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 15th, 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 10th, 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 23rd State to Approve Medical Cannabis
On July 7th, Governor Andrew Cuomo held a signing ceremony for legislation (A 6357) that makes New York the 23rd 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 13th, 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 3rd, 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 20th, 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 23rd 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](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](http://bit.ly/IRADonation).

**In the States**

**Ohio Exempts Schedule V Drugs From Monitoring**

On June 16th 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](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, 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](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](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 Bases 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](http://bit.ly/EFHF2463).

Marijuana

Representatives Blumenauer and Griffith Work to Reschedule Marijuana


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

**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](http://bit.ly/DEAResched).

**Florida Passes CBD Bill**

On June 16th 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 2nd 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 30th 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 21st 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](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](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 17th.

- **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.

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. One April 16th 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](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](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 as 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 4th 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 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 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 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 24th, 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 5th 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 20th 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.


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**February 4, 2014**

**Congress Approves Funding Government Through Fall**

On January 17th, 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 14th, the Virginia state legislators gathered for the annual Use a Helmet Prevent Epilepsy campaign awards breakfast to congratulated 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

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**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 updated this page as we develop additional resources that will help you navigate the new health insurance marketplace.

Most American 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 Neupace 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!

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.

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 can 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 copays 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 advice 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 e 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](http://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](http://www.capwiz.com/efa).

**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 Yea s. 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

The Combined Federal Campaign (CFC) is the world's largest employee workplace giving campaign in the world, and has donated over $7 billion to 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. While the CFC has been so successful in the past, the Office of Personnel Management (OPM) has proposed a series of changes to the CFC that 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 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 MODDERN Cures Act as a pathway to hope was one of the key messages epilepsy advocates brought to the Hill on April 23rd. The MODDERN 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 MODDERN 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 MODDERN 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:

**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 \( \frac{1}{2} \text{ of } 1\% \) 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](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](http://www.biocenturytv.com/player/2229685559001/2231455514001) 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](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 is 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](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/](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](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](http://capwiz.com/efa/issues/alert/?alertid=62442346).

**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=62515306

**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

December 12, 2012

Congressional Schedule: As many have heard Congress is still in session dealing with the "fiscal cliff.” Discussions continue with congressional leaders negotiating deficit reduction, taxes, and spending cuts. At the same time, there is a possibility that FY 2013 annual funding bills could be completed before the end of the 112th Congress this year. The Epilepsy Foundation has joined hundreds of millions of Americans who support and benefit from nondefense discretionary (NDD) programs—urging Congress and the President to work together to ensure sequestration does not take effect. We are advocating a balanced approach to deficit reduction that does not include further cuts to nondefense discretionary (NDD) programs.

These programs have already contributed substantially to deficit reduction through the bipartisan Budget Control Act and prior spending cuts. NDD programs are core functions government provides for the benefit of all, including medical and scientific research; education and job training; infrastructure; public safety and law enforcement; public health; weather monitoring and environmental protection; natural and cultural resources; housing and social services; and international relations. Every day these programs support economic growth and strengthen the safety and security of every American in every state and community across the nation. NDD programs represent a small and shrinking share of the federal budget and of our overall economy. The NDD budget represented just 3.4 percent of our country’s Gross Domestic Product (GDP) in 2011, consistent with
historical levels. Under the bi-partisan Budget Control Act, by 2021 NDD programs will decline to just 2.5 percent of GDP, the lowest level in at least 50 years. Follow the negotiation as and sign up to take action at: http://capwiz.com/efa

**RAISE Remains in Committee:** House Resolution 298 (the RAISE Resolution) currently has 107 cosponsors and has come a long way in the last few months. Still, **this important legislation is only days away from **

**dying in committee**. For the last year, RAISE has been sitting in the Health Subcommittee of the House Committee on Energy and Commerce. **The Epilepsy Foundation needs every advocate to reach out in every way to Speaker John Boehner (OH) and Representative Fred Upton (MI) - Energy & Commerce Committee Chairman and ask them to release H. Res 298 so that it be voted on and passed.** There are only a few work days remaining in the 112th Session and the Foundation is doing all that it can to get the resolution out of committee and onto the House floor for a vote. Please join us in fighting for nationwide epilepsy awareness and take action here: http://www.capwiz.com/efa/issues/alert/?alertid=62193601

**U.N. Disability Treaty Defeated in U.S. Senate:** On December 4th, the Senate voted against ratification of the Convention on the Rights of Persons with Disabilities (CRPD). The treaty received YES votes from sixty-one Senators, just six votes short of the two-thirds majority required for ratification. In voting against ratification of the CRPD, the Senate has turned its back on the American disability and veteran communities and failed to live up to the example of America’s role as a leader on disability rights.

