

Written Testimony of
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Joint Committee on Public Health

SB654 An Act Concerning the Availability of Prescribed Antiepileptic Drugs

Thank you for giving me the opportunity to speak today about SB 654.

My name is Cheryl Tine and I have had epilepsy for 9 years. I want to try to help you understand what days may be like for someone with this disability.

Seizures occur in different areas of the brain. For the purpose of this story, imagine that each of you has seizures located in your temporal lobe, an area of the brain that controls speech, smell and fear.

You're a teacher and one day in class you have a seizure. Your employer knows you have epilepsy and calls 911. The EMTs arrive and want to take you to the hospital. You tell them "it is not necessary". A teacher is driving your car home and "family will be waiting there to take care of you." The EMTs still insist you have to go. Again you say "no" and that you want to make a phone call. The EMTs refuse to let you use the phone. After the third or fourth time asking, not only are they still saying no, they want to know who you're going to call. The EMTs start raising their voices. You start walking toward the door in the classroom so you can go to the office and use the phone. As you reach the door, one of the EMTs places his foot by the door so you are unable to open it. Both EMTs start yelling, one coming inches away from your face. They both start mocking you. One threatens "if you don't leave with us in five minutes, we will call the police." You sit and wait; you think if the police are called, they will help you. Four of them arrive, three men and one woman. They will not let you use the phone either. One male officer in a white shirt gives you an ultimatum; "either you leave with the EMTs in 15 minutes or we will drag you out of here." To protect yourself you plant your feet. They drag you out of the classroom. The ambulance bed is in the parking lot. The police throw you face down on the bed, hand cuffing your left hand to the left side of the bed, right hand to the right side and tie your legs to the bed. You tell them you are going to get sick. They all start laughing and say "go ahead, we don't care".

Yes... this really happened to me one day at work. I was treated worse than a criminal, not even allowed to make a phone call. My crime... having a seizure. I had, and will have for the rest of my life, post traumatic stress syndrome from that incident. I was afraid to leave my house for three months. Every day I am fearful I will have a seizure and be treated like that again.

You may have 1 to 100 seizures a day, with no warning or control over them. To allow pharmacies to replace effective medication with something potentially less adequate, for the purpose of making a larger profit is overwhelming and unacceptable.

By passing this bill you will allow us to have control over one thing, making the decision to choose the most effective medication for ourselves.

Thank you for listening!