Spot News

Melanoma New Zealand

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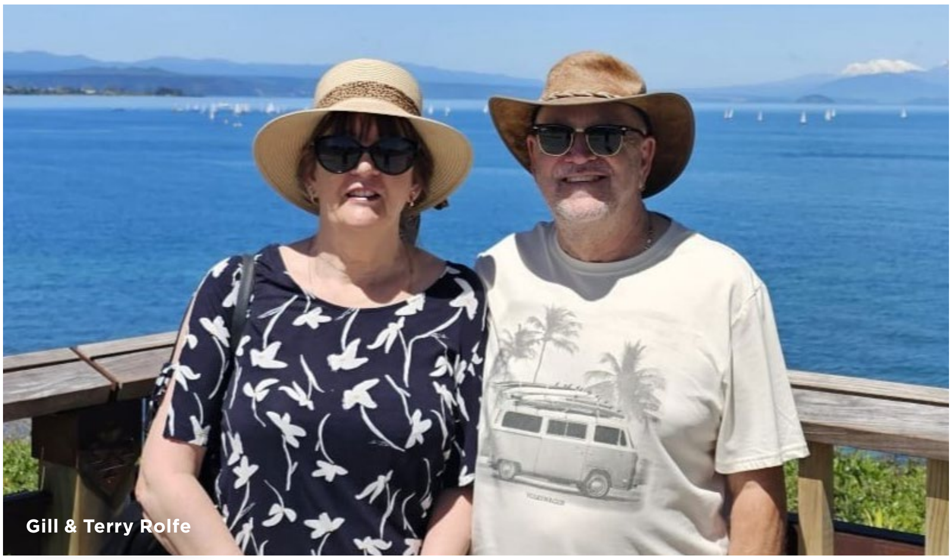
WINTER 2024



Gill & Terry Rolfe

Pink Spot More Sinister Than It First Seemed

Melanoma New Zealand Nurse Educator Gill Rolfe has spent much of her career working with melanoma patients. Now, she is supporting her husband through his own battle with the disease after he was diagnosed last year, just as they were about to start their retirement.

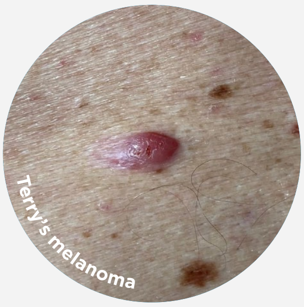
Gill's vast experience in this field has made her an advocate for sun safety and regular skin checks. She has always been particularly vigilant with her family members, especially the redheads among them.

She says that, given Terry's number of moles and the years he spent working outside in England without a shirt on, she took every opportunity to go over his skin and look for suspicious lesions.

Late last year, Gill noticed a pink spot on his lower back and kept an eye on it. As soon as it became raised and itchy, they immediately made an appointment with a skin specialist in the community to get it checked.

Gill says both she and the specialist thought it had the characteristics of a basal cell carcinoma and were both shocked when his biopsy results showed he had a 3.3mm ulcerated melanoma with a mitotic rate of 5 – which Gill explains is how fast cancer cells are dividing and growing.

"It was reasonably fast growing and needed treatment, so if we hadn't had it checked and left it any longer, it would have been deeper and possibly spread further. As the specialist said, sometimes biology throws unexpected things at us," says Gill



Terry's melanoma

"Terry was referred to North Shore Hospital for further treatment. He then had a sentinel node biopsy, which involved injecting dye into the excision site and having a scan to see where it travelled and which lymph node the melanoma was draining to. He had the two nodal basin biopsies taken from his groins and a PET CT scan with a wide local excision performed at the same time. Thankfully, all the results were negative."

With no family history of melanoma, Terry says he never thought about skin cancer, particularly back in the 1960s when he said no one used sunscreen in England.

"If you were working outside, you would get burnt, go red, and peel. It wasn't until people started to go to Europe on holiday, where it was warmer, that they started using sunscreen."

