

**December 18, 2014**

## **Spending Bill Includes Increases for NIH, CDC, Neurological Research, Others**

On December 16<sup>th</sup>, President Obama signed a \$1.1 trillion spending bill to keep most government programs funded through the current fiscal year, which ends on September 30<sup>th</sup>, 2015. This bipartisan spending bill includes important provisions that will be beneficial to the epilepsy community, which include:

- The National Institutes of Health (NIH) will receive \$30.3 billion, an overall increase of \$150 million focused on brain research programs and Alzheimer's disease. NIH and its institutes, especially the National Institute on Neurological Disorders and Stroke, conduct important research on epilepsy and seizures.
- The Centers for Disease Control and Prevention (CDC) will receive \$6.9 billion, an increase of \$42.7 million. CDC has been a valuable partner as we raise awareness of epilepsy and how to help someone experiencing a seizure.
- The National Science Foundation will receive \$35 million, a significant increase of \$21.15 million, focused on the BRAIN Initiative, a promising and ambitious program, lead by federal research agencies and private sector foundations and partners, to map the human brain and further the development of treatments and cures for epilepsy and other neurological conditions.
- The Office of Disability Employment Policy will receive \$38.5 million, an increase of about \$1 million, to support activities that help transition youth with disabilities into competitive, integrated employment.
- Language prohibiting the Department of Justice from interfering with medical cannabis programs in states where these have been legalized. This protection will benefit people living with epilepsy who rely on medical cannabis and their families.
- Requirement of a report on progress by the Department of Veterans Affairs on neurological disease, particularly traumatic brain injury and post-traumatic stress disorder.

We are encouraged by these funding increases and will continue to advocate for greater funding for initiatives that benefit the epilepsy community when the new Congress reconvenes in January.

## **Look #BeyondPremiums When Considering Health Plans During ACA Open Enrollment Season**

As a leader of the I Am (Still) Essential campaign, the Epilepsy Foundation has been actively advocating with HHS Secretary Burwell and other agency staff about the need to improve access to care in ACA Marketplace plans, especially for people living with chronic conditions like epilepsy. We have gathered support from more than 260 other state and national organizations who have signed onto a letter commenting on rules proposed recently by HHS that would address many of the concerns raised by the I Am (Still) Essential campaign. As we continue to advocate for increased access to care in ACA Marketplace plans, **we want to hear from you about any challenges you've faced this year when trying to gain access to and affording the medications and specialists you need.** Are your medications covered by your plan? Have you

faced high out-of-pocket costs for them? Did you have to switch medications or specialists because they were not covered by your plan? **We have created a survey at <http://bit.ly/EFSurv> to capture this information, which will make it easier for us to raise awareness with federal and state officials about the need to look #BeyondPremiums and improve access to care in ACA Marketplace plans**, especially for people living with chronic conditions like epilepsy.

You can also learn more about the I Am (Still) Essential campaign and help us spread the message about looking #BeyondPremiums by visiting and liking the campaign's Facebook page at <http://bit.ly/IAEBP>, where the latest news and resources are posted.

### **New Advocacy Opportunities Coming in the New Year**

With the New Year will come a new Congress. With more than 70 new Members of Congress and a switch in the majority party in the Senate, the 114<sup>th</sup> Congress presents an opportunity to raise awareness with new Members of Congress and their staff about epilepsy and seizures. We need your help so we can speak together as a community about the challenges we face but also the opportunities to improve the care and quality of life for people living with epilepsy. Please encourage your friends and family to sign up for our Speak Up, Speak Out network at <http://bit.ly/Capwiz> so they can join us in sharing their story and in taking action on issues that are important to our community.

**November 22, 2014**

### **New Congress Brings New Advocacy Opportunities**

As Congress works to wrap up business in the lame duck session, we are working to make sure the epilepsy community is heard, but we have also begun to prepare for the new session in January. The elections earlier this month propelled more than 70 new Members of Congress and a switch in the majority party in the Senate. All these changes for the 114<sup>th</sup> Congress present an opportunity to raise awareness with new Members of Congress and their staff about epilepsy and seizures, and the critical support we need for increased funding for epilepsy research and public health programs, and to improve access to care and treatments. We need your help so we can speak together as a community, about the challenges we face but also the opportunities to improve the care and quality of life for people living with epilepsy. Please encourage your friends and family to join our Speak Up, Speak Out network at <http://bit.ly/Capwiz> so they can join us in sharing their story and in taking action on issues that are important to our community.

### **Health Organizations Outline Goals for 21<sup>st</sup> Century Cures Initiative**

The House Energy and Commerce Committee's 21<sup>st</sup> Century Cures initiative, focused on changing the health landscape and increasing and improving research and treatments for chronic conditions, has been working with diverse stakeholders in the health community to gather ideas and goals for the upcoming Congress. The Epilepsy Foundation has joined with nine other national health organizations on a joint letter recommending a list of actions that the 21<sup>st</sup> Century Cures initiative should focus on as it formulates policy solutions. We believe that it is vitally important that Congress help accelerate critical research and drug development as well as

creating avenues for increased investment in this research. To read the full letter, please go to <http://bit.ly/21stLetter>.

### **Health Community Urges Congress to Pass Charitable Giving Incentives**

The Epilepsy Foundation has joined with more than 1,000 other organizations in a letter to Congress urging them to permanently enact charitable giving tax incentives, including an IRA incentive that prompted more than \$140 million in gifts to non-profit organizations throughout the country in its first two years. This permanent incentive has already been passed in the House of Representatives, in part due to the advocacy of our community. We are now looking to the Senate to pass this tax incentive to benefit non-profits who depend on these contributions to support valuable programs and services for patients. To read the full letter, please go to <http://bit.ly/GivingIncentives>.

### **Look #BeyondPremiums When Considering Health Plans During ACA Open Enrollment Season**

As a leader of the I Am (Still) Essential campaign, the Epilepsy Foundation has been actively advocating with HHS Secretary Burwell and other agency staff about the need to improve access to care in ACA Marketplace plans, especially for people living with chronic conditions like epilepsy. Despite the high numbers of newly insured and lower premiums for many enrollees, we remain concerned about confusing and missing plan information on ACA Marketplace websites, high co-insurance and other barriers to lifesaving medications, and narrow provider networks that make it difficult or impossible to see the specialist you need.

As part of this effort, and with the ACA open enrollment season starting November 15<sup>th</sup>, we encourage you to look #BeyondPremiums when selecting a health plan. We have developed a plan checklist to help you understand your health care needs, and gathered additional resources, at [www.epilepsy.com/aca](http://www.epilepsy.com/aca). **We also want to hear from you about any challenges you've faced this year when trying to gain access to, and affording, the medications and specialists you need.** Are your medications covered by your plan? Have you faced high out-of-pocket costs for them? Did you have to switch medications or specialists because they were not covered by your plan? **We have created a survey to capture this information, which will make it easier for us to raise awareness with federal and state officials about the need to look #BeyondPremiums and improve access to care in ACA Marketplace plans,** especially for people living with chronic conditions like epilepsy.

**Take a few moments to complete the survey today at <http://bit.ly/EFSurv>.**

You can also learn more about the I Am (Still) Essential campaign and help us spread the message about looking #BeyondPremiums by visiting and liking the campaign's Facebook page at <http://bit.ly/IAEBP>, where the latest news and resources are posted.

### **In The States**

#### **Op-Ed by Connecticut Affiliate Highlights Access Barriers in Marketplace Plans**

A recent op-ed by Epilepsy Foundation of Connecticut Executive Director, Linda Wallace, highlighted barriers to quality care for individuals on ACA Marketplace plans. As part of the I Am (Still) Essential campaign, 33 Epilepsy Foundation affiliates from across the country joined the letter to HHS Secretary Burwell and are raising awareness with local media and policymakers about the need to improve access to care in Marketplace plans. You can read the op-ed and other recent op-eds by other Foundation affiliates at <http://bit.ly/EFACA>.

