Written Testimony of
Nancy McDonald
Wednesday, March 12, 2008
Joint Committee on Public Health

SB654, An Act Concerning the Availability of Prescribed Antiepileptic Drugs

Thank you for the chance to speak in support of Senate Bill #654.

My name is Nancy McDonald and I live in Monroe, originally from Norwalk. I am the mother of an adult son with epilepsy. He's almost 34 and struggles with horrific seizures, pretty much on a monthly basis. Because of the nature of his seizures, he strives to make a living and to hold down a job. He's had numerous jobs and they all have either ended up letting him go, or not advancing him because of the violent seizures he has. I've witnessed these attacks on many occasions and they are horrible. I've seen his tongue swollen three times it's size from him biting down on it during a seizure. I've seen his body stiffen up like a surf board in the back of my car during a tonic/colonic seizure, and then slam down, and his head hit the back car window with a sickening crash.

No mother should have to endure knowing at any given time without warning their son may go into a horrible tonic/colonic convulsion never knowing what damage he may be doing to his body and his brain. I've been informed by doctors that the more seizures a person has, the more the brain is conditioned to have seizures. Not only that, but due to the lack of oxygen during one of his seizures, brain damage can be very real. My son's doctor has recently increased his medicine dosage and we can only hope that this will help for now. Currently, my son takes two different medicines, Depakote and Tegretol. Our concern now is that with these drugs coming off patent shortly, the same manufacturer be what he receives each and every time he renews his prescription so that we can better track and manage his medications. If we have to worry that he may be getting a different manufactured version at any given time, how do we do that?

The goal for a person with epilepsy is no seizures with as few side-effects as possible. With a consistent supply of medication that goal is much more likely to be achieved. This bill is a critical tool to help my son who has epilepsy attempt to achieve the goal of becoming seizure free. No one wants to hire or keep a person who has severe seizures. Because of that, you can imagine what my son's life is like. When there's no work, there's not only no income, there's no insurance, no place to live, no food, etc. I am here to plead with you as the protectors of the people of CT, to pass this bill, so that we can be assured the medicine my son is prescribed is the exact dosage he needs so he won't have a break-through seizure or become toxic. I can't tell you enough about the worry I experience as his mother except to say when my son has a seizure, the pain is so intense, that not only does my heart ache, but my skin hurts, as well. Knowing the medicine my son's doctor prescribes is exactly what my son is getting would only help to alleviate the anxiety we have to endure on a daily basis. I hope you realize the responsibility of helping pass this bill for those who suffer with this debilitating condition and for the family members who love them.

Thank you again for giving me the chance to tell you our story.