

Community rallies to help Ben take on the world



By Brock Weir

Ben Ho Lung is ready to take on the world.

Next month, Ben and several of his new friends will head to West Palm Beach, Florida, as members of the only Canadian delegation to challenge teams from across the United States and as far away as Cuba, Portugal and Taiwan for the ultimate glory.

The ultimate glory this time is in Beep Baseball, a variation on America's favourite pastime, specifically tailored for those living with vision loss.

Just a couple of years ago, Beep Baseball wasn't even close to hitting the 19-year-old's radar, but it has become a welcome release for the Aurora man who is adapting to his new normal with rapid onset blindness, or Retinitis Pigmentosa.

Diagnosed with the degenerative eye condition last fall, he was initially told he had about 10 to 15 years of progressive vision loss. However, the condition swiftly took its toll and he was declared legally blind within two months of the diagnosis.

Since then, Ben has been travelling back and forth to New Jersey for innovative micro-acupuncture treatments which have significantly improved and maintained his vision.

Each trip, however, comes at a cost and the community has banded together to support Ben's course of treatment.

In addition to setting up a GoFundMe campaign to help Ben's single parent family shoulder the burden, community members came together last Monday for a special fundraiser at Joia Ristorante to help raise the necessary cash.

'It's nothing short of remarkable,' says mom Leslie Burns. 'It's hard to find the words to describe how it felt. We weren't looking for help, but we were stunned that these people who were doing everything in their power to help us out and make it so that Ben could continue with the treatments.'

Little over a year ago, Ben was like so many other high school students this week wrapping up their high school careers.

With dreams of being a teacher, he was well underway into his bilingual degree at York University's Glendon College when he noticed an emerging problem.

His local optometrist noted some unusual pigmentation on his retinas and the rounds began on a number of appointments both here in Aurora, in Toronto, and beyond to reach his unusual diagnosis.

His vision began to fade, he says, but for a while still kept up driving. 'Not the best idea!', he admits, but was soon tripping over curbs, people and garbage cans making his way around campus.

'I want to say it was gradual because even as it was happening I didn't notice at all, but according to the tests it was fairly rapid,' says Ben, with Leslie adding she would receive a simple, 'Mom, I've got this!' when they were out driving and Ben, with decreasing peripheral vision, veered a little bit too close to another car.

'But did we crash?' says a grinning Ben.

"No, we didn't thank god!" replies Leslie with a hearty laugh.

That, in a nutshell, sums up the family Ben highlighting the light side of things, and Leslie his most enthusiastic cheerleader. This enthusiasm is palpable as she leafs through a binder of images showing Ben's marked improvement following his micro-acupuncture treatments. After several sessions, Ben noticed significant improvements with his light sensitivity as well as with his peripheral vision.

"It was pretty exciting to see because everyone was telling us there was nothing we could do," says Leslie.

Ben too fielded similar responses. Even now he says he has trouble explaining what he's experiencing to his friends.

"People tend not to get a good understanding of what is actually going on because they can't really see through your eyes and that is not a metaphor!" says Ben. "If I tell them my field of vision is a pinhole, they ask if there is a black border around the edge, because that is what they see because they still have their peripheral vision."

They might not be able to see through his eyes, but they can see how he has adapted. Due to remaining sensitivity, lights at home are kept to a minimum. Movie nights at Cineplex are out, and his white cane is propped against the living room coffee table.

He is able to navigate swiftly around the house. Muscle memory, he says something which has enabled him to continue his passions, which range from piano to breakdancing. He typically gets around by bus after all, he jokes, he was used to buses already with only one car to go around between himself, his mom and brother and has become a fan of nights out with friends in Toronto because the TTC gets him usually within a block or two of where he wants to go.

"You have to be prepared to make a lot of compromises, but don't stop doing the things you love doing," he offers. "If you like doing something, don't let the loss of vision stop you from doing that. It's a lot to deal with, so it is good to have some things in your life you still enjoy doing because this big thing is going on with you that, for most people, is not reversible or treatable in any way. It is just a big thing hanging over your head all the time. Don't just sit around and be bummed out about it; life shouldn't stop just because you've got a big change going on."

"For me, even though it is a big thing that affects every aspect of my life, overall I want to say it is just a minor setback. Just have a positive attitude and be willing to adapt. If we listened [to original diagnoses] I would have been blind by Christmas. I don't know exactly what I want beyond being able to feed myself, house myself, clothe myself and do something fun now and again."

At press time, Ben's Go Fund Me campaign was less than \$500 away from its \$15,000 goal. To help send him over the top, visit gofundme.com/bens-adventure-plan-2wtga4.