He said his attitude changed when they moved to New Zealand more than 20 years ago.

"I remember putting a chair outside and thinking I'd have a quick suntan, and in about 10 minutes, I could feel myself burning - which is when I knew you couldn't sit out in the sun here."

Unfortunately for Terry, the damage had possibly already been done.

After his diagnosis, he was selected to be part of a clinical trial, which was open to patients with stage 2b to stage 4 melanoma.

The 12-month study, which is now closed to recruitment, involves 17 three-week transfusions of pembrolizumab (Keytruda) plus the study drug vibostolimab.

Gill explains that it is a randomised, double-blind study, which means neither the participants nor the medical team knows who actually receives vibostolimab.

"The great thing about being on a clinical trial is that the patients get regular access to otherwise unfunded drugs, checkups with the same people, three monthly CT scans, blood tests every three weeks and a consultation two days before their infusions.

"We're hopeful that the drugs will mop up any cancer cells that might have strayed into his bloodstream that aren't visible on scans yet."

A side effect that Terry experienced from the trial was a severe rash all over his body, which meant he had to come off treatment for a period to have steroids to clear it.

Unfortunately, after resuming the trial, the rash has returned.

Gill says there is a risk that he might have to stop treatment because the study drugs can disrupt the body's immune system, resulting in thyroid issues or accelerated diabetic risk.

Despite these issues, they both feel extremely fortunate that Terry has had the opportunity to participate in the study.

"This treatment is usually funded only for stage 4 melanoma patients in New Zealand while their bodies respond to it, which not everyone does. If you are not stage 4, you could pay up to $107,000 a year for adjuvant therapy," says Gill.

Gill advises other melanoma patients to speak to their GP or other specialists to see if they are eligible for clinical trials.

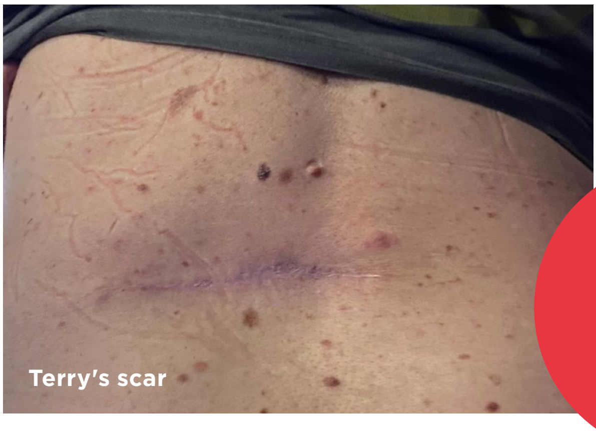
Terry says he is grateful Gill has always encouraged him and the family to be safe in the sun and check their skin.

"The consequences of sunburn and lots of UV radiation can result in melanoma. Make sure you know your skin so you can spot something new or changing.

"Like other regular Joes, I wouldn't know what to look out for without Gill's experience, especially pink spots.

"We live on three acres, so I have a lot of lawn to mow and could be out there for a couple of hours. I'm always well covered. I wear long pants, a hat, sunscreen, and gloves.

"If you get melanoma, it's not just about getting the mole or spot cut out; it's all the stuff you have to go through afterwards. It's a journey."


Terry's scar

Our Spot Check Van featuring in FMG's latest ad

Finding Skin Cancer At Fieldays

Our team has just returned from another successful Fieldays event in the Waikato, working alongside other health providers at the Hauora Taiwhenua Health & Wellbeing Hub to foster a culture of proactive health management.

Farmers are more at risk of melanoma because they largely work outdoors and the majority of skin cancers are caused by UV radiation.

The annual event allows us to directly engage with Fieldays' large rural audience and raise awareness about the importance of early detection and prevention of melanoma.

