



State of Connecticut
HOUSE OF REPRESENTATIVES
STATE CAPITOL
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March 11, 2011

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H.B. 5610 AN ACT CONCERNING THE DUTIES OF A PHARMACIST WHEN FILLING A PRESCRIPTION USED FOR THE TREATMENT OF EPILEPSY OR PREVENTION OF SEIZURES

Good morning Senators Gerratana and Slossberg, Representatives Ritter and Lyddy, and all the members of the Public Health Committee. I am testifying today in support of H.B. 5610 AN ACT CONCERNING THE DUTIES OF A PHARMACIST WHEN FILLING A PRESCRIPTION USED FOR THE TREATMENT OF EPILEPSY OR PREVENTION OF SEIZURES. This bill aims to protect people with epilepsy from dangerous switching of medications.

60,000 Connecticut citizens currently are affected by epilepsy. It is a non-discriminate disease, but its effects are most dangerous for two traditionally vulnerable populations- the very young and the elderly. About one-third of every epilepsy case in Connecticut and nationwide affects a child under the age of five, and a majority of the time, a child will experience a discomfoting and dangerous febrile (fever-caused) seizure (this according to The Epilepsy Foundation). The debilitating effects can hurt any individual's school attendance, employment, driving, and poses a new hazard to independent living for Connecticut seniors.

The most common remedy to avert seizure episodes has been preventative drug therapy. In recent years, patents on brand name epilepsy medication have expired and the market is open to generic substitutions that have lowered the cost for the consumer. However, "small variations in an epileptic's seizure medications can have devastating effects," (Epilepsy Foundation, Connecticut). In certain cases, toxicity or recurrence of seizures can suddenly reappear in individuals who had no incidents during the time that they were administered brand name prescriptions. It was only when the substitution occurred that these side effects arose.

Under current law, the physician's written request stating "Brand Medically Necessary" does not cover generic substitutions. Therefore, a pharmacist can elect to substitute a medication from a new generic manufacturer or distributor each time the prescription is filled. This jeopardizes the health and wellness of epileptic patients who find themselves reacting to new side effects without any notice of the substitution.

This legislation stands to improve trust and accountability in our healthcare system. It is legislation that promotes a cooperative effort between pharmacists, physicians, and patients in order to avoid harmful prescription substitutions. Thank you for your time and consideration.

Sincerely,

A handwritten signature in cursive script that reads "Betty Boukus". The signature is written in black ink and is positioned below the word "Sincerely,".

Elizabeth "Betty" Boukus

Chiara, Adam

From: Kevin DiMinno [kevin.diminno@gmail.com]

Sent: Friday, March 11, 2011 12:20 AM

To: Rep. Boukus, Elizabeth "Betty"

Subject: Letter regarding the use of generic medications for patients with seizure disorder
Epilepsy and the way it affects our family

This is a very interesting statement, one I had never really thought about until I was asked to write something about it. Epilepsy affects all aspects of the family's life. It literally touches every part of your being, every part of your day or night, every part of every thought or action. Epilepsy in a word "sucks!" We have been living with epilepsy and its affects for nearly seven years now. My daughter was first diagnosed as having seizures just short of being 24 hours old. From that very day when our pediatrician came into our hospital room and closed the door behind him, nothing has ever been the same. We had started that day off like any excited new parent would. I was busy getting our other daughter ready to go meet her new sister at the hospital and my wife was recovering from a long labor. There was an excitement in the air, we were now a family of four and the hopes of life, happiness and dreams all hung around us like the sweet smell of a fresh bouquet, only better.

