

# Dancing Eyes

*Tyler Pantella*

I heard about my eyes all the time in school – elementary, middle, and high school, where you're thrust in with hundreds (eventually thousands) of peers and forced to interact. Nobody in my distant family has documented congenital nystagmus. Just me. My grandma recalls a grandparent who had a "twinkle in her eye" that could have been nystagmus as well. This is probably the recessive form of the disease.

The biggest problem for me has been the social awkwardness. Countless times, I've met or been introduced to someone, and they notice my nystagmus. Instead of "Hi, how are you?" it's "What's wrong with your eyes?" That phrase is the most common reaction, followed by "Why do your eyes do that?" I prefer the second question because it doesn't set me as far apart as a freak.

I phone my family doctor and speak with the receptionist. I explain, as officially as I can, that I'm doing some research into my medical history, and if there were any sorts of medical reports or letters in my file from the early nineties relating to my congenital nystagmus, that'd be, you know, pretty cool. "We've moved offices, you know?" she reminds me. Yes, I'm aware. "When was the last time you saw him?" I tell her it's been a few years. I don't bother to explain that I'm still in the same city, but his office is quite far from the house I moved into with my best friend, so I usually go to

walk-in clinics when I need to. "He might have them at home." She absent-mindedly takes down my cell number and never calls me back.

The front row sits and waits, looking restless. Two of them wear windbreakers, probably slipped on by careful parents eyeing the overcast sky. In the back, the teachers hang on to the bordering kids and flash distracted smiles. And there I am. Middle row, third from the right, giving that look.

In most photographs of me as a young child, my head is tilted to the left of the frame. I look suspicious of the camera and world, giving everything a sidelong glance. Sometimes I look mischievous, like I just stole someone's Power Rangers action figure. Sometimes I look to be facing something more exciting, maybe a pod of magical birds on the horizon. Always, I look out of place.

That wasn't even my problem. It was my coping mechanism, according to my operating surgeon from the mid 90's. Dr. Margaret Kilshaw.

I do a Google search for Kilshaw. "Margaret Kilshaw Victoria," I type as keywords. Search. RateMDs.com has recent reviews of her. She's still in practice! Everyone loves her, even now; "I will be very sad the day she retires," "When she is with you, it is as if you are her ONLY patient," "She is the only one that took me seriously and recognized that I did in fact have a vision problem." And she's at... 3066 Shelbourne Street. A five minute walk from my house.

My eye disorder is specifically called “congenital motor nystagmus” – meaning a genetic case of involuntary eye movements. Jerky eyes. Mine are horizontal. To others, it looks as though my eyes are constantly jerking around within a few millimeters. I can’t stop them to look at something. They become more still with certain eye and head positions. It used to be the left side of my head until the surgery. Meaning I always sat at the right side of the class, not out of choice, but out of necessity.

Nystagmus is often paired with other disorders. It wouldn’t be strange to see it in an albino person, someone with Down’s Syndrome, or someone with Cerebral Palsy. I’m lucky enough to have avoided those. I just have the jumping eyes.

One situation that happens a lot, to my embarrassment, is what I call the “restaurant situation”. A friend will ask me to meet them in a low-light situation, like a party or restaurant or any other gathering of people.

This was the case about a month ago at The Mint in Victoria. I was meeting my friend Jordon for her birthday. The Mint is notoriously dimly lit. I fidgeted in my jacket pockets as I walked closer. I could feel it starting. I finally caved in and phoned my girlfriend to ask, “Can you meet me outside?” So she left her seat and met me on Douglas Street, slightly confused, and brought me inside.

What would have happened if I went in on my own? I’d get inside and be bombarded with a fresh canvas of lights and faces. And my eyes wouldn’t be able to scan the situation in an ordinary manner. The nystagmus, amplified by my own fear of

embarrassment, would make my eyes dart around and not long enough to recognize faces. And I'd probably walk right by my friends.

I call Dr. Kilshaw's reception desk. Again, I try to explain my case. I'm embarrassed. Here's this amazing surgeon, still saving eyes, and who am I to interfere with my bumbling questions from my ancient history of a childhood? "We're booked into March for regular patients," the desk girl explains. I give my name and cell number like in my last phone call. This seems right, it was too good to be true.

A few hours later, I'm watching Frasier on TV, on the couch. Frasier is telling one of his callers a story about his dad's dog's depression. For some reason, I think this is hilarious. "Oh my, Fraiser," I say in a mock Mid-Atlantic high society accent. I'm startled with a call of my own from an unknown number. I mute the TV and grab my notebook.

