TEXAS STATE OPTICAL
BANDERA

Date: 07.01.2025

To every specialist who helped me along the way:

My Journey to an Eagle's Syndrome Diagnosis

Re: Victoria Perez (Established Patient)

DOB: XX.XX.XXXX

As the sole provider of my independently owned practice, I understand just how limited one's time can be. The purpose of this letter is to share my story from both a provider and a patient perspective of the journey that led to my Eagles syndrome diagnosis. My hope is that I can in turn be a better provider to my own patients and spread awareness to other specialists like yourself to help save a life.

For the past 2.5 years I have suffered from debilitating, unilateral, orofacial pain that has only progressed in severity. It started with what felt like possible TMD pain from suspected nightly teeth grinding/clenching. Initial treatments with mouth guards seemed to alleviated the pain for a short period of time. Unfortunately, with continued use of the mouth guards my bite began to shift so severely that I was facing orthognathic surgery relapse. Multiple rounds of Botox were attempted in my masseter and temporalis muscles and trigger point injections provided no relief. Months of physical therapy, acupuncture, and dry needling only lead to more pain. In desperation, I sought for more treatment only to undergo nonexistent cavity fillings, an uncertain diagnostic root canal on my lower rear molar, and a third round of sinuplasty surgeries. I was now no longer able to speak without my teeth feeling as if they were going to shatter. A persistent, pulsatile, pain that matched my rapid heart rate (110 – 120 bpm resting) was now at a constant state. My level of depression reached a suicidal low. The "TMD" pain progressed to sharp shooting pains in my lower jaw that would come and go, I was then given a new diagnosis of "atypical trigeminal neuralgia". Oral treatment of anticonvulsants such as oxcarbazepine were initiated, but side effects were so significant I literally lost the ability to walk and was completely incapacitated. Thankfully, neurologists, neuro surgeons, pain specialists, and spinal surgeons all advised against gamma radiation, vascular decompression, spinal implants and epidural injections preventing me from further permanent harm. I had to face the reality that this debilitating pain would never go away. At the age of 34 I was no longer capable of running my practice that I had worked my entire life time to achieve. I had become a medical mystery, that as a provider, I had ignorantly ignored the possibility of ever becoming. My lifeline was now dependent on a collection of pills to keep me functional and the hope of starting a family was shattered.

This 2.5-year time frame involved over 35 specialists. I sought care with 5 dentist, 2 TMJ specialist, 2 maxillofacial surgeons, 2 pain specialist, 1 neurologist, 2 neurosurgeons, 1 spine specialist, 3 ENTs (1 Ear, 1 Neck and 1 Sinus specialist), 3 Airrosti specialists, 4 orthopedic specialists, 3 physical therapist, 3 chiropractors 1 rheumatologist, 2 acupuncturists, 1 craniosacral therapist, and 1 craniosacral orthodontist. I am also now having to undergo 3 years of ALF treatment to correct my malocclusion as a result of the worsening of my bite due to improper management for "TMD" treatment. I was diagnosed with anxiety induced heart palpations, orthostatic hypotension, TMD, cavities, a failed crown, sphenopalatine neuralgia due to a chronic sinus infection, Ernest syndrome, vestibular migraines, hyper mobility, scoliosis, temporal tendonitis, pituitary adenoma, snapping scapula syndrome, hemiplegic migraines, and atypical trigeminal neuralgia. Every X-Ray, MRI, and CT- done two folds of both the jaw, head, neck, ear, and spine were inconclusive. Each upcoming appointment forced me to hold onto 2-3 more months of hope, only to have my heart crushed with more unknowns or complete dismissals of my concerns. I experienced zero communication with my providers outside my 10-minute time slots, after waiting months to get put on the schedule. Phone calls never returned, messages never passed along, I showed up in literal tears asking if imaging could be handed to my doctors and was told they could not accept it because "there was a chance it would be lost". I was even given a 6 month wait after stating I was at risk of a stroke at any moment. My overall, out of pocket cost of finding this diagnosis and treatment has exceeded over $100k (with insurance). This does not factor in the expenses for travel nor the time out of my office. Most importantly it was 2.5 years of my life and precious time lost.

