

December 20, 2013

Two Year Budget Agreement Heads to President's Desk

The House and Senate have passed a two-year budget deal that will help avoid another government shutdown when the current continuing resolution runs out in mid January. The budget deal was worked out through a specially formed committee led by Representative Paul Ryan (R-WI) and Senator Patty Murray (D-WA), and is intended as a compromise by the two parties. This bipartisan agreement will replace \$63 billion of sequester cuts with new airline fees and cuts to some federal programs. Although the Epilepsy Foundation would have liked to see higher spending levels for National Institutes of Health and the Centers for Disease Control and Prevention, we are happy that Congress has passed the compromise legislation and that the effects of the sequester will be lessened. The Foundation is confident President Obama will sign the bill into law and we can look towards increased funding for epilepsy programs in the coming years.

Epilepsy Foundation Receives Funding from PCORI

On December 17 the Patient Centered Outcomes Research Institute (PCORI) announced the organizations that will receive funding as part of the Patient Powered Research Network (PPRN) funding opportunity. The Epilepsy Foundation was one of 18 groups chosen out of 61 applicants for the PPRN contract, which will focus on setting up the network for the rare epilepsies. The Foundation will partner with seven rare epilepsy organizations, the Dravet Syndrome Foundation/ICE, Hope for Hypothalamic Hamartomas, Aicardi Syndrome Foundation, Phelan-McDermid Syndrome Foundation, Tuberous Sclerosis Alliance, Dup15q Alliance, and the Lennox-Gastaut Syndrome Foundation, to gather data from patients living with rare epilepsies. We have already surveyed close to 900 patients, and hope to get up to 1,500 as we launch the network. The Epilepsy Foundation is confident that this research network will provide valuable insight into the lives of those living with rare epilepsies, and hopeful that these insights can lead to real and productive breakthroughs. To see our press release regarding the funding opportunity please click [HERE](#).

PCORI Announces Two New Advisory Panels

The Patient Centered Outcomes Research Institute (PCORI) has recently approved the formation of an advisory panel on [rare diseases](#) and one on [clinical trials](#). These panels will respectively focus on research and development regarding rare diseases and how best to run clinical trials. PCORI is looking for voices from the patient and caregiver community and we believe these panels would benefit from a voice out of the epilepsy community. [Please take a look at the application page and make sure to apply by January 10, 2014 if you are interested in being a part of either the rare disease or clinical trial advisory panels.](#) The panels are limited to between 10 and 15 members, and a limited number of seats are reserved for patients, caregivers and members of advocacy organizations.

The Epilepsy Foundation supports comparative effectiveness research with the belief that this research could support patient access and informed health care decision-making while fostering continued medical progress. For this reason, the Foundation was a strong supporter of the creation of PCORI as part of the Affordable Care Act. Please note on your application your connection to the Epilepsy Foundation and any other patient advocacy organizations that you have worked with on research or in a leadership role.

New Affordable Care Act Resources

The Epilepsy Foundation recently updated our [Access to Care & Treatments](#) page to help you better navigate the health insurance marketplace. The new page features a [checklist](#) that will help you compare different health plans as well as information on what to look for when comparing health plans, so that you can look beyond premiums and consider other factors important to epilepsy care, like a plan's formulary and specialist network. The Foundation will continue to update this page as we develop additional resources that will help you navigate the new health insurance marketplace.

Most Americans must have health insurance starting in 2014 or pay a penalty. For people living with epilepsy who've had a hard time securing affordable health insurance in the past due to pre-existing conditions, the health insurance marketplaces created by the Affordable Care Act make it possible to gain access to health insurance and may even qualify for government assistance to cover the cost of premiums. The deadline to sign up for coverage starting January 1st is December 23, 2013. The deadline to sign up for coverage and avoid the penalty is February 15, 2014 with coverage starting March 1st.

STATES

Texas Preserves Access to AEDs in Medicaid Program

On November 22nd the Texas Medicaid Pharmaceutical and Therapeutics (P&T) Committee reviewed the anticonvulsant drug class and decided not to make changes to the formulary, meaning they will not designate some anti-epilepsy drugs (AEDs) as non-preferred drugs, thus preserving access. There is always a possibility that the drug class may come up for review at a future date, but this is a victory for the epilepsy community in Texas. The P&T Committee heard from Epilepsy Foundation Central & South Texas staff and epileptologist Deborah Briggs, MD, about the need to preserve comprehensive access to AEDs so individuals living with epilepsy can maintain seizure control and avoid breakthrough seizures. The public testimony along with the letters submitted to the P&T Committee by the Foundation and other stakeholders expressing their concerns with restricting access for patients with epilepsy all contributed to the P&T Committee's decision to preserve access to epilepsy treatments in the Medicaid program.

Illinois Medicaid Program Exempts AEDs from Prior Authorization and Drug Limits

Earlier this year, Senator Dan Kotowski successfully championed legislation to exempt anti-epilepsy drugs (AEDs) from the state Medicaid program's four prescription drug limit created by the Specialized Mental Health Rehabilitation Act of 2013. On December 10th the Illinois Department of Healthcare and Family Services issued a notice clarifying that Medicaid will not require individuals with a diagnosis of epilepsy or seizure disorder to seek prior approval or Four Prescription Policy overrides when filling a prescription for an AED. Removing arbitrary barriers like prescription drug limits and prior authorization for AEDs will protect access to physician directed care for people living with epilepsy and help Illinois residents gain and maintain seizure control.

Legal Defense Newsletter is Out Now!

The winter edition of the Jeanne A. Carpenter Epilepsy Legal Defense Fund Newsletter is out and available to read. This edition profiles John T. Wagener, an attorney in our network who has fought diligently to help those living with epilepsy. Click [HERE](#) to read about him and other important news for the epilepsy community.

November 21, 2013

CRPD Hearing Highlights Support for Ratification

The Senate Foreign Relations Committee held two hearings on the Convention on the Rights of Persons with Disabilities (CRPD), an international disabilities treaty modeled after the Americans with Disabilities Act. These hearings are a big step towards moving the treaty towards ratification. Attendance by supporters of ratification was strong with overflow rooms set up for both hearings. Secretary John Kerry spoke at the second hearing and urged the committee to support the CRPD. Secretary Kerry noted that by ratifying the CRPD the United States will have more leverage to influence other nations to improve the rights of those living with disabilities. Testimony by other witnesses highlighted the benefits of ratification and stressed the need for the United States to reclaim its position as a world leader for disability rights.

Ask your Senators to support ratification of the CRPD by clicking [HERE](#).

Epilepsy Foundation Seeks Update to Medicare Guidelines for Prescription Drug Coverage

The Epilepsy Foundation submitted public comments to United States Pharmacopeia (USP) proposed update to the Medicare Model Guidelines. USP is charged by Congress with maintaining the Medicare Model Guidelines that guide formulary coverage in Medicare Part D plans, which provide access to prescription drugs for Medicare beneficiaries. Part D plans must cover at least two drugs in each USP class.

The Epilepsy Foundation asked USP to update the current classes under the Anticonvulsant category to reflect anti-epilepsy drugs' methods of action. Updates to the USP classes within the Anticonvulsant category would improve access to prescription medications to Medicare beneficiaries living with epilepsy by requiring Medicare Part D plans to cover a greater number of anti-epilepsy drugs. To read the letter please click [HERE](#).

Budget Conference Committee Discussing Budget Deal

As part of the agreement reached by Congress to end the recent government shutdown, a committee charged with exploring a budget deal before the current continuing resolution runs out was formed. The House and Senate budget committee has begun meeting to discuss proposals to reach an agreement on a Fiscal Year 2014 budget and avert sequestration cuts at least for the coming year. As the committee looks to address the impact of the sequester, Congress must remember that nondefense discretionary (NDD) programs have borne the brunt of sequestration cuts up until now, with defense programs scheduled to take a big cut this coming year. It may look like defense is being hit hardest, but only because up until now the sequester cuts have disproportionately impacted NDD programs, like the Centers for Disease Control and Prevention (CDC) and the National Institutes of Health (NIH). Ask your Members of Congress to replace the sequester with balanced cuts that do not disproportionately impact the programs that support the epilepsy community by clicking [HERE](#).

