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Volunteer Engagement Opportunities

Be a Voice for the Epilepsy Community – Apply to Become an Epilepsy Advocacy Champion

Are you from CT, HI, LA, ME, MN, MS, MT, NH, NM, NV, RI, TN, VT, or WV? If so, apply to become an Epilepsy Advocacy Champion! Champions will learn how to educate federal lawmakers about epilepsy and the policies that can impact the epilepsy community. No legislative or prior advocacy experience is required, just a willingness to share your experiences.
The volunteer program is open to those over age 18 who are living with or affected by the epilepsies. Champions will receive specialized training, resources, and support from the Foundation’s national advocacy team, be connected with their local Epilepsy Foundation if they aren’t already, and be eligible to attend a biennial advocacy conference in Washington, D.C. to advocate on Capitol Hill. Advocates are expected to serve two-year terms with the possibility of renewal. Learn more and apply here.

National Advocacy

Disability Community Expresses Concern and Demands Action over CDC Director Remarks

On Friday, January 7th, the Director of the Centers for Disease Control and Prevention (CDC), Dr. Rachelle Walensky, made comments in a television appearance regarding a research study on COVID-19 deaths. She remarked that the “overwhelming number of deaths, over 75%, occurred in people who had at least four comorbidities. So really, these are people who were unwell to begin with. And yes, really encouraging news in the context of Omicron.”

In response to these comments, over 130 health and disability advocacy organizations, including the Epilepsy Foundation, sent a letter to Director Walensky expressing frustration, disappointment, and concern. People with disabilities and chronic conditions, particularly those who live in congregate settings and/or those who are Black, Indigenous, and people of color, have been disproportionately impacted by the pandemic. Whether intentional or not, the remarks convey a harmful misconception that the lives of people with disabilities are valued less. On Friday, January 14th, various groups, including the Epilepsy Foundation, had a meeting with Director Walensky. Via the letter and this meeting, the groups have called on Director Walensky to take several actions to help rebuild the trust in the CDC, including regular meetings with disability stakeholders and CDC leadership, as well as ensuring all COVID-19 guidance is inclusive of the needs of people with disabilities.

State Advocacy

Seizure Safe Schools Legislation Forges Ahead Across the Country

With the start of the 2022 state legislative session this month, many Seizure Safe Schools bills have also been introduced or re-introduced. The Epilepsy Foundation is excited to continue working with grassroots advocates, local Epilepsy Foundation staff, state legislators, and partner organizations to pass
this legislation in all 50 states and Washington, D.C. Currently, there is active legislation in Florida, Hawaii, Iowa, Maryland, Michigan, Missouri, Rhode Island, South Carolina, and Vermont – with many more bills forthcoming.

Just this week, Maryland, Missouri, and South Carolina’s bills were heard by the committees of jurisdiction. South Carolina’s bill successfully passed through the committee and will now move to the House floor. Missouri’s bill will be voted on by the committee next week. Michigan’s bill passed through the House before the holiday season and has gone to the Senate. If you are interested in learning more about your state’s legislative efforts on this issue or would like to become involved, please contact the national advocacy team at publicpolicy@efa.org or contact your local Epilepsy Foundation office.

Visit our Action Alert Center to see if you can take action to support the bill in your state!

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