vali first started feeling unwell at the age of 16 but it wasn't until three years later, during an operation for endometriosis, that doctors found a tumour and she was diagnosed with ovarian cancer.

"I got dismissed a lot ... people don't expect younger women to be diagnosed so it's not the first thing they'll look for," Vali says. "They'll look at other options first. The symptoms are so vague, and they could be attributed to period pain or many other things that impact women and girls. It took a long time to find someone who actually listened.

"I knew there was something wrong. The biggest thing I learned was that, as a woman, you really have to advocate for yourself. Only you know what's truly going on inside you."

Vali's cancer was slow growing, which meant that, while it was malignant, it didn't develop as rapidly as other types of ovarian cancer. Vali describes the importance of early detection tests in the context of her long road from symptoms to diagnosis:

"The type of ovarian cancer I had was slow growing. It had been growing for three years. If it was any other type of ovarian cancer, without an early detection test I wouldn't still be here."

At 24 her cancer came back, so doctors removed her second ovary and she underwent chemotherapy. Vali was left infertile from ovarian cancer treatment and in 2013 went on to have the world's first successful pregnancy from an ovarian tissue graft to her abdomen.

When her twin girls were born by via caesarean section, doctors discovered that Vali's cancer had returned. Fortunately, they were able to remove it during the same surgery and she was given the all clear.

"I'm one of the very lucky ones," Vali says. "I've been dealing with ovarian cancer about half my life. Most of the women I've met in that time have lost their battle."

Monika Tasic (NSW)

- Monika lives in New South Wales
- She was diagnosed with ovarian cancer in late 2017
- She finished her treatment in 2018 and there is currently no evidence of recurrence

In 2017, at the age of 27, Monika started to feel bloated and lost her appetite. Working in mental health, Monika was asked by a patient - who noticed she had gained weight exclusively in her belly - if she was pregnant. Monika decided to visit her GP who performed a physical exam. In a matter of seconds, she was referring Monika to an ultrasound technician. A CT scan found a large mass in her abdomen measuring 27 x 18 x 15cm.

Because she was young and otherwise healthy, Monika expediated her treatment, enduring a high- dose of chemotherapy. It was decided she would receive treatment every day for a week, then come back for one day on the second week and one on one the third week for a period of ten weeks.

While going through this intense period of treatment, Monika managed to raise $10,000 for OCRF and became an ambassador.

“They were a massive part of that time in my life when I thought the world was caving in on me,” she said.

While out at a musical one night, Monika experienced a pain in her neck and had trouble breathing. She went to the emergency room where 1-2 dozen blood clots were discovered across her lungs. As a result, her chemotherapy was stopped so she could treat the blood clots. While she counts herself as “one of the lucky ones”, Monika felt that she never got the closure from completing her chemotherapy.

“You know that moment where you get to ring the bell after completing chemo. In the early days and still now, I didn’t get that closure,” she said.

Monika spoke of the importance of an early detection test, and holistic approach to treatment.

“Early detection is the pinnacle because it’s going to determine the treatment options. And when it’s detected early, there are more treatment options. So an early detection test lays out the foundations for everything moving forward,” she said.

Monika saves her most glowing praise for her GP and spoke about the importance of an attentive doctor saying:

“My GP saved my life. I was lucky that my GP was so fast-acting and I would wish that for every woman. She valued my concerns about my body and I think everybody deserves that.”

Jody Euler and Patrice Jamison (Nude Lunch, Mackay QLD)

- Jody and Patrice live in Mackay, Queensland
- They are both directors of *Nude Lunch,* founded by Trudy Crowley to raise funds and awareness for ovarian cancer

Jody and Patrice are directors of *Nude Lunch* in Mackay, Queensland. Nude Lunch was founded by their close friend Trudy Crowley, who lost her battle with ovarian cancer in 2018. They continue Trudy's legacy through fundraising and raising awareness of ovarian cancer with their annual *Nude Lunch* event in Mackay.

Trudy was diagnosed with Stage 4 Ovarian Cancer in 2016. Initially she was told that her symptoms were caused by a recurring urinary tract infection. Through her journey she discovered how little awareness and funding there was for ovarian cancer, particularly in regional areas. She founded *Nude Lunch* to create a conversation and raise funding through her community. In the past four years, the lunch has raised $300,000.

Patrice says Trudy's ovarian cancer was so far advanced at diagnosis that she would have been lucky to survive 12 months. She got to two and a half years.

"Being faced with that reality that your friend could be gone in 12 months changed so many things for all of us in the community. We're mothers, we're aunts, we're sisters. We can't accept this anymore," Patrice says.

Jody says ovarian cancer symptoms can come across as so many other things.

"Being a regional city, we don't have any dedicated services for ovarian cancer. Trudy went out to neighbouring mining communities and spoke to women with ovarian cancer who didn't want to talk to anyone who wasn't walking in their shoes," she says.

Jody and Patrice are committed to carrying on their friend's legacy and highlight the gap in early detection and detection of symptoms for ovarian cancer.

