

October 12, 2022

The Honorable Patrick Leahy
Chair
Committee on Appropriations
U.S. Senate
Washington, DC 20510

The Honorable Richard Shelby
Vice Chair
Committee on Appropriations
U.S. Senate
Washington, DC 20510

The Honorable Rosa DeLauro
Chair
Committee on Appropriations
U.S. House of Representatives
Washington, DC 20515

The Honorable Kay Granger
Ranking Member
Committee on Appropriations
U.S. House of Representatives
Washington, DC 20515

Dear Chairman Leahy, Chairwoman DeLauro, Vice Chairman Shelby, and Ranking Member Granger:

The undersigned epilepsy-related organizations thank you for your ongoing support for medical research, public health, and health care programs within the Fiscal Year (FY) 2023 appropriations bills and for your commitment to funding programs at various Departments including the Department of Health and Human Services, Department of Defense, and Department of Veterans Affairs that support the epilepsy community.

We appreciate and recognize that you are working to finalize top-line funding levels for all FY 2023 appropriations bills. The epilepsy advocacy community supports robust funding for a wide array of agencies and programs including the National Institutes of Health, Food and Drug Administration and National Neurological Conditions Surveillance System at the Centers for Disease Control, but today focus on a few epilepsy-specific programs:

- We very much support the House recommendation to increase the Centers for Disease Control and Prevention's **(CDC's) Epilepsy Program to \$13 million** in the Labor-HHS-Education bill. We are hopeful that this funding level can be maintained during final negotiations. This increase will significantly advance public and provider awareness and improve care for the epilepsy community through meaningful investments in successful public health activities.
- Please include **\$164 million for the Safe Motherhood and Infant Health Program** consistent with the Senate recommendation in the Labor-HHS-Education bill. Increased investment should allow more states to participate in the Sudden Death in the Young registry which has the ability to track Sudden Unexpected Death in Epilepsy (SUDEP) of individuals under age 20—yielding more data to better understand and prevent SUDEP.
- Please include a **specific funding level for the VA Epilepsy Centers of Excellence (ECoE) and we recommend this to be \$19.08 million,** consistent with the House recommendation in the MilCon-VA bill. Increased funding for the VA ECoE will enhance their value in coordinating innovative clinical care, education, and research efforts for our nation's veterans who acquire epilepsy through a variety of means, including Traumatic Brain Injury.
- Please include specific funding levels for both the Epilepsy Research Program and the Tuberous Sclerosis Complex (TSC) Program within the Department of Defense's Congressionally Directed Medical Research Programs (CDMRP). We urge this to be **at least \$12 million for the Epilepsy Research Program** as recommended by the Senate DOD bill and **at least \$8 million for the TSC Program** as recommended by the House DOD bill. These important programs fund research to better understand

the incidence of post-traumatic epilepsy (PTE) following a traumatic brain injury (TBI), understand TSC and in turn, improve patient care and outcomes.

Once again, thank you for the opportunity to provide input on research and programs that important to the epilepsy community as Congress finalizes the FY 2023 spending bills. For additional information please contact the Epilepsy Foundation's Vice President of Government Relations & Advocacy Laura Weidner at lweidner@efa.org.

Sincerely,

BDSRA Foundation
CFC International
Child Neurology Foundation
Coalition to Cure CHD2
COMBINEDBrain
CURE Epilepsy
Cure GABRB2
DEE-P Connections
Dravet Syndrome Foundation
Dup15q Alliance
Empowering Epilepsy
Epilepsy Alliance America
Epilepsy Foundation
Epilepsy Leadership Council
FamilieSCN2A Foundation
Glut1 Deficiency Foundation
Hope for HIE
International Foundation for CDKL5 Research
International SCN8A Alliance
Jordan's Guardian Angels
Koolen-de Vries Syndrome Foundation
Louie's Huwe for HUWE1 Research
Mickie's Miracles
Paul's Purple Warriors
Phelan-McDermid Syndrome Foundation
Rare Epilepsy Network (REN) Coordinating Committee
Ring14 USA
STXBP1 Foundation
SYNGAP1 Foundation
TESS Research Foundation for SLC13A5 Epilepsy
The Brain Recovery Project*
The Cute Syndrome Foundation
TSC Alliance

**Effective November 1st, The Brain Recovery Project is changing its name to the Pediatric Epilepsy Surgery Alliance*