



Photo credit: Warren Buckland, Hawke's Bay Today

Jason and Mikes Hooker

Cancer strikes Hawke's Bay family, twice

When former port worker Jason Hooker was diagnosed with stage 4 melanoma in January this year, his whānau had just celebrated the news that their 19-year-old son, Mikes, had gone into remission after a seven-year battle with brain and spine cancer.

Mikes was only 12 when he was diagnosed. For the past seven years, the whānau had supported him through a nine-hour operation to remove a brain tumour, 30 doses of radiation and three months of chemotherapy before he finally went into remission in December 2022.

Now, 42-year-old Jason feels he is one of the unlucky ones as he fights for his life and the chance to carry on parenting his three boys, 22-year-old Avian, 19-year-old Mikes and 20-month-old Edward.

Jason says he thought melanoma was uncommon for Māori but now understands they often have thicker, more aggressive melanomas and can have poorer outcomes.

He doesn't recall education about the importance of being sun smart being marketed to the public when he was young and remembers being exposed to a lot of sun during his 20s when he worked as a logger.

In 2015, Jason found mole-like skin growths on his back and went to the GP, who told him to get checked by a skin specialist immediately. The lesions were

removed with large margins, and he was diagnosed with melanoma.

A few months later, a PET scan showed no other cancer, and they thought he was all good.

He did have some nerve pain around the site, which he followed up on, and was recommended pain relief as removing the mole had affected some of the nerves in his back.

Years went by with no further symptoms, so Jason thought he was okay.

In December last year, Jason started having back pain, but he says, like so many others, he just got on with it. When he began feeling pain in his arm in January, he returned to his GP and was diagnosed with terminal metastatic melanoma, which has spread to his lungs, spine and brain.

Continued on page 2

Cancer strikes Hawke's Bay family, twice (continued)

He travelled to Palmerston North on 23 January for radiation to treat the tumours along the length of his spine. Although he had a small tumour at the base of his brain, Jason said they wanted to immediately concentrate on the spinal tumours attached to nerves to avoid him becoming paralysed.

When he returned home to Hawke's Bay, he was told that surgery to debulk the largest lower tumour was a possibility. He spent five days at Wellington Hospital, where he underwent several scans that revealed part of his spine had fractured, which meant if they attached plates and screws to it, it would crumble.

So, their hope for surgery was gone, and non-funded treatment was his only option.

"I would have been paralysed and in a wheelchair if my mother-in-law and father-in-law hadn't paid for my first round of encorafenib/binimetinib," says Jason.

Jason said the treatment is working well and giving him a quality of life with his family. His biggest fear is not being around for his partner Kylie and their boys in the future and being unable to raise enough money to complete the five months of non-funded cancer treatment.

"Kylie is my biggest supporter, and I want to do everything I can to know that my children, especially my youngest, Edward, can get an education without her having to struggle."

Jason is grateful to those who have donated towards his treatment, but he struggles with the fact that so many cancer drugs are still not funded in New Zealand.

"If I can raise funds for treatment and continue to get better, I would like to advocate for better funding of treatments for melanoma patients in New Zealand and raise awareness about the dangers of UV radiation.



Jason and Edward

"I want to make a positive impact and encourage change with simple measures, like getting regular check-ups, wearing sunscreen, and never taking your health for granted, as life can change quickly.

"Don't live in regret." ●



Avian, Jason, Kylie and Mikes

“ I would have been paralysed and in a wheelchair if my mother-in-law and father-in-law hadn't paid for my first round of encorafenib/binimetinib

– Jason Hooker ”

Speed up and step up, PHARMAC!

Unfortunately, stories like Jason's are far too common and are a cruel reminder of how PHARMAC's lack of funding makes life-saving and life-extending treatments financially out of reach for many New Zealanders.

What's more, the speed and transparency of PHARMAC's decision-making is also adding to the burden being placed on patients.

For example, in February 2019, PHARMAC received an application for KEYTRUDA funding for adjuvant treatment of stage 3 melanoma, yet four years later, there has still been no decision made.

An extraordinary young advocate to take on PHARMAC was Jeff Paterson, who sadly passed away in 2016 from melanoma at just 23 years old.