***October 24, 2014***

### **Senator Harkin Holds Last Hearing as Chairman of HELP Committee**

On September 18th, Senator Tom Harkin held his last full hearing as Chairman of the Health, Education, Labor, & Pensions (HELP) Committee before his retirement. The hearing focused on overcoming the barriers that many people with disabilities face when trying to achieve economic self-sufficiency. Many assistance programs limit the total assets that a person with disabilities may have, and once they exceed that they are considered ineligible. Senator Harkin and the HELP Committee would like to change these limits so people with disabilities can work and save for emergencies without the fear of losing important services. We applaud Senator Harkin for his work on this issue as well as his decades of service to the disability community.

### **Disability Treaty Fails to Get Vote**

On September 17th Senator Harkin asked the full Senate to agree to vote on the Convention on the Rights of Persons with Disabilities (CRPD). His proposal would have brought the CRPD to the floor this session and given the disability community a chance at US ratification of this important treaty. Unfortunately, Senator Harkin's proposal to bring the CRPD to the Senate floor, which required unanimous consent, was opposed by Senator Lee from Utah. Senator Harkin has vowed that while he is retiring from the Senate, he will not be retiring from the disability treaty fight. We look forward to continuing to work with him to ratify the CRPD.

### **Legislation Would Make DEA Scheduling Process More Efficient**

The Regulatory Transparency, Patient Access, and Effective Drug Enforcement Act (S. 2862), recently introduced by Senators Whitehouse and Hatch, would bring transparency to the Drug Enforcement Agency (DEA) scheduling process and get new treatments to patients in a timely manner. We strongly support S. 2862, as well as similar legislation in the House (H.R. 4299), which would speed up the DEA scheduling process, which can take more than a year after the treatment has been approved by the Food and Drug Administration (FDA). The Foundation recently led an effort to bring together the epilepsy community on a group letter to Congressional leadership urging them to support S. 2862 and H.R. 4299. You can read the letter at <http://bit.ly/DEASignOn>. You can also speak up on the need for new therapies to reach patients quickly after FDA approval by asking your Members of Congress to expedite and bring transparency to the DEA scheduling process by supporting S. 2862 and H.R. 4299 at <http://bit.ly/SchedAlert>.

## **Children's Health Insurance Program Funding At Risk**

The Foundation joined 1,200 leading national, state, tribal, and local organizations on an October 23rd letter urging Congressional leaders to provide continued funding for the Children's Health Insurance Program (CHIP) to ensure that states can continue to provide health coverage for millions of children. For nearly two decades, CHIP has been an essential source of coverage for families, ensuring access to high-quality, affordable, pediatric-appropriate health care for children in working families whose parents earn too much to qualify for Medicaid but too little to purchase private health insurance. You can view the letter at <http://bit.ly/EFCHIP>.

## **In The States**

### **Pennsylvania PDMP Expansion Will Limit Access to Epilepsy Medication**

The Pennsylvania legislature sent to the Governor's desk legislation that would expand the state's prescription drug monitoring program (PDMP) to include Schedule V medications (SB 1180). The expansion would make it harder for patients to access some epilepsy medications, and would create an additional reporting burden for physicians, which may discourage them from seeing and caring for epilepsy patients. The Foundation, our local affiliates, and legislative champions like Representative William Adolph (PA 165), have advocated throughout the year for an exemption for epilepsy drugs, because delays in accessing medication due to onerous drug monitoring requirements can lead to breakthrough seizures and related complications, including death. Despite this setback, the epilepsy community will continue to raise awareness about the critical role medications play in seizure control and advocate for an exemption for epilepsy medications from the drug monitoring program, which intends to curb abuse of prescription medications. You can learn more about the issue at <http://bit.ly/EFPenn>.

### **Op-Eds by Affiliates in Kentucky and New England Highlight Access Barriers in Marketplace Plans**

Recent opinion editorials, by Epilepsy Foundation of Kentuckiana Executive Director, Deb McGrath, and Epilepsy Foundation New England Director of Advocacy & Policy, Bill Murphy, highlight barriers to quality care for individuals on Marketplace Plans created by the Affordable Care Act. Many individuals living with pre-existing conditions, like epilepsy, can now gain access to health insurance through the Marketplace, but some are still facing barriers to care due to limited benefits, and high cost-sharing. As a leader of the I Am Essential campaign, the Foundation and its affiliates have called on Health & Human Services Secretary Burwell to address barriers to care in Marketplace plans. With open enrollment for the Marketplace just a few weeks away (November 15th), we will continue to advocate for affordable access to medications and health providers with state and federal regulatory agencies and legislators, and raise awareness with local and national media about the need to improve access to care in Marketplace plans. You can read the op-eds and learn more about the I Am Essential campaign at <http://bit.ly/EFACA>.

### **Iowa Issues Proposed Rules on Prior Authorization Deadlines**

The Iowa Insurance Division recently released proposed rules on the prior authorization process. Despite the legislature's intent to streamline and standardize the prior authorization process when it passed H.F. 2463, the proposed rules would lead to confusion by creating two urgent claim standards, and allowing plans up to 15 days for non-urgent claims. Some plans would have to respond to urgent claims within 24 hours (including Marketplace plans) while others would have up to 72 hours (including employer-sponsored plans and Medicaid). The Foundation submitted comments in partnership with the Epilepsy Foundation of North/Central Illinois, Iowa, & Nebraska, urging the Division to institute a 24 hour turnaround for all urgent claims, not just Marketplace plans, and no more than 72 hours for all other claims, not 15 days as proposed. Responding within 72 hours to a request for prior authorization, and within 24 hours for an urgent claim, is commonplace throughout the country and necessary for providing timely access to care, especially for individuals seeking access to lifesaving medications, like those needed by people living with epilepsy. Restricting access to physician-directed care through unnecessary delays can significantly increase medical costs related to preventable seizures, along with lost wages and productivity. Read the comment letter at <http://bit.ly/EFIAPA>.

### **Iowa Cannabidiol Committee Considers Future of Program**

On September 11th Iowa's Cannabidiol Implementation Study Committee held a hearing to discuss the proposed rules for the program and what still needs to be done to bring meaningful access to the people of Iowa. The Foundation partnered with the Epilepsy Foundation of North/Central Illinois, Iowa, & Nebraska to send a letter urging them to work towards a comprehensive cannabidiol program.

The affiliate also testified before the committee and urged legislators to create meaningful access to cannabis as a treatment option for people living with intractable epilepsy and uncontrolled seizures. The state's current medical cannabis program does not allow for growing, processing, and dispensing cannabis and products derived from the cannabis plant. This means that families seeking this treatment option would have to travel out of state to obtain CBD oil, and break federal laws by bringing it across multiple state lines. Although a number of states have medical cannabis programs, none except Oregon allow out of state residents to legally access CBD oil, and even in Oregon the patient must obtain a registration card and a recommendation from a physician licensed in Oregon. Families may seek products marketed as CBD oil that may turn out to be unsafe preparations with little or no CBD oil or medical benefit. Additionally, clinical trials for drugs derived from medical cannabis have limitations on the numbers and types of patients they can enroll, making it hard or impossible for families to enroll in trials.

The epilepsy community urged the Committee to protect Iowa residents by recommending that the legislature allow for growing, processing, and dispensing of CBD so families can have safe and legal access to this treatment option. The Committee appeared to understand the concerns of epilepsy community and passed a motion in support of these steps. Read the comment letter and stay informed about the latest developments to ensure safe and meaningful access to CBD oil in Iowa by visiting the medical cannabis section of the Foundation's website at <http://bit.ly/EFAccessAdvocacy>.