NeuroPace Therapy is Approved by FDA

NeuroPace© RNS© System received premarket approval from the Food and Drug Administration (FDA) earlier this month. The RNS System is an implantable device that uses neurostimulation to detect when a seizure is oncoming and then sends imperceptible levels of electrical stimulation to disrupt the impending seizure. The device is intended for patients who have not been able to reach an acceptable level of seizure control with drug combination therapy.

In a recent study 55 percent of patients who had the device for at least two years experience a 50 percent or greater reduction in seizures. Frank Fischer, NeuroPace CEO said that he believes “physicians will be able to make this breakthrough therapy available to eligible patients in the very near future.” To read more on the Neuropace RNS System please click [HERE](#).

Letter to State Insurance Commissioners About EHBs

The Epilepsy Foundation is working with our affiliates to write to state insurance commissioners about Essential Health Benefits (EHBs) in the new marketplace plans. We believe that the EHBs are not sufficient to ensure adequate access for many who will be purchasing a Qualified Health Plan (QHP). The federal government hasn’t provided satisfactory guidelines, and therefore it falls to state Insurance Commissioners to set up further rules. We are encouraging more robust prescription drug coverage as well as requirements to review new drugs within a set timeframe in order to determine if the drug should be included in the QHPs. We are also asking that the Commissioners establish limits on cost sharing for higher tier medications, among other recommendations. We are working closely with our affiliates to make sure our concerns are heard and recognized.

STATES

Wisconsin Holds Advocacy Day

The Epilepsy Foundation Heart of Wisconsin, together with the Epilepsy Foundation Western Wisconsin and the Epilepsy Foundation Southeast Wisconsin, held an epilepsy advocacy day on October 23rd, with the support of a grant from the Epilepsy Foundation. The event brought 55 advocates together in Madison, Wisconsin for a two day event where they received advocacy training the first day, and met with their state Senators and Representatives on the second day. Participants advocated for increased funding for epilepsy through the Wisconsin Department of Health Services; improved access to prescription drugs through changes to prior authorization and fail first practices; and requiring that medical examiners and coroners document history of seizure disorders or epilepsy on death certificates that involved an unexplained or premature death of a person with epilepsy.

New Hampshire Legislature Fails to Pass Medicaid Expansion

Governor Hassan had called a special legislative session for November 7th through the 21st to review the recommendations released on October 15th by a bipartisan commission charged with exploring how New Hampshire could expand Medicaid to low income individuals currently not eligible. Medicaid expansion would help tens of thousands of New Hampshire residents who need medical coverage, including people living with epilepsy. The Epilepsy Foundation had called on our grassroots supporters in New Hampshire to support expansion, but unfortunately Medicaid expansion barely failed this session. We will continue to monitor this issue for next

session. Please click [HERE](#) to urge your state representatives to expand Medicaid in New Hampshire next session!

State Medicaid Programs Review Coverage for AEDs

The Epilepsy Foundation Central & South Texas and the Epilepsy Foundation Texas – Houston/Dallas Fort Worth/West Texas wrote to the state's Health and Human Services Commission urging them to maintain access to all anti-epilepsy drugs (AEDs) in the Medicaid program. Allowing comprehensive access to AEDs helps to reduce costs for the Medicaid program individuals who achieve and maintain seizure control utilize emergency and urgent care resources less frequently. Furthermore, forcing patients to switch medications can result in breakthrough seizures and additional side effects, a result that is not beneficial to the patient or Medicaid program. The Pharmaceutical and Therapeutics Committee, which develops preferred drugs lists recommendations for the Commission, will meet on November 22nd to review AEDs in the Medicaid formulary. We are hopeful that they will stand with the epilepsy community and maintain access to a wide variety of epilepsy treatments. To read the letter please click [HERE](#).

Pennsylvania PDMP Bill Passes House with AED Exemption

The Pennsylvania legislature has been considering a bill (HB 1694) that would expand the prescription drug monitoring program to include Schedule V drugs, the schedule that contains the vast majority of antiepilepsy drugs (AEDs). Last Highlights from the Hill we asked all Pennsylvania residents to reach out to their state Representative and urge him or her to support an exemption for all Schedule V drugs, or at the very least AEDs. Thanks to everyone's advocacy efforts there is now an amendment that exempts all non-narcotic Schedule V AEDs, which means most AEDs are exempted. We are very happy with this amendment and so proud of the epilepsy community for stepping up and voicing their opinion. We will be watching this legislation as it heads to the Senate, so keep an eye out for more chances to advocate for access to AEDs!

New York Affiliates Go to Albany For Advocacy Day

Epilepsy advocates met in Albany, New York for a productive advocacy day as they met with several state senate and assembly offices. The four Epilepsy Foundation affiliates in New York organized this great day, with grant support from the Epilepsy Foundation, as they spread epilepsy awareness and urged support for S.D. 57, an important piece of step therapy legislation that the affiliates have been supporting. Advocates from the Epilepsy Foundation Long Island, Epilepsy Foundation Rochester/Syracuse/Binghamton, Epilepsy Foundation Northeastern New York, and Epilepsy Foundation Metropolitan New York also presented many offices with a petition that they have been circulating that has garnered over 300 signatures.

2014 Annual Walk for Epilepsy

The 2014 National Walk for Epilepsy is taking place Saturday March 22, 2014 in Washington, D.C. Last year almost 500 teams came together to raise awareness and funds to continue the fight to stop seizures, find a cure and overcome the challenges created by epilepsy. Click [HERE](#) to learn more and sign up!

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Healthcare Reform Resources

Next week the healthcare access page will be updated to a new layout and with more resources to help you navigate the Marketplace. Most importantly there will be a checklist that you can fill out for each plan you are considering. It will be an important tool for working through the plans that are out there. Keep an eye out on the [Access to Care & Treatments](#) page for the coming changes.

October 17, 2013

Government Shutdown Ends but Adequate Funding for Epilepsy Program Remains at Risk

The federal government reopened today after having been shut down since October 1st. This was the first government shutdown in 17 years, with the last one happening in 1995 and lasting for 22 days. During the shutdown Democrats and Republicans struggled over funding levels and House Republican leadership attempted to use the budget battle to defund and delay the Affordable Care Act (ACA) implementation, while the Senate Democratic leadership favored a continuing resolution that was limited to maintaining current funding levels. Increasingly the discussions also included addressing the need to raise the debt ceiling to avoid a default by the federal government. Congress reached a deal late last night that the House and Senate voted on as a compromise that funds the federal government through January 15, 2014, increases the debt limit until February 7th, and sets up a new budget committee to help figure out a long term deal.

The shutdown led to thousands of government workers being furloughed at federal agencies like the National Institutes of Health (NIH) and the Centers for Disease Control (CDC), which are responsible for programs and research vitally important to the American people, especially those living with chronic conditions like epilepsy. While all federal agencies have now reopened, we urge Congress to work diligently on a long term budget and avoid another shutdown, and will remain vigilant to make sure the research and programs so critical to the epilepsy community are preserved. Please click [HERE](#) to contact your Representatives and urge them to fund important epilepsy programs.

Health Insurance Marketplaces Created by the Affordable Care Act Open Up

The Health Insurance Marketplaces opened on October 1. People living with epilepsy and other pre-existing conditions who've had a hard time securing affordable health insurance can now purchase health insurance through the health insurance marketplaces, and may even qualify for government assistance to cover the cost of premiums. Everyone can access their state's Health Insurance Marketplace, whether it is run by the federal government or by their state. Each state also has officially designated Navigators, organizations with staff who can provide one-on-one help to individuals navigating the new health insurance marketplaces. Many states are also

expanding their Medicaid program starting in 2014. Learn more at www.healthcare.gov.