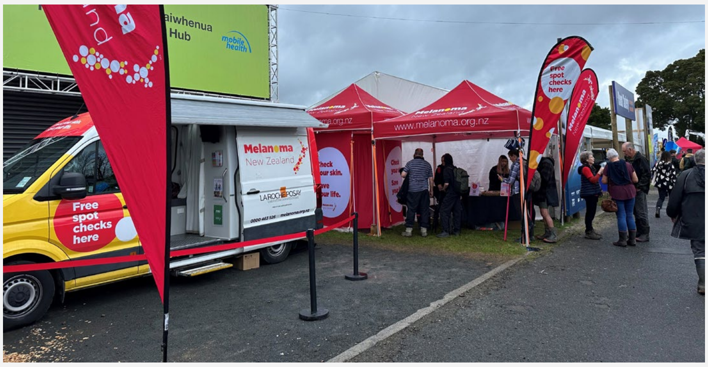
This year, several people returned to our site to thank our Nurse Educators for finding skin cancer on them at the last Fieldays. These encounters motivate and inspire our team to keep raising awareness in the hope of potentially saving lives.

Our prime spot right outside the Health Hub and the addition of our Pop-Up Pod this year made our site hard to miss. A constant stream of people lined up for a free spot check and education about adopting good sun-smart practices on the farm.

We are grateful for the support of our rural partner, FMG, whose team members assisted us in welcoming and registering visitors to our site.

Over the four days, we provided free spot checks to 577 people and found 103 suspicious lesions, including 21 suspected melanomas.

Together, we are not just raising awareness — we are saving lives and shaping a healthier future for rural New Zealand.



Slip Slop Slap Seek Slide

For more information go to melanoma.org.nz

Message From Our Chief Executive

Welcome to the Winter issue of *Spot News*.

As this newsletter finds its way to your inbox or mailbox, our team will have just wrapped up at Fieldays in the Waikato.

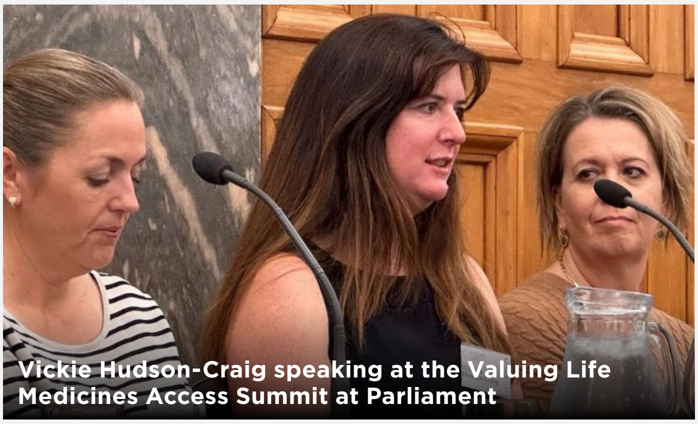
The annual Fieldays event enables us to reach vast numbers of the rural community, who typically spend considerable time working outdoors and so are at increased risk of melanoma. At this year's Fieldays, we provided free spot checks to 577 people and found 103 suspicious lesions, including 21 suspected melanomas. We also provided all visitors to our site with education about melanoma prevention and empowered them to know what to look for when checking their skin. Huge thanks to our rural partner, FMG, for providing us with some of its team members to lend us a hand at the event.

This issue of *Spot News* includes a story that is very close to all our team member's hearts. Our Nurse Educator Gill Rolfe's husband, Terry, was diagnosed with melanoma late last year, and they generously agreed to share their experience to help raise awareness about the importance of regular skin checks and taking action as soon as you notice any changes.

We also introduce our newest Nurse Educator, Jade Castaños-Bosnić. Jade has had an extensive nursing career and is a qualified dermoscopy nurse, clinical teacher, and trainer. We are very excited to have her on board, working alongside Gill and our other Nurse Educator, Sue Bibby, to deliver patient support via our free online and phone consultations and provide skin checks and education at events nationwide.

