Attachment D

Seizure Action Plans save lives
Do you have one?

March 29, 2021

The Honorable Barbara McLachlan
Chair, Education Committee
200 E. Colfax, HCR 0107
Denver, CO 80203

Dear Chair McLachlan and Members of the Education Committee:

On behalf of the Dravet Syndrome Foundation, the Lennox-Gastaut Syndrome Foundation, and the Tuberous Sclerosis Alliance, collectively the “Seizure Action Plan Coalition,” we write today to urge your support for HB 21-1133, Joey’s Law. The Seizure Action Plan Coalition is a collaborative effort designed to raise awareness of what a Seizure Action Plan (SAP) is; the importance of a SAP in health management of those with epilepsy; and resources to develop an individualized SAP.

Joey’s Law is an important piece of legislation that will help ensure proper health management for students living with epilepsy and seizures. By ensuring that school personnel are trained in seizure recognition and first aid, and by ensuring that school personnel are equipped with SAP that show individualized health concerns of students, we can help make sure students are well supported in the school setting.

Epilepsy is a spectrum condition, and treatment is not one-size-fits all. There are also a number of different seizure types that present differently. For instance, most people are familiar with convulsive seizures, but seizures can also look like “daydreaming” in the classroom in the case of absence seizures or take the form of more subtle ticks. The SAP is a very important tool for informing school personnel of the particulars of a student’s condition, as well as clearly laying out processes in the event of a seizure.

We urge your support for HB 21-1133, Joey’s Law. By passing this act, we can take one step closer to ensuring that children with epilepsy and seizures are safe in settings where their primary caregiver is not present.

Sincerely,

Dravet Syndrome Foundation
Lennox-Gastaut Syndrome Foundation
Tuberous Sclerosis Alliance

<u>Additional Organizations Signing on to this Letter:</u>

Child Neurology Foundation
Batten Disease Support and Research Foundation
BPAN Warriors
CFC International
Coalition to Cure CHD2
COMBINEDBrain
CureGRIN
CureSHANK3
DEE-P Connections
Doose Syndrome Epilepsy Alliance
Dup15Q Alliance
Families SCN2A
Glut1 Deficiency Foundation
Hope for HIE
Hope for Hypothalamic Hamartomas
International Foundation for CDKL5 Research
KCNQ2 Cure
KIF1A.org
Mickie’s Miracles
NORE Institute
PACS1 Syndrome Research Foundation
PCDH19 Alliance
Phelan-McDermid Syndrome Foundation
Ring 14 USA
SLC6A1 Connect
SNAP25 Foundation
STXBP1 Foundation
SynGAP Research Fund
Tbc1d24 Foundation
TESS Research Foundation
The Brain Recovery Project: Childhood Epilepsy Surgery Foundation