- [Get Covered: A one-page guide to the Health Insurance Marketplace](#)
- [What is the Marketplace in my state?](#)
- [How do I get help enrolling in the Marketplace?](#)
- [What if my state is not expanding Medicaid?](#)

EFA Comments on Proposed Changes to the Medicare Physician Fee Schedule

The Epilepsy Foundation submitted comments to the Centers for Medicare & Medicaid Services (CMS) about their proposed changes to the Physician Fee Schedule. While we applaud many of the proposed changes we are concerned with proposed cuts to the reimbursement of electroencephalogram (EEG) services. Such cuts would prove detrimental to the epilepsy community and those living with other neurological conditions as it may force patients to seek EEG services in a hospital setting, establishing a barrier for those who cannot easily access a hospital. The Foundation also joined other patient advocacy organizations of the Regulatory Education and Advocacy for Patients (REAP) Coalition in detailed comment on a wide range of issues covered in the proposed rule. You can view the Foundation's comment letter by clicking [HERE](#), and view the REAP's comment letter by clicking [HERE](#).

EFA Advocates for Transparency on Out-of-Pocket Costs for Health Plans in the Exchanges

The Affordable Care Act requires each health insurance marketplace to establish an electronic calculator to determine the actual cost of coverage in health insurance plans offered through the marketplace, known as qualified health plans (QHPs).

The Epilepsy Foundation believes individuals need access to a tool that assists in the calculation of expected out-of-pocket costs across an entire plan year to adequately compare costs across available QHPs. A similar tool is available for Medicare beneficiaries shopping for Medicare Advantage plans, which allows a beneficiary to calculate the approximate cost of coverage for a person with a health status similar to their own.

The Epilepsy Foundation recently joined other groups in a letter requesting that the Department of Health and Human Services (HHS) more actively pursue an out of pocket calculator tool in the health insurance marketplaces so individuals and families with chronic conditions and disabilities have the information they need to choose the right plan for them and their family. Click [HERE](#) to view the letter sent to HHS.

Legislation to Modernize the Drug Development Process Reintroduced

A bipartisan group of Representatives recently introduced the MODDERN Cures Act (H.R. 3116), legislation that would accelerate the search for treatment options by removing barriers that limit medical innovation and by encouraging the development of new treatments and diagnostic tools that can improve, prolong, and, ultimately, save lives.

The Epilepsy Foundation supports policies that create a pathway for hope for the 20 to 30 percent of people living with epilepsy who experience intractable or uncontrolled seizures or have significant adverse effects to medication. The legislation would encourage innovative treatments for smaller patient populations by establishing a “dormant therapies” group for treatments that have limited patent protection but could address an unmet need. These “dormant therapies” would hold 15 years of data exclusivity once approved by the FDA allowing companies to work on drugs that may take significant time to develop without the fear that their work would not be patented when out on the market.

Contact your Representatives and encourage them to support a pathway for hope, especially for those individuals living with epilepsy who currently don't have an effective treatment, by clicking [HERE](#).

EFA Advocates for Improved Access to Specialty Drugs in Medicare and Commercial Health Plans

A bipartisan group of Senators and Representatives recently introduced the Part D Beneficiary Appeals Fairness Act (S. 1365 and H.R. 2827), legislation that would allow Medicare Part D beneficiaries to request lower co-pays for high-cost specialty drugs used to treat chronic illnesses and conditions.

Prescription benefit plans can shift high-cost medications to a specialty category, jeopardizing access to treatment for Medicare Part D beneficiaries who must pay a larger share of the drug's cost. Many medications that cost more than \$600 are often placed by insurers on specialty tiers that require patients to pay from 25 to 33 percent of the drug's total cost, instead of a flat copayment rate. Currently, Medicare Part D beneficiaries are prohibited from seeking exemptions that could lower their cost-share for specialty drugs – despite the exemption process being available in other areas of the Medicare program.

People living with epilepsy rely on consistent access to affordable prescription medications to maintain their seizures under control. Limiting access to medications can lead to life-threatening health complications that include breakthrough seizures and injury, emergency room visits, hospitalization or other types of costly medical interventions. Medications for epilepsy are not interchangeable and treatment decisions must be individualized, which is why meaningful access to all available treatment options is so important. Please urge your Representatives to support S. 1365 and H.R. 2827 by clicking [HERE](#).

The Epilepsy Foundation also joined many other patient and community groups in a letter to the Department of Health and Human Services' Office of Civil Rights (OCR), requesting that they look into specialty tiers as a discriminatory tool when evaluating health plans. The letter is a response to a Request for Information by OCR as they draft regulations to implement the nondiscrimination requirements of the Affordable Care Act. You can view the letter by clicking [HERE](#).

Changes to the Combined Federal Campaign on Hold for Now

Earlier this summer the Office of Personnel Management (OPM) proposed a series of changes to the Combined Federal Campaign (CFC), including moving from small localized campaigns to more centralized programs, instituting an application fee for charities who wish to participate, and only allowing electronic donations. These changes would dramatically alter the program and jeopardize millions of funds raised through CFC each year by making it harder for individuals to donate. In August many of you contacted your representatives and asked them to encourage OPM to refrain from making these changes to the CFC that could lead to a loss of millions of dollars in donations to local and national charities that rely on CFC funds. Our voices joined those of many others in the non-profit world, and on July 10th, the House of Representatives held a hearing with OPM and questioned the agency regarding the proposed changes to the CFC. The hearing highlighted the need for careful consideration to the consequences of any proposed CFC changes and OPM has agreed to form focus groups with CFC stakeholders, which would help advise on future changes. Despite no firm commitments by OPM, we believe there will be no major changes to CFC for now, but we must continue to be vigilant and encourage the agency to be transparent and receptive to the non-profit organizations that rely on CFC funds for many of the services they provide to their communities. Thank you for making your voice heard and reaching out to Congress in support of CFC.

In the States

Pennsylvania: As part of a growing trend towards the creation and expansion of drug monitoring programs, the Pennsylvania House of Representatives is considering legislation to expand the state's prescription drug monitoring program to include Schedules II-V, including anti-epilepsy drugs (AEDs) (HB 1694). Drug monitoring programs have been established in many states, including Pennsylvania, to address prescription drug abuse by closely monitoring and restricting access to medications with abuse potential (scheduled drugs). The planned expansion may have the unintended consequence of limiting access to AEDs and could negatively impact the health and privacy of those living with epilepsy in Pennsylvania. The Epilepsy Foundation and our two Pennsylvania affiliates, Epilepsy Foundation Eastern Pennsylvania and Epilepsy Foundation Western/Central Pennsylvania, have reached out to state legislators to express concern over the proposed expansion and have asked the legislature to consider an amendment that exempts all Schedule V drugs, or at the very least AEDs, as well as exempting samples from reporting requirements.

The legislature received nearly 70 letters from people living with epilepsy who were concerned about the negative impact of the proposed changes on access to medication and has postponed bringing HB 1694 to the floor for now. As the Epilepsy Foundation continues to advocate with House leaders for an amendment to exempt Schedule V drugs we need your support. If you're a Pennsylvania resident please click [HERE](#) contact your state legislators and ask them to support an amendment that exempts Schedule V medications and AEDs from the proposed expansion of the prescription drug monitoring program to preserve and protect access to medications and privacy for individuals living with epilepsy in Pennsylvania. To see the letters sent by the Epilepsy Foundation to House leaders please click [HERE](#).

District of Columbia: The City Council of the District of Columbia is considering legislation to create a prescription drug monitoring program that would include Schedule V drugs, including anti-epilepsy drugs (AEDs) (B20-0127). Drug monitoring programs have been established in nearby Maryland and Virginia and across the country. The planned expansion may have the unintended consequence of limiting access to AEDs and could negatively impact the health and privacy of those living with epilepsy in the District.

Epilepsy Foundation reached out to the D.C. Council and its Committee on Health to express its concern with B20-0127, particularly the sampling limit. We are also concerned with potential barriers to physician directed care and an unnecessary administrative burden that may jeopardize patient privacy. We have asked the D.C. Council to exempt all Schedule V drugs from the program as well as exempting samples from the reporting requirements.

As with prescription drug monitoring programs in Pennsylvania other states, the Epilepsy Foundation strongly believes that monitoring programs that create burdensome reporting and access barriers for Schedule V medications, which do not pose the risks for abuse posed by Schedules II-IV, are unnecessary. AEDs have no documented history of abuse by people living with epilepsy when used for the treatment of epilepsy to achieve seizure control. To see the letter sent by the Epilepsy Foundation to the District's Committee on Health please click [HERE](#).

