Written Testimony of Dwayne Paul
Friday, February 6, 2009
Public Health Committee

SB 757 An Act Concerning the Filling of Prescriptions for Antiepileptic Drugs

Good morning Senator Harris, Representative Ritter and members of the Public Health Committee.

My name is Dwayne Paul and here with me today is my daughter, Shelby. We are here on behalf of the many people who suffer from Epilepsy and would benefit greatly from your support of Senate Bill 757.

Shelby was diagnosed with Epilepsy NINE years ago. She has absence seizures, which are characterized by a staring episode followed by a period of disorientation. Due to the frequency of seizures that Shelby experiences she will very often lose focus for up to an hour or two.

Over the past NINE years we have tried to control Shelby's seizures by utilizing 16 different anti-epileptic medications singularly and in various combinations. These include keppra, lamictal, zonegran, dilantin, pregablin, and others. In addition to these medications not controlling Shelby's seizures they have also caused a number of side effects including rashes, significant weight gain, significant weight loss, tremendous fatigue, and hallucinations! Even Shelby's brain surgery in 2005 has not helped to gain control over her seizures.

To this day we continue to try different Anti-Epileptic Drugs and combinations in the hopes of controlling or minimizing Shelby's seizures. It would be much more difficult to obtain this control when numerous generic manufacturers are added into the AED mix.

In order to help Shelby's doctor gain control we have kept a detailed journal of Shelby's seizures and various medications. During the past month Shelby has had 28 seizures, over the past six months Shelby has had 116 seizures, over the past year Shelby has had 287 seizures. And these are only the ones my wife and I have witnessed.

In short, epilepsy is different than high cholesterol. Because it is different, special precautions should be taken. People living with epilepsy welcome these safeguards and would not find them to be an inconvenience.

In closing I would like to say that if none of you have Epilepsy then:

No, you will never know…how it feels to not be able to get your license when all your friends are getting and talking about theirs,

No, you will never know…how it feels to experience rapid weight gain due to the Anti-epileptic drugs you are taking,

No, you will never know…how it feels to be so tired in the morning that you have to be physically dragged out of bed for school,

No, you will never know…how it feels to be in the middle of doing something then totally and completely blank out and not remember what you were doing,

No, you'll never know what it is like to experience any of this, but you can know the personal satisfaction that will come by your supporting the Epilepsy Patient Protection Act.

Thank you for taking the time today to consider this important legislation!