Despite the judgmental tones, and levels of dismissal from providers at every level, my husband continued to search the internet for answers. YouTube and Reddit had become or only valuable sources for information. We persisted with one last CT of the neck with contrast, where the results were "NORMAL" but ossification of the styloid ligaments were noted. "Eagles' syndrome" was at last discovered. When asked about the possible diagnosis of Eagles, 3 ENT's, 2 TMJ specialist, and 1 maxillofacial specialist ensured me that this was far too "rare" to be the case.

Synopsis: Eagle's syndrome is a "rare" condition where an elongated styloid process or calcified stylohyoid ligament causes pain in the head, neck, and face. It's characterized by symptoms like throat pain, difficulty swallowing, and a sensation of something stuck in the throat. (Please note, these symptoms are end-stage symptoms) The pain can be sharp, sudden, and nerve-like, often triggered by swallowing, jaw movement, or head turning. Causes are still unknown, but correlation to whiplash neck trauma, teeth clenching, tonsillectomy and a history of underling connective tissue disorders are known to be a possible causation. Many of the diagnosis depend on the length of calcification as opposed to patient symptomology which adversely results in a misdiagnosis and is why this condition is known as a "mimicking disease".

After having exhausted all local sources, we began to look in other states. (4 states in total) We connected with Dr. Middleton of Fort Lauderdale (Chiropractor). He conducted a CT-Angiography with venous phase at .625mm dissection. He computed theses scans into a 3-D rendering that showed the impingements of my vascular structures and the 8 major cranial nerves that are were trapped between the transverse process of the C1 and the elongated styloid processes (calcified stylohyoid ligaments). A video of my scans and diagnosis can be found on YouTube. The intent was to be able to share this with my specialist back home. Of the 8 specialist I reached out too, only 1 responded. (Search: Dr. Middleton-Atypical Neuralgia)

What I didn't know… I didn't know my own symptoms. In short, my symptoms ranged from severe pulsatory orofacial nerve pain that seemed to run along the trigeminal nerve branches of mandibular, maxillary, and occipital nerve, severe neuralgia type headaches and migraines with visual auras as well as tingling in the arms, constant tinnitus and fullness in the ears, heart palpations and a racing resting heart rate of 110 – 120 bpm, shortness of breath, cold and heat intolerance, enlarged lymph nodes under arm, temporary loss of vision upon moving or standing too fast, shoulder pain, increased intraocular pressure, unilateral dry eye and nerve pain on one finger (ipsilateral side). Many of these symptoms were things I had been living with for over a decade. Each symptom was given its own explanation as to why it was normal, with a new pill to treat each symptom. These broad symptoms often spill over the scope of one specialist and are often then overlooked because of how many other "common" conditions they mimic.

June 25th and 30th 2025 I proceeded with bilateral styloidectomies conducted by Dr. Ryan Osborne in California. He is widely regarded as one of the top 3 most experienced surgeons in the United States for Eagles Syndrome. We obtained a virtual visit in the weeks prior to surgery. I had reached the end of my journey and if he couldn't help me, I accepted that it would be the end of my life. There was nothing left to say at this point, my husband had become accustomed to speaking for me, and I sat there feeling broken and empty. But this interaction was different. Not only in what he said, but more so in what he didn't say. Despite me trying to hide my fear, he looked at me in a way where I knew he completely understood the pain I had been through in the road to finding him. When I thanked him for working me in on a same day appointment at 6:00PM, on a Friday, after a full day of surgery; he shared with me, a story of a 18-year-old boy who committed suicide 1 week prior to his visit, and how he struggled daily to reach everyone in time.