September 18, 2013

Federal Budget

Congress returned from their August and Labor Day recess and the Fiscal Year 2014 appropriations bills and other fiscal issues remain unresolved-- including the debate over raising the debt ceiling and the sequester. The Epilepsy Foundation is on the hill advocating for preserving epilepsy research and program funding that is vital to our community. While the Obama administration says it does not plan to cut spending for a raise in the debt ceiling, some House Republicans have expressed a desire to couple a raise in the debt ceiling with cuts to initiatives created and funded by the Affordable Care Act, continued cuts to public health funding, as well as potential changes to programs like Social Security, Medicaid and Medicare.

The Epilepsy Foundation will continue to monitor the appropriations process and advocate for policies that preserve programs and services vital for the epilepsy community. We have joined in nonpartisan health funding outreach and education on the hill. Your voice is vital to these efforts. Share your story about epilepsy to support our outreach on NIH funding and CDC programs www.capwiz.com/efa.

Drug Enforcement Administration

The Epilepsy Foundation submitted a [letter](#) to the Drug Enforcement Administration (DEA) calling on the agency to change its policies regarding new drug approvals. After the Food and Drug Administration (FDA) approves a drug for use, the DEA must then evaluate the drug and label it with the controlled substance schedule. The DEA's evaluation process has not been made public and the time it takes to complete can vary significantly. These delays negatively impact the epilepsy community as they must wait for DEA approval before gaining access to

drugs approved by the FDA. **Every second they wait is another second some must live with intractable or uncontrolled seizures.**

To read more about our letter to the FDA or to send a message yourself please click [HERE](#).
Food and Drug Administration

The Epilepsy Foundation has sent a [letter to the FDA](#) requesting that the FDA hold a public hearing or stakeholder meeting focused on epilepsy. The Epilepsy Foundation would like to bring the epilepsy community to the FDA for a one day event that would focus on a public hearing where patients, clinicians, and caregivers can share their views on epilepsy, unmet needs, research, and areas for the FDA to improve its policies. We believe that this could make great progress to ensuring that the agency not only understands our patients' needs, risk tolerance, and the impact on their quality of life from pharmaceutical treatments to medical devices.

Generic Drug User Fee Amendment

The Food and Drug Administration (FDA) held a public meeting regarding priorities for generic drugs for FY2014. **The Foundation submitted [comments](#) on the topic and were very pleased that anti-epilepsy drugs (AEDs) were one of the most frequently mentioned topics received by the FDA!**

We commend the FDA for its inclusion of epilepsy research as a priority for FY2014 GDUFA research. With this move, the FDA will continue to look into bioequivalence for AEDs as well as looking into pharmacokinetic studies and evaluations. We are very excited that epilepsy remains a priority and look forward to the results of the work done to be done by the FDA in the coming year.

In the States

New Jersey: Governor Chris Christie was the first in the nation to sign into law a bill requiring medical examiners to look into Sudden Unexpected Death in Epilepsy (SUDEP) as a cause of death. Medical examiners will be required to inquire into a history of epilepsy and then ask the family of the deceased if the medical findings and records can be submitted to a SUDEP registry for research on the cause of SUDEP.

SUDEP is the most common cause of death in epilepsy, yet goes underreported or unacknowledged. With laws like this we can raise awareness for SUDEP and work towards finding a cause and a cure.

New Jersey also made a regulatory change to their driver's licensing law. Now a person must be seizure free for six months before they can qualify for a driver's license, down from the year long period that it was before. Dr. Marcelo Lancman of the Northeast Regional Epilepsy Group met with the Department of Motor Vehicles and state representatives to urge them to make this change. This change will help take some of the burden off of many of the residents of New Jersey who live with well controlled epilepsy.

Governor Christie also signed into law S2353, extending the term of the Epilepsy Task Force by another year. The task force was formed to “develop recommendations to educate public and health professionals about screening, diagnosis and treatment of epilepsy and its complications.” The task force has been important in its first two years, and we are happy to hear that it will continue for another year and help those living with epilepsy in New Jersey.

New Jersey also passed an amendment to their medical marijuana program allowing minors with specific conditions, including epilepsy, to use medical marijuana in an edible form. These minors must have the permission of a physician, psychiatrist, and their parents before medical marijuana is an option. While there has been some anecdotal evidence about medical marijuana helping treat certain forms of epilepsy, we believe more studies are needed to prove the impact of marijuana as a treatment. The Epilepsy Foundation urges anyone exploring epilepsy treatments, as permitted under their state law, to work with their treating physician to make the best decisions for their own care. To read more about medical marijuana and the Epilepsy Foundation’s stance please click [HERE](#).

Illinois: Last month Illinois Governor Pat Quinn signed the *Danny Stanton SUDEP Act* into law. This new law, the second in the nation after New Jersey, requires medical examiners and coroners to look into a history of epilepsy and seizures as part of a standard autopsy. If they conclude Sudden Unexpected Death in Epilepsy to be the cause of death, they must report it to a national registry. We look forward to seeing other states follow the example set by New Jersey and Illinois.

Florida: The Epilepsy Foundation of Florida (EFOF) has been awarded a Navigator grant from the Department of Health and Human Services (HHS). A Navigator grant establishes the EFOF as an important resource for those looking to find the right plan for them in the new Health Insurance Marketplace this fall in Florida. Navigators will receive extensive training and be held under strict rules regarding privacy of information for their clients. The EFOF will be invaluable in Florida as citizens begin to work through the new marketplace. We congratulate the EFOF and know that they will be very successful.

August 2, 2013

Legislative Session Alert

The House and Senate will be in recess for the month of August and will not be holding any votes. We encourage you to contact the regional office of your representative and attend events your representative is holding. If you need to find the contact information please click [HERE](#).

CRPD

On July 26 we celebrated the 23rd anniversary of the Americans with Disabilities Act (ADA). Passage of the ADA helped secure essential rights for those living with disabilities in the United States. As we celebrate the 23rd anniversary of the ADA we continue to urge Congress to hold a vote on the Convention on the Rights of Persons with Disabilities (CRPD). The CRPD is a vital framework for creating legislation and policies around the world that embrace the rights and

dignity of all people with disabilities, and Ratification of the CRPD would allow the United States to continue to be a leader in disability rights.

The CRPD is consistent with U.S. laws and was modeled after the ADA, with principles that include equality, non-discrimination, full inclusion in society, accessibility, and respect for an individual's dignity. The CRPD aims to ensure that countries across the globe provide for people with disabilities the same rights as everyone else in order to live full, satisfying and productive lives. The President signed the treaty on July 30, 2009 but it must be ratified by the Senate by a two thirds majority for the United States to become a legal party to the treaty under international law.

Click [here](#) to call your Senators and urge them to have the CRPD scheduled for a vote! Make sure they know how important it is and encourage them to support ratification.

Generic Drug User Fee Amendments Comments

The Epilepsy Foundation provided comments to the Food & Drug Administration (FDA) on the Generic Drug User Fee Amendments of 2012 and its regulatory research science plan related to bioequivalence and epilepsy drugs. For many people living with epilepsy maintaining access to physician-directed care is critical for maintaining seizures controlled. For some individuals forced to switch medications, from brand to generic, or between generics, the change leads to a return of uncontrolled seizures and the associated complications and health care costs.

The Epilepsy Foundation has joined with the FDA, the National Institutes of Health (NIH), and the American Epilepsy Society (AES) to collaborate on research that can help address safety, efficacy, and quality concerns on generic substitution of anti-epilepsy drugs (AEDs). The Foundation's comments focused on the need for pharmacokinetic studies and evaluation of anti-epilepsy drugs to remain on the agency's GDUFA Regulatory Science Plan as a priority for 2014.

Read more at www.efa.org/advocacy

Changes to the CFC

The Combined Federal Campaign (CFC) is the world's largest employee workplace giving campaign, and has raised over \$7 billion for thousands of charitable organizations since its inception in 1961. These donations are unrestricted funds that have helped charities, like the Epilepsy Foundation, leverage billions of dollars in additional funds at the local level. Despite the CFC's successful past, the Office of Personnel Management (OPM) has proposed a series of changes would do significant damage to the CFC and will result in the loss of millions of dollars in donations every year.