My older daughter Grace was very excited to meet her new sister and just had to stop by the gift shop to get her a stuffed animal. She must have searched for just the right one for around a half an hour. On the way up the hospital room Grace was asking me when her new sister would be able to play with her or when they would be able to run outside together. The innocence of my daughter as well as both my wife and I were quite naive given what we were about to encounter. Grace and I walked into the hospital room filled with the anticipation of seeing our yet to me named daughter. This is when Dr. Roo (his real name is Dr. Lameroux, but we call him Dr. Roo) came into the room and closed the door behind him. What he said and what we felt sort of felt like a dream, but this was no dream, this was no fairy tale, this was life. He came in to tell us that our new baby was having something called "dusky episodes" where she would turn blue and have trouble breathing. Dr. Roo informed us that she was on a series of tubes and was also in the ICU unit for newborns. Still, I waited for the dream to end but no luck there. Dr. Roo left the room, we shed a few tears but were optimistic about our hopes of a normal life. Gracie never did get to meet her sister that day, in fact it was nearly 3 weeks before our new daughter was to come home from the hospital.

Normal life as it turns out is all relative in the grand scheme of things. Normal is something that many people take for granted in life. Normal is far from where we were or where we were going to be. Normal is almost forgotten now, just a faint memory of a distant time in our lives that was carefree, fun and exciting. After a series of tests our new daughter continued to have problems, many of which occurred during the testing process. Every time she went for a test we would hear things like "it was difficult to bring her back" or "we almost lost her there". Things in life you never want to hear when it refers to your own child or loved one. On an especially hard test they were wheeling our daughter away and both my wife and I said "wait a minute, she doesn't have a name, and if something happens to her in this test we need to give her a name". And so it happened, in the middle of a long scary hallway, our new daughter was given the name of Mary Rose Faith. Mary Rose is one tough kid. She has seen the inside of more hospitals, ambulances and doctors offices than most people see in their entire life. Yet she is still a spunky, hilariously funny and dare I say a happy person. She has been tested for everything and medically, nothing is wrong with her brain, blood or nervous system. On paper Mary Rose is normal. There is that

word again "normal". Technically Mary has idiopathic epilepsy meaning there is no medical reason for her condition. She has partial onset epilepsy that becomes generalized throughout her entire brain. Mary Rose, who is nearly seven years old now most likely doesn't realize that something is wrong in her life. She often wakes up in a strange hospital room but her mommy and daddy are there to greet her each time. She is loved more than anyone can imagine and she knows it. To her life may be normal, like I said it is all relative.

On the medical aspect Mary has baffled many of her doctors and continues to baffle us. Seizures used to come and go without much warning. Some would come due to illness where others where a mystery. Some cases she would go as many as eight months without a seizure then all of a sudden she started having them all over again. On certain cases we found was that the when we renewed her prescription the doctor failed to write "brand name required" and we were given a generic. After speaking with her neurologist we were told that that generic drugs do not work the same as brand name. After further research we found that many of her other seizures in the past all seemed to coincide with a time when a generic drug was introduced either through a renewal or when we were trying a new medication out to control the seizures better as she grew older. It seemed that if we used name brand medications and she remained healthy etc we were pretty much seizure free. Thankfully we seem to have Mary's seizures under control now and have gone over a year seizure free with the right mix of medication and using all name brands.

With all of this said there are two huge areas intertwined that do affect us daily. The main one is our financial ability or in some cases lack of ability to pay for the medicine that Mary needs. Though my wife's employer has a great health plan we are "encouraged" to use the plan that is for 90 day supplies or more and in all cases obtaining name brand drugs requires special written notice from the doctor or a generic drug will automatically be given. In addition to this their policy states that if a brand-name medication is used when a generic is available then the member is responsible for the difference in cost between the brand name and the generic. Needless to say, this is very costly for us, but if Mary were to receive generic medications it has resulted in seizures occurring in the past, and this is something we are not willing to risk. Like I said we have been seizure free for over a year now and we would like to keep it that way. The reason for this letter is to request that the general assembly pass a bill that will require insurance companies to use name brand medications for people with seizure disorders and other similar disorders that require such legislation. The consequences really do affect the "normal" life for people.

Thank you.

You have my permission to use this or any portion of this letter/email

Sincerely,

Kevin DiMinno and Sheila DiMinno
Parents to Mary Rose Faith DiMinno –