**August 21, 2014**

### **Representative Perry Introduces Bill to Improve Access to CBD**

On July 28th Representative Scott Perry introduced the Charlotte's Web Medical Hemp Act of 2014 (H.R. 5226), which would remove therapeutic hemp from the Controlled Substances Act. This legislation would expand the availability of this treatment option and make extracting cannabidiol (CBD) oil legal at the federal level by allowing cannabis with less than .3% THC to be grown as therapeutic hemp.

About a third of people living with epilepsy suffer from uncontrolled seizures, despite available treatments, which can lead to disability, injury and even death. In states where medical cannabis is legal, many patients with epilepsy have reported beneficial effects from using CBD. This is why people living with uncontrolled seizures turn to medical cannabis when all other options have failed.

We were proud to be present at the introduction of the bill and will continue to work for the passage of this much needed legislation. You can read more about this bill at <http://bit.ly/EF5226>. Call your Representative and share your support at <http://bit.ly/5226Call>.

### **Disability Treaty Passes Out of Committee**

On July 22nd the Convention on the Rights of Persons with Disabilities (CRPD) passed out of the Senate Foreign Relations Committee, an important step towards ratification. The CRPD, the Americans with Disabilities Act, and embodies principles of equality, non-discrimination, full inclusion in society, accessibility, and respect for an individual's dignity. Ratification of the CRPD is important to all people with disabilities, and will help to ensure that people living with epilepsy or disabilities throughout the world can have the same rights as everyone else in order to live full, satisfying, and productive lives, and will allow the United States to maintain its position as a leader on disability rights. Please ask your Senator to vote for ratification at <http://bit.ly/CRPDAlert>.

### **Charitable Giving Incentives Pass House**

The House of Representatives passed legislation that would encourage charitable giving by allowing individuals over the age of 70 to donate up to \$100,000 directly from their IRA with tax benefits. This incentive has prompted more than \$140 million in gifts to non-profits since it was enacted in 2006. It was in part due to the advocacy of our community that this bill has passed the House, and we are now looking to the Senate to pass this tax incentive and help non-profits who depend on these contributions.

### **In the States**

#### **California Looks to Limit Cost Sharing**

The California legislature is considering legislation (AB 1917) that would limit cost-sharing in state commercial health insurance plans, including plans sold in the state's Health Insurance Marketplace. For persons living with chronic conditions, like epilepsy, this would improve access to lifesaving medications by making them more affordable. At the August 5th Senate Appropriations Committee hearing on AB 1917 the committee heard testimony from an epilepsy advocate who has struggled to maintain access to the medication his physician recommends. The bill passed out of committee, and we need your help to get it through the full Senate and to the

Governor's desk. If you live in California, please ask your Senator to support AB 1917 at <http://bit.ly/AB1917>.

**July 22, 2014**

### **Patient Groups Advocate to Improve Access to Care in Marketplace Plans**

The Epilepsy Foundation is among the patient groups leading the "I Am Essential" campaign to improve access to quality care in ACA Marketplace plans by addressing limited benefits, high cost-sharing, and lack of transparency that makes it hard for individuals, especially those living with chronic conditions, to receive the care they need. We are preparing a letter from patient and community organization urging the Department of Health and Human Services (HHS) to enforce the ACA non-discrimination provisions, prohibit restrictive formularies and inadequate provider networks; address high cost-sharing, including inappropriate use of coinsurance; and improve plan transparency so that consumers can make informed decisions. To view the letter, please go to <http://bit.ly/IAMEssential>.

### **Report Highlights Effects of Cuts to Public Health Programs**

On July 15<sup>th</sup>, the Coalition for Health Funding, a group of health organizations that advocates for increased funding for public health programs, held a briefing to unveil *Faces of Austerity: How Budget Cuts Hurt America's Health*, a report focused on the impact of budget cuts on public health programs. The report highlights more than 20 stories from across the country that show how sequestration and further budget cuts have impacted our public health. To learn more and read the report please go to <http://www.cutshurt.org/>.

### **Meet with Your Legislators in August**

Congress is preparing to leave Washington, DC in August and head back to their home districts to meet and work with constituents. August is a great opportunity to meet with your Members of Congress, and share your stories and the issues that are important to you. We encourage you to set up a meeting with the district offices during this time and urge your Representatives to support the *Improving Regulatory Transparency for New Medical Therapies Act* (H.R. 4299), bipartisan legislation that would end delays that keep new epilepsy drugs from entering the market.

Find out how to contact your Representative at <http://bit.ly/EFRepInfo>

Read more about H.R. 4299 and download a fact sheet you can print and bring to your district meeting at <http://bit.ly/DEAdelays>.

### **States**

#### **Pennsylvania Approves Funding for Epilepsy Programs**

On July 10<sup>th</sup>, Governor Tom Corbett signed the Pennsylvania budget which included \$550,000 for epilepsy programs administered by the two Pennsylvania affiliates, the Epilepsy Foundation of Eastern Pennsylvania and the Epilepsy Foundation of Western/Central Pennsylvania. Our affiliates advocates with the legislature and the Governor's office to maintain epilepsy funding, which will support training for school nurses and teachers, local support groups, information services, and other important programs for Pennsylvanians living with epilepsy.

## **Marijuana**

### **New York Becomes 23<sup>rd</sup> State to Approve Medical Cannabis**

On July 7<sup>th</sup>, Governor Andrew Cuomo held a signing ceremony for legislation (A 6357) that makes New York the 23<sup>rd</sup> state to approve a medical cannabis program. This new program, which may take up to 18 months to implement, will allow for the use of medical cannabis by New Yorkers with epilepsy and other debilitating conditions. If you live in New York please thank your legislator at <http://bit.ly/NYMMJThanks>.

### **Missouri Passes CBD Bill**

On July 13<sup>th</sup>, Governor Jay Nixon signed into law legislation (HB 2238) that will allow the use of cannabidiol (CBD) oil for those living with intractable epilepsy, with a recommendation from a neurologist.

### **North Carolina Approves Use and Research on CBD**

On July 3<sup>rd</sup>, Governor Pat McCrory signed into law legislation (HB 1220) that will allow the use of CBD oil for those living with intractable epilepsy, with a recommendation from a physician. It will also set up a research program to study the effects of CBD on seizures using hemp grown by North Carolina universities.

### **Illinois Expands Medical Cannabis Program to Include Epilepsy**

On July 20<sup>th</sup>, Governor Pat Quinn signed into law legislation (SB 2636) that will add epilepsy to the list of qualifying conditions for the state's medical cannabis program, and also expand access for minors living with epilepsy.

### **Texas Advocates Educate Lawmakers on Need for CBD Oil Legislation**

On June 23<sup>rd</sup> the Compassionate Access For Epilepsy (C.A.F.E.) Texas coalition held an educational presentation for members of the Dallas/Fort Worth legislative delegation. At the event, hosted by Representative Stephanie Klick and held in Grapevine, Texas, members of the Texas House of Representatives and Texas Senate and their staff heard from prominent speakers about CBD and epilepsy. Speakers included Paige Figi, the mother of Charlotte Figi, a child living with epilepsy and the focus of the CNN's Dr. Sanjay Gupta documentary Weeds 2; and Joel Stanley, the cultivator of Charlotte's Web, a strain of marijuana that has been shown to improve seizure control. Paige Figi and Joel Stanley, both with the Realm of Caring group in Colorado, are leading advocacy efforts in support of CBD oil legislation in other states. Dr. Scott Perry of Cook Children's Hospital and Donna Stahlhut, CEO for one of the Epilepsy Foundation affiliates in Texas, also spoke at the event. The presentation was well received and made an impact on those in attendance.