Jeff had been studying for his master's in architecture and was a talented all-rounder – intelligent, good at sports and music. He loved socialising with his family and friends and battled melanoma on and off from age 16.

Towards the end of his life, despite being unwell, tired and in pain, Jeff fought an heroic battle to get PHARMAC to fund KEYTRUDA for advanced melanoma patients. Although his campaign was partially successful, the job remains far from done. There are thousands of New Zealanders, just like Jason Hooker, battling melanoma right now, and unfunded treatments remain at the heart of this.

Around 300 people in New Zealand die from melanoma each year. Yet, the most effective treatments remain unfunded and are financially out of reach for many New Zealanders – immunotherapy drugs

at stage 3 and BRAF-MEK inhibitors at stages 3 and 4. These melanoma drugs that aren't funded in New Zealand are: dabrafenib, trametinib, vemurafenib, cobimetinib, ipilimumab, encorafenib, binimetinib, pembrolizumab (for resected stage 3 patients) and nivolumab (also for resected stage 3 patients).

PHARMAC must step up to the plate and make the changes needed to act on the undeniable lessons learned from Jeff's death and the extraordinary cause he championed.

Jeff's family had the ongoing stress of having to raise \$11,000 each month for treatment.

His mother, Anita Kooge, says they raised around \$120,000 throughout Jeff's illness by holding galas, raffles, and sausage sizzles, and Jeff sold donated items on Trade Me to remain on his treatment. This included taking dabrafenib, which Anita said within two weeks of starting this drug, his tumours had gone.

"It's all-consuming. You do it because you'd move mountains for your child, but you shouldn't have to. Looking back, I wish we hadn't done it. It took away precious time. It wasn't fair on us," said Anita.

"It went beyond just financial implications, too. The psychological stress of knowing your child's life depended on your ability to find the next dollar was unbearable."

Anita recalls having to decline a combination of BRAF/MEK inhibitor drugs on offer because of the unaffordable \$20,000-a-month cost.

"The stress of organising those fundraising events was huge," says

Anita. "When you're sick, you need to concentrate on getting well, not having to fundraise for treatment."

Jeff's melanoma had spread to his brain, and he had four inoperable lung tumours – so drugs were the only option to save his life.

"He wasn't able to have KEYTRUDA in the end because he was just too sick. But if it had been funded and given to him at stage III, when it was in his glands, he may still be with us. That makes me so angry. It was too late," says Anita.

"PHARMAC has been sitting on KEYTRUDA's funding application for treatment of patients with stage III melanoma for more than four years," says Anita.

"When are they going to act? PHARMAC buries its head in the sand while we bury our family members."

"One of the last things Jeff said to me in his final weeks before he died, and as he was slipping in and out of consciousness, was, "Keep going, Mum".

"So here I am, many years on and still asking the Government to give PHARMAC the funding for melanoma drugs so others don't have to suffer the way Jeff did." ●

The psychological stress of knowing your child's life depended on your ability to find the next dollar was unbearable.

- Anita Kooge

Jeff Paterson



Message From Our Chief Executive

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

In our last issue, we shared that we were chosen as the official charity for the 2023 Southern Cross Round the Bays.

The event was an all round success and an excellent opportunity for Melanoma New Zealand to raise awareness about melanoma prevention and early detection and to fundraise for the cause. I was fortunate to be part of the action behind the scenes and as a fun run participant together with our Trustee, Dr Sonja Bodley, who took part virtually from Wellington. Our Nurse Educator, Sue Bibby, was kept busy at the finish line providing free spot checks to participants and supporters. And the rest of the team had the support of more than 60 students (and a few staff) from Auckland Grammar School and St. Cuthbert's College, as well as several locals from the area. I want to express our gratitude to everyone involved, especially Stuff Events and Southern Cross Round the Bays, for this incredible opportunity and the generous \$50,000 donation they gave us.

