

MEDIA PRESS RELEASE

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February 1, 2024 – The <u>Seizure Action Plan Coalition</u>, a collaboration managed by <u>Epilepsy</u> <u>Alliance America</u>, will hold the 4th Annual Seizure Action Plan (SAP) Awareness Week Feb. 12-19, 2024. The campaign is underwritten by gold sponsor Neurelis, Inc. and silver sponsor UCB, Inc. More than 60 organizations are awareness partners of the Seizure Action Plan Coalition.

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 for when a seizure occurs. The social media campaign incorporates the hashtag #SAPAW2024 and urges people to learn more at <u>SeizureActionPlans.org.</u>

"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," said 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."

"It is an honor to support the epilepsy community by helping educate on the critical importance of seizure preparedness and the need for having a seizure action plan," said Craig Chambliss, president and CEO of Neurelis, Inc. "Our focus on advancing life-changing treatments for epilepsy is driven by a mission to reduce fear and empower people with epilepsy, their care partners and loved ones. We are pleased to collaborate with the Seizure Action Plan Coalition in promoting efforts to achieve effective management of seizures and help realize better futures for those living with epilepsy."

In a recent <u>study</u>, only 30% of adult patients and 45% of pediatric patients responded that they have a seizure action plan. The plan can offer more control to patients and caregivers by providing consistent, patient-specific guidance regarding seizure management. It also educates and empowers people to know what to do in the event of a seizure, such as by defining the

appropriateness of watchful waiting, when to intervene with at-home rescue medications, when to call 911 or go to the hospital, and much more.

"As leaders in the fight against epilepsy, we continually innovate to deliver a portfolio of unique solutions for people living with epilepsy and rare syndromes. We strive to create a future where understanding and preparedness prevail, partnering with community towards a seizure-smart and stigma free world. Let's unite to raise awareness during Seizure Action Plan Awareness Week," said Brad Chapman, Head of U.S. Epilepsy and Rare Syndromes. "Together, we can illuminate the path of understanding and support for those living with and caring for those with epilepsy and rare syndromes, ensuring every action is a step towards a seizure-safe world."

The Seizure Action Plan Coalition website has tools and resources from its awareness partners for individuals with epilepsy and their families. Newly added to the site are resources for <u>Seizure Response and First Aid including downloadable posters in multiple languages</u> that can be posted so that individuals know how to respond in the event someone has a seizure.

For more information on Seizure Action Plan Awareness Week, visit <u>SeizureActionPlans.org</u> today.



About the Seizure Action Plan Coalition

The <u>Seizure Action Plan Coalition</u> began in 2020 as a labor of love between the <u>LGS</u> <u>Foundation</u>, <u>Dravet Syndrome Foundation</u>, and <u>TSC Alliance</u>. 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 <u>presently more than 60 awareness partners</u> 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.

<u>American Brain Coalition / Sami Alert / Angels of Epilepsy / Anita Kaufman Foundation / CACNA1A</u> <u>Foundation / Child Neurology Foundation / Children's Brain Institute</u> / Chloe's Fight with Photosensitive Epilepsy / Danny Did Foundation / Defeating Epilepsy Foundation / Dravet Syndrome Foundation / Dup15qAlliance / Epilepsy Advocacy Network / Epilepsy Alliance America / Epilepsy Alliance Florida / Epilepsy Alliance Louisiana / Epilepsy Alliance North Carolina / Epilepsy Alliance Ohio / Epilepsy Alliance West Central New York / Epilepsy Association / Epilepsy Association of Western and Central PA / Epilepsy Foundation of America / Epilepsy Information Service of Wake Forest School of Medicine / Epilepsy Services Foundation / Epilepsy Services of New Jersey / Epilepsy Support Network of Orange County / Epitome of Epilepsy Eric's Corner / FND Hope USA / GRIN2B Foundation / Gulf Coast Epilepsy Alliance / Hope for HIE / IFCR: International Foundation for CDKL5 Research / International SCN8A Alliance/DEE-P Connections / JoshProvides - Epilepsy Assistance Foundation / KIF1A.ORG / Koolen-de Vries Syndrome Foundation / Legacy Bridges Foundation / LGS Foundation / Live Life with Zest / Living Well with Epilepsy / Malan Syndrome Foundation / Neureka / Paul's Purple Warriors / Phelan-McDermid Syndrome Foundation / Purple Peace Foundation / Rare Epilepsy Network / Ring14USA/ Sail For Epilepsy / Sociedad Puertorriquena de Epilepsia / Sofie's Journey - DBA Epilepsy Awareness Day at Disneyland / South Carolina Advocates for Epilepsy / Steunpunt Kinderepilepsie / STXBP1 Foundation / TBC1D24 Foundation / Tess Research Foundation / The Connected Parent / The Cute Syndrome Foundation / The Sturge-Weber Foundation / TSC Alliance / Valley Children's Healthcare - Epilepsy Support Program

The Seizure Action Plans Coalition is underwritten by gold sponsor Neurelis, Inc. and silver sponsor UCB, Inc. Additional support is provided by SK Life Science and Catalyst Pharmaceuticals.



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.

<u>Services</u> 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 <u>**Current Members**</u> to identify your local epilepsy organization and the services and supports available in your region.