These changes include instituting a nonrefundable application fee that imposes an unfair administrative burden on charitable organizations; creating regional organizations to run the CFC, which would remove the local organizations now doing this job and causing federal employees to lose their sense of ownership; and moving towards an overreliance on technology and fundraising methods that have not been thoroughly vetted. These changes to the CFC will lead to a loss of millions of dollars as employees lose interest and find it more difficult to donate to the campaign. Please help the Epilepsy Foundation, as well as the thousands of other organizations participating in the CFC, and ask your Representatives to encourage the OPM to shelve these changes by clicking [here](#).

In The States

Texas

Texas recently passed legislation creating a standard prior authorization form for prescription drugs and services for health insurers in the state (SB 644). The prior authorization form will match federal standards and insurers will be required to respond to all requests within two days, after which the request is considered automatically granted. This is a great step towards improving access to treatment for all Texans, especially those living with epilepsy and other chronic conditions.

Texas also passed legislation that made changes to the state's Medicaid program (HB 595 and SB 7) that aims to remove barriers to treatment and improve the quality of care. HB 595 establishes a single formulary that applies to all Medicaid providers in the state and eliminates the need to go through prior authorization again when switching Medicaid plans. SB 7 implements a variety of measures to curb costs in the Medicaid program. Some of the changes are positive for patients, including changes to the reimbursement for physicians and other health providers under Medicaid and CHIP to align payments with patient outcomes rather than quantity of services.

June 26, 2013

Legislative Session Alert:

The House and Senate will be in session Monday through Friday throughout the month of June and July, but will take June 29-July 7 off for constituent work. Be aware that the House has an adjusted schedule during this time, and they will not be holding votes on alternating Mondays and Fridays starting Friday, June 7th. Please focus your advocacy efforts during this time and make your voice heard!

CRPD Alert

Last congress, a bipartisan group of lawmakers, including Senators Kerry (MA), McCain (AZ), Durbin (IL), Barasso (WY), Harkin (IA), Udall (NM), Moran (KS) and Coons (DE) played a leadership role in moving the Convention on the Rights of Persons with Disabilities (CRPD) treaty to the senate floor with the support of the disability community. The treaty received YES votes from sixty-one Senators, sadly just six votes short of the two-thirds majority required for ratification.

The CRPD is consistent with U.S. laws such as the Americans with Disabilities Act (ADA), with principles that include equality, non-discrimination, full inclusion in society, accessibility, and respect for an individual's dignity. The CRPD aims to ensure that countries across the globe provide for people with disabilities the same rights as everyone else in order to live full, satisfying and productive lives. The President signed the treaty on July 30, 2009 but it must be ratified by the Senate for the United States to become a legal party to the treaty under international law.

While the Epilepsy Foundation was greatly saddened by the treaty's defeat, we are encouraged by the bipartisan support it received among the 61 Yeas. Disappointed, but not deterred, we are confident that the CRPD will be reintroduced during the 113th Congress with your help! Please take a moment to call your senators and ask them to stand up for the disability community both

here and abroad, by reintroducing and ratifying the CRPD! To get more information and talking points for calling your senators please click [here](#).

Changes to CFC

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These changes include instituting a nonrefundable application fee that imposes an unfair administrative burden on charitable organizations; creating regional organizations to run the CFC, which would remove the local organizations now doing this job and causing federal employees to lose their sense of ownership; and moving towards an overreliance on technology and fundraising methods that have not been thoroughly vetted. These changes will cause millions of dollars to be lost from the CFC as employees lose interest and find it more difficult to donate to the campaign. Please help the Epilepsy Foundation, as well as the thousands of other organizations participating in the CFC, and ask your representatives to encourage the OPM to shelve these changes by clicking [here](#).

Federal funding allocations

The Republican controlled House Appropriations Committee has put forward their proposed fiscal year (FY) 2014 302(b) allocation for the Labor-HHS-Education Appropriations bill, and it entails dangerous cuts that the epilepsy community cannot afford. This proposal is 22.2% below FY 2013 levels and even 18.6% below sequester levels, making it the largest of all proposed cuts by the House Appropriations Committee.

These cuts will result in increases in disease and sickness, halting critical biomedical research, as well as impacting job training and education. If these cuts are taken evenly across all Labor, HHS, and Education programs the Centers for Disease Control and Prevention would lose over \$1 billion, the Health resources and Services Administration would also lose over \$1 billion, and the National Institutes for Health would lose \$5.38 billion. Such cuts would be devastating to already underfunded epilepsy programs.

While the Department of Labor, HHS, and Education is threatened with funding levels not seen since 2001, the Defense Department, Homeland Security, and the Legislative branch are being funded at levels above those imposed by the sequester. We must urge the Committee to reject the proposed 302(b) allocations. Instead of almost quadrupling the sequester cuts to these critical programs that serve Americans of all ages every day, the Congress must enact a bipartisan balanced deficit reduction plan that replaces the sequester cuts.

Please take a moment to urge your Representatives to stand with the epilepsy community, and the health community as a whole, and oppose these allocations by filling out the form [here](#).

Brain Initiative

The American Brain Coalition held a Congressional Neuroscience Caucus Briefing that discussed the Brain Research through Advancing Innovative Neurotechnologies (BRAIN) Initiative. The purpose of the BRAIN Initiative is to work on a public-private partnership that aims to revolutionize our understanding of the brain and provide new tools to treat, prevent, and even cure brain disorders.

At the briefing Dr. Francis Collins, Director of the National Institutes of Health, and Dr. Story Landis, Director of the National Institute for Neurological Disorders and Stroke, spoke about the importance of the BRAIN Initiative and outlined the near future for the program. The NIH BRAIN Working Group will seek broad input and will deliver a final report, complete with timetables and expected milestones, in June of 2014.

Dr. Landis also spoke about the potential that the BRAIN Initiative has for helping to treat a variety of brain disorders. This promising initiative will hopefully yield great results for the epilepsy community as we work ever closer to a cure.

In the States:

Illinois: The Illinois Senate has passed the Medicaid Expansion bill, and it now heads to Governor Quinn who has promised to sign it. When signed into law this bill will give Medicaid coverage to hundreds of thousands of Illinois residents to whom it has previously been unavailable. Health care for these new enrollees will help bring \$4.6 billion to the state as the federal government covers their healthcare costs and reduces the burden on the state.

As well as expanding coverage, the bill also exempts anti-convulsants used to treat epilepsy from the four prescription drug limit imposed by the SMART Act. Many people living with epilepsy must take multiple different prescriptions in order to control their seizures, so by exempting these drugs we allow them to access the most effective treatment for them while still maintaining an affordable cost. The Medicaid Expansion bill is a great step forward for the state of Illinois as well as those fighting for access to care. Now those living with epilepsy in Illinois will better be able to afford medication to control their seizures.

Ohio: The Pharmacy & Therapeutics Committee in Ohio is considering changes to the Medicaid formulary and a restructure of the list of “preferred drugs.” These changes would require that patients fail twice on preferred drugs before gaining access to a physician prescribed, non-preferred drug, seriously hampering a patient’s ability to get the right medication maintain seizure control .

The Epilepsy Foundation and its Ohio affiliates submitted letters to the Pharmacy & Therapeutics Committee urging them to reconsider the proposed changes to the formulary. Step therapy and fail-first policies have been shown to be ineffective at saving money. Keep your eyes open for further developments on this issue.

District of Columbia: The Council of the District of Columbia is considering legislation (B20-0127) that would institute a Prescription Drug Monitoring Program. While the Epilepsy

Foundation appreciates the need to address prescription drug abuse, we are concerned that the plan would negatively impact those living with epilepsy in the District. We are asking the council to amend the legislation to exempt all Schedule V drugs from monitoring or at least to exempt anti-epilepsy medications prescribed to individuals living with epilepsy.

Schedule V drugs carry the minimum risk of abuse of any schedule of drugs and there is no reason to believe epilepsy patients are abusing their anti-epilepsy medication, thus no need for monitoring programs that may compromise access to medication as well as patient privacy. If you live in the District of Columbia, or if you know someone who does, please encourage the Council to amend the legislation and protect access to medication and the privacy of those living with epilepsy.