**June 18, 2014**

### **Congress Looks to Limit Restraint and Seclusion**

Congress is considering two bills that would protect all students from unnecessary restraint and seclusion. The Keeping All Students Safe Act (S. 2036, H.R. 1893) would ban the use of restraint and seclusion, except in emergency situations where there is the danger of physical harm to someone. The Civil Rights Data Collection report concluded that more than 110,000 students were subjected to restraint and seclusion in 2011-2012 and these techniques are used on students with disabilities at a higher rate than the rest of the student body. Please take a moment to urge your legislators to support S. 2036 and H.R. 1893 by taking action at <http://bit.ly/EFKSSA>.

## **Bring Back the IRA Charitable Incentive**

The House of Representatives is considering reinstating incentives that would encourage charitable giving by allowing individuals over the age of 70 to donate up to \$100,000 directly from their IRA with tax benefits. This incentive, which was allowed to expire in January, has prompted more than \$140 million in gifts to nonprofits since it was enacted in 2006s. Congress needs to hear from the epilepsy community that charitable gifts are vitally important for nonprofits like the Epilepsy Foundation because they allow us to provide services to thousands of individuals throughout the country. Please take a moment to contact your Representative at <http://bit.ly/IRADonation>.

## **In the States**

### **Ohio Exempts Schedule V Drugs From Monitoring**

On June 16<sup>th</sup> Ohio Governor John Kasich signed into law legislation that will exempt Schedule V drugs, including many anti-epilepsy drugs (AEDs), from the state's prescription drug monitoring program (HB 483). This bill. The Epilepsy Foundation urged the Ohio legislature to exempt Schedule V drugs from the monitoring program. The inclusion of Schedule V drugs in the monitoring program caused unnecessary delays and prevented timely access to physician-directed care. HB 483 removes unnecessary barriers to care for people living with epilepsy and other conditions treated by Schedule V medications. Read our letter to the Ohio legislature at <http://bit.ly/OHExempt>.

### **Pennsylvania Affiliates Look to Preserve State Funding**

The Epilepsy Foundation of Eastern Pennsylvania and the Epilepsy Foundation of Western/Central Pennsylvania are advocating to preserve state funding for epilepsy services like Project School Alert, training for school nurses and teachers, patient education conferences, local support groups, and first responder training. . Without state funding, these programs face cuts that would severely impact the epilepsy community of Pennsylvania. Currently, the state budget includes funding for epilepsy programs in the Department of Health budget, but that funding may be in jeopardy as the state government deals with revenue shortfalls. If you live in Pennsylvania please take a moment to contact your legislators and urge them to support the funding for epilepsy programs at <http://bit.ly/EFPAFunding>.

### **Pennsylvania Prescription Drug Monitoring Program**

The Pennsylvania Senate recently passed legislation (SB 1180) which would expand the state's prescription drug monitoring program to include Schedule V drugs and create an additional reporting burden for physicians who prescribe Schedule V drugs. These changes would cause unnecessary delays and prevent timely access to physician-directed care. We are urging the legislature to amend SB 1180 to include an exemption for Schedule V anti-epilepsy drugs (AEDs) similar to the one championed by Representative Adolph in the House version of the bill

(HB 1694). The reporting burden will negatively impact access to epilepsy care if physicians are reluctant to see epilepsy patients or to prescribe AEDs due to the burden of reporting and checking the database. Read our letter to Representative Adolph at <http://bit.ly/SB1180Adolph>.

### **Iowa Approves Increased Funding for Affiliate**

Iowa Governor Terry Branstad signed into law legislation (HF 2463) which increases funding for the Epilepsy Foundation of North/Central Illinois, Iowa, and Nebraska so they can expand their services into the eastern portion of Iowa. The increased funding will support training for first responders, medical professionals, and school personnel, as well as support and education programs for people living with epilepsy.

HF 2463 also funded the Home and Community Based Services (HCBS) waiver program to allow those living with disabilities to receive services in their home and community. These programs are especially important for individuals living with uncontrolled or intractable epilepsy who cannot drive and experience many transportation and mobility challenges. Read our letter to the Governor in support of HF 2463 at <http://bit.ly/EFHF2463>.

### **Marijuana**

#### **Representatives Blumenauer and Griffith Work to Reschedule Marijuana**

Representatives Blumenauer and Griffith have each introduced bills that would reschedule cannabis to a lower class and protect state medical marijuana programs. Moving cannabis to a lower schedule would make it easier to perform research on this promising treatment. Please take a moment to urge your Representative to support H.R. 689 at <http://bit.ly/EFHR689> and H.R. 4498 at <http://bit.ly/EFHR4498>.

#### **House Supports Amendment to Limit DOJ Interference**

The House of Representatives recently supported an amendment to the Department of Justice (DOJ) appropriations bill that would prevent the DOJ from interfering with state medical cannabis programs. This strong show of support for medical cannabis programs is an important step towards securing safe and legal access to this promising treatment option. We need to encourage the Senate to support the same protections for state medical cannabis programs. If your Senator is on the Appropriations Committee please take a moment to urge him or her to support this important protection at <http://bit.ly/DOJApprops>. To see if your Senator is on the appropriations committee, please go to <http://bit.ly/AppropsMembers>.

#### **Foundation Urges DEA to Reschedule Marijuana**

The Epilepsy Foundation is encouraging the Drug Enforcement Administration (DEA) to reschedule cannabis in order to make it easier to perform research on this important treatment option and its connection to epilepsy. Please take a moment to contact the DEA and urge them to allow for increased research on cannabis by rescheduling cannabis at <http://bit.ly/DEAResched>.

#### **Florida Passes CBD Bill**

On June 16<sup>th</sup> Florida Governor Rick Scott signed into law legislation (SB 1030) that allows those living with uncontrolled seizures to be prescribed cannabis that is high in cannabidiol (CBD) if other treatment options have failed.

### **South Carolina Allows CBD for Patients with Refractory Epilepsy**

On June 2<sup>nd</sup> South Carolina Governor Nikki Haley has signed into law legislation (S 1035) which will allow physicians to prescribe cannabis high in CBD to patients living with refractory epilepsy. The bill will also allow for Food and Drug Administration (FDA) approved clinical trials on CBD to take place in South Carolina.

### **Iowa Allows CBD Cannabis**

On May 30<sup>th</sup> Iowa Governor Terry Branstad signed into law legislation (SF 2360) that allows neurologists to provide a written recommendation for cannabis high in CBD to patients who live with intractable epilepsy if other treatment options have failed.

### **Illinois Adds Epilepsy as a Qualifying Medical Condition**

On May 21<sup>st</sup> the Illinois Legislature passed legislation (SB 2636) that would add epilepsy as a qualifying medical condition for the state's medical cannabis program. The bill would also allow patients under the age of 18 who live with intractable epilepsy to use cannabis as a treatment option. We are hopeful that Illinois Governor Quinn will sign the bill.

**May 19, 2014**

### **Legislation to End DEA Delays for New Epilepsy Drugs**

The *Improving Regulatory Transparency for New Medical Therapies Act* (H.R. 4299), bipartisan legislation introduced by Representatives Joe Pitts (PA) and Frank Pallone (NJ), would end delays that keep new epilepsy drugs from entering the market by requiring that new molecular entities be scheduled by Drug Enforcement Agency (DEA) within 45 days of Food and Drug Administration (FDA) approval. The bill would also improve the registration process for the use of controlled substances in clinical trials. The Epilepsy Foundation has been gathering Congressional support for H.R. 4299 but we need your help. Please contact your Representatives and them to support H.R. 4299 to improve access to new epilepsy medications at: <http://bit.ly/EFHR4299>.

### **Congress Urging HHS to Remove Barriers to Marijuana Research**

Representatives Blumenauer, Griffith, Rohrabacher, and Schakowsky, are circulating a letter with their Congressional colleagues urging the Secretary of the Department of Health and Human Services (HHS) to remove barriers for medical marijuana research. Studies on marijuana must go through extensive review processes beyond what is required for other Schedule I substances, making it harder for research into the connection between seizures and marijuana to take place. Ask your Representative to sign onto this letter and support greater access to research into marijuana at: <http://bit.ly/EFDearCol>.