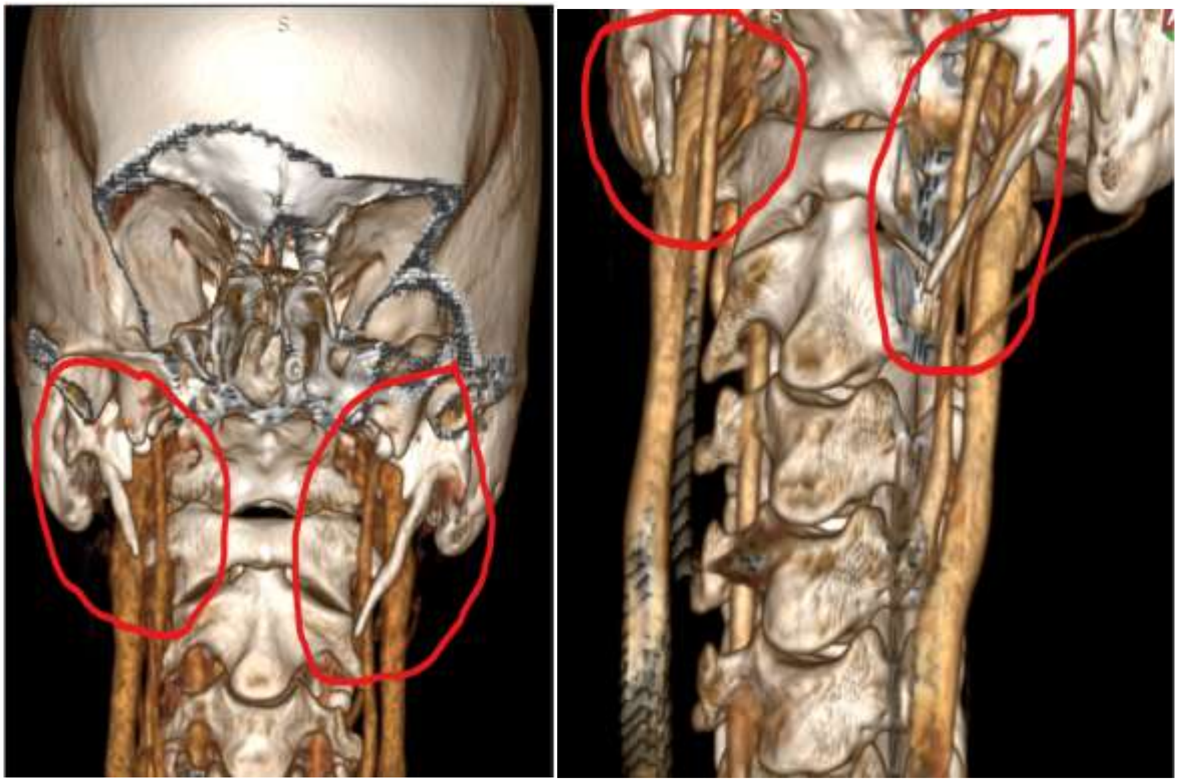
While my physical scars are well on their way to recovery, I know the emotional trauma of this experience will have lifelong effects on me. It's unfair to ask how, and why, so many people suffer from health conditions or accidents, but I know the only way I can move on from this, is if I do better by my own patients. This letter is not intended on shaming health care providers but rather to enlighten them on a patient perspective in a complicated world they have less understanding of. The purpose of this letter is to ensure I establish a connection with providers across all specialties so we can work together to provide whole picture care.

The world of eyecare is fast paced. Today's patients can be demanding, walk in visits are expected, convenience is their priority, and having more than a 20 min delay can result in the dreaded 1 star review. Insurance is an endless battle, not only do we have to fight to provide adequate care but we have to fight for reimbursements. I have grown accustomed to long work hours, over loaded patient schedules, mountains of prior authorizations and pharmacy refills that I just can never seem to finish. I am 9 years into practice and 5 years into ownership, and managing a team on top if it all adds to the endless problems to continually solve. Despite the daily battles of ownership and patient care, I know my patients find value in the commitment and dedication both my team and I strive to provide.