Joining a disability community, universally disappointed by the treaty’s rejection in the Senate, White House Press Secretary Jay Carney had this to say, “Ratification would require no changes to U.S. law…it would position the United States to support extending across the globe the rights that Americans already enjoy at home. This in turn would improve the lives of Americans with disabilities – including our wounded service members – who wish to live, work, and travel abroad. We hope the Senate will reconsider this treaty soon in the next Congress. As President Obama declared…disability rights should not stop at our nation’s shores.”

“The Epilepsy Foundation was proud to join such a strong group of disability and veteran organizations in working for the ratification of this treaty and with people like Tony Coelho leading this effort, I have no doubt that we’ll be able to encourage the Senate to stand up for the disability community and declare their equal rights in the U.S. and around the world,” said Epilepsy Foundation President & CEO Phil Gattone.

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, including Senators John Kerry and John McCain. The CRPD was also bolstered by former Presidents George H.W and George W. Bush as well as disability rights champions, former Senate Majority Leader- Robert Dole and lead sponsor for the Americans with disabilities Act and current Epilepsy Foundation board member Tony Coelho. Coelho had this reaction to the vote, “Egregious partisanship, the first of its kind with disability rights legislation, is what kept us from ratifying this treaty. And now egregious partisanship will cost us the respect of our closest global allies. We are battered but not broken. This fight is not over. People around the world count on us and we will not stop our tireless advocacy for them.”

Disappointed, but not deterred, we are confident that the CRPD will be reintroduced during the 113th Congress. Upon reintroduction, the CRPD will have no greater champion than the Foundation and its advocates, who will as always, be ready to fight for the rights of the epilepsy community and all Americans living with disabilities both here and abroad.

**EFA Joins Other Groups in Preserving Charitable Deductions:** The Epilepsy Foundation joined 936 other nonprofit community organizations in a letter created by Independent Sector, asking the White House and Congress to preserve the current caps of tax deduction for charitable gifts given to non-profit organizations. The letter also asked that any cuts made in negotiations to avoid the Fiscal Cliff, do not include cuts to programs that help serve basic needs for low-income families. This letter was featured as an advertisement in
Epilepsy Foundation Applauds the Social Security Administration New Compassionate Allowance Listing for Dravet Syndrome: The Social Security Administration (SSA) announced a very important policy change for individuals with Dravet syndrome and their families. Michael J. Astrue, Commissioner of Social Security, announced that the agency will add Dravet Syndrome and 34 other additional conditions to its Compassionate Allowances program.

Dravet syndrome is a severe childhood epilepsy that strikes during the first year of life. Epilepsy Foundation President & CEO Phil Gattone shared the gratitude of the epilepsy community, “Dravet has a dramatic impact on a young infant's development and leads to significant disabilities. This policy change was a critical need for families who rely on the SSA programs, and is an important example of a condition where beneficiaries and families should not be overly burdened in proving a disability. “

The Compassionate Allowance Initiative (CAL) is a way to expedite Social Security Disability Insurance Program (SSDI) and SSA Supplemental Security Income program disability determinations. Under the authority of the agency, CAL conditions are deemed so severe that they meet the SSA definition of disability. SSDI and SSI applications will be expedited for action by the agency when applicants note CAL conditions as a basis for their disability. This can bring their disability determination process down from months to weeks. There are now 200 conditions that qualify for processing under this program.

Link to Dravet CAL listing: https://secure.ssa.gov/apps10/poms.nsf/lnx/0423022943

Applications for disability may be filed online, in the local field office, or by calling our toll-free number 1-800-772-1213. To learn how to apply for disability benefits please use this link: http://www.ssa.gov/dibplan/dapply.htm

October 17, 2012

Federal Funding for Epilepsy Research & Programs: The federal government supports many programs that benefit all Americans, including medical and scientific research; public health; education and job training; public safety and law enforcement; weather monitoring; housing and social services; and international relations. In Washington, these programs are collectively referred to as “nondefense discretionary” or simply “NDD” programs. On January 2, 2013 these programs will face devastating, across-the-board cuts of 8.2 percent through an arcane budget tool known as "sequestration" unless Congress works together to prevent these cuts through a bipartisan, balanced approach to deficit reduction. The Epilepsy Foundation continues to advocate for a balanced approach to deficit reduction that does not include further cuts to NDD programs, including public health and research (like epilepsy research and programs at the Centers for Disease Control and Prevention, the Health Resources and Services Administration, and the National Institutes of Health).