May 13, 2013

Annual Policy Conference and Hill Day Brings Together Families Living with Epilepsy:

The Epilepsy Foundation's annual Public Policy Institute and Kids Speak Up! conference was held April 21st through 23rd in Washington, DC. Representatives from 28 states and 35 affiliates participated in the conference and Hill day, which brought together 154 teens, parents, affiliates and volunteers for a day and a half of learning and advocacy training that culminated with a Hill day on April 23rd. Families and affiliates shared their personal stories and advocated in support of the Epilepsy Foundation's legislative goals through more than 170 Congressional meetings.

The families who attended this year's Public Policy Institute and Kids Speak Up! conference learned about the importance of speaking up to raise awareness of the challenges of living with epilepsy, and were also inspired by hearing from individuals who are living with epilepsy, including Tony Coelho, a former Member of Congress and the lead author of the Americans With Disabilities Act; Mighty Mike Simmel of the Harlem Wizards; and Chanda Gunn, Team USA's goaltender at the 2006 Winter Olympics. The families understand how each of us can take a role in educating policymakers at all levels about our needs and now return home ready to be epilepsy advocates in their communities. The Foundation will work with families, affiliates and volunteers over the course of the next year to do more to share information on living with epilepsy and how to be seizure smart. [Click here](#) to learn more about this year's conference and view pictures from the Hill day.

Sequester and Budgets for FY 2014:

On Wednesday, April 10, President Barack Obama introduced to Congress a \$3.8 trillion federal budget plan for Fiscal Year 2014. The budget provides \$80 billion in discretionary funding for the Department of Health and Human Services (HHS), which is \$3.9 billion above the level enacted in 2012. Highlights from the HHS budget include \$31 billion for the National Institutes of Health, with \$1.6 million for National Institute of Neurological Disorders and Stroke (NINDS) and \$100 million for the Brain Research through Advancing Innovative Neurotechnologies (BRAIN) Initiative; \$11 billion for the Centers for Disease Control and Prevention (CDC); and \$ 9 billion for the Health Resources and Services Administration (HRSA).

The President's budget serves as a blueprint for the administration's funding priorities, and now lawmakers, especially those who serve in the House and Senate appropriations committees, are

working on funding levels for the agencies. Representative Ed Perlmutter (CO-7) urged the Labor, Health and Human Services, Education and Related Agencies Subcommittee of the House Appropriations Committee to support federal funding for several programs important to the epilepsy community in a letter to the Committee's leadership on April 22. [Click here](#) to view the letter.

Representative Perlmutter's request reflects the Epilepsy Foundation's support for \$3.7 million for the Health Resources and Services Administrations' Project Access and \$12.8 million for the CDC's epilepsy programs in support of Healthy People 2020 goals. Both programs work closely with people living with epilepsy and health professionals caring for individuals with seizure related conditions. In 2012 the Epilepsy Foundation, through a cooperative agreement with the CDC, provide direct education and/or training to 10,000 veterans, 8,500 school personnel, 660,000 first responders, and 208, 000 students. Continued funding for epilepsy programs at HRSA and CDC is critical to the epilepsy community. This is the message epilepsy advocates brought to the Hill and highlighted while sharing their personal stories about living with epilepsy. [Click here](#) to learn more about the Epilepsy Foundation funding priorities (<http://www.epilepsyfoundation.org/getinvolved/advocacy/positionstatements/index.cfm>)

MODERN Cures Act: Support for the MODERN Cures Act as a pathway to hope was one of the key messages epilepsy advocates brought to the Hill on April 23rd. The MODERN Cures Act would accelerate the search for treatment options and encourage the development of new treatments and diagnostic tools that can improve, prolong and ultimately save lives. The changes to drug development proposed by the MODERN Cures Act shows great promise in helping those living with uncontrolled seizures or those with epilepsy syndromes like infantile spasms, Lennox-Gastaut syndrome, or Rasmussen's encephalitis, all rare conditions that begin in childhood. [Click here](#) to learn more about MODERN Cures.

Convention on the Rights of Persons with Disabilities: Epilepsy advocates that participated in this year's Hill day spoke with Senators and their staff about the need for reintroduction and ratification of the Convention on the Rights of Persons with Disabilities (CRPD) this Congress. Advocates emphasized the need for the U.S. to continue to be a leader in promoting and protecting disability rights and why the treaty is important for the epilepsy community. Many organizations representing the disability community, led by the U.S. International Council of Disabilities (USICD), continue to advocate for ratification of CRPD by addressing concerns about provisions in the treaty, providing education on why the treaty is important to the American disability community and urging Senators to reintroduce the CRPD this Congress.

Affordable Care Act Out of Pocket Costs: The Department of Labor has issued a set of Frequently Asked Questions (FAQ) and their answers regarding the Affordable Care Act (ACA), and in this FAQ they state that certain group plans will have a total out of pocket limit that is twice the amount of other plans for the year 2014. This grace period could increase out of pocket costs for those with chronic conditions to around \$12,000, a burden that is simply impossible for some families to bear. For this reason the Epilepsy Foundation has added our signature to a letter by the National Health Council asking the Department of Labor to revise this grace period and to treat all group plans the same. To see the letter we signed onto [click here](#).

In the States:

Illinois: On April 23rd legislation to improve awareness and gather research concerning sudden unexpected deaths in epilepsy (SUDEP) passed the State Senate. The measure, introduced by State Senator Dan Kotowski (D-Park Ridge), would create a national model to further SUDEP research by providing accurate data to a national SUDEP registry. SUDEP is the most common cause of death from epilepsy and accounts for an estimated 20,000 of deaths in people with epilepsy every year.

Michigan: For people living with epilepsy, being without health care coverage can impact their seizure control, endanger their health, and risk their employment. The Governor's proposals to expand Medicaid coverage in Michigan for families making less than 138 percent of the federal poverty level would help people with epilepsy and others who are working at one or more part-time or minimum wage jobs that do not offer health insurance. Please help vulnerable state residents with your support of the Medicaid expansion. If you are a Michigan resident please urge your legislators to support Medicaid expansion to help the many low-income individuals living with epilepsy by filling out the form at the following link:

<http://capwiz.com/efa/issues/alert/?alertid=62606121>.

Florida: Funding for Florida's Epilepsy Service Providers (FESP) was in jeopardy during this legislative session because it was not included in the Governor's budget. However, the Florida Senate and House have included funding for FESP in their budgets. Thank you to the many advocates who reached out to their legislators in support of funding for epilepsy programs in Florida!

Washington: Thanks to the work of advocates and the tireless effort of the Epilepsy Foundation Northwest the epilepsy community has secured another great advocacy victory. On May 8, Gov. Jay Inslee signed a bill into law that allows for the administration of emergency medication in schools. This legislation allows designated and trained employees who are not school nurses to administer necessary medication to students.

SHB 1541 passed both houses of the legislature unanimously in March and April and is a great reflection of the important advocacy work the Epilepsy Foundation Northwest has been doing as well as the impact many of our epilepsy advocates have made by speaking up. You can show your support for this legislative victory by taking action on the Epilepsy Foundation's page <http://capwiz.com/efa/issues/alert/?alertid=62656981>.

April 9th, 2013

BRAIN Initiative: The Epilepsy Foundation is excited about the new research initiative recently proposed by the White House— the new BRAIN (Brain Research through Advancing Innovative Neurotechnologies) Initiative being run by the National Institutes of Health (NIH). The goal of BRAIN, as announced by President Obama, is to "help researchers find new ways to treat, cure, and even prevent brain disorders, such as Alzheimer's disease, epilepsy, and traumatic brain injury." The initiative – launched with approximately \$100 million in the President's Fiscal

Year 2014 Budget – calls upon the private and scientific community to form partnerships to further this research. The White House Office of Science and Technology Policy (OSTP) also announced a goal last week to "work with all relevant stakeholders to consider how incentives could hasten the development of new prevention and treatment options for neurological diseases and disorders, and to recommend options for such incentives."