### **Legislation to Incentivize Development of New Diagnostic Tools Signed Into Law**

The Epilepsy Foundation has been a leading advocate for the *MODDERN Cures Act* (H.R. 3116), legislation that would encourage the development of new drugs and diagnostic tools. A portion of the legislation dealing with diagnostic tests has been signed into law as a part of the *Protecting Access to Medicare Act of 2014* (PL 113-93), which creates incentives for innovative diagnostic tests by allowing changes in payment rates for diagnostics and assigning them a temporary code so health providers can begin using the test right away. Diagnostic tests can help determine what treatment options are best for a particular patient, and could help epilepsy specialist determine the best epilepsy treatment option faster, while reducing failed drug attempts.

### **SSA Reviewing Criteria for Evaluating Disability Claims from Epilepsy Patients**

The Epilepsy Foundation recently submitted comments to the Social Security Administration (SSA) on the proposed revised criteria for disability claims involving neurological disorders. We urged SSA to revise their definition of epilepsy in adults and children, as well as their rules for counting seizures.

We believe that SSA's definition of epilepsy for disability claims should also include simple partial seizures, refractory drop attacks, and refractory absence seizures because these seizures are just as disabling as generalized tonic-clonic or partial onset seizures. Furthermore, SSA's proposal to count multiple seizures within a 24-hour period as one seizure; and count status epilepticus as one seizure does not reflect the severity of these events and should be revised. We also believe that one seizure a month should be considered disabling as this frequency can prevent a person from driving a car. Without a license, people living with epilepsy, especially in rural parts of the country, cannot perform many daily activities. Read our comment letter at: <http://bit.ly/EFSSA>.

## **STATES**

### **Iowa Legislature Supports Increased Funding for Epilepsy and Improved Access to Medication**

The Epilepsy Foundation worked closely with the Epilepsy Foundation of North/Central Illinois, Iowa, & Nebraska to encourage legislators in Iowa to support increase funding for epilepsy programs and the Home and Community Based Services waiver, as well as streamline the prior authorization process, which would improve access to care for Iowa residents living with epilepsy. Legislation with that would increase funding for epilepsy services and streamline the prior authorization process (HF 2463) has passed both chambers and is now awaiting the Governor's signature. Increased funding would allow the Epilepsy Foundation of North/Central Illinois, Iowa, & Nebraska to expand their services in the eastern part of Iowa. The creation of a standardized prior authorization process and the requirement that insurance companies respond to all prior authorization requests within 72 hours will speed up and streamline the whole process and allow Iowa residents to access the medication they need in a safe and timely manner. Read our letter to the Governor urging him to sign the bill at: <http://bit.ly/EFHF2463>.

### **New York State Considering SUDEP Legislation**

The New York legislature is considering legislation (SB 6232 and AB 8444) which would require the medical certificate portion of a death certificate to include whether the deceased

suffered a sudden, unexpected death in epilepsy (SUDEP). Illinois and New Jersey already have passed similar SUDEP laws. Collecting SUDEP data is critical to improve our understanding of epilepsy related deaths and will allow us to discover risk factors and ways to prevent it. If you live in New York please urge your legislators to pass this important legislation at <http://bit.ly/EFNYSUDEP>.

### **Pennsylvania Drug Monitoring Program Would Limit Access to Epilepsy Medications**

The Epilepsy Foundation and our Pennsylvania affiliates, Epilepsy Foundation Eastern Pennsylvania and Epilepsy Foundation Western/Central Pennsylvania, have urged the Pennsylvania legislature to amend SB 1180 to exempt Schedule V anti-epilepsy drugs (AEDs) for the prescription drug monitoring program (PDMP). Currently, SB 1180 would expand the PDMP to cover all scheduled drugs, which can cause a delay in accessing AEDs for those living with epilepsy. Similar legislation in the House would exempt Schedule V AEDs from the drug monitoring program. Schedule V AEDs do not pose the risk for abuse that the PDMP aims to stop, and instead these requirements will be a significant barrier to access and may delay a patient from receiving proper medication, which can lead to breakthrough seizures or other serious consequences. Read the letter to the Pennsylvania Senate please at: <http://bit.ly/EFSB1180>.

### **Florida Legislature Supports Increased Funding for Epilepsy**

The Epilepsy Foundation and the Epilepsy Foundation of Florida are urging the Florida legislature to increase funding for Florida's Epilepsy Service Providers (FESP), a vital source of epilepsy support in the state Floridians living with epilepsy. The legislature understands the importance of these programs and has added additional funds for the FESP to the budget. If you live in Florida please thank your legislators and ask them to urge the Governor to sign the General Revenue Budget at: <http://bit.ly/EFFLGRB>.

### **Illinois Advocacy Day**

On May 16th the Epilepsy Foundation affiliates in Illinois held an advocacy day in Springfield where more than one hundred advocates came together to meet with their legislators. These epilepsy advocates urged legislators to support funding for important epilepsy programs throughout the state as well as adding epilepsy as a qualifying medical condition for the state's medical marijuana program.

### **Medical Marijuana Legislation in the States**

There has been a lot of movement in the states surrounding medical marijuana and cannabidiol (CBD) oil legislation. Below is an update on bills that have been signed into law, have passed the legislature and are awaiting the Governor's signature, or are still being debated.

- **Florida** passed a bill (SB 1030) that would allow those living with intractable epilepsy to access marijuana high in CBD. The Governor is expected to sign the bill.
- **Minnesota's** Senate passed a bill (SF 1641) that would allow those with epilepsy and other debilitating medical conditions to access medical marijuana from registered dispensaries. It is unsure if the Governor will sign the bill if it passes the House.

- **Pennsylvania's** Governor has recently changed his position on medical marijuana and now says he supports a limited program that will allow children with severe seizure conditions to access to CBD oil.
- **Iowa** has passed a bill (SF 2360) that would allow those living with intractable epilepsy to use CBD oil if it is recommended by their neurologist. The Governor has until the end of the month to sign the bill.
- **Missouri** has passed a bill (HB 2238) that would allow research on hemp, which is high in CBD, and will allow CBD extract to be used to treat certain individuals with epilepsy. It is unsure if the Governor will sign the bill.
- **New York** is considering legislation (A. 6357-A and S. 4406-A) that would allow residents living with epilepsy and uncontrolled seizures to gain access to medical marijuana if it is prescribed by a qualified physician. To urge your legislators to support this bill go to: <http://bit.ly/NYCCA>.
- **Mississippi's** Governor signed legislation (HB 1231) that will allow patients with epilepsy to access CBD oil from the University of Mississippi. The Governor signed the bill on April 17<sup>th</sup>.
- **Illinois** is considering a bill (SB 2636) that would add epilepsy to the list of qualifying medical conditions for its medical marijuana program. We have sent a letter thanking the House sponsor for his support and urging the House to support the bill. To see our letter please go to <http://bit.ly/EFSB2636>. If you live in Illinois please take a moment to contact your Representative and urge him or her to support this important bill at <http://bit.ly/ILMMJ>.

**April 17, 2014**

### **Sign the White House Petition on Medical Marijuana Research by April 19th**

The epilepsy community is calling on the President and the Drug Enforcement Administration (DEA) to reschedule marijuana to a lower level to make it easier for researchers to explore the connection between seizure control and medical marijuana. Sign the epilepsy petition today at <http://bit.ly/epilepsywhitehouse> and share it with family and friends!