It's Dr. Kilshaw. She's interested in helping me and wants to meet with me at 2:30 the next day and has a bunch of old paperwork.

I'm allowed to drive. I don't have my license, but I'm allowed to get one. I'm not visually impaired by ICBC's standards. I'd like to defend myself and justify this but really it just comes down to the fact that I think I can drive safely and they won't notice anyway.

I remember my embarrassment at baseball practice when I was eleven. I was never incredibly good at baseball. Hell, I'm not even sure why I played. Maybe it gave me something to do. It's more likely that I felt forced into it by my parents. Betrayed.

One of the other parents approached me during a practice and asked, “Have your mom and dad ever thought of getting you glasses to fix your eye problem?” It’s not nice to tell a kid he has a problem. So I had to awkwardly explain, to an adult, that two lenses in front of my eyes wouldn’t stop my eyes from moving. I was sensitive and felt like crying. Sure, I struck out a fair amount. Missed the occasional pop fly. My hand-eye coordination sucked and years of baseball didn’t fix that. Tracking a moving ball and predicting where in the air it’s going to go, and how quickly, was not a skill I could easily pick up. And I didn’t need a parent to point out my problems. But I believed her, that really I just sucked at baseball and was bringing her kid down with me. Because I still believed that all adults were right.

I find the building and ascend the staircase. It’s like a hiding place for doctors. I find Dr. Kilshaw’s door on the 4th floor. Dr. Kilshaw, Ophthalmologist, littered with credential and degree abbreviations. Her receptionist gives me the paperwork – letters from her to my family doctor and background information on the surgical procedure.

One, from 1991, reads, “I examined this 3 year old boy on April 23rd.” After a listing of test results, it goes on to say “This three year old boy therefore has good vision despite his congenital nystagmus,” and, “I would, however, recommend that he is followed in a yearly basis and more detailed testing as indicated.”

Another, from 1996, reads in part, “A year ago Tyler was examined by Dr. Jean Carruthers who confirmed the diagnosis of congenital motor nystagmus. She felt that Tyler was a suitable candidate for the Anderson’s Kestenbaum repair. The family are

now keen to proceed with the eye alignment in order to help Tyler to see clearer with his head in a more comfortable position. I have discussed this procedure with Tyler's mother and they are keen to proceed."

There's something golden about childhood. Something you can still feel if you try really hard. Nostalgia is like a drug – it brings quick happiness but mostly longing. I remember the surgery and I remember how it changed my life. But I want more. I'm in my early twenties and living as an adult. I deserve some understanding. I still have nystagmus, and it isn't curable, but that surgery made my life a million times easier. The surgery that fixed my head tilt and made my nystagmus that much less prominent.

I call my mom and talk to her about the surgery for the first time in years. Maybe one of the first times since having it. "We took you to see a specialist in Vancouver as well, but they recommended the same procedure that Dr. Kilshaw in Victoria could do."

"Do you remember what book you were reading?" I do. It was a Goosebumps book called Let's Get Invisible. It's about a bunch of kids who find a magic mirror that lets them turn invisible. The ending plot twist still bugs me – one of the kids is banished to the mirror realm forever, replaced by his mirrored counterpart. This really scared me. More than the surgery itself did. The surgery seemed like it was going to be fun and Kilshaw made me feel comfortable.

Dr. Kilshaw comes from around the corner and asks me to follow her. She stirs my memory and seems to look exactly as she did thirteen years ago. Her gray hair is medium length, voluminous, and straight cut along the bottom. She's genteel and retains an air of authority. She says I can sit in the leather chair in the examining room rather than the examining chair, hooked up to a daunting array of eye measurement gear.

"The patient adapts a head position in order for the eyes to get to a null position. As you turn the head, the eyes still, and then the vision is significantly better," she tells me about my childhood head tilt. She's in awe of the body's ability to cope with a genetic disorder, not derisive like many of the kids on the playground were.

"Our aim is to move the eyes into a straighter head position," Kilshaw says on the Kestenbaum Anderson procedure. Sure enough, she did just that. Detailed in surgical language on the operative report, every step is described. "The lateral rectus muscle was approached first, and an incision was made over the lateral rectus muscle." These are my eyes they're talking about slicing open. It's like documenting a shooting by saying that "the man's epidermis was punctured with four successive holes" or something. It continues. "The conjunctiva was closed with interrupted 6-0 catgut." Catgut? This report is both dry and fascinating.

Dr. Kilshaw continues, in that articulate manner of speaking she has. "It's certainly been known about for several years. Initially there was some skepticism about it, but I think any of us that do pediatric strabismus work know about it." Strabismus means crossed or divergent eyes, one of Kilshaw's specialties.

