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MEDIA PRESS RELEASE

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February 1, 2023: The THIRD ANNUAL Seizure Action Plan (SAP) Awareness Week will be held February 13-20, 2023, organized by the Seizure Action Plan Coalition, a collaboration managed by Epilepsy Alliance America. The campaign is underwritten by presenting sponsor Neurelis, Inc., with generous supporting funding from UCB, Inc.

SAP Awareness Week highlights the need for people having seizures to have a conversation with healthcare providers," said Peggy Beem Jelley, Epilepsy Alliance America's Board Chair. Suppose you or someone you love is part of a high-risk group, someone with frequent seizures, someone with clusters of seizures, , has seizures at night or generalized tonic-clonic seizures. In that case you should talk to your doctor about having a Seizure Action Plan and what people can and should do to help when you do have a seizure."

SAP Awareness Week features a social media campaign and website designed to highlight the need for people with epilepsy, their caregivers and healthcare providers to develop detailed plans, especially should an emergency occur. The social media campaign incorporates the hashtag #SAPAW2023 and urges people to learn more at SeizureActionPlans.org.

"According to the Centers for Disease Control and Prevention, approximately 3.5 million Americans have epilepsy, which is roughly 3 million adults and 470,000 children and teens," explained Lisa Gallipoli, COO of Epilepsy Alliance America. "About one-third of people with epilepsy do not achieve adequate control of their seizures with current treatments, making a seizure action plan an important management tool. This awareness week is critical for educating people of all ages in the epilepsy community about this important issue."

"A seizure rescue plan is a critical component in the overall management of seizure emergencies," said Craig Chambliss, President and Chief Executive Officer of Neurelis, Inc. "We are excited to see the launch of this website as an important new resource that will benefit people living with epilepsy and those who care for them. In addition, the launch of Seizure Action Plan Awareness Week helps spotlight the important need for everyone with epilepsy to have a thoughtful and comprehensive seizure action plan. It is our privilege to partner in this effort and many other initiatives in the epilepsy community."

In a recent study, only 30% of adult patients responded that they have a seizure action plan, and only 45% of pediatric patients had a seizure action plan. A seizure action plan can offer more control to patients and caregivers by providing consistent, patient-specific guidance regarding seizure management. A seizure action plan can also clarify patient and caregiver concerns, such as understanding what to do during a seizure, when watchful waiting is appropriate, when to call 911 or go to the hospital, and much more.

"We continually strive to partner and deliver a portfolio of unique solutions that meet the needs of people living with epilepsy. A Seizure Action Plan has the potential to make a huge difference to a person living with a seizure disorder," said Brad Chapman, Head of U.S. Epilepsy and Rare Syndromes at UCB. "We are proud to continue to support this important education initiative so that people living with epilepsy have the tools and care they need, and we are committed to developing patient-focused treatment options with a focus on individual needs."

All adults and children with epilepsy need a seizure action plan – especially those with new-onset epilepsy and those with ongoing frequent convulsive seizures who had more than one seizure in the previous year. Seizure-free patients with risk factors for breakthrough seizures may also benefit from a seizure action plan. In addition, key subgroups who would benefit from a seizure action plan are those who need help identifying their individual seizure pattern, do not have a plan, or live far from medical facilities.

For more information on Seizure Action Plan Awareness Week,
visit SeizureActionPlans.org today.

About the Seizure Action Plan Coalition

The Seizure Action Plan Coalition began in 2020 as a labor of love between the LGS Foundation, Dravet Syndrome Foundation, and TSC Alliance. The organizations knew there was an opportunity to bring the epilepsy community together to bring attention and awareness to Seizure Action Plans for people with epilepsy. **Epilepsy Alliance America became the managing organization of the Seizure Action Plan Coalition on January 1, 2023**. There are presently more than 35 awareness partners to whom we committed to expanding the reach and impact of the Coalition. We are committed to continuing this important work and expanding the reach and impact of the Coalition.

About Epilepsy Alliance America
Epilepsy Alliance America is a growing national organization representing like-minded local, regional, statewide, and even other national agencies dedicated to serving the everyday needs of people who live with seizures and epilepsy every day.

Epilepsy Alliance America was founded in 2018 by eight leading grassroots epilepsy organizations who are unified in their mission to provide direct support to people with epilepsy and the people who care for them.

Member organizations of Epilepsy Alliance America have been collectively supporting people with epilepsy for decades through support services, information, education, advocacy, and public awareness. As a result, the Alliance provides real epilepsy help to approximately 1 million Americans living with epilepsy.

Services provided by Member Organizations vary but include educational programs in schools, individual/family consultations, legislative and special education advocacy, medication assistance, camp programs, and telephone support.

Please visit **Current Members** to identify your local epilepsy organization and the services and supports available in your region.