The Epilepsy Foundation has been a continued champion of the NIH, and supports funding for a cure and better treatments for epilepsy. Each year the government spends \$30 billion on medical research at the National Institutes of Health. Yet just ½ of 1% is spent on epilepsy. Funding is needed to make progress against epilepsy and improve health outcomes. As the 2012 Institute of Medicine report *Epilepsy Across the Spectrum* noted, epilepsy is the 4th most prevalent neurological disorder, yet "gets less funding than the other neurological disorders when adjusted for prevalence." The BRAIN initiative is an important step to increase that investment in neurological and epilepsy research, and we believe it is a promising program that will greatly help the epilepsy community.

Sequester and Budgets for FY 2014: President Obama signed HR 933, completing appropriations work for the year and keeping the automatic spending cuts caused by the sequester in place. These cuts will force federal agencies to make spending reductions by September 30th, the end of the fiscal year. Overall the federal government's operating expenses will be reduced by \$59 billion dollars.

These cuts pose a real threat to Nondefense Discretionary (NDD) programs, including the epilepsy community. The Department of Health and Human Services will see a \$4 billion cut, giving it a budget \$6.1 billion below FY 2010. Cuts such as these will make providing service to those who need it much more difficult in the coming year, but the Epilepsy Foundation will do everything it can to make sure we continue to help those living with epilepsy as we have in the past.

Now lawmakers are looking at budgets for FY 2014, and the first step in the budget process begins with the House and Senate appropriations committee. The Epilepsy Foundation supports a funding level of \$3.7 million for the Health Resources and Services Administrations' Project Access and \$12.8 million for the CDC's Health People 2020. Both programs work closely with people living with epilepsy and health personnel who handle seizure related conditions. Last year, due to a cooperative agreement between the CDC and the Epilepsy Foundation we were able to provide direct education and/or training to 10,000 veterans, 8,500 school personnel, 660,000 first responders, and 208, 000 students. Without this continued funding we put the epilepsy community at risk.

To contact your representative and let them know you support these two great programs click on the following link and send them an email: <http://capwiz.com/efa/issues/alert/?alertid=62558536>

Traumatic Brain Injury Reauthorization Act: Representatives Bill Pascrell, Jr. (NJ) and Thomas J. Rooney (FL) have introduced the Traumatic Brain Injury Reauthorization Act of 2013 (H.R. 1098) to continue with advocacy and support efforts surrounding traumatic brain injuries (TBI). Congress first passed a TBI bill in 1996, and these efforts remain as important as ever as

1.5 million Americans experience a TBI every year. H.R. 1098 would allow the 21 states and provinces currently developing TBI support structures to continue this important work in conjunction with the Health Resources and Services Administration.

TBI is also strongly related to epilepsy as studies have shown that 25-50 percent of TBIs develop into epilepsy within 3-5 years. Now 5.3 million Americans live with a long term medical condition including epilepsy, as a result of TBIs. With further research we can hopefully figure out the reason certain TBIs develop into epilepsy or other conditions and work to prevent this from happening. To read more about the Epilepsy Foundation's efforts to raise awareness for these veterans click [HERE](#).

Urge your Representative to support H.R. 1098 today! Click on the link below and send an email to your members of Congress. <http://capwiz.com/efa/issues/alert/?alertid=62540021>

MODERNN Cures Act: The MODERNN Cures Act would encourage innovation by opening up patent pathways for unused or expiring patents that show promise of treating medical conditions that have limited to no treatment options. The Epilepsy Foundation supports the reintroduction MODERNN Cures Act as it shows great promise to help those living with uncontrolled seizures or those with epilepsy syndromes like infantile spasms, Lennox-Gastaut syndrome, or Rasmussen's encephalitis, all rare conditions that begin in childhood. The MODERNN Cures Act also works to increase the amount of diagnostic data that is collected so that we can better predict how certain patients will react to drug treatments and which drugs may be most effective. To read more about Epilepsy and the MODERNN Cures Act see our [position statement](#) from the past session of Congress.

Watch a video from BioCentury about MODERNN Cures Act with Myrl Weinberg, President of the National Health Council at:
<http://www.biocenturytv.com/player/2229685559001/2231455514001>

FDA Looks at NeuroPace RNS© System: Epilepsy Foundation President and CEO Phil Gattone and Board Member Warren Lammert encouraged the FDA to approve the NeuroPace RNS© System as a new treatment for epilepsy. The RNS System is an implant under the skin of the skull that delivers short electrical pulses intended to interrupt the triggers that cause epileptic seizures.

The system has proven to be effective in lowering the rate of seizures by 37.9% in a 3-month evaluation period when turned on. Such a promising treatment would be the first epilepsy treatment device to be approved in the last 15 years. Such a break since the last approval is unacceptable to the Epilepsy Foundation as there are too many people who must live with uncontrolled seizures.

Read the full news article [HERE](#) and the testimony of [Warren Lammert](#) and [Phil Gattone](#).

Convention on the Rights of Persons with Disabilities: The Convention on the Rights of Persons with Disabilities (CRPD) was signed by President Obama in 2009 and aims to protect those living with disabilities throughout the world. The CRPD is consistent with U.S. laws such

as the Americans with Disabilities Act, with principles that include equality, non-discrimination, full inclusion in society, accessibility, and respect for every individual's dignity.

While 10 percent of the world's population lives with a disability, including epilepsy, the United States must continue to be a leader in fighting for the rights of the disabled. Disappointingly, the treaty was sadly not ratified during the last session of Congress, falling just six votes short of the necessary two-thirds majority. The Epilepsy Foundation is still encouraged by the bipartisan support that the treaty received, including Senators John Kerry and John McCain. We are confident that the CRPD will be reintroduced during the 113th Congress, as Senators McCain and Reid have already stated their intentions to reintroduce the treaty. The Epilepsy Foundation will continue to support the reintroduction and ratification of the Convention on the Rights of Persons with Disabilities. You can view the Senate voting record on the treaty here: <http://capwiz.com/efa/issues/votes/?votenum=205&chamber=S&congress=1122>

In the States:

Florida: Despite threats to the budget and potential cuts of up to \$7.5 million dollars in state funding for epilepsy programs, lawmakers have sided with the epilepsy community and advanced budget proposals that will keep the funding intact. Florida's Epilepsy Service Providers (FESP) advocated for the continuation of funding, to prevent a devastating impact on many people living with epilepsy.

The Epilepsy Foundation viewed this cuts to be harmful and potentially costly as those no longer be covered would end up costing the state much more in the overall health care costs through more frequent emergency room visits. This could have cost the state roughly \$13,450 per person instead of the \$891 that it costs for clients in the network. To read more about this decision go to: <http://politics.heraldtribune.com/2013/03/27/lawmakers-back-7-5-million-epilepsy-program/>. Join us in thanking your lawmakers for standing with the epilepsy community, and urge them to finalize this support by taking action here: <http://capwiz.com/efa/issues/alert/?alertid=62367481>.

Maryland: The Maryland House is considering HB1015, with a sister bill in the Senate (SB746), which would limit the duration of fail first protocol and allow for override procedures by physicians. Fail first, or step therapy, procedures are measures taken to restrict costs, that can be dangerous to patients. By forcing patients to go through a series of less costly medications until they reach a medication that works and disregarding physician directed care recommendations, these measures can prolong the period of time before a person gets seizure control, disrupt the seizure freedom they had, and could have negative health consequences. This increases the danger for many people who have epilepsy as they must complete these lengthy procedures before obtaining access to their physician directed therapy.

Fail-first procedures also lead to additional issues for those attempting to get the correct medication. **According to key studies, limiting access to treatment options for epilepsy does NOT reduce overall healthcare costs.** The Epilepsy Foundation strongly supports these bills as

we believe they will allow for more effective and appropriate treatment for those with epilepsy or other medical conditions. **Click on the link below to let your representatives know that you support HB1015 and SB746:** <http://capwiz.com/efa/issues/alert/?alertid=62438021>

Massachusetts: Massachusetts is considering amendments to the Controlled Substances Act, which in its current form would establish a Prescription Monitoring Program (PMP). The goal of the program is to prevent prescription drug abuse by checking patient prescription history and informing prescribers before additional prescriptions can be written.