### **Advocates Speak Up for Epilepsy Community on Capitol Hill**

Nearly 200 teens, parents, affiliates, and volunteers gathered in Washington, DC for the Epilepsy Foundation's annual Public Policy Institute and Teens Speak Up! (PPI/TSU) conference held March 23rd through 25th. Representatives from 30 states and 35 affiliates participated in a day and a half of learning and advocacy training that culminated with a snowy Hill day on March

25th. Conference attendees learned about the importance of raising awareness of the challenges of living with epilepsy with elected officials and heard from experts about the Foundation's policy priorities. Families and affiliates shared their personal stories and spoke up for the epilepsy community through almost 200 Congressional visits. TSU participants also made a year-long commitment to the Year of Service campaign, which calls on them to be advocates for epilepsy in their communities. Interested in participating in the Year of Service? Learn more at <http://bit.ly/YOS14>.

In the spirit of the conference, Liza Gundell, deputy director at the Epilepsy Foundation of New Jersey, was recognized with the Sara Stubblefield Advocacy Award for her leadership in advocating for the lives of the millions of Americans affected by epilepsy. To view pictures from this year's conference, go to <http://bit.ly/TSUPics>.

### **Legislation Would Reduce DEA Delays for New Treatments**

For the nearly three million people living with epilepsy, especially those living with uncontrolled seizures, new medications bring hope for improved quality of life. But delays in the scheduling process can mean waiting for months for Food and Drug Administration (FDA) therapies to become available for patients. On March 26th Representatives Joe Pitts (PA) and Frank Pallone (NJ) introduced the Improving Regulatory Transparency for New Medical Therapies Act (H.R. 4299), bipartisan legislation which would require that new molecular entities be scheduled by the Drug Enforcement Agency (DEA) within 45 days of FDA approval, and would improve the registration process for the use of controlled substances in clinical trials.

New therapies are approved by FDA with a scheduling recommendation and are not available to patients until they have been scheduled by the DEA. There is no known timeline for DEA scheduling after a drug has been approved by FDA, and the delay between FDA approval and DEA scheduling has increased nearly five-fold over the past 15 years. People living uncontrolled seizures or significant side effects to medication cannot afford to wait for bureaucratic delays and must gain timely access to FDA-approved, lifesaving medications. Urge your Representatives to support H.R. 4299 to improve access to new epilepsy medications at <http://bit.ly/EFHR4299>.

### **Funding for Epilepsy Centers of Excellence in Jeopardy**

Last year, the Epilepsy Centers of Excellence (ECoEs) received a \$2 million budget increase, bringing the total budget to \$8 million dollars. Last month, the ECoEs were told they would have to return the \$2 million, which would mean a halt to construction on a new center in San Antonio and other program cuts. The ECoEs have been a tremendous success since their inception, leading to improved epilepsy care, research, and education for our veterans, and estimated inpatient costs for veterans with epilepsy have dropped by more than \$14 million. Representative Perlmutter (CO) and other Congressional champions are speaking out on behalf of the ECoEs. Read the letter to the House Subcommittee on Military Construction and Veterans Affairs urging them to help resolve this issue so the Centers can continue to provide quality care

to veterans at <http://bit.ly/ECOEFund>. Ask your friends and family to sign up for Action Alerts at <http://bit.ly/Capwiz> to receive messages when the ECOEs' budget goes to committee.

## **In The States**

### **Advocacy Days in Pennsylvania and Minnesota**

On March 11th the Epilepsy Foundation affiliates in Pennsylvania hosted a legislative breakfast in the capitol rotunda to raise awareness about epilepsy with members of the Pennsylvania General Assembly. Following the breakfast, advocates visited all 253 offices of the Pennsylvania General Assembly to share their stories and urge the legislature to preserve funding in the state budget for epilepsy programs. Read more at <http://bit.ly/InTheStates>.

On March 4th more than 65 advocates from across the state participated in the Epilepsy Foundation of Minnesota's advocacy day in St. Paul. Advocates raised awareness about the challenges of living with epilepsy and urged the legislature to promote improved access to medical care, support programs to end discrimination and stigma, and Sudden Unexpected Death in Epilepsy (SUDEP) education.

### **Iowa May Streamline Prior Authorization**

The Iowa Senate is considering a Human Services Appropriations bill (HF 2436) which includes language that would standardize the prior authorization process and require insurance companies to respond to all prior authorization requests within 72 hours to improve access to care and health outcomes for Iowa residents living with epilepsy and other chronic conditions. The inclusion of this language comes on the heels of, a Prior Authorization Reform bill (HF 2376), which passed the House with overwhelming support but stalled in the Senate. The Iowa legislature will adjourn for the year soon and we need your help.

**If you live in Iowa ask your Senators to ensure people living with chronic conditions, including epilepsy, have access to medications in a safe and timely manner at <http://bit.ly/IAHF2436>.**

### **Pennsylvania To Restrict Access to Epilepsy Medications**

The Pennsylvania Senate is considering a bill (SB 1180) that would expand the state's prescription drug monitoring program (PDMP) to include all Schedule V drugs, including anti-epilepsy drugs (AEDs). The Epilepsy Foundation is concerned that including AEDs in the PDMP will lead to delays in access to epilepsy medication due to onerous monitoring requirements. The House passed a similar expansion bill that included an amendment to exclude Schedule V epilepsy medications from the monitoring program and we need your help to secure a similar amendment in the Senate.

**If you live in Pennsylvania ask you Senators to exempt all Schedule V AEDs from the monitoring requirements at <http://bit.ly/PASB1180>.**

### **Maryland May Limit Step Therapy**

Both chambers of the Maryland legislature passed a bill (SB 622) that would limit step therapy and “fail first” policies before adjourning for the year. The bill is awaiting the Governor’s signature. Step therapy can unnecessarily prolong ineffective treatment and limit access to appropriate medications for people with epilepsy jeopardizing seizure control and quality of life for people living with epilepsy.

### **Medical Marijuana Legislation in the States**

There has been a lot of movement in the states surrounding medical marijuana and cannabidiol (CBD) oil legislation. Below is an update on bills that have been signed into law, have passed the legislature and are awaiting the Governor’s signature, or are still being debated.

**Kentucky** passed a bill (SB 124) that will allow doctors at two university research hospitals to prescribe CBD oil. On April 10th the Governor signed the bill into law.

**Utah** passed a bill (HB 105) that will allow families to possess CBD oil so long as they have a state issued card. On March 20th the Governor signed the bill into law.

The **Mississippi** legislature overwhelmingly supported a bill (HB 1231) that would allow patients with epilepsy to access CBD oil from the University of Mississippi. The Governor has voiced concerns over legalizing medical marijuana, but we remain hopeful he will sign the bill.

The **Illinois** House is considering legislation that recently cleared the Senate (SB 2636) that would add CBD oil to the state’s medical marijuana program and allow patients under the age of 18 to access CBD oil (currently the medical marijuana program is limited individuals 18 and older, and epilepsy is not listed debilitating condition).

**Wisconsin** passed a bill (AB 726) that will allow individuals living with uncontrolled or intractable seizures to use CBD oil. On April 16<sup>th</sup> the Governor signed the bill into law.

**Maryland** passed medical marijuana bills (HB 881 and SB 923) that amend their current medical marijuana program, which hasn’t been fully implemented. The new program would allow licensed growers to provide marijuana to dispensaries, similar to many other programs throughout the country. On April 14th the Governor signed the bill into law.

The **Louisiana** legislature recently introduced a bill (SB 541) that would create a medical marijuana program in the state. The Epilepsy Foundation of Louisiana is advocating for expanding the program to include access for children with epilepsy and to explicitly include CBD oil. As currently written, SB 541 restricts access to medical marijuana to individuals 21 and

older. If you live in Louisiana, ask your State Senator to support the bill at <http://bit.ly/SB541LA>.

