Spot New Zealand



ISSN 2703-5689 (Print) | ISSN 2703-5697 (Online)

AUGUST 2023





Chance Check Leads To Diagnosis

It seems to have become a regular and rewarding occurrence for the Melanoma New Zealand team to have a former visitor from one of our spot check events pop in to thank the team at Mystery Creek Fieldays. These visits mean so much to us, especially our nurses who work hard to provide free spot checks nationwide.

One of those who took the time to share her appreciation was Te Awamutu Phlebotomist Julia Robertson.

Having grown up on farms, Julia and her husband Aaron are Fieldays regulars. They made a special effort to come to our site this year to explain if Julia had not visited us at the 2022 Fieldays, she

probably would not have done anything about a spot on her face, which has since been diagnosed as melanoma.

"I have always had lots of freckles but never gave them much thought. But there was one spot on my nose that was raised, and I just happened to stumble across you guys at the last Fieldays, so I decided to get it looked at.

"Your nurse was more concerned about a mole on my cheek that was about the size of my small fingernail and had fuzzy edges around it. Looking back at old photos, I have had the mole for about three years.

"I followed her advice and saw my doctor, who took photos and referred me to a specialist "

Julia said because she had been seen by Melanoma New Zealand's Nurse and recently connected with her birth family where she learned some had melanomas and squamous cell carcinomas removed. she insisted on asking to have the spot excised.

Six weeks later, she had surgery and assumed no news was good news when she didn't hear any more.

"Unfortunately, I had slipped through their follow-up appointment system, but they then rang to say I had melanoma in situ and would be booked for more surgery."

The week before Fieldays, Julia had undergone further surgery to go in deeper and wider to remove more tissue. She has recently been given the 'all clear' and will return for a check-up next month to see how the healing is going, and then have six monthly check-ups after that.

Julia urges others to check their skin regularly for suspicious spots and to trust their instincts

"If something doesn't feel right, follow it up. I would hate to think where I would be (or wouldn't be) in another three years if I hadn't acted!" •

I Am Lucky

From her home in Lyttelton, Emma de Teliga shares her own account of navigating a melanoma diagnosis and considering herself lucky, despite the challenges she faces.

Emma de Teliga

I live with metastatic melanoma. And I am lucky...

In 2000, I had recently returned home to Hong Kong, when two friends cornered me, concerned about a mole on my arm.

Heeding their advice, I booked to see a doctor the next day, who looked disturbed and mumbled, "Excision...biopsy..." etc.

I immediately flew back to family in Australia and to have it treated. I was poked and prodded, and the mole was chopped out. Even when they explained melanoma to me in detail, I didn't comprehend the seriousness and ignored the cause of my scar. Ignorance is bliss, so it is said by the ignorant.

Fast forward to September 2016. I was in New York City training to teach aerial yoga, and a small pea-sized lump under my arm started to hurt every time I put the hammock under my arm. But my New York doctor said it was probably an ingrown hair. So, I carried on, and back in Hong Kong a month later, the pea was now the size of a quail's egg, so I had a biopsy and was told to return in two weeks.

In between the biopsy and heading out to one of the government hospitals to get my results, I married my Kiwi partner, Sean. I am lucky, indeed.

But our celebration was cut short. I could not have been more surprised to be told I had metastatic melanoma. Whether it was stage III or IV, they were unclear. But it was not good.

I wondered how I could have melanoma when they'd removed it 16 years ago. The margins were great, and everyone was happy.

What did I do wrong? Me, the vegan with fish, yogini, rock climber, skier, kayaker, diver, and trekker, could not possibly be dying - again!

Three years earlier, severe headaches had forced me to see my doctor. I was scanned and seen by a neurosurgeon within a few hours. A tumour was pressing into my right frontal lobe. Brain surgery removed the beast that was, thankfully, benign.

Sean and I were still recovering from that exceptionally traumatic episode. Neither of us was prepared for this new diagnosis' drastic changes to our lives. There was no question of having treatment in Hong Kong, I was no longer eligible for insurance, and their health system, like most, was overstretched. Treatment in Australia was free and among the most advanced in the world. So, I headed to Sydney and quickly prepped for surgery to remove all my left axillary lymph nodes. The surgery was horrendous and left me with a nice big scar and constant nerve pain. Apparently, they had had a good look around and removed all the nodes

I began yo-yo-ing between Sydney and Hong Kong with my Mother, sisters, and friends as support in Australia. As I said, I am lucky.