On page 4, you can read about the launch of the Melanoma New Zealand Research Fund. Melanoma New Zealand has partnered with Cancer Research Trust New Zealand to grow melanoma research opportunities for New Zealand clinicians, scientists and researchers alike. Together, we aim to improve outcomes for those affected by melanoma by funding groundbreaking research that advances earlier diagnosis, new treatments and better care of people living with melanoma. This is an exciting and significant new area of investment for the organisation, and we are looking forward to the fund enabling innovative and meaningful research that has the potential to shift the dial on the dire melanoma incidence and mortality rates in New Zealand and create outcomes that directly benefit patients and communities. It was a generous bequest from the estate of Carol Ann James that enabled the Melanoma New Zealand Research Fund to be established – and although Carol Ann is dearly missed by friends and family, her legacy will live long into the future.

In May, I attended the Valuing Life Medicines Access Summit at Parliament, which included expert panel discussions and workshops that encouraged high-level talks on ways to advance medicine access. The agenda also included input from patients, including melanoma patient and advocate Vickie Hudson-Craig, who gave a very moving account of her experience. Vickie also recently organised a very successful fundraising event in Christchurch, donating half the proceeds to Melanoma New Zealand, so I want to take this opportunity to thank Vickie for everything she does to advocate for melanoma patients throughout the country and for her support of our organisation's work.


Vickie Hudson-Craig speaking at the Valuing Life Medicines Access Summit at Parliament

At the time of going to print, the Government had just announced a Pharmac funding boost of $604 million over the next four years towards an estimated 54 drugs (26 of which are for cancer). Although this is a significant and positive step for medicines access in New Zealand, uncertainty and concern remain for many melanoma patients in New Zealand.

National had previously committed to 13 new cancer drugs it would fund, but six of those (including, according to reports, treatments for melanoma) were not included in the June announcement and will now be replaced by alternative drugs that are either "as good or better".

New Zealand has the worst mortality rate of melanoma in the world, so funding of more melanoma drugs is welcome and very much needed. However, those melanoma patients who relied on the promise of their drugs being funded could now miss out, and all melanoma patients are still in the dark as to what treatments will be funded and when.

The need is urgent – cancer patients don't have time to wait in hope for answers and for funding. We will continue to advocate on this issue on behalf of melanoma patients and hope the details are confirmed soon.

I want to express my heartfelt gratitude to everyone who generously supports our organisation. Your support is not just appreciated, it's crucial. I am deeply grateful to our corporate partners, patrons, ambassadors, donors, fundraisers, grant providers, and volunteers who support our cause and make Melanoma New Zealand's efforts across the country possible.

Andrea

Andrea Newland
Chief Executive
Melanoma New Zealand

Opportunity Opens For Melanoma Researchers

Melanoma New Zealand is proud to introduce the Melanoma New Zealand Research Fund – bolstering opportunities for impactful research focused on improving melanoma outcomes and patient experiences in New Zealand.

Melanoma New Zealand has partnered with Cancer Research Trust New Zealand to grow melanoma research opportunities for New Zealand clinicians, scientists and researchers alike.

Together, we aim to improve outcomes for those affected by melanoma by funding groundbreaking research that advances earlier diagnosis, new treatments and better care of people living with melanoma.

