



May 26, 2017

The Honorable Brian Sandoval
State Capitol Building
101 N. Carson Street
Carson City, NV 89701

Dear Governor Sandoval:

On behalf of the Epilepsy Foundation and our Nevada chapter, Epilepsy Foundation Nevada, we urge you to carefully evaluate proposals within Senate Bill 265 intended to create greater transparency but that may instead stifle biomedical innovation and participation by the patient community in the conversation on the value of health care.

The Epilepsy Foundation is the leading national voluntary health organization that speaks on behalf of more than 3 million Americans with epilepsy and seizures. We foster the wellbeing of children and adults affected by seizures through research programs, educational activities, advocacy, and direct services. Epilepsy is a medical condition that produces seizures affecting a variety of mental and physical functions. Approximately 1 in 26 Americans will develop epilepsy at some point in their lifetime. For people living with epilepsy, timely access to appropriate, physician-directed care, including epilepsy medications, is a critical concern. Epilepsy medications are the most common and cost effective treatment for controlling and/or reducing seizures, and breakthrough seizures lead to related medical costs and complications, including death.

Like many of our partners in the patient advocacy community, we are concerned about high cost-sharing that makes it hard for people living with epilepsy and other chronic conditions to access the medications and services they need. We support policies that create greater transparency in the health care system and that reduce or limit cost-sharing for the medications and services that our community relies on to maintain their quality of life. But we have significant concerns about the overall effects of proposals included in Senate Bill 265, outlined below.

Although SB 265 is limited to medications for treating diabetes, we are concerned that the bill could set the precedent for similar policies for other/all prescription medications in the state. Pricing controls can lead to restrictive formularies and create barriers to physician-directed care. Epilepsy medications are not interchangeable and treatment of epilepsy is highly individualized. Maintaining seizure control with minimal side effects requires careful evaluation and monitoring by physicians and their patients. To limit or deny access to medications could be extremely dangerous.

We are supportive of transparency requirements that truly give health care consumers information they need to make decisions. The cost-sharing burden for medications for an individual is determined by a complex process and consumers need the full picture, not just one aspect of a complicated structure that impacts what they pay for medications. Policies should

take into account all stakeholders, not just manufacturers and patient advocacy groups, but also pharmacy benefit managers (PBMs), insurers, and pharmacies.

Further, SB 265 does not seem to acknowledge the value of medications and the cost associated with medical discovery. Prescription medications make up only about 10 percent of health care spending but lead to significant improvements in quality of life. Medications play a critical role in reducing unnecessary hospitalizations and surgeries; lost productivity and wages; and decreased quality of life for the patients and their family and caregivers.

The proposals in SB 265 could stifle biomedical innovation, which is exceptionally important to the epilepsy community because no cure exists for epilepsy and one third of people with epilepsy live with uncontrollable or intractable seizures – and many more live with debilitating side-effects from medications. The Epilepsy Foundation is committed to accelerating the development and approval of new therapies, especially to benefit those in our community with difficult to control seizures and those who experience significant side effects from existing therapies. Manufacturers spend millions of dollars over several years on research and development of potential therapies, many of which never make it to the market. We need an environment that encourages investment in biomedical innovation.

SB 265 would require a nonprofit organization to report to the state the amount of funds donated to the organization by a drug manufacturer. These reporting requirements would divert precious resources dedicated to supporting and educating our patient communities towards unnecessary administrative burdens that do not translate into lower cost-sharing for patients.

They also perpetuate an inappropriate assumption that funds from manufacturers impact the overall mission of a nonprofit. Funds from both individual donors and corporations are essential to the success of any nonprofit and disincentivizing this giving would limit the ability of nonprofits to serve and advocate for their patient community. Brining the patient experience to the dialogue is a unique role that organizations like the Epilepsy Foundation play as we need patients to have a greater voice in the conversation on the value of health care.

We urge you to continue discussions with all stakeholders as you explore policies that would addresses the cost-sharing burden on patients while bringing greater transparency to the entire health care system. The patient voice is critical in the conversation on the value of health care and we hope you will consider the impact on meaningful access to care and biomedical innovation as you move forward with SB 265. Please do not hesitate to contact Angela Ostrom, Chief Legal Officer and Vice President Public Policy at our national office at 301-918-3766 or aostrom@efa.org with any questions.

Sincerely,



Danielle Marano
Executive Director
Epilepsy Foundation Nevada



Philip M. Gattone, M.Ed.
President & CEO
Epilepsy Foundation