Luckier still, I had Sean, our cat, and our home on an idyllic beach island in Hong Kong. I worked hard to regain the mobility in my arm and exercised daily. I was mostly super positive, thinking they got it all. Until days when pain, doubt and horror descended with, "But what if they haven't?"

They had not. They cut the first subcutaneous lesion from my leg

at the April check-up. By July, six more were growing rapidly all over my abdomen. My oncologist said chopping it all out was not viable, and I needed systemic treatment.

I cannot tell you how devastating this was for a hippy like me! He explained immunotherapy and suggested joining a trial for two years, which meant being away from Sean and Hong Kong again.

I searched for alternatives but soon realised I had to do the immunotherapy trial or go live alone in a cave in the Himalayas, or I would die very soon.

Dealing with cancer is exhausting! It is a full-time job - dealing with appointments, blood tests, scans, and treatment days. Six months of treatment on Keytruda and Yervoy floored me with side effects, and trips home to Hong Kong every three weeks were financially and physically unviable. I had lived on my savings since the brain tumour, and the kitty was dry. I was now on an Australian disability pension and no longer had my jet-setting job. Now another massive chunk of my life was being taken from me.

My amazing trial coordinators in Sydney and Christchurch worked together to gain approval for me to continue the rest of the trial in Christchurch. So, on April Fool's Day 2018,

I arrived in Lyttelton with a couple of suitcases to live in an off-the-grid cabin in the woods. My landlady became a fast friend and support person as I struggled through treatment, and when Sean and our belongings finally arrived from Hong Kong, we resumed our active life together, just a little bit slower.

Sean had been a Chief Financial Officer in Hong Kong and soon found out he was less employable for the New Zealand market, so he changed clothes and is now a fantastic builder. I am forever grateful for his support, sacrifices, and adaptability, but mostly for his love. As I said, I am lucky.

Although I have survived a lot, I do not call myself a survivor. I am in remission and not cured, but I see my oncologist only once a year. Ongoing side effects from treatment, including nausea, headaches, fatigue, night sweats and pain from surgery, are now my 'normal'.

I am one voice of thousands of patients in New Zealand suffering financial, physical, and mental consequences of melanoma.

For any country to be on the list of highest melanoma rates worldwide is a disgraceful honour. Patients in New Zealand at stage III must wait until stage IV to be eligible for funded treatment! As if it is not enough to deal with the actual disease and death sentence! Melanoma patients in New Zealand are facing the question, "Do I sell my children's future to afford the treatment that is free in other countries around the world so I can live?"

What kind of a decision is that to have to make?

Melanoma New Zealand is our voice and hope for many, advocating for earlier access to lifesaving medicines and supporting melanoma patients nationwide.

I am alive, I am lucky to be here and I wish the best possible outcomes for other melanoma patients. •





Message From Our Chief Executive

Welcome to the August edition of our Melanoma New Zealand newsletter, Spot News.

A recent highlight for our team was being part of the Hauora Taiwhenua Health and Wellbeing Hub at the 55th Fieldays at Mystery Creek, where more than 105,000 people attended the four-day event. Our entire team, including some of our wonderful volunteers, participate in this annual event. The sheer size of the crowd means we need all hands on deck to provide free spot checks and share our messaging with the large rural community, who typically spend much of their time working outside and have a heightened risk of getting melanoma.

Once again, our rural partner FMG lent us some of its fantastic team members to help welcome and coordinate the 610 people who signed up over the four days to learn about melanoma and have a free spot check.

Dr Anthony Tam from Melanoma New Zealand's Clinical Advisory Board also kindly volunteered his Saturday morning to help our nurses provide spot checks, and from all the people seen, 53 suspicious lesions, including 14 potential melanomas, were identified.

At the event, we had a very special visit from Julia Robertson, who had been to our site at the 2022 Fieldays and was encouraged by our Nurse Educator, Gill Rolfe, to have a spot on her face investigated further. She followed Gill's

advice which resulted in a confirmed melanoma diagnosis and two surgeries to remove it. We all shed a few tears as Julia and her husband sought us out to heartfeltly thank us for alerting her to it. Receiving feedback from people like Julia truly means so much to us. You can read Julia's story on page 1 of this newsletter.

