7.3 LMM 26/03/2024 - MARK HUGHES FOUNDATION 10 YEAR ANNIVERSARY

MOTION:

That City of Newcastle:

- 1. Notes that 6 March 2024 marked 10 years since the official launch of the Mark Hughes Foundation.
- 2. Acknowledges its founders, former Newcastle Knight Mark Hughes and his wife Kirralee, for their strength and leadership in starting the foundation in the midst of their own cancer journey following Mark's brain cancer diagnosis.
- 3. Notes that brain cancer is the leading cause of cancer death in children, and adults aged under 40 in Australia with a very high mortality rate and survival rates which have hardly changed for more than 35 years.
- 4. Acknowledges that to date, around 1 million MHF Beanies have been sold, raising millions of dollars for research, Brain Cancer Care nurses in regional Australia and supporting brain cancer patients, carers and their families. Indeed, in this time the Mark Hughes Foundation has raised around \$30 million dollars in support of its goals, with a \$25 million research centre established at the University of Newcastle to assist in fast tracking brain cancer research, reduce mortality rates, and hopefully one day find a cure.
- 5. Congratulates Mark, Kirralee and everyone at the Mark Hughes Foundation for reaching this inspiring milestone.

ATTACHMENTS:

https://www.newcastleherald.com.au/story/2263071/mark-hughes-tackling-brain-cancer/

MARK HUGHES TACKLING BRAIN CANCER

By Brett Keeble 12 May 2014

EVEN as he lay in his hospital bed after surgery last August to have a cancerous brain tumour removed, Mark Hughes was thinking about how he could help others.

For those who know him, that would come as no surprise, but even he conceded he had to take care of himself before he could commit to establishing what he hopes will be his life's legacy.

So after seven weeks of radiation treatment and six months of chemotherapy, the two-time premiership-winning former Newcastle Knights utility back feels as strong and as healthy as he did at any stage of his 161-game National Rugby League career.

Strong and healthy enough to head up the Mark Hughes Foundation, the charity organisation he launched on Tuesday in conjunction with the Hunter Medical Research Institute (HMRI) to raise funds and awareness to improve brain-cancer research in his home town



Kicking off with \$50,000 already in the bank, the foundation is a project he and his wife, Kirralee, have dedicated their lives to since he was diagnosed with an avocado-sized malignant brain tumour almost 12 months ago.

"Over the years I've done a lot of functions for charities, and for the last year or so [before the diagnosis], I'd been hounding Kirralee a bit about what am I going to do," Hughes told Weekender.

"I was helping other people out but I wanted to really try to do something to make a difference through a charity of my own. That was before I was sick.

"I was a bit ahead of myself. I probably didn't realise what was ahead for me, so at the time I don't think I knew what was coming up."

BORN and bred in Kurri Kurri, where he was an apprentice fitter and machinist before making a career out of rugby league, Hughes was accustomed to fending for himself and showing no signs of weakness.

Those traits made it difficult for him to accept the generosity of others when he was vulnerable.

"He does find it hard to sit back and let other people help him, and you get blown away by the amount of support you get," Kirralee said.

"He feels like he's got to do something for them in return, but it's his turn to have people do something for him, so he just has to accept it. But that's just Mark."

After the initial surgery, Hughes had to be driven to and from Gosford every day of the working week for seven straight weeks just to spend eight minutes in a face mask for his radiotherapy.

That gave the 37-year-old former NSW fullback a chance to catch up with family members, friends "and a lot of old footy mates".

"That was during the summer and I was doing a fair bit of training with [former Knights team-mate] Ben Kennedy," he said.

CITY OF NEWCASTLE Lord Mayoral Minute

"We'd do some running, then we'd jog to the ocean baths and do some swimming, so that got me through the radiation and kept me moving and kept up my fitness."

Then came a six-month course of chemotherapy, which he completed late last month.

A couple of other former team-mates in Danny Buderus and Bill Peden joined Hughes and Kennedy for early-morning hot yoga sessions three times a week to help clear his mind and ease the physical discomfort.

"It felt like I had half the team in there with me doing stretching and holding and coming up with some funny moves," he laughed.

"It's a mind and body thing, so that made me feel really good and it's helped me through the chemo side of things since Christmas."

Kirralee overhauled his diet by increasing his intake of green vegetables, reducing how much meat and wheat-based products he eats, and cutting out dairy and sugar where possible.

"If we go out for dinner, I'm not going to ask for a couple of sticks of celery and go sit in the corner," he said.

"I've still got to live, and I'm even getting back to having a few beers, so that's good.

"Kirralee's done an awesome job looking after me, helping me with my diet, and being so positive, so to have that support around the home has made a huge difference.

"I wanted to come through this whole thing feeling good, feeling fitter, and I didn't want people saying that I look like crap.

"I was thinking what would the average radiation and chemotherapy patient be doing, and would they be doing all this. It was probably a bit of the competitive rugby league player coming out of me, where I felt I needed to do that little bit extra to win and get there.

"I was always doing extras at training when I played footy, so it was the same thing here.

"I felt that if I was doing everything I could, it could only help my recovery. It's not going to cure anything, no-one's saying that, but it's certainly going to help.

BEFORE brain cancer called his number, Hughes said he and Kirralee were considering committing to a childhood epilepsy charity after the eldest of their three children, nine-year-old Zac, was diagnosed with the condition early last year.

"We were weighing up things and seeing what we could do there, then the old brain cancer picked us, so we found our charity," he said.

"We knew then that this was the path we were going to take to help people, so we just had to work out the best way to set something up.

