Dr. Ryan Thomas – Bonus Episode Transcript

Dr Ryan Thomas 00:00
[bubbly, pensive electronic music] My name is Ryan Thomas. I'm a physician working at the Elisabeth Raab Neurofibromatosis Clinic at UHN, and I, myself, am a patient living with the condition. I was diagnosed in my late twenties, so it wasn't an early or childhood diagnosis, which other patients may have experienced. From early childhood, I had always noticed a few lumps and bumps and café-au-lait macules – light brown, sort of spots on the skin that look like birthmarks. However, depending on whether it's a child or an adult, there's a certain number and a certain size that can be one of the clinical manifestations of neurofibromatosis.

But it never really amounted to anything, and I otherwise felt fine. It wasn't until my late twenties, when my very dedicated family physician used a stethoscope, said that she couldn't really hear a lot of movement in the right side of my chest, and then decided to organize some follow-up testing which eventually led to the discovery that I had a very large tumour in my chest and that's why she wasn't able to hear anything. And I eventually needed to have surgery to have that dealt with.

[music continues] It was a big shock, especially because it was both discovering the large tumour, as well as the diagnosis of neurofibromatosis at the same time, and then all of the investigations, appointments, and planning that then went into it, it was sort of a life-changing experience. I was in the middle of my family medicine residency in Australia and my wedding was also a few months away, as well. To, then, have to be faced with not only the diagnosis but the need for fairly urgent surgery, it sort of put everything else on pause. It was a fairly serious finding and, from what, you know, I could initially see, it may have been something that may not have given me a lot of time left.

[music continues] After the initial diagnosis and discovery, I had to have, you know, several sets of imaging, biopsies, scans. I met with a few different specialists and all of that went into sort of planning for the surgery, which happened about two to three months after the initial diagnosis. And then, it took about six months for me to recover from the surgery because it was quite an extensive surgery that was needed.

[music continues] Because of my upcoming wedding and the fact that my family was in Toronto, I had decided to have the surgery back in Toronto to make sure that I was safe to be able to fly on a plane. While I was in Australia, I had to undergo what was called a high-altitude stimulation test to see whether it would be okay to fly with such a large tumour in my chest. Initially, we weren't sure, in terms of timing, when the surgery would occur so, as we found out the surgery date, we found out that we, thankfully, didn't need to change the wedding date, but there was a possibility that that would have needed to have happen.

I had the surgery prior to the wedding. It was about two months before, so it was just enough time to, you know, allow me to sort of heal enough to be able to stand up. The surgery, what was required was open-chest surgery, what was called a posterolateral thoracotomy, so they needed to go in from behind to take out the tumour. The tumour was about 10 centimetres and, from what I was told, it was about five and a half to six hours of surgery time. You know, thankfully, I didn't notice the time go by, but my family said it was quite a long time. [chuckles lightly]

[glitchy electronic music] The initial one to two months was quite tough, in terms of sort of pain and not being able to, you know, move around as much as I was used to, but with physiotherapy, I was able to

gradually recover, and I found it really took me about six months in total to feel somewhat back to how I felt before, but there has always been a lingering amount of pain, given the type of surgery that was needed, that won't go away.

[music continues] Six months after the surgery, I was able to resume my training and eventually complete it. In terms of the types of treatment, I do have regular monitoring with MRI; that's kindly organized through the Elisabeth Raab NF Clinic. I see the specialist there once a year, myself, and that's just been to track any sort of recurrence of the tumour. [music fades out]

[bubbly electronic music] It's really helped me, you know, being able to relate to patients to know what it's like to live with it on a day-to-day basis, how the tumours feel, how it feels like to go for regular scans, what's involved, how to interpret the pain. I do see that a lot of patients are quite grateful when I'm able to share that with them because they may not often meet another person with NF1, as well, so they they really do seem to appreciate that I can understand what they're going through. [music fades out]

[upbeat electronic music] There are a few different types of neurofibromatosis. Most commonly is neurofibromatosis type 1, and there is another related condition called neurofibromatosis type 2. However, that's been reclassified as NF2-related schwannomatosis, and there's another group of conditions called schwannomatosis. So, all of these conditions have some overlapping or similar conditions, but they're actually considered genetically and clinically distinct conditions with their own treatment, their own symptoms, as well.

[music continues] At the clinic, we see patients with NF1, NF2, and schwannomatosis. There is a lot of stigma associated with NF1, especially as one of the symptoms are cutaneous neurofibromas or lesions on the skin. [music fades out] So this will lead to sort of a lot of people in the general public not knowing what it is. Some people may think it's infectious; some people may not understand what it is. I've had patients tell me that people have just come up to them in public and just asked them, so it's really unfortunate that there isn't a better understanding in the general community about it, given how common it actually is.

[uplifting electronic music] With myself, one of the reasons, in my case, that it wasn't discovered earlier is because I didn't really have many on the surface of my skin, so it wasn't obvious from, sort of, an outside perspective. When I was first diagnosed, I only knew a bit about the condition, myself, and it did feel very isolating, not knowing who to turn to, but, thankfully, there is an NF clinic here in Toronto. There was one in Sydney, in Australia, where I was initially seen, as well, and it really made me feel very comfortable and at ease knowing that there were specialists in the area that knew and understood the diagnosis and how to help me, and that's something that I'm thankful to now be a part of, as well.

[music continues] While it can run in families and some patients may have a family member that's affected, for many, they're the only one that they know with neurofibromatosis, so even being able to come and see other patients in the waiting room and see someone else with the condition, many patients have just found that very nice and, commonly, they'll just break out in conversation amongst themselves, as well, but then even be able to speak to me and want to share that. A lot of people really appreciate that. [music fades out]

[upbeat electronic music] To have a condition that's genetic, which is therefore, you know, being told that there's no cure, to then be given some hope that there are treatments to both help some of the

physical manifestations as well as pain, and it gives me a lot of hope for the future that there are now drugs that are available to treat, you know, certain cases of people with NF1 as well as, you know, there's a global conference as well that happens, so it's very exciting to be in, and something I hope to, you know, be a part of in the future.

[music continues] There is a lot of momentum in the field of NF now – a lot of excitement, which gives me hope for the future that we'll all be able to better benefit and treat patients, to not only help them with, say, pain, weakness that may associate from nerves that are being compressed, but also from the physical manifestations, as well. [music fades out]

[bubbly electronic music] It's been extremely rewarding that I've been able to help and work with other patients with it. It's been able to help me use the diagnosis that I have to help other patients and, if I can share some stories and relate with them and make them feel better, then, I mean, that feels really great to me. And it's because of Dr Vera Bril that had, you know, invited me to join the clinic, and I'm thankful for the opportunity and, you know, thankful that I can help other people with the condition. [music fades out]

[bubbly, pensive music] Given how common it is and how, you know, there's still a lack of understanding, I would say it's extremely important that there is a centre like this, and patients travel from several hours, all over the province, to be able to come and be seen here, so it's great that they know, as well, that there's a home for them to know where they can turn to where the physicians will understand and know how to help them.

[music continues] My message to our patients is, "Don't give up hope. We understand you. If you have concerns, then we're here to help you. New research is evolving and we're hoping to be able to better treat and understand this condition as time goes forward." [music fades out]