### **New Hampshire Expands Medicaid**

Last month Governor Maggie Hassan signed a bill that expanded Medicaid to provide health insurance to an estimated 50,000 low-income adults in a 2 and a half year pilot program that will pay private health insurers with federal Medicaid money. New Hampshire estimates that 12,000 adults could receive coverage within the next month through an existing program to subsidize employer-based coverage, while 38,000 adults would receive coverage through New Hampshire's Medicaid managed care program starting on or shortly after July 1st.

### **Epilepsy Foundation Supports Family's Housing Discrimination Case**

The Epilepsy Foundation recently signed onto an Amici Curiae brief in a case about alleged housing discrimination of a family with a child with epilepsy and on the autism spectrum. The case, Rodriguez, et al. v. Village Green Realty, et al., revolves around the Fair Housing Act, because the landlord refused to renew the family's lease to rent a home and told them that they should live closer to treatment facilities due to the child's epilepsy. Read the Amicus Brief at <http://bit.ly/HousingAmicus>.

**March 10, 2014**

### **Medicare Proposal Threatens Six Protected Classes**

The Centers for Medicare & Medicaid Services (CMS) issued a proposed rule that would make significant changes to Medicare Part D by removing three of the six protected classes. Anticonvulsants would remain a protected class, but we are deeply concerned by the move to restrict access to physician directed care for the most vulnerable Medicare beneficiaries.

Scaling back this lifesaving Medicare Part D policy would be devastating for many patients - and costly to our healthcare system. Therapies in the six protected drug classes are not interchangeable, and patients need access to the medication, or combination of medications, most effective in treating their conditions based on factors unique to the individual. Limiting access to the most appropriate medications will drive up costs by increasing the amount of people who need in-patient care and emergency department services due to the changes in their conditions. The six protected classes policy has enjoyed strong, bipartisan support since its inception in 2006 and House and Senate leaders sent several letters to CMS in the past few days opposing the change and affirming it is a critical mechanism for protecting the most vulnerable Medicare patients.

To view the Epilepsy Foundation's comments to CMS urging them to reconsider these changes and keep all six protected classes click [HERE](#).

**\*UPDATE:** Thanks in part to your Epilepsy advocacy, CMS has announced that they are rescinding the proposal to alter the protected classes! Read more [HERE](#)

### **President's Budget Kicks-Off Appropriations Season**

On March 4<sup>th</sup> President Obama released his \$3.9 trillion budget proposal for Fiscal Year (FY) 2015. The budget proposal marks the start of the appropriations season and serves as a guide into the Administration's funding priorities. Under the President's budget epilepsy programs at the Centers for Disease Control and Prevention would be funded at the same level as in FY 2014, a good sign for the epilepsy community. The Epilepsy Foundation and several Epilepsy Foundation affiliates signed onto a letter sent by the Coalition for Health Funding to the House and Senate Committees on Appropriations asking them to restore funding back to Fiscal Year (FY) 2010 levels for the Department of Labor, Health and Human Services (HHS), and Education. We will continue to advocate for sustained funding for epilepsy programs and research at the Centers for Disease Control and Prevention (CDC) and the National Institutes of Health (NIH) as Congress begins debating funding for FY 2015. To read the letter click [HERE](#).

### **Epilepsy Foundation Advocates for Access to Quality Care in ACA Marketplaces**

The Epilepsy Foundation recently submitted comments to the Centers for Medicare & Medicaid Services (CMS) urging them to strengthen formulary, network adequacy and patient protection requirements for health plans offered in the federally run marketplaces. We are concerned about limited formularies, prohibitive cost sharing, and restrictive policies like step therapy that make it hard for insured patients to access or afford their medically necessary prescription medications, as well as narrow provider networks that restrict access to physicians and specialists. We call on CMS to make it easier for individuals to view and compare plan benefits, so they can find out if their drugs and providers are covered, and to simplify and standardize the appeals process so they can gain timely access to quality care. To read our letter click [HERE](#).

### **FDA Expedited Review**

The Epilepsy Foundation joined 32 patient organizations in a letter thanking Congresswoman Rosa DeLauro for her support of biomedical research and affirming our support of accelerated approval programs at the Food and Drug Administration (FDA). These accelerated programs target promising, often lifesaving, drugs that address unmet medical needs. Patients with few or no treatment options are willing to accept the risk that goes along with the expedited timeline. This program brings hope to individuals living with uncontrolled or intractable seizures, and the devastating side effects from medications. To read the letter click [HERE](#).

### **IRS Rule on Political Activity Could Limit Advocacy by Patient Organizations**

The Internal Revenue Service (IRS) recently proposed a rule to more clearly define what is considered political activity by tax-exempt organizations. Unfortunately, the proposed definitions are too broad and threaten nonprofits who engage in nonpartisan political activities or who even mention a candidate's name in public materials close to Election Day. We welcome clarity on federal rules governing political activity by tax-exempt organizations, but fear that the proposed rule would seriously hamper the ability of charitable and social welfare organizations to participate in important public policy debates. The Epilepsy Foundation joined more than one hundred

organizations in a letter to the IRS urging the agency to preserve the nonprofit sector's critical advocacy role. To read the letter click [HERE](#).

### **Epilepsy Foundation Works to Preserve Orphan Drug Tax Credit**

The Epilepsy Foundation signed onto a letter from the National Organization for Rare Disorders (NORD) encouraging Congress to preserve the Orphan Drug Tax Credit (ODTC). The ODTC has been one of the most successful tax credits, allowing companies to claim a tax credit on a portion of research costs for orphan drugs (drugs that affect less than 200,000 Americans). This tax credit, as well as others, has led to the development of numerous new drugs and helped save thousands of lives. By removing this tax credit, further research and millions of lives would be put in jeopardy as companies cannot afford to continue research on these rare disorders. We will continue to work with Congress to preserve the ODTC and help further research to save lives.

### **Senator Harkin's Restraint and Seclusion Bill**

On February 24<sup>th</sup>, Senator Tom Harkin introduced the "Keeping All Students Safe Act," (S. 2036), legislation designed to protect all students nationwide from unnecessary restraint and seclusion. A Government Accountability Office study found that children were injured, traumatized, and even killed through restraint and seclusion in schools. The Civil Rights Data Collection found that restraint and seclusion are used at a higher rate upon students with disabilities. S. 2036 would ban these techniques except in emergency situations where there is the danger of physical harm to someone. It would also require that parents be informed if their child was restrained or secluded on the same day the event occurred. Please click [HERE](#) to contact your Senators and ask them to support S. 2036 and limit the use of restraint and seclusion in schools.

## **STATES**

### **Maryland Bill on Step Therapy**

The Maryland legislature is considering legislation (HB 1233/ SB 622) to limit "fail first" or step therapy practices and ensure people living with chronic conditions, including epilepsy, can have access to physician directed care in a safe and timely manner. Step therapy limits access to appropriate medications for someone with epilepsy, potentially causing a breakthrough seizure that can lead to serious injury or death. Maintaining seizure control with minimal side effects requires careful evaluation and monitoring by the physician and patient. HB 1233/SB 622 would implement recommendations from a report on step therapy recently released by the Maryland Health Care Commission, which includes grandfathering exemptions and requiring payors to incorporate step therapy approval and override processes in their automated preauthorization applications.

If you live in Maryland or know someone who does please click [HERE](#) to contact your Representatives and ask them to support access to medications for residents living with epilepsy and other chronic conditions.

### **Iowa Legislatures Supports Bill to Simplify Prior Authorization**

On March 5<sup>th</sup> the Iowa House unanimously approved a bill (HF 2376) to standardize the prior authorization process and form, and require insurance companies to respond to all prior authorization requests within 72 hours. This would ensure people living with chronic conditions, including epilepsy, can have access to physician directed care in a safe and timely manner.

