

For the record, I'm Representative Michelle Bos-Lun, from the Windham 3 District.

I'd like to thank the Chair and all of you on the Health Committee for taking time to hear about the issue of medication from specialty pharmacies being allowed in all inpatient settings in Vermont.

To explain how I came to introduce this bill, I'm going to tell you a little about my health situation.

I was diagnosed with a rare form of lung cancer last November. Neither surgical treatment nor radiation are possible in my case, the only treatment to reduce the cancer in my body and keep it from metastasizing is a targeted therapy which comes in the form of a prescription from a specialty pharmacy. I need to take three pills every day. I reorder these two weeks in advance.

There are many medications that come from specialty pharmacies that hospitals & nursing facilities don't stock. There are over 7000 rare disorders and not all of them have specialty prescriptions, but for those that do, being able to continue a prescription can literally determine life or death.

When I asked Leg Counsel about this issue I was told something like "there is nothing in statute that requires hospitals to let you take your own medicine". I learned last night that Devan did a survey and all Vermont hospitals already do allow people to take their own drugs in this type of situation.

But, long term nursing & rehabilitation facilities are also inpatient options where someone like me might have an in-patient stay. The way I learned about this type of situation was from a person who shares my diagnosis and was preparing for a knee replacement; not in Vermont. He was planning to go to a nursing facility for a multi-week recovery period, and was told he could not bring the oral chemo medicine that is critical to controlling his cancer.

There is no such thing as a simple bill, but compared to most, this one is simple. Put into statute that people with rare diseases have a right to take their own medicine.

H736 would ensure that Vermont hospitals continue to allow people to take their own rare drugs, that any future medical centers with inpatient stays would do so and that long term nursing or rehabilitation facilities would allow this as well.