Written Testimony of
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Joint Committee on Public Health

SB654 An Act Concerning the Availability of Prescribed Antiepileptic Drugs

Good Morning. I am Martha Epstein-Semega, 52 years of age, from Bridgeport, and was diagnosed at 12 years of age with Chronic Stable Seizure Disorder. In other words, I have Epilepsy. I am here today to ask you to support Senate Bill #654.

When a person has a disorder, such as Epilepsy, that needs to be maintained with medication(s), that person needs to trust their medical professionals. They also need to know that they will be given the proper medication for their seizures.

Now, 40 years later, I am a college graduate, own a home and car, am in a long term relationship, and have lived a huge majority of my life questioning what it means to have a life living with Epilepsy.

For some time I had questions, but no answers. People in my life were instructing me just take medication, just go to my doctor when ordered to, not to think or play sports and not to expect a lot from me because I have Epilepsy.

It is hard to imagine an adolescent or young adult having to worry about these issues, but back in the 1970's; that is unconditionally what I was going through.

All this time, I was always concerned with when and where I would have a seizure and whether it would prevent me from achieving my goals.

Luckily, now I have a medical professional/neurologist and pharmacist who listen to my concerns, but that was not always the norm. There was a time when I, unknowingly, was given a generic form of Dilantin labeled as Phenytoin.

This change in my medication impaired my cognitive-sensory-motor functions temporarily; it could have been worse. I could have lost my driver's license or worse yet, I could have had a seizure while driving or had an episode in a public place with no medical support. To have my medication switched without notification could have had permanent disastrous results. In that instance, I consider myself fortunate.

People who live their life with Epilepsy are not robots, androids, or lab rats. We are people/human beings who want to continue taking the medicine or medicines that keeps us seizure-free so we can live our lives. It is not about choosing brands over generics, it is being allowed to stay on whatever works. Every person who is unaware of what they are ingesting into their biological system is being demeaned. I always want to know what is going into my system and have the right to decide the yes or no in that regard.

I insist that a pharmacist notify my doctor and I before switching my medication and I ask you all to please support this bill.

Thank you for taking the time to listen to my testimony!