

WRITTEN TESTIMONY OF GRETCHEN KNAUB  
BEFORE THE PENNSYLVANIA HOUSE CONSUMER AFFAIRS COMMITTEE  
ON HB 2113  
MONDAY, APRIL 30, 2018

Good morning Chairman Godshall and Caltagirone and members of the committee. My name is Gretchen Knaub and I am the regional director of the Epilepsy Foundation Western/Central Pennsylvania. I am here today because House Bill 2113 is critical for Pennsylvanians living with epilepsy – the people whom I serve. I am also here because this legislation is just as critical for any Pennsylvanian who relies on insurance coverage to obtain health care services or treatments.

In the epilepsy community, losing health plan coverage abruptly or facing unexpected costs for therapies you need is all too common. Even though these individuals and families are careful to shop for health plans that cover the benefits they rely on, that coverage is changing during the policy year, when they are essentially stuck with their plan with no recourse. Just imagine for a moment that you are living with epilepsy. For years you have been stable on a treatment that controls your seizures allowing you to work, drive your car, care for your child and yourself, and do the daily tasks that most people take for granted. It is important to note that the specific treatments you take for your epilepsy make all the difference. Members of the epilepsy community often experience seizures and other harmful side effects after switching from one version of an anti-epileptic drug to another – even drugs that are thought to be equivalent with one another. The smallest changes in the amount of medication, or in the formula of the medication taken by a person with epilepsy, can mean the difference between a fully controlled condition and breakthrough seizures – increasing the likelihood of serious bodily

injury and death. Even when there is no physical injury that results, seizures often carry other substantial personal, social, legal and developmental consequences. For example, they can bring about the loss of a patient's driver's license and sometimes even their job and personal independence. In other words, your specific treatment regimen is a lifeline when you live with epilepsy. Your livelihood depends on access to that treatment and your health plan makes that possible.

Now imagine that your health plan makes a coverage change on a whim and suddenly you can no longer access the treatments that give you a full and independent life. Too many Pennsylvanians do not have to imagine that scenario; they are living it. Lorraine Ramirez of Hamburg is a mother of a child with epilepsy and an advocate for the Epilepsy Foundation Western/Central Pennsylvania. Her daughter, Kiley, has lived with epilepsy since she was two years old. Thanks to her prescribed medication, Kiley's seizures were stable for a time. One day, Kiley began to have involuntary tics. Concerned, Lorraine checked her daughter's medication and realized that her pills had been switched. The switch had been ordered by her family's health insurer in the middle of a policy year. On top of the injustice of having benefits change mid-year, neither Lorraine nor her daughter's doctor were even notified. Her daughter's medication was changed just because an insurance provider decided it. Eventually, through a long appeals process, Lorraine was able to convince the insurance company that Kiley needed her initial medication to remain stable, yet the health plan now requires the family to pay four times more per month for the treatment.

Pennsylvanians with epilepsy and other medical conditions should not be at the mercy of insurance coverage changes that can erode their health and independence. The coverage they

purchase should be the coverage they get each year. It is not only fair, but necessary to keep them stable – and safe. Please stand with your constituents and support House Bill 2113.

Thank you for your time and consideration on this important issue.

Respectfully,

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