

Thank you members of the Committee for providing me the opportunity to submit testimony for SB 270 Ameloblastoma Awareness Day.

My name is Emily Hosler and I live in Cincinnati Ohio. I was diagnosed with Ameloblastoma. Which is a benign, rare, aggressive tumor that grows inside your jawbone mainly by the molars. Tumor what an ugly word, well that's what these lesions are. With eating at anything that gets in the way.

For me, when my tumor was found it ended up being almost 6 cm long that ate through my lower right jawbone. This tumor comes without any symptoms and if it's detected too late not only will it grow throughout the face and throat and be fatal but can turn cancerous.

Ameloblastoma counts for 1% of jaw-based tumors. I, like most people are unaware of this diagnosis. Because I had little education of Ameloblastoma in the early stages it was very hard to know the direction on where to start and what is out there is very little. Going into all of this I felt very unprepared.

Yes, this tumor is benign in most cases, however it is treated as cancer due to the fact it will grow back if anything is left behind.

The most common procedure to remove this tumor is to take your fibula and mold it into your new jaw where the tumor was. Might sound easy. Well, this consists of a 12 in cut on your lower leg to take your fibula bone out and have another cut done under your jaw to remove the tumor/jaw effected and replace with the molded fibula. That's 2 weeks in the hospital and learning how to walk again.

I however, chose what I thought at the time was the less invasive route. This was to take a titanium plate for the jaw structure while building my own jaw out of bone graft from my femur. This is an overnight stay in the hospital and being sent home in a walker for a couple of days.

Unfortunately, my bone graft got infected and ultimately failed. I lost the majority of my graft during the infection, with the titanium plate structure failing. This means my jaw during that healing stage moved out of alignment. I ultimately needed a second surgery to regain bone graft and fix the alignment.

To protect my alignment after the second surgery I had my mouth rubber banned shut. Yes, my alignment got better, however, I ended up with another infection.

This resulted in 3 abscesses around the bone graft. I had to get an emergency I & D surgery to drain the infection. After 5 days in the hospital, I was on the path of healing.

The outcome to all these surgeries I've lost all feeling in my lower lip and chin, I've lost 60 pounds in 3 months due to a restricted diet change from the healing of these surgeries and I'll also be on antibiotics for the next year from these infections.

Yes, this hasn't been the easiest journey and 8 months later after my first surgery I'm not fully recovered.

Luckily, in our country we have the medicine and the tools to care for the surgery (part 1). However, after surgery people with this diagnosis have issues with insurance not covering part 2 which is getting implants. Most insurance companies consider this cosmetic.

The financial and mental healing process to this diagnosis is the most extensive part to the journey.

My goal is to not only make more awareness to insurance companies but get more out there for Ameloblastoma to help start the journey for others. Making a day of awareness is a place to start.

Thank you for the time and the platform to speak.