

Written Testimony
Senate Bill 27: Ameloblastoma Awareness Day
Submitted to: Senate Health Committee
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Submitted by:
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Thank you members of the Committee for providing me the opportunity to submit testimony for SB 27 Ameloblastoma Awareness Day.

My name is Emily Hosler, I live in Cincinnati Ohio and I'm not only 1 out of 1,000,000 people nationwide who are diagnosed with Ameloblastoma but 1 of 12 people that are diagnosed in the state of Ohio annually.

This is a rare, aggressive tumor that grows inside your jawbone mainly by the molars and counts for 1% of jaw based tumors. In most cases these tumors are benign and come without any symptoms. If these lesions are left untreated they will continue to grow and eat at everything that gets in the way and potential be fatal. Yes, this tumor is benign in most cases, however, it is treated aggressively due to the fact it will grow back if anything is left behind.

I, like most people are unaware of this diagnosis. With little education on this in my early stages it was extremely hard to know the direction on where to start, and the education that is out there is very little.

For me, my tumor was found during my annual x-ray visit with my Dentist and ended up being 3.5 cm long and was eating through my lower right jawbone. After being told that "they've never seen this before", I was referred to get it biopsied.

There are a couple of procedures to remove this tumor. One of them is to take your fibula and mold it into your jaw where the tumor was with a titanium plate as a structure. This consists of a large cut on your lower leg, a cut on your neck, feeding tubes with a possibility of trachs, physical therapy and a long stay at the hospital. This option to me sounded so complex and extensive for something that's benign and what I thought was so little.

The second procedure is what I chose. This consisted of removing over 2 inches of jawbone where the tumor was with an incision on my neck. Removing a total of 5 teeth and replacing with a titanium plate for structure. While building my own jaw out of bone graft from my femur through a 2 inch incision through my knee. This is an overnight stay at the hospital and being sent home with a walker for a couple of days.

Unfortunately, I was part of the small percentage where my bone graft and titanium plate structure failed. I lost majority of my graft from an infection and the titanium plate structure shifting due to swelling. I ultimately needed a second surgery to regain bone graft and fix the titanium plate.

The second surgery resulted in 3 abscesses around the bone graft. I had to get an emergency I & D surgery to drain the infection which led to 5 days in the hospital. With the infection now at bay, I still don't have enough bone growth from the grafts to receive implants. For me to get implants I will need to do another reconstructing surgery and decided the fibula in my case is the best option.

This unexpected diagnosis has been an everyday thought since this was brought to my attention in November of 2023. This has led to missing a total of 12 weeks of work, I've lost feeling in my lower lip and chin, I've lost 60 pounds during my healing stages of surgeries. When having a conversation with someone, I can't help but think "Are they looking at how I talk"? or "Are they looking at my scar on my neck"? At this moment I have what is called "chronic infection" due to back-to-back infections and have been on antibiotics since August 29th, 2024.

A lot of people would think surgery is the most extensive part. Going through it, it's the physical, mental, emotional, spiritual and financial part that is extensive. I am extremely grateful for my tumor to be benign and this is what I have to go through.

Luckily, in our country we have the medicine and the tools to care for the reconstruction piece which is only part 1. After the surgery people with this tumor need implants which is part 2. Typically the surgeons who perform the surgery partner with your dental office to get the implants made. This second part is not covered by medical insurance, this would be under dental insurance and in the dental insurance world, implants are considered cosmetic and not covered. This goes for both benign and malignant jaw tumors.

The reason why I'm taking my time and explaining my experience in great detail is because Ameloblastoma is monumental for the person experiencing it. This is a journey taken blindly due to the lack of information out there. More information needs to be out there not only for the patient experiencing it but for the dentists, the doctors, and insurance companies. It is ridiculous to think that implants, the final stage of these surgeries, are considered cosmetic not only for benign tumors like mine but cancer patients who are enduring the same surgery. There is a need for awareness and eyes must open. Insurance companies need to understand jaw tumors like Ameloblastoma so eventually the implant portion will be covered. Making a day of awareness is a great way for me to start.

Thank you for the time and the platform to speak. I would be pleased to answer any questions you may have.