People living with epilepsy who experience a delay in accessing their medication, or have their medications switched, due to onerous prior authorization requirements, are at higher risk for developing breakthrough seizures and related complications. Maintaining seizure control with minimal side effects requires careful evaluation and monitoring by the physician and patient. HF 2376 would shorten delays and allow individuals living with chronic conditions to avoid unnecessary interruptions in medication access.

Iowa advocates made their voice heard by sending messages in support of the hearing and floor vote on the bill. The bill now goes to the Senate, where a hearing will be scheduled for this week. Stay tuned for an alert in support of the bill in the coming days.

### **Connecticut Bill Would Allow Emergency Seizure Medications in Schools**

Representative Kim Fawcett recently introduced legislation that would allow trained, non-medical personnel to administer FDA approved emergency medication for seizures in schools. (HB 5303). The legislation would ensure children living with epilepsy have appropriate and timely access to lifesaving emergency seizure medication, and access to the full range of school and related experiences.

Many children with epilepsy who need access to emergency seizure medication have been denied access to school and related experiences, or are forced to live with unnecessary medical risks. . To read our letter in support of HB 5303 please click [HERE](#).

If you live in Connecticut, or know someone who does, please click [HERE](#) to contact your Representatives and ask them to ensure children living with epilepsy have appropriate and timely access to life saving emergency seizure medication and access to the full range of school and related experiences.

### **Medical Marijuana in the States**

On February 20<sup>th</sup> the Epilepsy Foundation released a statement in support of increased medical marijuana access and research. You can read the statement [HERE](#).

The Maryland legislature is considering legislation (SB 923) to set up a regulated medical marijuana program. To read our written testimony in support of SB 923 click [HERE](#).

Kentucky is considering legislation (SB 124) that would allow individuals living with uncontrolled or intractable seizures to use cannabidiol (CBD) oil as an epilepsy treatment. If you live in Kentucky, or know someone who does, please click [HERE](#) to contact your Senators and ask them to support SB 124.

**National Epilepsy Walk!** If you cannot join us in Washington, D.C. on Saturday, March 22<sup>nd</sup> please consider making a donation to our advocacy team for the 8<sup>th</sup> Annual Epilepsy Walk: <http://bit.ly/EFAdvocacyWalk>.

**February 4, 2014**

### **Congress Approves Funding Government Through Fall**

On January 17<sup>th</sup>, President Obama signed a bipartisan bill, the Consolidated Appropriations Act of 2014, which will fund the government for the remainder of Fiscal Year (FY) 2014 and increase funding for the Department of Health and Human Services (HHS). Funding for HHS remains too low, below FY 2010 levels, but passage of the bipartisan funding agreement will

ensure research and programs that benefit and support people living with epilepsy at the National Institutes of Health, the Centers for Disease Control and Prevention and in other agencies can continue through September of this year.

### **Epilepsy Foundation Urges Senate Leaders to Return to Disability Treaty Negotiations**

The Epilepsy Foundation has joined many in the disability community calling on the Senate Foreign Relations Committee to move forward on the bipartisan Convention on the Rights of Persons with Disabilities (CRPD). To read the letter sent by the Epilepsy Foundation of East Tennessee to Senator Corker, click [HERE](#).

### **Epilepsy Community Advocates for Access to Medication in ACA Marketplaces**

The Epilepsy Foundation is advocating for strong formularies and meaningful access to medications in the health insurance plans offered in the marketplaces established by the Affordable Care Act (ACA). In partnership with our affiliates across the country, we have reached out to state agencies that run and oversee the state run and federal partnership marketplaces to express our concern with limited formularies that restrict access to epilepsy medications. Current federal guidelines for setting up formularies in health insurance plans offered through the marketplace are not robust enough to ensure meaningful access to physician directed care in a timely manner. States can require plans with robust formularies that cover multiple drugs and do not rely on "fail first," prior authorization and high cost-sharing policies to limit access to care and discriminate against individuals based on a chronic condition. States can also require a transparent appeals process and pursue other measures to ensure that insured patients can access and afford medically necessary medications. To read one of the letters we've sent to state agencies on this issue, click [HERE](#).

### **Senators Express Support for Charitable Deductions That Fund America's Non-Profits**

As Congress considers tax reform, charitable deduction contributions, which fuels America's non-profits, could be in danger. The Epilepsy Foundation relies on generous contributions from the public to provide the education and services needed by millions of Americans impacted by epilepsy and seizures. Senators Thune and Wyden recently sent a letter signed by 31 fellow Senators to the Chairman and Ranking Member of the Senate Finance Committee. This letter urged the committee to preserve the charitable deduction, in an effort to prevent decreases in the quantity and quality of services from the nonprofit sector that are available for millions of Americans in need. Threats to the charitable deduction could potentially increase demand for government services, while costing jobs in the non-profit sector, which accounts for nearly 10 percent of America's work force. The Epilepsy Foundation sent a letter to the 33 Senators that signed on to the letter thanking them for their support of the charitable contribution. To read the letter, click [HERE](#).

## **STATES**

### **Colorado Affiliate Fights Discriminatory Proposal on Driver Licenses for People with Epilepsy**

The Colorado legislature is considering a bill (HB 14-1068) that would require a physician to report if a patient has epilepsy and seizures, so the state can immediately revoke the individual's driver's license. The proposal endangers the confidential nature of the relationship between patients and their physicians, and would lead epilepsy patients to withhold information from their physicians or even forgo medical care. It also reflects a poor understanding of epilepsy by the authors of the legislation. If you or someone you know lives in Colorado, please click [HERE](#) to send a letter to your local Representatives and urge them to oppose HB 14-1068.

### **Virginia Holds Awards Breakfast for Epilepsy Awareness Campaign**

On January 14<sup>th</sup>, the Virginia state legislators gathered for the annual Use a Helmet Prevent Epilepsy campaign awards breakfast to congratulate students from across the state who designed the winning posters for the awareness campaign. The event, organized by the Epilepsy Foundation of Virginia, was held at the General Assembly Building in Richmond. Virginia's Lieutenant Governor Ralph Northam, a pediatric neurologist, addressed the families and teachers in attendance. To see a picture of Lieutenant Governor Northam with all the awardees, click [HERE](#).

### **Help us Ensure Access to Medication in Ohio**

The Ohio legislature held a hearing today to consider changes to the state's monitoring program, which currently monitors Schedule V anti-epilepsy drugs (AEDs) and restricts samples provided by physicians. This endangers the health of epilepsy patients by creating unnecessary barriers to physician directed care, which is critical for achieving and maintaining seizure control. The Epilepsy Foundation and the two Ohio affiliates wrote a letter to State Representative Smith urging him to amend HB 341 to exempt AEDs from the prescription drug monitoring program and from sampling limits. To see the letter, click [HERE](#).

If you're an Ohio resident please [contact your Representative](#) today and ask them to exempt Schedule V drugs or, at a minimum, AEDs from the monitoring program, and to lift restrictions on samples provided by physicians. This exemption will improve and protect access to medications for individuals living with epilepsy in Ohio. To send an email to your Representative, please click [HERE](#).

### **FDA Funded Study on Generic and Brand Medication**

The Epilepsy Foundation has strongly supported FDA research and understanding of bioequivalence issues related to epilepsy medications and switching. You can support this ongoing research and take part in this national advocacy priority! Learn more about this topic and consider participation in research that can assist with our understanding of AEDs and potentially impact FDA policy.

Eligibility to participate includes:

- Controlled epilepsy
- Between age 18-55

- Be healthy, taking a stable dose of anti-epileptic therapy
- Not taking the drug Depakote® (divalproex sodium).

This is a study that provides compensation for time and travel. For more information: [https://www.vinceandassociates.com/includes/fda\\_epilepsy.pdf](https://www.vinceandassociates.com/includes/fda_epilepsy.pdf) or contact: 913-696-1601