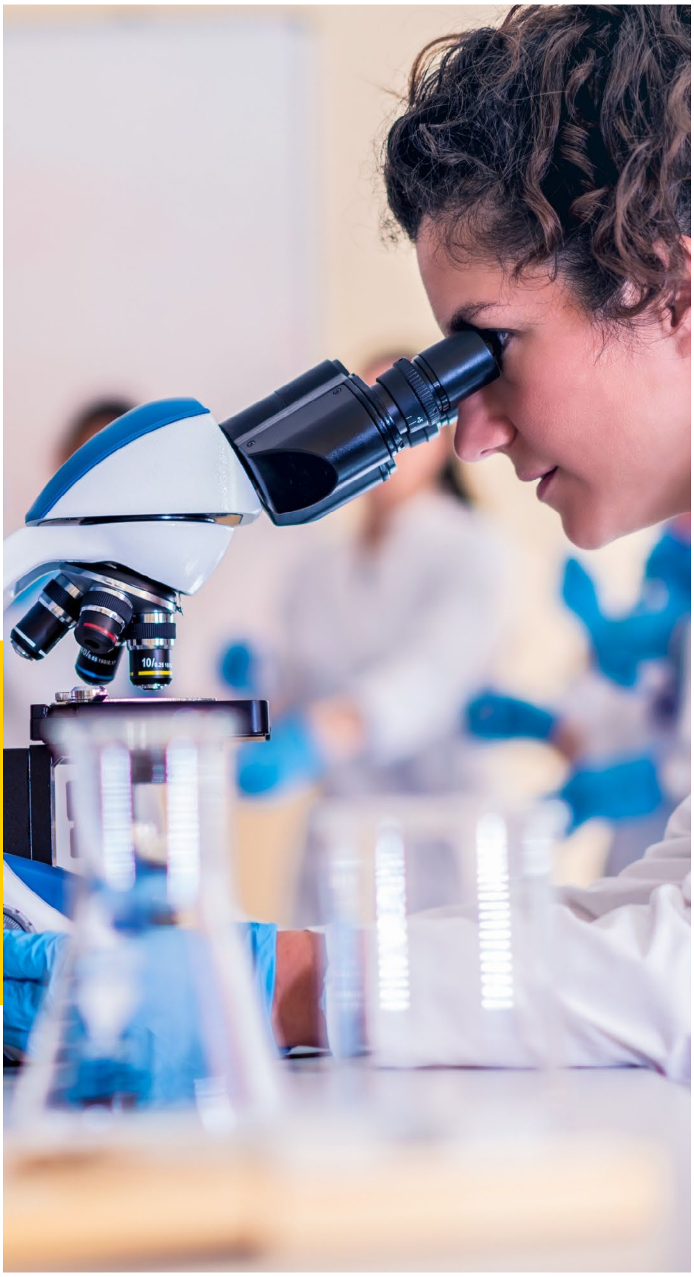
The Melanoma New Zealand Research Fund is open to receiving applications covering a wide range of areas, including:

- Prevention
- Early detection
- Diagnosis
- Patient wellbeing and support
- Precision medicine
- Technology and innovation
- Immunotherapy advancements
- Epidemiological studies
- Behavioural studies

Whether you are a researcher, clinician, philanthropist, social scientist, or advocate, there will be numerous opportunities to contribute to Melanoma New Zealand's research initiatives.

Together with Cancer Research Trust New Zealand, we are committed to making a tangible difference in the fight against melanoma.

For more information, please visit
https://melanoma.org.nz/all-about-melanoma/research-fund/



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 fund research and 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.**

Welcome Jade!

Since starting her new role in April, Melanoma New Zealand's newest Nurse Educator, Jade Castaños-Bosnić, has hit the ground running.

Together with fellow Nurse Educator Sue Bibby, one of the first big events she undertook in the new role was the Hawke's Bay Marathon – providing education and spot checks to 184 participants and finding 18 suspicious lesions, including eight suspected melanomas.

Jade says that in the Philippines, where she was born and raised, part of the culture is to follow the path given to you by your family.

"My mother dreamed of becoming a nurse, but her parents sent her to be a chemical engineer," says Jade. "So, she was adamant that her daughters pursue nursing."

Jade completed her Nursing Degree in 2010 and her Master's in 2013. She started her career in community and corporate nursing and then spent four years as a clinical teacher at the College of Nursing.

In 2018, Jade moved to New Zealand, where she has family and friends. Jade says this was the best decision she ever made.

Her first job in New Zealand was as a registered nurse in a private hospital and dementia unit, followed by a role at MoleMap where she discovered her passion for dermoscopy.

Jade completed her dermoscopy training and Preceptorship of Nurses in Practice through the Waikato Institute of Technology. She worked as a senior melanographer for nearly four years, playing a pivotal role in skin cancer treatments and surgeries. She also trained and audited other melanographers in Auckland.

