



Highlights from the Hill

January 2016

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2016: New Year, New Advocacy Opportunities

Welcome to the first Highlights from the Hill of 2016! We wanted to thank our entire grassroots community for the work you've done in 2015 and we hope you're ready to continue working to help the epilepsy community in 2016. As last year was coming to a close we began the transition to a new advocacy platform, so our action center has a new look! You can check it out at www.cqrcengage.com/efa. We will be launching even more new pages soon, so keep an eye on this space!

We're excited for the coming year and we'd like to expand our network so that the epilepsy community can speak with an even louder voice as we advocate for policies that improve the lives of people living with epilepsy. Please take a moment to encourage your friends and family to join our Speak Up Speak Out network at <http://bit.ly/EFSignUp> and share the link on your Facebook and Twitter. Together we can make a difference.

Finally, 2016 is an election year and it's important that we all vote and encourage our candidates to support the epilepsy community. If you aren't registered to vote, take a moment and go to <https://www.usa.gov/register-to-vote#item-212126> to find out how to register in your state. You can also go to <http://cqrcengage.com/efa/Candidates> to view candidates for your district as well as other important election information.

We are looking forward to working together in 2016!

Epilepsy Advocate Selected as Peer Reviewer

We would like to congratulate Jay Hennessy for being selected to participate as a patient reviewer in the Department of Defense (DOD) Epilepsy Research Program, which is part of the Congressionally Directed Medical Research Program (CDMRP). Jay was diagnosed with epilepsy in 2010 and since then has

continued to live his life to its fullest potential. The CDMRP program was looking for current or former members of the military who were living with epilepsy to serve as peer reviewers to help evaluate research proposals related to epilepsy. Jay, as a former Army National Guard member, was eager to serve and learned about the opportunity through his local affiliate, the Epilepsy Foundation of Florida (EFOF).



Jay has been an active volunteer for EFOF and they were happy to nominate him for the peer review opportunity. While Jay continues to live with intractable epilepsy, he is using his experiences to bring hope to others as he trains to become a HOPE Mentor for EFOF to continue his advocacy and assist with support groups and other EFOF programs. We're extremely excited that Jay will be representing the epilepsy community in this position and can help direct the CDMRP Epilepsy Research Program in a direction that will be best for our entire community.

Epilepsy Foundation and I Am Essential Coalition Urge HHS to Improve Access to Care in ACA Marketplace Plans

In late November the Department of Health and Human Services (HHS) released the Notice of Benefit and Payment Parameters (NBPP) proposed rule, which outlines regulatory proposals for how insurers that offer plans in the Affordable Care Act (ACA) Marketplace must operate. This proposed rule is part of the annual ACA implementation regulatory process. In response to the proposed rule the I Am Essential coalition sent HHS a letter signed by 124 national and state groups expressing support for many of the proposals and urging the Department to continue to explore ways to further ensure meaningful access to physician directed care. As in previous years, the Foundation submitted detailed public comments on the proposed rule as well.

Earlier this week 124 groups came together again for an I Am Essential coalition letter to HHS voicing support for the patient protections outlined in the *Draft 2017 Letter to Issuers in the Federally-facilitated Marketplaces*, which offers guidance for health plans offered in the ACA Marketplaces during the 2017 plan year. While the guidance in the Letter to Issuers doesn't have the force of law of the regulations in the NBPP final rule, both these documents create the framework under which health plans offered in the ACA Marketplace will operate. This is why the Foundation actively engages in regulatory advocacy with HHS.

You can view the comment letters and learn more about the coalition and the Foundation's advocacy activities at www.epilepsy.com/ACA.

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