

Jack Conway – S2E5 Extra

Hello. My name is Jack Conway. I am 18 years old and I love video games and roller coasters. Well, I can't say explicitly how people might describe me or especially my family, but they would say that I am very passionate about politics and theme parks, and they know I love my video games. So in my family, I have my mom named Kim. I have my dad, Steve. I have an older brother named Brian who I don't see much because he's in college. We had another member of our family, our dog, Charlie. Unfortunately, we lost him back in the end of January. But right now it's just the three of us for the most part. When my brother comes home, it's the four of us. But, you know, that's kind of my immediate family.

So I play video games with my friends or by myself, whatever, just kind of doing whatever I feel like doing. I play a variety of games from *Call of Duty* to *Minecraft* and all sorts of things. So I'm able to kind of express my creative mindset in *Minecraft* or just kind of unleash any stress or whatever and *Call of Duty*, that sort of thing. So I have those releases and then I also love rollercoasters. You could pull up a picture of a roller coaster and I could either name the coaster park itself or both. I'm kind of a roller coaster nerd. But yeah, I absolutely enjoy riding and researching roller coasters. And other than those too, I'm also into model trains, which is something I'd like to get into. I have some stuff to build a model train layout. We don't have the space for that. That's the only thing we're missing.

When I was six months old, I was diagnosed with an optic pathway glioma brain tumour, which is a tumour that grows on the optic nerve. And that tumour, even after treatment with chemotherapy, excuse me, did damage the optic nerve. And therefore I have a vision impairment. I do have a vision impairment. It's not a huge impairment, but it's a significant one where I do have trouble reading small fonts and according to the government I can't get a driver's license. When I was diagnosed, we did meet Dr. Bouffet and he ended up being my neuro oncologist for the duration of my first battle. He put me on a I believe it was a 14 month protocol of being Vincristine. I finished my first rounds of chemo and beat the tumour for the first time, and we still see him every few months for MRI's or appointments and that sort of thing. And then when I was diagnosed I was put on Vinblastine, which is a chemo treatment that he created himself along with members of his team. And that treatment is now the number one course of action that they will use for other children that are diagnosed with the same tumour that I had. And I was one of the first children in the world to receive that treatment. I do understand the fact that I spent my first birthday on Christmas at SickKids. I spent some time there for appointments and stuff when I was on treatment. The second time would take the whole day and be 6 hours of waiting for treatment. Most cases, I would say I probably, if I add it up all the time, I've probably lived at SickKids for probably four years of my life in total with all the visits and stuff combined, which is a lot of time.

School can be challenging for me specifically because of my vision. It can be difficult to engage in uncertain activities. In Vizag, for example, I enjoy being active, but when we were doing games like badminton, it was impossible for me to see the birdie. I actually couldn't play badminton because I had that inability to play or kind of discern the birdie from the surrounding area. Even when we tried spray painting it different colours to help it stand out, it still didn't work, I would say for small text. So if I were to pull something up on my phone, I would be like this close to reading it. So my nose would be a couple inches from the screen and that would be the same with books and in fact with school textbooks. My nose would be pressed up against the page of the book. So it's mostly with reading. I do have good visual observations just around in general, so I can see things like I could

see oncoming cars or oncoming street signs, things like that. I could still make details and that when it comes to reading, that's really where I struggle.

We have tried glasses and fortunately, while they have improved certain elements slightly, like I know the last couple of glasses I had, I did make the images. I saw like trees a little clearer, like I could see more of the individual leaves instead of just clumps of leaves or something. Glasses don't unfortunately work, but they can make some improvements. Sometimes I actually quite often will walk by people I know and not say 'Hi' to them because I didn't realize who they were until I was basically right next to them because I didn't see that they'd pick up their facial details from afar distance. And then when I was in a small group of friends a few weeks ago, I would walk by them and they would all laugh because they think I'm blind. Well, I kind of and blind. It's funny. I like the jokes that people make about it.

I first heard about the study from Dr. Uri Tibori from SickKids during one of my follow ups in 2018. He did mention that a vision study was going to be conducted at Toronto Western with McMaster and other teams from SickKids involved, and we put our names on the interest list. It was round summer of last year. We did find out that it was going ahead and we went ahead with it. What it is, is using virtual reality goggles. So I would wear these virtual reality goggles on my face that are Oculus Quest two headset, I believe. And there's a program in there that I would pull up, and it was called revision, I believe. And it was a black screen with a white box or I guess the silhouette of a box in the box or several balls that were yellow. And then they would be organized at the beginning in a diamond shape and one of them would flash red. So that would be the ball I would focus on. And then after a few seconds the game would start and then they would all move around. It would start off very slowly. They would kind of move, bounce off each other and bounce off the box, that sort of thing. And they would do that for about 15 seconds and after 15 seconds it would stop and I had to click the ball, I believe was the correct ball. And then if I was free, you would say correct. And if it wasn't, it would show me the correct one. And it got harder as time progressed, it would do three rounds of of 15 or three. It was a three-part thing. Each time I did it, it was three 15 rounds, excuse me, sessions and took about 45 minutes in total. It got faster. As each round progressed, the speed did increase to the point where at the very end it was like rocks in a blender, just bits flying all over the place.

They would do an eye exam and see kind of where my vision was at. And then after two weeks of the trial, they would have me come back in to do another vision exam to see where my vision was, if there were any improvements. And then two weeks after that, I would go in for a third exam and then they would do the same thing. And then after the fourth, they would also check. I would do this every other day for the duration of that four-week period, and we actually had to extend it to six weeks. They got a two-week extension on it at each appointment. They did find that my vision had improved slightly because of the frequency in which I did it and just the way I was supposed to do it, which was by just using my eyes and not moving my head in any way. So I was really focusing on kind of using my peripheral vision or my central vision for it. However, everything I've, I've gone through with needles and MRI's and all that stuff. Yeah, this was definitely the most fun thing I've done for the rest of the night.

After I would do it, my vision or my focus was better. My eye fatigue was less prevalent and I did find that when I was playing my games, my accuracy in those games was definitely enhanced because of the fact that I was more focused and my peripheral vision because it kind of got a workout, it was better as well. I think it's an incredible idea that vision can be restored using technology as opposed to procedures and surgeries. I think

it's incredible that you could just put on a pair of virtual reality goggles every other day and improved vision. I do get very excited about the fact that vision can be corrected using technology with the way technology is advancing with all the new tools that are being created. The fact that, like I said, you can just put up, pull up a program on a device and then use that program in that program will actually improve your quality of life is remarkable to me. I have gotten into all six college programs that I applied for through Algonquin, George Brown and Durham College.

My message to those who are in a similar situation to me, vision wise, is to just try not to let it get the better of you. I know there's going to be some things you won't be able to do, but there are alternatives, like taking public transit, which is improving, especially in Toronto. I would absolutely continue to do this specific program. I think that the six week trial could open the door for maybe a more permanent sort of idea or habit of going on every day, every other day, excuse me, in and doing this. And yeah, that takes time. But if it improves my quality of life over time, then it's worth taking that time to do that. And I enjoyed doing it.