This experience has given me a new perspective on my career, on my field, and quite frankly on life. I ask you to take a moment from all the chaos and ask yourself if you feel you are truly able to connect with your patients? Have you considered the time they waited for their appointments and more importantly, did you take the time to address all of their concerns? How many patients have you confidently diagnosed only to find out they were still suffering from symptomology? How many "atypical" or "idiopathic" patients have you come across, and what did you do to get them in the right direction? How large is your network of specialists to be able to refer to? Can you ask yourself at what limit you would go to help your child or your spouse? I ask you to consider the training of your front desk. Do they understand critical questions to ask when scheduling an emergency and do they understand that they are the true heroes behind the quality of care you can provide.

I am available, and would love to share more insight to the world of Eagle's Syndrome. Please do not hesitate to reach out via phone call, text, or email. I have included some basic information on Eagle's, please take an extra spare moment to gain a better understanding of this condition and be the provider who can possibly save a life like mine.

My Scans…



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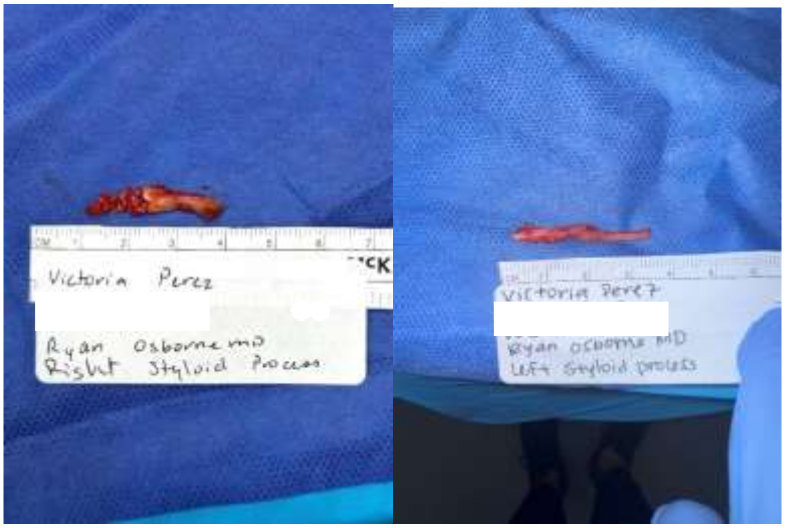

*Photos of my calcified styloid ligaments. Diagnosis requires styloid to exceed 3cm. <u>THIS IS WRONG, DIAGNOSIS NEEDS TO AND MUST BE BASED OF PATIENT SYMPTOMS.</u> What fits in a 250-pound man may cause jugular vein compression in a 95-pound female. Majority of my symptoms were caused by my "shorter" styloid.

We cannot diagnosis what we aren't looking for…

While google will tell you about 4% of the population is found to have elongated styloids / Eagles Syndrome, Dr. Osborne who has committed decades of care in this field, feels it's closer to 8% (Some sites say as low as 1% others as high as 20%). He often finds that many of the diagnosis are found only by **dentist and chiropractors** and often fall flat after imagining is ruled "normal" by radiologists. This condition has clinical findings in EVERY specialty. (See notes below) I encourage you to get connected to prominent imaging providers in your area. Connect with radiology as they need to know what we are searching for in order to have the best knowledge on how to navigate the imaging. All it takes is a CT of the neck with and without contrast. Gold standard would be a 3D imaging of the CT angiogram with venous phase at high resolution (Couldn't find a local place in San Antiono). Dr. Ryan Osborne is in Los Angeles, California, he provides tele-med visits, thus can allow access to him for patients here in San Antonio or anywhere needed.