In this issue of *Spot News*, we share the heartfelt story of Jason Hooker, who only just got through his 19-year-old son's seven-year cancer journey when he was diagnosed with melanoma earlier this year. Jason and his whānau are now juggling his illness with finding ways to pay for his treatment. Unfortunately, this is an all too familiar situation in New Zealand. The advance in treatments available to melanoma patients in the last 10 years has been extraordinary. Yet, New Zealanders have not been able to benefit from these advances to the same extent as melanoma

patients in many OECD countries because these treatments remain unfunded and financially out of reach for many New Zealanders. Improving access to these lifesaving and life-extending treatments for patients like Jason is crucial, which is why we are once again asking PHARMAC to speed up and step up. See page 3 of this issue for a very moving account by Anita Kooge, who, many years on from her son Jeff's untimely death at the age of 23, is asking for PHARMAC funding for melanoma drugs so others don't have to suffer the way Jeff did.

Thank you to our Founding Patron, Lynn Stratford, who sponsored the opportunity for children with a family connection to melanoma to deliver the ball to the court at all Mainland Tactix netball home games this season. This allowed Melanoma New Zealand to share its messaging with the vast netball audience for a sustained period, both at games in Christchurch, online and on television. It has also been an exciting way to give the participating children a very memorable experience.

Our rural partner FMG continues to help us make a real difference amongst farmers and growers around the country. We headed to Northland Field Days in Dargaville in early March for two packed days of spot checks on the FMG site. Then later that month, we ventured to Feilding for the Central Districts Field Days, and in April, our nurse visited Taranaki to provide free spot checks and education at an FMG rural wellness event. In June, our team is heading back to Mystery Creek Fielddays, which undoubtedly will be another action-

packed few days. Thanks to a grant from the Great Barrier Community Organisation Grants Scheme, in April, we travelled to Great Barrier Island to offer free spot checks to locals like Lisa Davenport, who kindly shares her story on page 6 of this issue and ensured we were kept busy on our visit by spreading the word about our upcoming visit on her radio show.

Our work is made possible thanks to the generosity and involvement of so many people, like Matthew Rose, who recently completed his 1,400-kilometre walk traversing Te Araroa Trail. This challenge was both a personal mission and an endeavour to help raise awareness and funds for 10 charities close to his heart, one of which was Melanoma New Zealand. To date, Matthew has raised more than \$230,000, to be shared equally among the chosen charities.

We are so grateful to the many people and organisations - including our corporate partners, patrons, ambassadors, donors, grant providers and volunteers - who support our work. As always, it is a privilege. ●

Thank you!



Andrea Newland
Chief Executive
Melanoma New Zealand



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.**



Delivering the ball...and our key messages!

To help Melanoma New Zealand raise awareness, our Founding Patron, Lynn Stratford, generously sponsored the opportunity to have all of this season's Mainland Tactix netball home games feature ball deliverers with a family connection to melanoma.

The first to be honoured was the Mainland Tactix coach Marianne Delaney-Hoshek's father, John Delaney. Marianne's two sons, Zac (13) and Sam (11), carried the ball out onto the court to start the Tactix home games in memory of their grandfather.

Marianne had led her team to a 55-49 win over the Stars at the start of their ANZ Premiership season, and she wished her dad, John, could have seen it. He passed away in October last year after living for 13 years with skin cancer.

A sports coach himself, Delaney would call his daughter after every netball match and give her advice - mainly things to work on, even after a win.

Delaney, a police officer, was diagnosed with squamous cell carcinoma - a form of skin cancer - in 2009 after discovering a tumour above his ear. He had a 14-hour operation to remove his ear and inner ear. A significant portion of tissue and skin was also excised, leaving a large gap on the side of his head.

"At the time, they said they couldn't get all the cancer and only gave him three to six months to live," recalls Delaney-Hoshek. Her son, Zac, was just months old at the time.

But her dad managed to beat the odds and watch Delaney-Hoshek's two sons grow and start playing sports themselves.

"We've been so lucky, so grateful that we've had all that time with him," Delaney-Hoshek says.

"My two boys had a relationship with him. Even though it is obviously a sad story, there's some great parts to it as well."

"My boys had that special relationship with Dad around rugby. He would ring them after all their sports and they would report in," says Delaney-Hoshek.