Programs like this are necessary and laudable in order to limit prescription drug abuse, but the inclusion of anti-epilepsy drugs (AEDs) is a real danger to those living with epilepsy. Such programs can cause interruptions in medication regimens as patients switch doctors or as young adults move on from pediatricians and children's hospitals. These breaks can be incredibly dangerous and even life threatening as a break in medication can bring about a series of seizures.

AEDs and other Schedule V drugs should not be included in the PMP due to the low risk of abuse and addiction, and the Epilepsy Foundation has encouraged Massachusetts to exempt these drugs from PMP regulations. To read the Epilepsy Foundation's letter to the Massachusetts Department of Public Health click [HERE](#).

Texas: Representative Zerwas introduced HB 1032, with a companion bill in the Senate (SB 644). These bills would create a standard prior approval form to be used by many health insurance carriers in the state. This two page form would streamline what is now a complicated and time consuming process and ensure that people with epilepsy and other medical have efficient access to care and treatments. These bills will also reduce the administrative burden on healthcare providers so more time can be spent on patient care. HB 1032 and SB 644 further encourage health care carriers to increase their efficiency in this area as any prior authorization request is assumed to be approved if two business days pass without action. **Click on the link below to tell the Governor and your representatives that you support this bill:** <http://capwiz.com/efa/issues/alert/?alertid=62442346>

Washington: The Washington State Legislature is currently considering **Substitute House Bill 1541**, this legislation would allow designated and trained employees who are not school nurses to administer necessary medication to students. The Epilepsy Foundation supports this bill because we know how critical access to emergency medication can be for safety and peace of mind in school settings. SHB 1541 includes requirement for simple safety training and it eliminates any criminal or civil liability in the event of student injury or death, provided that all instructions are followed. This is an important inclusion for school personnel. **Click on the link below to tell the Governor and your representatives that you support this bill:** <http://capwiz.com/efa/issues/alert/?alertid=62515306>

February 22, 2013

Effects of Appropriations on Nondefense Discretionary Spending: As Congress faces the debt ceiling, fiscal year 2013 spending bills, sequestration, and the fiscal year 2014 budget, March 1st will bring about a series of automatic cuts - called a sequester - if Congress cannot agree to a debt deal. These cuts are poised to disproportionately harm the Nondefense Discretionary (NDD) programs; including health funding that serves epilepsy research and programs.

The Epilepsy Foundation joined over 3200 groups in calling on Congress to maintain a **balanced approach to deficit reduction that does not include further cuts to discretionary programs**. The approach to deficit reduction has thus far been unbalanced. Discretionary programs have contributed \$1.5 *trillion* in spending cuts from the Fiscal Year 2011 Continuing Resolution, the bipartisan Budget Control Act, and the bipartisan American Taxpayer Relief Act, while revenues have contributed just \$600 billion. The US Department of Health & Human Services in FY 13 will see a \$4 billion cut from nondefense discretionary (NIH, CDC, HRSA, SAMHSA, etc). This is \$6.1 billion below FY 2010 levels. Including mandatory cuts, HHS will lose \$16 billion. Read our coalition letter [here](#) and stay active in our [Speak Up Speak Out network](#) to receive action alerts related to funding and the budget.

Epilepsy Foundation Responds to Affordable Care Act (ACA) Rules: The Epilepsy Foundation sent comments to HHS Secretary Kathleen Sebelius in response to proposed rules on the ACA and coverage of essential health benefits. This is the core package of items and services that most health insurance plans must cover starting in 2014; and is often referred to as the essential health benefits. The essential health benefits consists of ten categories: ambulatory patient services; emergency services; hospitalization; maternity and newborn care; mental health and substance use disorder services, including behavioral health treatment; prescription drugs; rehabilitative and habilitative services and devices; laboratory services; preventive and wellness services and chronic disease management; and pediatric services, including oral and vision care.

The Epilepsy Foundation believes that expanded care and benefits that will be provided through the ACA are critically important for the millions living with epilepsy. To fulfill this promise, the Foundation urges HHS to research and clearly address, in policy, the numerous hurdles and restrictions that come with chronic disorders like epilepsy within health care insurance systems. You can read our comments and find out more [here](#).

Within the Medicaid program, the Foundation joined a joint letter to urge the Secretary Sebelius to guarantee that the needs of Medicaid patients are met and that benefits and services are meaningful and affordable. You can read this joint letter [here](#)

ADA Compliance Key Message of Comments on Wellness Programs: The Epilepsy Foundation joined national disability groups on comments to the Department of Labor on proposed rules implementing the ACA's provisions concerning non-discrimination in workplace wellness programs. While the proposed rules included some protections for consumers in workplace wellness programs, the groups called for a clear requirement that wellness programs must comply with the Americans with Disabilities Act. The groups recognize the potential of wellness programs to discriminate against individuals with disabilities, particularly with the use of financial incentives and penalties tied to health status that jeopardize employee's access to

affordable, quality health care. More information and a joint letter signed by the Epilepsy Foundation is available [here](#).

Accessing VA Benefits Eased by Proposed Amendments: The Epilepsy Foundation praised the Department of Veterans Affairs (VA) for its [proposal](#) to add “unprovoked seizures following moderate or severe Traumatic Brain Injury (TBI)” as one of the five diagnosable illnesses as secondary conditions to service connected TBI to its adjudication rules relating to veteran’s access to disability benefits, treatment services and other relief. The amendment is based on evidence-based research findings supported by the Institute of Medicine (IOM) report (December 2008), “Gulf War and Health, Volume 7: Long –Term Consequences of TBI,” and its conclusion that sufficient evidence of a causal relationship exists between moderate or severe levels of TBI and diagnosed unprovoked seizures. The Epilepsy Foundation noted the proposal will also help further the goals of the VA Epilepsy Centers of Excellence that provide specialized assessment and treatment services for military service members and veterans with TBI and epilepsy, and advance innovative research on prevention and treatment of epilepsy after TBI.

In the States

Arkansas: The Arkansas legislature is considering a bill that would undermine the relationship between physicians and their patients by allowing pharmacists to substitute a completely different medication without prior authorization of the physician. To permit these substitutions at the pharmacy counter undermines the treatment decisions made between patient and physician based on the patient's individual medical needs and life circumstances. HB 1185 would put the health of those with epilepsy at risk by allowing pharmacists to substitute a completely different medication in a drug class without physician approval. Many epilepsy patients must take multiple medications to keep their symptoms under control, and the balancing of these prescriptions takes an intimate knowledge of the patient and the interactions between all of the active ingredients. Allowing these substitutions without the input of the patient’s physician could seriously endanger the life of a person living with epilepsy. If you live in Arkansas, or have family and friends there, please take a moment today to share this link to oppose this bill: <http://capwiz.com/efa/issues/alert/?alertid=62428301>

New Jersey: Advocates in the state and the Epilepsy Foundation are working to support training for medical examiners about sudden unexpected death in epilepsy (SUDEP) and encouraging the medical information and the brain donation of the deceased for further research about SUDEP. SUDEP is the most common cause of epilepsy-related death. SUDEP may be underreported for many reasons, including unawareness among medical examiners and those filling out death certificates, coupled with the misconception that seizures cannot have fatal consequences. With better data on those who die and identification of risk factors for SUDEP, progress can be made to diminish the danger of SUDEP. **Join the Epilepsy Foundation in asking New Jersey to help promote awareness, education and prevention of SUDEP. Read more here:** <http://capwiz.com/efa/issues/bills/?bill=62407226>

New Mexico: Most health care plans use tiers or levels as a pricing structure for prescription drug benefits. New Mexicans are currently subject to health rules that allow plans to move brand

name medications from a lower tier to a higher tier at any time during the contract year. People with epilepsy and co-occurring medical conditions may need access to drugs that are covered in a tier called the "specialty tier" and cost increases for medications at this level can be substantial. Unexpected increases in prescription drug prices can endanger patient adherence to their physician directed care and medication treatments, this can be detrimental to their health.

For those in New Mexico: Help support SB 156 to secure much needed protections that guarantee the terms of prescription drug converge will remain constant during the contract year. <http://capwiz.com/efa/issues/bills/?bill=62405476>