"There's breast cancer, you have your symptoms, you have your early detection tests, there's cervical cancer, you have your symptoms, you have the early detection tests, then there's this big gap when it comes to ovarian cancer."

Tasha Armour

- Tasha's daughter Mikayla was diagnosed with a rare form of ovarian cancer in 2016
- She founded *Rare Ovarian Cancer* in 2018
- She is the Consumer Chief Investigator on Hudson Institute research into juvenile granulosis

Tasha's daughter Mikayla was diagnosed with juvenile granulosis, a rare form of ovarian cancer, at the age of 16. At the time, there was no research into juvenile granulosis. Mikayla was in treatment for three months. She is free of the disease at present but is monitored with blood tests and CT scans every three months and has a high risk of recurrence.

Tasha founded Rare Ovarian Cancer in 2018, raised essential funding and is now the Consumer Chief Investigator for research into juvenile granulosis.

She highlights the subtlety of the symptoms. Mikayla initially missed her period for two months and describes how the initial presentation to the doctor was dismissed without thorough examination. "He didn't even touch her stomach," Tasha says.

After further symptoms, an ovarian mass was found. She was told it wasn't cancer. Mikayla was eventually diagnosed in July 2016 after undergoing surgery for a tumour which measured 25cm by 20cm by 5cm.

Mikayla is now at high risk of recurrent cancer, a fate that may have been avoided with an early detection test or more thorough awareness in the initial presentation.

"If the proper examinations and tests had been ordered immediately – then it may have not grown to that extent," Tasha says.

Tasha continues her research and is committed to raising the awareness of ovarian cancer. "If we all step back [advocates], what will happen? Sadly, we lose advocates because women die quickly having been diagnosed in late stages."

Sarah Tidey

- Sarah lives in Melbourne
- She is a freelance writer and former lawyer
- She was diagnosed with ovarian cancer in 2015

Sarah was diagnosed with ovarian cancer in late 2015. Like so many others, her symptoms were vague. But thanks to a thorough gynaecologist who identified swollen ovaries, she was quickly sent for further tests, scans and eventually a hysterectomy. In July 2020 she is currently undergoing treatment.

“If there was an early detection test, things might have been quite different for me, but I don’t dwell on what might have been – I can’t change the fact that I have ovarian cancer but I can choose how I deal with it,” Sarah says.

“There is some great research going on in the early detection space, which looks positive and will greatly improve the prognosis of those being diagnosed but we also need more research for a cure.

“We are all here on this earth because the woman who gave birth to us had ovaries – there needs to be more education and awareness of this cancer, I hope I can play a part.”

Reflecting on her life pre and post-diagnosis, Sarah’s message for all women is to slow down and appreciate what’s in front of you.

“I now realise how important it is to prioritise your health as when you are unwell it impacts your ability to enjoy other aspects of your life,” she says. “I’ve had lots of time to reflect on the way I was living before I was diagnosed and it was crazy, I was always racing around and stressed. Being unwell has forced me to slow down and focus on what is really important.

“I’m much calmer these days, which is a good thing! I’ve become more focused on my relationships with my family and friends. I still feel optimistic, I think it’s important to have hope.”

Dr. Michael Bunting (Tas)

Dr Michael Bunting is currently the only Gynaecological Oncologist working in Tasmania. State-wide services for Tasmania are centred in Hobart with an outreach clinic in Launceston once a week at the Launceston General Hospital. While patients need to travel to Hobart for surgery, they can access necessary treatments in the north of state in Launceston and Burnie. Dr Bunting works closely with a number of experienced medical oncologists in the south and north of Tasmania.

Dr Bunting runs a holistic service with a state-wide cancer care coordinator for women with gynaecological cancers who attends to women at the coalface as well organising outpatient clinics with medical and radiation oncologists and organising support groups. Dr Bunting says that while the benefits of working in a small state mean women get a less fragmented service, they are underfunded.

Dr Bunting is also involved with placing women in clinical trials to investigate newer more effective treatments. While COVID-19 restrictions have put pressure on these trials with participants often unable to travel interstate, a number of them have been able to continue in Tasmania.

Prof. Yee Leung

Professor Leung is the Head of Department of the Western Australian Gynaecologic Cancer Service, Director of Surgical Education at King Edward Memorial Hospital for Women and Professor in Gynaecologic Oncology at the University of Western Australia.

His research interest includes Gynaecologic Oncology clinical trials, basic and epidemiologic research. He obtained ethical approval to commence a gynaecologic cancer biospecimen bank for the Western Australian Gynaecologic Cancer Service in 2013, and successfully obtained a $1.25 million grant from the Cancer Research Trust for the Western Australian Gynaecologic Cancer Research Initiative. He is also conducting research into single-cell abnormalities in an attempt to develop early stage detection.

Professor Leung collaborates with a number of partners including Tarek Meniawy who is based in WA and Principle Investigator in iPrime: a phase II trial to determine how effective it is to combine two targeted cancer drugs (durvalumab and tremelimumab) with standard chemotherapy treatment in patients with ovarian, fallopian tube or peritoneal cancers.