During one session with a trainee, she asked them to practice taking an image of a lesion on the side of her torso and said she was shocked to find out she had a possible melanoma.

"I was fortunate that it didn't turn out to be anything sinister. But whenever I have patients who are skin type 3 or 4 (darker skin), I always reiterate to them that melanoma can affect any ethnicity regardless of skin colour."

Since moving to New Zealand, Jade has been struck by the harshness of the sun compared to the Philippines. When she sees people basking in the sun at the beach, she cannot help but wonder if they are aware of the potential danger. So, she is eager to share her knowledge and experiences with people from all walks of life across the country and contribute to raising awareness about the importance of early detection and prevention of melanoma.

She also enjoys having the opportunity to provide support to patients and their families via Melanoma New Zealand's online and phone consultations and to share her knowledge and experience about melanoma with the general public.

Jade Castaños-Bosnić

Uncertainty And Concern For Melanoma Patients Following Pharmac Funding Boost Announcement

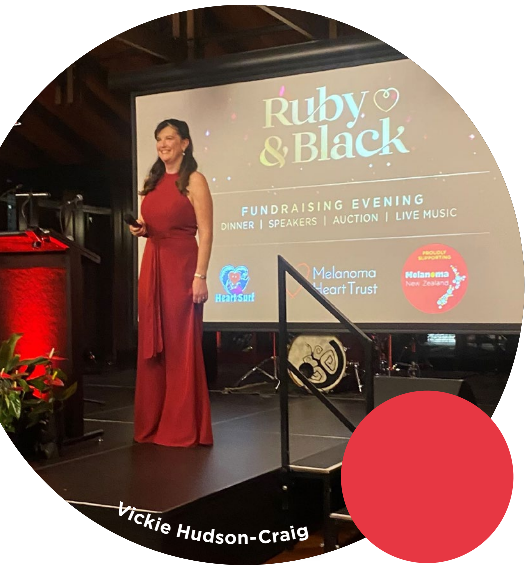
Although the Government's recent (24 June) announcement of a Pharmac funding boost is a significant and positive step for medicines access in New Zealand, uncertainty and concern remain for many melanoma patients in New Zealand.

Pharmac will receive an extra $604 million over the next four years towards an estimated 54 drugs (26 of which are for cancer). National had previously committed to 13 new cancer drugs it would fund, but six of those (including, according to reports, treatments for melanoma) were not included in the June announcement and will now be replaced by alternative drugs that are either "as good or better".

New Zealand has the worst mortality rate of melanoma in the world, so funding of more melanoma drugs is welcome and very much needed. However, those melanoma patients who relied on the promise of their drugs being funded could now miss out, and all melanoma patients are still in the dark as to what treatments will be funded and when.

The need is urgent – cancer patients don't have time to wait in hope for answers and for funding. No patient who relied on these promises should be left out. Access to essential medicines must be a priority for improving health outcomes and saving lives.

We will continue to advocate on this issue on behalf of melanoma patients and hope the details are confirmed soon.



Vickie Hudson-Craig

Ruby & Black

Despite battling stage 4 melanoma, working as a lawyer, and being a mother to six-year-old Ruby, Vickie Hudson-Craig recently organised a successful event, Ruby & Black, in Christchurch to raise funds for Melanoma New Zealand and Melanoma Heart Trust.

Vickie is a tireless melanoma advocate and support for her ongoing efforts to raise awareness about this disease and the drug funding crisis was evident on the night. Attendees generously participated in an auction that helped raise $12,357 for Melanoma New Zealand.

The Melanoma New Zealand Pop-Up Pod was on site so people could have a free spot check and learn more about melanoma. Our Nurse Educator was kept busy, with attendees lining up throughout the night to take advantage of the opportunity.

We want to say a huge thank you to Vickie and her family, event sponsors, her colleagues and the community for supporting this fantastic event.

Thanks to our supporters.

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