On page 2, you can read Emma de Teliga's personal account of navigating a melanoma diagnosis and considering herself lucky, despite the challenges she faces. I had the pleasure of meeting Emma when she was the guest speaker at a fundraising event in support of Melanoma New Zealand last year – and I continue to be humbled by her remarkable resilience and her generosity in sharing her story so willingly.

In this issue, we also feature stories about Melanoma New Zealand Ambassadors Adine Wilson, Laura McGoldrick, and Martin Guptill. Adine and her husband, Jeff Wilson, share how their personal experience of melanoma has shaped their family's habits in the sun. And Laura and Martin feature in a story about a school fundraising project, where they generously lent their artistic talents in support of Melanoma New Zealand.

We are delighted that, once again, the generous team at Gibbs Farm has donated the use of its spectacular property for a Melanoma New Zealand fundraising event in November. Details are on **page 4**.

Our annual Get Spotted melanoma awareness campaign kicks off on 16 October. The distinctive campaign is our opportunity to get schools, early childhood centres, kindergartens and workplaces involved to help us raise awareness about the dangers of UV radiation, and the importance of being sunsmart.

We are very grateful to all the people and organisations - including our corporate partners, patrons, ambassadors, donors, grant providers and volunteers - who continue to support our work.

Thank you!

Indies

Andrea Newland Chief Executive Melanoma New Zealand

Creating Great Habits



Melanoma New Zealand Ambassador Adine Wilson and her husband Jeff getting behind our Get Spotted campaign Melanoma New Zealand Ambassador and New Zealand netball legend Adine Wilson and her husband, former All Black and Black Cap Jeff Wilson, have used their own experience with melanoma to pass on good sun-safe habits to their children.

Adine had just completed her first year as a commercial lawyer, was captain of the Silver Ferns and was about to marry Jeff when he noticed a freckle-like dark spot on her arm that he had not seen before.

Thinking it might be something that needed looking at, Adine booked to see her doctor, who agreed it needed to be taken off and tested.

A few days later, she got a call asking her to come in and see the doctor.

"I said 'no, I don't need to go back in yet', but they insisted I did - so that was when the bombshell hit that it was melanoma.

"It was certainly a shock. No one in my family I knew of had ever had melanoma."

Jeff said when the operation was done, and the news came out that they had got everything, they felt a huge sense of relief and a realisation that they had done a good thing by getting it seen, as it could happen to anybody at any age.

Looking back, Adine feels terrible about her relationship with the sun and says it is not surprising she got melanoma.

"I was an outdoorsy person, which is great, but I took very little protection in the sun."

Adine and Jeff have made sure their two sons, Lincoln and Harper, are well-educated about the dangers of the sun and know that if they are outdoors, they need to protect their skin, including wearing sunscreen, and if the family are at the beach, they take an umbrella.

"All those little things become a habit," said Adine. •



Opportunity to Experience Gibbs Farm

Once again, Gibbs Farm has kindly provided us access to its stunning property for an unforgettable day held in support of Melanoma New Zealand.

Join us on Friday, 14 November, at the celebrated Gibbs Farm - an expansive open-air sculpture park in the beautiful Kaipara Harbour, north of Auckland. It houses the country's greatest collection of large-scale outdoor sculptures, with works by some of the world's most renowned artists, including Andy Goldsworthy, Anish Kapoor and Richard Serra. Our Nurse Educator will also provide free skin cancer spot checks on the day.

Tickets are strictly limited and typically sell out quickly – please visit https://events.humanitix.com/melanoma-new-zealand-fundraiser-gibbs-farm-2023 for more information and to purchase tickets.



Will You Help Save A Life?

Every donation we receive from you, our wonderful donors, goes towards supporting the urgent work we do at Melanoma New Zealand to help save lives. Tragically, we lose too many of our loved ones to this terrible disease, and yet if caught and treated early, melanoma is nearly always curable.

To try to turn around New Zealand's terrible statistics, we need to fight for better funding, as well as reach as many people as we can with our life saving

messages about the vital importance of both staying safe in the sun, and getting regular skin checks.