NDD programs represent a relatively small and shrinking share of the federal budget and our overall economy—already reduced to levels not seen since President Eisenhower held office. They are not the drivers of the debt. In fact, even completely eliminating all NDD programs would still not balance the budget. Yet to date NDD programs have borne the brunt of deficit reduction efforts. If sequestration is allowed to take effect, core services upon which Americans have come to rely will be greatly curtailed or even eliminated. Follow our efforts as we work to support this balanced approach. We expect more action by Congress after the November elections. Share this newsletter with your friends, family and fellow advocates as they to contact their Representative or Senator and let him/her know how deep cuts to disability programs will affect
millions living with epilepsy in this country. Go to our Action Alert by clicking here http://capwiz.com/efa/home

The RAISE Resolution Awaits Release from Committee: House Resolution 298, the RAISE Resolution, now has 104 cosponsors thanks to the addition of Representative Louise Slaughter (NY). The bill awaits release from committee so that it can be brought to the House floor for a vote. We need your help to ensure that the resolution gets brought to the floor and passed by the House of Representatives before the end of the year. When Congress returns from elections recess, we need the RAISE Resolution to be at the top of their priority list.  

House Resolution 298 asks for no money, merely a greater effort by the federal government to coordinate the use of epilepsy awareness and educational programs that have already been created. Congress is in recess until after the Presidential election. If the resolution does not get to the floor for a vote before the end of the year it will not pass. Please contact your Representative and ask them to bring House Resolution 298 to the floor so that this important legislation can help the millions across the nation living with epilepsy. http://www.capwiz.com/efa/issues/alert/?alertid=61631906

Veterans Administration Epilepsy Centers of Excellence: The Foundation supported “Dear Colleague” letter championed by Representative Ed Perlmutter (CO) requesting continued funding of the VA Epilepsy Centers of Excellence (ECoEs). These centers are advancing epilepsy care for soldiers and veterans --- providing best care models that may help improve care for everyone with epilepsy and seizures. Funding for these centers is scheduled to end sunset at the end of FY 2013. We believe that abandoning the ECoE would stop to potential improvements in treatment for the entire epilepsy community. 

Since the passage of the VA Centers of Excellence Act of 2007, the VA has established these centers to provide a nationwide network of support for epilepsy care. Among their many successes the ECoE has: 1) Helped secure the best care possible for soldiers and veterans suffering with Traumatic Brain Injury (TBI) and epileptic symptoms; 2) Reduced VA health care costs by up to $5.5 million per year; 3) Created a National Patient and Provider education program; and 4) In 2011 the ECoE Network Paid for Itself by Services that were not outsourced. 

The House “Dear Colleague” letter created by Representative Ed Perlmutter (CO), urged VA Secretary Shinseki to ensure continued funding of the Epilepsy Centers of Excellence, which does so much to help soldiers and veterans living with epilepsy to live the best life possible. The letter has been signed by a bipartisan collection of 43 Representatives. The final “Dear Colleague” letter can be seen here.

Convention on the Rights of Persons with Disabilities: There are only a few weeks left in the 112th Congressional Session and it is critical that the United States ratify the Convention on the Rights of Persons with Disabilities (CRPD) before the end of the year. The Epilepsy Foundation is asking everyone to call their Senators and ask for their support of this important step towards disability rights for the international community. Visit our Speak Up Speak Out network and take action by clicking here: http://www.capwiz.com/efa/callalert/index.tt?alertid=61576531

The Convention is consistent with U.S. laws such as the Americans with Disabilities Act (ADA), the Rehabilitation Act, and the Individuals with Disabilities Education (IDEA). The President signed the treaty on July 30, 2009 but it must be ratified by the Senate (67 yea votes) for the United States to become a legal party to the treaty under international law. Currently 116 countries have ratified the Convention. This treaty is being championed by a bipartisan group of including Senators McCain (AZ), Durbin (IL), Kerry (MA), Barrasso (WY), Harkin (IA), Udall (NM), Moran (KS), and Coons (DE).
The Epilepsy Foundation calls upon the U.S. Senate to quickly ratify the treaty thus showing the U.S. to be a leader in promoting and enhancing disability policies around the world. Please join our efforts by calling your Senators today!

