

October 31, 2024

Paul Reed, MD  
Deputy Assistant Secretary for Health  
Director, Office of Disease Prevention and Health Promotion  
U.S. Department of Health and Human Services  
1101 Wootton Parkway, Suite 420  
Rockville, MD 20852

Dear Dr. Reed:

Thank you for inviting comment on the proposed Healthy People 2030 objectives. The undersigned epilepsy organizations appreciate your leadership on this important project, and write in support of comments submitted by the Epilepsy Foundation of America (hereinafter “Foundation”) asking that an epilepsy objective be included in Healthy People 2030, as it was in Healthy People 2020.

As noted by the Foundation, like the other conditions included in Healthy People 2030, epilepsy is an important national issue that needs more surveillance data, research, and effective treatments. Epilepsy is an umbrella term for a large number of brain disorders that cause repeated, unprovoked seizures. Approximately 1 in 26 Americans will develop epilepsy at some point in their lifetime.<sup>1</sup> Epilepsy (also called the epilepsies) is a spectrum comprised of many diagnoses, including an ever-growing number of rare epilepsies. Among the epilepsies, there are many different types of seizures and varying levels of seizure control even with the best possible medical care. However, there are also significant health disparities for people with epilepsy in poorer socio-economic classes, those who are members of racial, ethnic, or gender minority groups, and those who live in rural or medically underserved areas.

For example:

- Women, the uninsured, and people residing outside of the Northeast were less likely to visit an epilepsy provider in the past year. In addition, poverty was the key social predictor of antiseizure medication use among adults with epilepsy. (Szaflarski M, Wolfe JD, Tobias JGS, Mohamed I, Szaflarski JP. Poverty, insurance, and region as predictors of epilepsy treatment among US adults. *Epilepsy Behav.* 2020 Jun;107:107050. Doi: 10.1016/j.yebeh.2020.107050. Epub 2020 Apr 12. PMID: 32294594; PMCID: PMC7242147.)

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<sup>1</sup> D.C. Hesdorffer, G. Logroscino, E.K.T. Benn, N. Katri, G. Cascino, W.A. Hauser (2011). Estimating risk for developing epilepsy: A population-based study in Rochester, Minnesota. *Neurology*, 76(1), 23-27.

- Epilepsy-related deaths are higher in non-Hispanic Black/African Americans with epilepsy compared to other groups. (Greenlund SF, Croft JB, Kobau R. Epilepsy by the Numbers: Epilepsy deaths by age, race/ethnicity, and gender in the United States significantly increased from 2005 to 2014. *Epilepsy Behav.* 2017 Apr;69:28-30. doi: 10.1016/j.yebeh.2017.01.016. Epub 2017 Feb 20. PMID: 28219043.)
- The incidence of Sudden Unexplained Death in Epilepsy (SUDEP) is highest for those people with epilepsy in the lowest quartile for socioeconomic status (SES). (Cihan E, Hesdorffer DC, Brandsoy M, Li L, Fowler DR, Graham JK, Karlovich M, Donner EJ, Devinsky O, Friedman D. Socioeconomic disparities in SUDEP in the US. *Neurology.* 2020 Jun 16;94(24):e2555-e2566. doi: 10.1212/WNL.00000000000009463. Epub 2020 Apr 23. PMID: 32327496; PMCID: PMC7455330.)

Due to its complexity and being a spectrum disease, there is no one-size-fits-all treatment for epilepsy. Approximately 1 million people with the epilepsies—more than 30% of adults—do not respond to currently available treatment.<sup>2</sup> And a concerning number of people who theoretically *should* be able to achieve seizure control do not because of lack of access or other barriers to adherence to treatment. Uncontrolled seizures not only affect the ability to drive, participate in school, or maintain employment but can lead to disability, injury, and even early death. Each year, about 1 out of 1,000 people with epilepsy die due to SUDEP.<sup>3</sup> For people whose seizures are not controlled, the SUDEP rate dramatically increases to 1 in 150.<sup>4</sup> The challenges of the epilepsies can also extend far beyond seizures to include cognitive, behavioral, and psychiatric mood disorders, as well as mobility, gastrointestinal, and respiratory issues. As a result, epilepsy and/or seizures impose an annual economic healthcare burden of at least \$54 Billion.<sup>5</sup>

The epilepsy objective in Healthy People 2020 was to “increase the proportion of people with epilepsy and uncontrolled seizures who receive appropriate

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<sup>2</sup> Kwan, P & Brodie, MJ. Early identification of refractory epilepsy. *N Engl J Med.* 2000;342(5):314-319. DOI: 10.1056/NEJM200002033420503.; Chen, Z., Brodie, M.J. et al. Treatment outcomes in patients with newly diagnosed epilepsy treated with established and new antiepileptic drugs: A 30-year longitudinal cohort study. *JAMA Neurol.* 2018;75(3):279-286. doi:10.1001/jamaneurol.2017.3949.

