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National Advocacy

Proposed Long-term Video EEG Coding Changes Will Impede Access to Critical Epilepsy Care for Medicare Beneficiaries

In July 2019, the Centers for Medicare and Medicaid Services (CMS) proposed significant changes to the value and reimbursement levels of long-term electroencephalograph (EEG) and video EEG (VEEG) professional and technical service codes, which could impede access for Medicare beneficiaries. Long-term video EEG is the key diagnostic tool for epilepsy.
specialists to identify what type of seizures someone is having, identify which part(s) of the brain are involved and establish the most effective treatment plan. These changes are likely to delay effective diagnosis and treatment which is dangerous for people with epilepsy and seizures and can increase overall healthcare costs.

We want to thank the almost 900 grassroots epilepsy advocates who contacted their members of Congress to explain why timely access to EEG monitoring services is so critical and to express concern over the proposed changes. As a result of your advocacy and efforts from the provider community, a bipartisan group of Representatives – Blumenauer (OR-03), Wenstrup (OH-02 ), Sewell (AL-07) and McMorris Rodgers (WA-05) – have circulated a letter in the House of Representatives that will be sent to CMS expressing their concerns over the proposed reductions and the impact this will have on care for the epilepsy community. The more Representatives that sign the letter, the more powerful the statement will be.

Read the Dear Colleague letter and letter that will be sent to the CMS.

>>>TAKE ACTION and ask your Representative to sign on to the letter!

Congress Passes Continuing Resolution to Avoid Shutdown

Congress has returned from August Recess and is in full swing. The House of Representatives and the Senate must push through dozens of spending bills to fund the government through Fiscal Year 2020 before the September 30th deadline. However, the House of Representatives passed a stopgap measure (H.R. 4378) on September 19 with the Senate passing it on September 26 to fund the government through November 21, 2019. This will grant more time for negotiation and avoid a government shutdown.

National Patient Groups Seek and Receive Clarity on Medical Deferred Action Program

In late August, without formal advance notice or explanation, the U.S. Citizenship and Immigration Services (USCIS) began issuing denial notices for non-military medical deferred action requests. The non-military medical deferred action program began in 2003 and allows immigrants with extremely serious medical conditions like epilepsy to apply to temporarily remain in the United States to receive life-saving medical care. In issuing denial notices, it became unclear if and how the program would continue in the future.

The Foundation, along with 8 other national patient organizations, released a statement earlier this month expressing concern with the shifts and uncertainty surrounding the medical deferred action program.
On September 19, the Department of Homeland Security’s Acting Secretary, Kevin McAleenan, directed USCIS to resume its deportation relief requests for people receiving treatment for serious medical conditions on a discretionary, case-by-case basis, except as otherwise required by an applicable statute, regulation, or court order. This decision reverses the earlier policy change made by USCIS in August.

**Epilepsy Foundation and Partners Weigh in to Support Access to Care in Medicaid**

In July, CMS announced a plan to rescind Obama-era regulations regarding access to care in Medicaid. The Medicaid statute requires that provider payments be sufficient to attract enough providers to serve Medicaid enrollees and the current regulations detail how states show compliance with that requirement. The Administration has previously proposed to exempt states with high managed care enrollment. Instead of implementing that proposal, the Administration has proposed to rescind the regulations entirely. The [Foundation submitted comments](#) and joined comments submitted by the [Consortium for Citizens with Disabilities](#) and a [national group of patient organizations](#).

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**State Advocacy**

**Epilepsy Foundation Rolls Out Seizure Safe Schools Initiative Nationwide**

On September 16, the [Epilepsy Foundation announced that it will be rolling out its Seizure Safe Schools initiative nationwide](#). For students living with epilepsy, it is important that schools are well-equipped with the tools necessary to provide a safe and enriching environment. Through this initiative, the Foundation hopes to continue to raise awareness and implement a uniform standard of care and response across the country so that students have access to the care they need.

Currently, four states – Kentucky, Indiana, Texas and Illinois – have successfully passed the legislation. The Foundation is in the process of working with legislators in many states to draft and introduce bills for the 2020 legislative session.

Learn more about the legislation and this initiative at [advocacy.epilepsy.com/seizuresafeschools](#).

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**New Jersey Introduces Seizure Safe School Legislation – Paul’s Law**
On September 12, 2019, Senate Bill 4141 – also known as Paul’s Law – was introduced in the New Jersey State Senate by Senator Beach. The bill would require all school personnel to be trained in seizure recognition and first-aid response and mandating that a Seizure Action Plan is part of a student’s file and made available for all school personnel responsible for the student.

**Access to Medical Cannabis and Cannabidiol (CBD) in Schools**

On September 17, the D.C. City Council passed emergency legislation to allow students, who are enrolled as patients in the District’s medical cannabis program, the ability to access such treatment in schools. The law would require a school to have a policy in place for allowing the administration of medical cannabis. Mayor Muriel Bowser is expected to sign the emergency legislation.

In California, Senate Bill 223 would authorize school districts to enact policies allowing students access to physician-recommended CBD-derived products during the school day. With almost 60,000 children living with epilepsy in California this is a critical first step. [Tell Governor Newsom to sign this bill into law!](https://www.edr.com/politico/?utm_source=edr&utm_medium=social&utm_campaign=epilepsy)

Read more about the Foundation’s position on medical cannabis and CBD at [advocacy.epilepsy.com/medical-cannabis](https://www.advocacy.epilepsy.com/medical-cannabis).

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We encourage you to invite others to join our [Speak Up, Speak Out!](https://www.advocacy.epilepsy.com/speak-up-speak-out)

advocacy network. Members receive the monthly *Capitol Circuit* newsletter and alerts about opportunities to advocate for the epilepsy community throughout the year. Growing our advocacy network is critical to achieving our public policy goals as we move through busy state and federal legislative sessions. Make a difference today by sharing our Speak Up, Speak Out! Network on [Facebook](https://www.facebook.com) and [Twitter](https://twitter.com).
Email us at TSU@efa.org

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