*September 28, 2012*

**Federal Funding for Epilepsy Research & Programs - EFA joins the Non-Defense Discretionary Community in United Campaign:** The Epilepsy Foundation joined the Coalition for Healthcare Funding (CHF) and other organizations that benefit from Non-Defense Discretionary (NDD) funding in contacting Congress through Twitter and email, asking them to avoid the scheduled 8% cuts to all NDD budgets. Thanks to your efforts and those of the NDD community, #NDDUnited, #Sequester #Sequestration were all trending on Twitter in the Washington D.C. Area.

These deep cuts to NDD would endanger critical epilepsy research initiatives. Funding for crucial community-based programs like first responder training, veterans and senior care all are at risk for the Center for Disease Control and Prevention (CDC) and the Health Resources and Services Administration (HRSA), if massive cuts are made. You can still join this effort! Share this newsletter with your friends, family and fellow advocates as them to contact their Representative or Senator and let him/her know how deep cuts to disability programs will affect millions living with epilepsy in this country. Go to our Action Alert by clicking here [http://capwiz.com/efa/home](http://capwiz.com/efa/home)

**The RAISE Resolution Waits for Passage:** House Resolution 298, the RAISE Resolution, now has 103 cosponsors thanks to the additions of Representatives John Lewis (GA), Mike Thompson (CA) and Collin Peterson (MN). Still, the bill waits in committee to be brought to the House floor. **We need your help to ensure that the resolution gets brought to the floor and passed by the House of Representatives before Congress recesses for the elections.**

House Resolution 298 asks for no money, merely a greater effort by the federal government to coordinate the use of epilepsy awareness and educational programs that have already been created. Congress is in recess until after the Presidential election. If the resolution does not get to the floor for a vote before the end of the year it will not pass. Please contact your Representative and ask them to bring House Resolution 298 to the floor so that this important legislation can help the millions across the nation living with epilepsy [http://capwiz.com/efa/issues/alert/?alertid=61631906](http://capwiz.com/efa/issues/alert/?alertid=61631906).

**State Highlight - Success in West Virginia:** The Epilepsy Foundation wrote a letter and contacted West Virginia Governor Earl Ray Tomblin and the state Drug Utilization Review Committee (DUR) to oppose any restrictions being considered by the DUR to require prior authorization (or any other restrictions such as step-therapy, prescription limits etc.) that may limit access to vital needed epilepsy medications. The DUR met and acknowledged local letters from neurologists and that of the Epilepsy Foundation. The DUR issued guidelines exempting those with a seizure diagnosis from the proposed restrictions.

**Reminder - Medicare Open Enrollment is October 15 - December 7:** We encourage everyone on Medicare to compare their benefit options and/or work with family members who are using Medicare to make the best choice for them. The following resources may be helpful to you, your local support group, or family member:

- Visit [www.medicare.gov/find-a-plan](http://www.medicare.gov/find-a-plan) to compare your current coverage with all of the options that are available in your area, and enroll in a new plan if you decide to make a change.
- Call 1-800-MEDICARE (1-800-633-4227) 24-hours a day/7 days a week to find out more about your coverage options. TTY users should call 1-877-486-2048.
Review the *Medicare & You 2013* handbook. It is mailed to people with Medicare in September.

If you have limited income and resources, you may be able to get Extra Help paying your prescription drug coverage costs. For more information, visit www.socialsecurity.gov/i1020 or call Social Security at 1-800-772-1213. TTY users should call 1-800-325-0778.

Get one-on-one help from your State Health Insurance Assistance Program (SHIP). Visit www.medicare.gov/contacts or call 1-800-MEDICARE to get the phone number.

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**August 15, 2012**

100 Cosponsors of the RAISE Resolution (House Resolution 298) & Counting: On Friday, August 3\textsuperscript{rd}, the Epilepsy Foundation reached its goal of securing 100 cosponsors for House Resolution 298, the RAISE Resolution. The Foundation would like to thank all of you who responded to our call to action on RAISE!

**Your work is not done yet; we want to ensure that the resolution is passed by the House of Representatives before Congress recesses for the elections.** The Foundation wants to get as many cosponsors for RAISE as possible to help push the resolution to the floor and guarantee enough votes to pass.

**Join us!** While your legislators are on recess, contact them to bolster support for H. Res. 298. Please contact your representative today!! If they are already a cosponsor, thank them and ask them to support the resolution once it goes to the floor for a vote. If they are not a cosponsor, share your story and personal connection to why epilepsy awareness is important to your community. Find out whether or not your representative is a cosponsor here [http://capwiz.com/efa/home](http://capwiz.com/efa/home) Congressional recess will end for the House on September 10\textsuperscript{th}. Your voice is needed now!