Your generous support enables us to get the message out into the community. Will you help save a life? No donation is too small, and we are very grateful for any support you can provide.

www.melanoma.org.nz/donate or phone 0800 463 526.

Get Involved and Get Spotted

Get involved in our annual Get Spotted melanoma awareness campaign, which runs from 16-22 October. Proudly supported by Lidgard Shades, the campaign is our opportunity to reach and educate people of all ages from around the country about the importance of melanoma prevention and early detection.

As well as individuals and workplaces getting involved, a large number of schools, kindergartens, and early childhood centres often participate in the campaign during October to promote sun safety with their students. These educational activities help our young people create good habits and encourage them to influence other family members to protect themselves from the sun.

A chance for schools, kindergartens and ECCs to WIN!:

- Enter the Get Spotted competition to be in to win a Lidgard Shade Sail valued at \$20,000.
- By registering to participate in Get Spotted, you'll receive a free subscription to our Melanoma workplace education course for all staff.

Once again, we will be selling our colour changing UV bands which which turn from white to purple when exposed to UV radiation. The \$3 bands were a huge hit last year, and are a great tool for, both education and fundraising. Both adults and children's sizes are available.

Please get behind this important campaign and help us raise awareness about melanoma. If you can throw in a spot of fundraising too, we would be very grateful for the support of our work across the country sharing lifesaving messages, providing patient support and offering free skin cancer spot checks.

Check out **www.melanoma.org.nz/get-spotted** to see what we have planned and to register your school or workplace to get involved.



Draw for a Cause

Melanoma New Zealand recently received a donation of \$654 from a long-term fundraising project that a group of Nelson College students developed as part of their Business Studies class.

Otago University student Sam Perkins said when he and his teammates, James Fleet, Paddy Beggs, and Jack Weaver, were in Year 12, they decided to focus their class project on something charitable and non-profit based and came up with the concept of 'Draw for Cause' where they would ask New Zealand celebrities to create a doodle for them to sell on behalf of their chosen charities.

Sam said they tried everything to find celebrities to participate, including searching for email addresses online. Then they realised the key to making it happen was to use their connections.

"We pitched it to everyone we knew, even our mates' parents, which helped."

The response from the celebrities was terrific, and the boys ended up with plenty of pictures to sell. Everyone who signed up received a plastic sleeve filled with paper, a Sharpie pen, and some drawings to inspire them.

A friend of Sam's mother connected the boys to Melanoma New Zealand Ambassadors Martin Guptill and Laura McGoldrick, who were happy to participate.

The boys raised \$2,500, and Martin and Laura's drawings fetched \$654, which was donated to Melanoma New Zealand.

We want to give a massive shout-out to all the celebrities who participated, especially Martin and Laura, and the project team for being so creative.

Melanoma New Zealand Ambassadors Laura McGoldrick and Martin Guptill





Our Amazing Volunteers

Melanoma New Zealand is truly fortunate to have the support of volunteers who, in the last year, have generously offered a combined total of 755 hours of their time to help us at events and with administrative tasks at our office in Auckland.

Two regular volunteers, Arundhati (Mia) Shankar and Dhara Sinhal, are busy students from the University of Auckland who dedicate much of their precious time to supporting our cause.

Mia was inspired to start volunteering after witnessing the pressures the healthcare system was under during the COVID-19 pandemic, and like Dhara, she decided to support Melanoma New Zealand after learning that New Zealand had the highest rate of melanoma globally.

"Melanoma New Zealand's work to ensure the safety of many Kiwis is very selfless, and I was eager to aid this in any way I could," said Mia. "Volunteering is something I treasure, knowing I can help make a difference in at least one person's life. I highly recommend it "

Dhara is working towards a Bachelor of Science with ambitions

to pursue dermatology and has gained many new skills since working with the team.

"I have learnt a lot, such as the Slip, Slop, Slap, Seek and Slide rule, which I have told all my family and friends about, and when I have helped out at spot check events, the nurse told me what to look for when looking for melanoma using the ABCDEFG

She said it feels amazing knowing she is making a positive change in the community and encourages everyone to volunteer at some point, "Everybody deserves this natural sense of accomplishment and an added sense of pride, identity, confidence and satisfaction."

If you're keen to support us by volunteering, please visit www.melanoma.org.nz to find out more. •

Thanks to our supporters.

