“It’s typically done as the child as maturing. I think an adult is more cautious about it. Ideally it’s done at age eight or nine but it could be done on an adult.”

But I wasn’t an adult. I was nine years old and, as Kilshaw says, “We would describe you as a delightful youngster.” But I was perceptive and they were sure of my nystagmus early on. “You described quite often a flickering of lights and things moving. You gave us quite good descriptions. You were very aware of it and were in Grade 1 at Sangster at the time,” she says, referring to her notes.

I remember not being scared. The surgery was like an adventure. Lying on the operating table, I counted to one hundred as the anesthetic kicked in. I was so sure I would make it to one hundred. Instead, I made it to twenty. And I’m sure I was counting fast.

I also remember waking up in a yellow room in a bed that didn’t look at all like a hospital bed. I had been sleeping for quite a while. I wore a tight gauze eyepatch and I wasn’t supposed to strain my eyes for a few days. Then I played a lot of Adventures of Dino Riki for the Nintendo Entertainment System. My mom wasn’t happy with this.

“You’ll strain your eyes!”

“Part of our frustration with the nystagmus is that we can’t do a lot to still the nystagmus. Botulinum toxin has been tried.” I think of the possible world of still eyes. I try to imagine what it would feel like but I can’t. It’s like the more I concentrate on my eyes being still, the less likely it is that it will happen. Instead, my eyes are only still



when I'm least aware of them. I can feel nystagmus when it happens. It's a sort of numbing energy behind my eyebrows and a realization that my perception has gone down. And what I do perceive could scare me. I'm suddenly afraid of people staring. I try to hide it. It gets worse. My head starts pulsing and I blush. Meanwhile, my eyes are darting around frantically. And the stress feeds it even more. I feel like being alone.

"I find it very interesting when you're able to express the frustrations," says Kilshaw. We get a chance to chat a little as well. Dr. Kilshaw has four girls and six grandchildren, with another on the way. She goes to the opera, likes walking and travelling. She perks up when hearing about my current life – my writing, my own interest in music. She really does care about my well-being.

My favourite people are those who convincingly pretend not to notice. Or acknowledge it without needing to vocalize any questions. Those who I can hang out with, get comfortable with, then hear "Oh, the eye thing? I don't know, I didn't really notice." It gives me the feeling of normalcy.

I can't easily meet someone's gaze. I used to think it was because of my nystagmus. Now, I've been trying harder, and I've come to realize that it's a barrier of my own. Maybe I'm so afraid of being called out that I try to hide the nystagmus. I'll look into the distance, or down to the ground, or distract myself. There are only a few people I'm comfortable with looking eye-to-eye. It's such a beautiful thing, to be able to look into someone's eyes, even a stranger's. I wish I could.

I see Kilshaw as strong and compassionate. You might just say that she's just doing her job. But I know that she loves her job. I can feel it. I wonder how she sees me. She described me in the past as delightful. Am I still delightful? Or have I lost my delight? Does she see me as a nervous young man? Some questions are just too personal to ask. Or maybe I'm just too nervous. But I hope that I became all that she hoped I would become.

I used to look down a lot as a kid. I remember getting in trouble in the old Mac lab at my elementary school. I had copied a game from the computer I sit at to a few friends' computers. Mr. Partridge took me aside. "Look at me." I couldn't do it. "Stop looking at the ground. Look at me." Nothing seemed more difficult. I could feel when the nystagmus was really bad. The ground gave me a comfort zone. "If you don't look at me, I'm extending your detention." I gave him a flicker of a glance. His face was veiny and intense. Those rough flabby cheeks and evil eyes. I hated him. The glance wasn't long enough. I think he gave me a week of lunchtime detention in total. It seemed so unfair at the time. Now, part of me thinks it was my fault for getting trouble in the first place.

But maybe he was exploiting my weakness. That could be what everyone who hurt me did. They saw my wound and tore it open with cold metal implements, let it get infected and gangrenous and never heal. Like kicking a paraplegic out of a wheelchair. Dominating, controlling, and screwing me up more than I'd think at the time.

I don't have a difficult life. I have a minor eye condition that's been made even less minor with corrective surgery. I still have all my senses. I don't have to use access ramps. I don't need an interpreter or caretaker. I have a small struggle in my privileged life in modern civilization. Revisiting and understanding the surgery is just one step in accepting my place in society. It's not all that different. It's just a journey of becoming comfortable with my body and hoping other people do the same. Dancing around the obstacles that people make for me. Then again, I never went to the school dances.