"Telling my story has helped people get a bit of an understanding of it, and it's helped me with the support I've received, so the foundation is the real positive thing to come out of all of this."

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Buderus's wife, Kris, joined the team later to co-ordinate the launch and other events.

"We didn't want it to impact on Mark's health, because Mark throws himself into things 100 per cent," Kirralee explained.

"There's so many rules and regulations when it comes to charities, and that was probably weighing us down a bit, because we've got three kids, we run a commercial cleaning business, so we wondered how we could make the whole thing work.

"Brain cancer is so under-researched and so under-funded, but we want to change that."

Mark added: "They're doing a lot of brilliant things up there at HMRI, and it's world-class, but they're a little bit behind in the area of brain cancer, so we're excited and they're excited to be launching into that field.

"We're hoping to create awareness and raise funds. They've got a great team there at HMRI and they work on two-year and three-year projects, and they need \$40,000 to do each one, so we hope we'll have four or five projects with them in the next few years. That's a goal for us.

"With the foundation, we're hoping people, anyone, organisations big or small, can help out in any way they can. It doesn't have to be tomorrow but just keep us in mind at some stage."

The foundation's website went live at the launch on Tuesday, and Danny Buderus was announced as the ambassador, saying he felt privileged to be asked.

There are plans in place for a fund-raiser at a Knights home game later in the year, a "beanie for brain cancer" day at Hunter schools and, down the track, a gala ball and other functions.

Former Knights and Raiders prop Luke Davico started the money ball rolling last September with a trek past the Mount Everest base camp.

Other friends organised a golf day at Crowne Plaza Hunter Valley last November, the Kurri Mongrels raised about \$10,000 at a five-day mountain-bike ride last month, and the Once-A-Knight Old Boys and Kurri Old Boys have nominated the Mark Hughes Foundation as their charity partner for the year.

"We don't want it all to be done and dusted by Christmas," Hughes said.

"This is something that is going to be around forever, so we're not rushing things. We're doing everything properly."

The foundation has also aligned with the Sydney Neurology Oncology Group (SNOG), a brain tumour research and support organisation that helped Hughes establish a blueprint for his treatment and recovery after the initial diagnosis.

SITTING alongside Kirralee on the balcony of their Merewether home on a sunny, postcard-perfect mid-autumn morning, Hughes looks anything but a cancer patient.

Enjoying the clear view all the way to Strzelecki Lookout, as their children Zac, six-year-old Dane and two-year-old Bonnie jostle for positions on the lounge to have their photo taken, Hughes gives the impression he hasn't a care in the world.

"I had a scan about two months ago and that was outstanding," he said.

"It looked excellent and everything's on the right track.

"We're ticking everything off so far, but it's cancer ... That's why we're really pushing for this funding and research because there's going to come a rainy day where we're going to need a bit of help again, and we want to make sure we've done everything we can to help.

"We just want to feel like we're controlling our own destiny a little bit, by our diet, our lifestyle, and by treating every day like a great day."

After adjusting her own outlook on life, Kirralee said they no longer plan beyond the present.

"At the start, it was horrendous, I can't explain it, but I feel like I've come out the other side a different person," she said.

"I was never someone who could live day to day. I was always worried about the future, but I don't look past today now. That was hard to adjust to but I don't. I can't."

There was no point arguing the referee's decision in this case, Hughes said, because "I think this is the journey that our family has been chosen for".

"I think once everything is sorted out, our lives are going to be better for it," he said.

"It's going to be very rewarding, we're going to do some good things with the foundation, and we're going to make sure we live for now and not be worrying too much about the future, which is a good way to live. Things really couldn't be going any better."

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- Brain cancer is one of the most lethal yet least studied of all cancers. It is the leading cancer killer for people under 39 and children under 10, yet receives very little research funding.
- In its malignant form, it is almost 100% fatal.
- About 1600 people will be diagnosed with brain cancer in Australia each year, and about 1200 will die.
- One person is diagnosed with brain cancer every six hours in Australia, and every eight hours one will die.
- Survival rates have hardly changed for 30 years, despite significant increases in survival for Australians diagnosed with other types of cancer, such as leukaemia and breast cancer.
- Brain cancer costs more per patient than any other cancer, yet only receives a small fraction of cancer research funding.
- Brain Cancer Action Week ran from April 27 to May 3.

When he sees his specialist for a progress report next week, Mark Hughes will pay a visit to the man who has attracted universal support from the rugby league community.

As he fights his own battle with brain cancer, Hughes has been inspired by Alex McKinnon's positive response to the career-ending spinal injury that the 22-year-old Knights second-rower suffered in Melbourne almost seven weeks ago.

"It sounds funny to say it when you've got brain cancer, but we feel really lucky because it could have been a lot worse," says Hughes, flanked by wife Kirralee.

"You see lots of stories every day out there in your paper, on the news, and there are other people who have always got something a lot worse.

"I've been very touched by Alex's story. My specialist is at the Royal North Shore Hospital so when I go down for my next appointment, we're going to go and visit him.

"I'm really looking forward to that because we've both had life-changing experiences, so we've got a little bit in common.

"I've been thinking a lot about Alex and it's been awesome seeing how positive he's been, and hearing feedback from Bedsy [Knights trainer and former skipper Danny Buderus] and the boys about how well he's going, so I take a lot of inspiration from him as well."

He hoped his own optimistic outlook elicits a similar response from other cancer sufferers.

"Everyone probably has a cancer story in their family, so I hope people with cancer see me and see that I'm out there living a normal life and doing well and gain some confidence out of it," he said.

"They'll see that I'm raising money for research and hopefully it will encourage more people to do the same."