

## Article ▶ Rare and In My Chair

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I was nervous and uncomfortable. I'd never seen nystagmus before, much less an esotropia, and this man had both and was requiring my care and attention. Talking with BL was moving. He would experience these “episodes” several times a month, especially if he was under any physical or emotional stress. These episodes were debilitating, affecting him socially, psychologically, and in the work place. He mentioned no longer being able to attend concerts—something he loved to do—and was having a hard time holding down two jobs to pay for his medical bills. This man not only wanted our help, but he needed our help. We wanted to give him at least some portion of a normal life back and jumped right in.

In the past, BL had visited every medical professional and had every test run with no luck. An abnormally high VEMP amplitude pointed towards superior semi-circular canal dehiscence (SSCD), but a CT scan of the inner ear showed no hole or tear. Talking with specialists in Belgium, they were completely bewildered at the findings—or lack thereof. Neuro-ophthalmologist after neurologist sent BL for multiple MRIs. You guessed it. They were all clean; no lesions, aneurysms, growths, or abnormalities were found. Just as if things couldn't get any weirder ... his personal and family medical and ocular histories proved to be unremarkable, with the exception that his father and brother both suffered from the same condition with similar onset (mid- to late twenties under stressful conditions).

BL came to see me (well, Dr. Coffey) to check in and see if we had any new ideas. He had just been prescribed clonazepam, which helped tremendously in alleviating his symptoms. He had not suffered an episode since starting the medication, but he wanted a more natural way

to control his condition, and he didn't want to wake up one day, tolerant to the clonazepam, unable to live his life again.

Not knowing where to even begin with this case, I went to a Pacific default, associated phorometry and red lens testing. After he mentioned that he drove to the clinic with a patch over one eye because he was diplopic in the distance, I was relieved when he was able to obtain fusion with 3<sup>Δ</sup> base down over the right eye and 8<sup>Δ</sup> base out split between the two eyes. A simple change in the prescription should work! Time to trial frame and finalize.

This could not be something so simple, of course. By the time Dr. Coffey came in to talk with BL, he was diplopic again. This time, his vertical had flipped, with the right eye image above his left eye's image. It was decided that the patient should come back for a second visit to re-evaluate the vertical prism and that the intern should review her notes on neutralizing verticals.

BL drove to his second visit with no patch. He was no longer diplopic, and his cover test was a bit more normal: ortho in the distance, 4 exo at near. He subjectively reported a vertical movement of the target, suggesting a right hyper. As an experiment, we had BL sustain fixation in upgaze for 30 seconds; cover test was then done in primary gaze. In upgaze, it was noted that he exhibited a left hyper, but in primary gaze, a right hyper was objectively noted, which slowly diminished back to the patient's subjective baseline after one minute of alternating cover test. This was repeated three times, with consistent results all three times. Scratching our heads after 20 minutes of playing peek-a-boo with BL's eyes, we asked him to keep a journal at home of his diplopia and whether it was crossed or uncrossed and if and when a vertical component was present.

The Academy break bought me some time before our third and final meeting. In New Orleans, I stopped by every nystagmus poster and attended more vision therapy lectures than I could handle. I wanted to learn something new, something that could help my patient live the life of a normal 30-year-old. Upon my return, BL and I met for a third and final time. He had recorded his diplopia, and it was very unusual, but at this stage, we weren't surprised. Sometimes he had uncrossed diplopia with a left hyper, others uncrossed diplopia with a right hyper; sometimes he had no vertical component in his diplopia. The worst was when he didn't know if he was diplopic, because he couldn't open his eyes from the intense vertigo and oscillopsia. Instead, he'd be lying on the floor completely debilitated.

We weren't confident in anything at this point, except for the fact that there might not be a concrete answer, a concrete ICD-10 worthy diagnosis for this patient. We charted acquired nystagmus, esotropia, and ocular neuromyotonia. Neuromyotonia being the newest, hardest-to-say word, after BL had survived my "learning experience."

Brainstorming treatments for BL was a whole new animal. Diplopia is obviously a very disturbing thing for a patient to experience and something 9 out of 10 times I feel comfortable in treating or referring out to an appropriate specialist. But with his diplopia stages being so unpredictable, we couldn't justify prescribing him glasses with prism.

We discussed daily contact lenses, hoping to alleviate the symptoms of oscillopsia as well as to help dampen the nystagmus and hopefully his episodes. BL could maintain his hipster appearance, as he still needed to wear glasses full-time to correct for his esotropia. BL was not crazy about this idea, as he really did not see himself "putting something in his eye." In addition, financing the contact lenses and a new pair of glasses were an issue. The patient said he would research contact lenses

and consider it at a future date if he thought it was a worthy investment.

We even went out on a limb and suggested that the patient discuss other medications (like baclofen) and prescription cannabis with his neuro-ophthalmologist. While the jury is still out on the medical efficacy of cannabis in treating nystagmus, it was worth throwing that in the discussion.

That final conversation with BL was tough. Here he had come to see us, he had missed valuable time off work, and was spending a lot of money on out-of-network office visits, only for us to not give him any answers. He could sense that I was down and disappointed. I really wanted to impress Dr. Coffey and bring new ideas to the table, but after having talked to BL for only a few minutes at the beginning, I wanted to be the one who helped him. I wanted to find a diagnosis and reasonable treatment for him and his family. I wanted him to have a normal life.

He recognized and thanked me for bringing new ideas to the table (like contact lenses) and mentioned that Dr. Coffey and Dr. Coffey's students were his favorite stop along the long medical professional trail because we cared the most. We took the time to listen and to try new things rather than just punting him along to the next specialty. BL might have said all of that to be a decent human so I could get some sleep at night, but it really made me realize what matters in a vision therapy practice.

I wish I could say that this story has a happy ending. I wish I could say I was able to diagnose and treat this rare condition that ended up in my chair fall semester of my third year. I wish I could say we got a call from BL, confirming he got fit with contact lenses and that has made all the difference in the world. I can't say any of that. What I can say is that if I bumped into BL on the street, he probably would not remember my name or even where he knew me from, and I'm strangely okay with that. This man had a huge impact on not

only my education, but my future career as an optometric physician and my standard of care. He taught me to never stop learning, to attend CE and lectures on topics that make me uncomfortable, topics that I'm not an expert in. He taught me to never be too proud to ask for help from other doctors and specialties. When in doubt, those connections are your greatest asset. Most importantly, BL taught me to fight for your patients, because you might be the only one standing in their corner. They may not remember that they are a 20<sup>A</sup> esotrope in the distance, but they will remember you advocating for them. BL was the cornerstone of my standard of care for the rest of my life.

To this day, I am still not confident in what is going on with BL. I don't know if I ever will be; what I am confident in is that I am a better future doctor, and my patients are in better hands after having met him.

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