The boys called their grandad 'JD' and loved his sense of humour, picking up phrases and words from him to use in their sports. John and his wife, Anne, would often look after Zac and Sam while Delaney-Hoshek was busy with netball; Anne also looked after John as his cancer progressed.

"She was crucial to him in terms of pretty much being his extra nurse for all those years as well. It was a pretty tough job, but she did amazing," Delaney-Hoshek says of her mum.

Around two years ago, Delaney was diagnosed with melanoma during a routine skin check. A tumour on his neck spread to his liver, and he passed away in hospice care on October 5.

Following Zac and Sam's on-court appearance, subsequent games have featured 10-year-old Emily and her sister Madeline (8), who went out for the Tactix vs Pulse game. The girls' parents are both qualified radiation therapists, and their mum Gill is involved in clinical trials for melanoma treatment. When the Tactix played the Magic, Georgie (12) and Annabel (10) Magrath delivered the ball in honour of their grandmother, former Silver Fern and Canterbury player Sandra Richards, who sadly died from melanoma in 2005. Although the girls never met Sandra, they know all about her and have followed her by playing netball since they were seven years old and have been to several Tactix games.

Five-year-old Ruby Hudson-Craig was the youngest of our ball deliverers and bravely stepped out on the court by herself to represent her mother, Victoria Hudson-Craig, who has stage four melanoma.

At the Tactix vs Stars game, Kingston and Savannah Boyd went out in honour of their dad Jeremy and uncle, both of whom have had melanoma. Jeremy also supported Melanoma New Zealand when we travelled to the South Island last year. He collected our nurse from the airport and looked after the Melanoma Spot Check Van between events.

Lynn Stratford's 11-year-old granddaughter Alice Johnston, whom Lynn also coaches, delivered the ball when the team played the Mystics. Lynn's daughter and Alice's mum, Amanda, has had melanoma and is a Melanoma New Zealand Trustee.

For the final home game of the season, our nurse Sue Bibby's daughter Coco proudly took the ball out on behalf of the Melanoma New Zealand team.

"We are so grateful to Lynn and to the Mainland Tactix for providing this opportunity - not only providing memorable experiences for special young people who have a family connection to melanoma but also enabling us to share lifesaving messages with the vast netball community," says Melanoma New Zealand Chief Executive, Andrea Newland. ●