<sup>3</sup> Thurman D.J., Hesdorffer D.C., French J.A. (2014). Sudden unexpected death in epilepsy: Assessing the public health burden. *Epilepsia*, 55(10), 1479-1485.

<sup>4</sup> Tomson, T., Nashef, L. & Ryvlin, P. (2008). Sudden unexpected death in epilepsy: Current knowledge and future directions. *The Lancet Neurology*, 7(11), 1021-1031.

<sup>5</sup> Moura, L.M.V.R., Karakis, I., Zack, M.M., Tian, N., Kobau, R., & Howard, D. (2022). Drivers of U.S. health care spending for persons with seizures and/or epilepsies, 2010–2018. *Epilepsia*, 63(8), 2144–2154. doi:10.1111/epi.17305.

medical care.” This measure, the first federally approved national objective on epilepsy, “ensured that epilepsy was recognized as a public health imperative and that its progress was measured over the decade.”<sup>6</sup> For the purposes of the survey, “appropriate medical care” was defined for persons aged 18 years and over with epilepsy and uncontrolled seizures as those who reported that they visited a neurologist or epilepsy specialist in the past year. It is critically important that people with the epilepsies receive appropriate medical care so that they can control their seizures and reduce the chance of disability, injury, or death from epilepsy. The Healthy People 2020 data gathered through the National Health Interview Survey found that the percentage of people with epilepsy and uncontrolled seizures who received appropriate care increased from 57.7% in 2010 to 65.7% in 2013, thereby exceeding the 2020 goal of 63.5%.<sup>7</sup> However, this dropped to 60.1% in 2017.<sup>8</sup> The inclusion of a Healthy People 2030 objective on epilepsy is critically important to evaluate our progress on the epilepsies, and to help determine what factors caused the decrease in the percentage of people with epilepsy and uncontrolled seizures receiving appropriate medical care.

People with the epilepsies deserve more. To prioritize and improve the status quo for people with the epilepsies and assist the federal government, medical professionals, and other stakeholders in understanding and addressing the gaps in access to care for people with epilepsy, we are proposing a Healthy People 2030 objective to target a ten percent increase in the proportion of people with epilepsy and uncontrolled seizures who receive appropriate medical care.

Thank you again for your work on Healthy People 2030, and for your consideration of this important request.

Sincerely,  
BDSRA Foundation  
CFC International  
Child Neurology Foundation  
Coalition to Cure CHD2  
COMBINEDBrain

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<sup>6</sup> Centers for Disease Control and Prevention, “CDC Activities Related to Recommendations of the 2012 IOM Report, *Epilepsy Across the Spectrum*, 2012-2022, Final Progress Report,” <https://www.epilepsyallianceamerica.org/wp-content/uploads/2022/09/Epilepsy-IOM-Report-FINAL-CLEARED-9-29-22-PDF.pdf>.

<sup>7</sup> Sinclair LB, Fox MH, Jonas BS, Berry HG, Quatrano LA, McGowan AK, Peacock G. Considering disability and health: Reflections on the Healthy People 2020 Midcourse Review. *Disabil Health J*. 2018 Jul;11(3):333-338. doi: 10.1016/j.dhjo.2018.04.001. Epub 2018 Apr 19. PMID: 29779959; PMCID: PMC6088746.

<sup>8</sup> CDC National Center for Health Statistics, Healthy People 2020 Progress Table, [https://www.cdc.gov/nchs/healthy\\_people/hp2020/progress-tables.htm](https://www.cdc.gov/nchs/healthy_people/hp2020/progress-tables.htm).

CSNK2A1 Foundation  
CURE Epilepsy  
CureGRIN Foundation  
CureSHANK  
Danny Did Foundation  
Decoding Developmental Epilepsies  
Developmental and Epileptic Encephalopathies Project (DEE-P Connections)  
DLG4 SHINE Foundation  
Dravet Syndrome Foundation  
Epilepsy Alliance America  
Epilepsy Foundation of America  
GABA-A Alliance  
International SCN8A Alliance  
KCNQ2 Cure Alliance  
NORSE Institute  
Rare Epilepsy Network (REN) Coordinating Committee  
Ring14 USA  
STXBP1 Foundation  
The FamilieSCN2A Foundation Inc  
The Sturge-Weber Foundation  
TSC Alliance  
v-ATPase Alliance, Inc.  
YWHAG Research Foundation