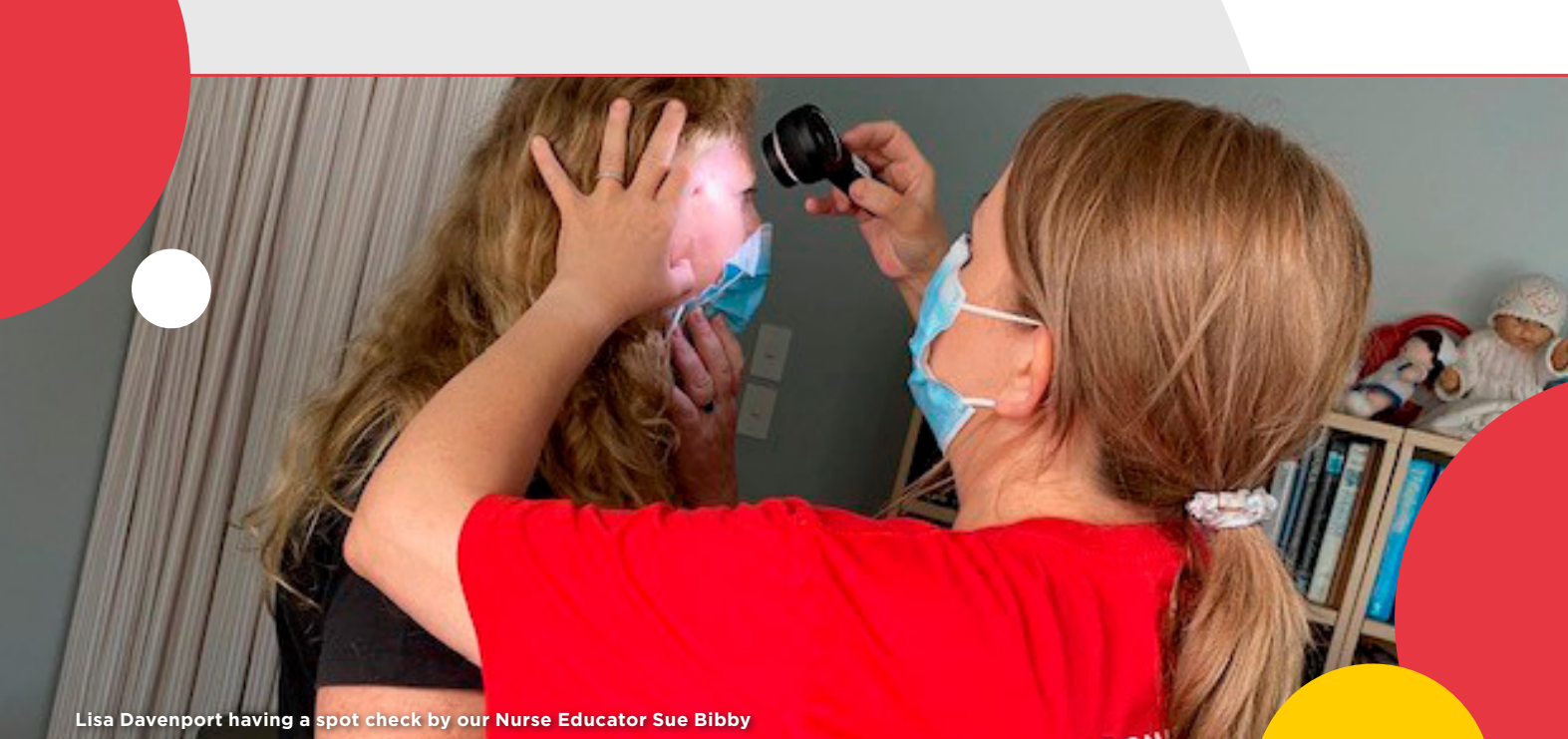
Parts of this story were originally published in LockerRoom and are republished with permission.



Sam and Zac Delaney-Hoshek



Ruby Hudson-Craig



Lisa Davenport having a spot check by our Nurse Educator Sue Bibby

Melanoma awareness advocate on Great Barrier

Great Barrier Island local Lisa Davenport uses airtime during her weekly Friday morning Aotea FM radio show to help raise awareness about melanoma.

Like so many other New Zealanders, melanoma runs in Lisa's family. She lost her uncle last year from the disease, and she, her mother, and her daughter have all had melanomas removed.

After her mother had melanoma, Lisa became extra conscious of checking her skin and other people's skin too. When she noticed a spot on her daughter's neck, she encouraged her to go to the doctor, where a biopsy confirmed it was melanoma.

She said the family was shocked because, unlike Lisa and her mother, her daughter never spent time in the sun.

Lisa's diagnosis two years ago came after having three biopsies done at her local GP. One showed she had melanoma. She travelled to Auckland to have it

surgically removed. Fortunately, because it was small and caught early, no further treatment was needed.

Now, Lisa always uses sunscreen, covers herself with clothing and stays out of the sun during the peak hours of the day.

"I keep an eye on my freckles and any new spots and talk to the doctor if I'm concerned about anything. My doctor also recommended going to a skin specialist every year for a thorough check-up, which I do."

Lisa joined the Melanoma Support "Melahomies United" Facebook group, which she said can be, at times, quite sad but also humorous and incredibly supportive to those people going through tough times.

There is another support group, Melanoma Support New Zealand, which is an excellent place for melanoma patients and their family members to share their experiences and navigate their journey with others going through similar experiences.

Lisa said her radio audience constantly gets a rev-up about their sun exposure and listeners are encouraged to check their skin. She uses examples like Bob Marley dying of melanoma to point out that it can happen to anyone, no matter what colour your skin is.

When our team visited Great Barrier Island in April, thanks to a grant from the Great Barrier Community Organisations Grants Scheme, word spread fast, and our nurse was fully booked. ●

Thanks to our supporters.



Lynn Stratford