**Federal Funding for Epilepsy Research & Programs:** Congress is currently in discussion about ways to reduce the national debt and there is a lot at stake for millions living with epilepsy and their families. Deep cuts in discretionary spending would endanger critical epilepsy research initiatives partially funded by the National Institutes of Health. This research provides hope for a cure about a disorder that is still widely misunderstood and stigmatized. Funding for crucial community-based programs like first responder training, veterans and senior care all are at risk for the Center for Disease Control and Prevention (CDC) and the Health Resources and Services Administration (HRSA), if massive cuts are made.

If deficit reduction proposals are not fair and balanced (include revenues as well as spending cuts), programs that provide support and services for people with epilepsy will face massive cuts. Over the August recess, Members of Congress will be in their home states and districts. Please call your Representative or Senator and let him/her know how deep cuts to disability programs will affect millions living with epilepsy in this country. Go to our Call Action Alert by clicking here [http://capwiz.com/efa/home](http://capwiz.com/efa/home)

**National Presidential Forum on Disabilities:** Registration is now open for the only presidential forum focusing on disability policy issues. This historic event will take place on September 28 in Columbus, Ohio. It will bring together the diverse disability community to demonstrate the power of the disability vote and raise the visibility of disability issues during the election. So far, over 50 disability organizations including the Epilepsy Foundation have come together to co-sponsor the event. Approximately 500 people will attend the event in person. Tickets are free and are available on a first-come, first-serve basis. Thousands of others across the country will join a live webcast of the event. This is the only forum of its kind and only the second time an event like this has ever been organized. More information about the forum can be found on the Forum website at: [www.nfdi.org](http://www.nfdi.org)

**Convention on the Rights of Persons with Disabilities:** July was a very exciting month as the U.S. moved forward with its ratification process of the Convention on the Rights of Persons with Disabilities. This international disability treaty affirms the values of the ADA including equality, independence, and dignity. Ratifying the treaty would allow the U.S. to formally participate in this important discussion around global disability rights.
The Senate Foreign Relations Committee successfully voted the CRPD out of Committee on July 26 with a vote of 13-6! Before taking its August recess, Senate Majority Leader Harry Reid issued a statement of support in the Congressional Record encouraging ratification of the CRPD. When the Senate is back in session in September, a bipartisan group of champions will lead the treaty to its final vote on the Senate floor. This bipartisan group of champions includes: Senators McCain (R-AZ), Durbin (D-IL), Kerry (D-MA), Barrasso (R-WY), Harkin (D-IA), Udall (D-NM), Moran (R-KS), and Coons (D-DE). The Epilepsy Foundation is working to secure a few more Senators as “yea” votes for the Treaty – thanks to the affiliates and volunteers who immediately agreed to help us! Read and share Senator Bob Dole’s op-ed in support of the CRPD http://www.mcclatchydc.com/2012/08/03/159788/advancing-the-rights-of-persons.html. Want more information about the CRPD? Visit the U.S. International Council on Disabilities: http://www.usicd.org/index.cfm/crpdupdates.

**June 4, 2012**

**Congressional Schedule:** Both the Senate and House will be in session June 4-8 and June18-29. The House is expected to be in their home states for district work June 11-15.

**Supporting RAISE House Resolution 298- Epilepsy Awareness:** Last week, the Epilepsy Foundation staff and advocates were on Capitol Hill and visiting house members who have yet to cosponsor the RAISE Resolution. In response, four members joined as cosponsors, Rep. Sandy Levin (MI), Rep. Ed Pastor (AZ), Rep. Stephen Lynch (MA), and Rep. Bill Cassidy (LA). This increased the total number of RAISE sponsors to 62. The Foundation's sponsorship goal for the resolution is 100. This number will help us push for a floor vote and passage of the resolution in the House. **The Foundation’s sponsorship goal for the resolution is 100.** This number will help us push for a floor vote and passage of the resolution in the House. June is our big push before congressional recess in July. The Foundation and our advocates will be working hard to gain 40 more cosponsors, so that the resolution can have 100 sponsors by July 4th. You can help! Find out whether or not your representative is a cosponsor here [http://capwiz.com/efa/home/](http://capwiz.com/efa/home/). Find more ways to support the RAISE Resolution here [http://www.epilepsyfoundation.org/getinvolved/advocacy/RAISE.cfm/login.cfm](http://www.epilepsyfoundation.org/getinvolved/advocacy/RAISE.cfm/login.cfm)

The Epilepsy Foundation strongly supports House Resolution 298 as a first step toward the introduction of legislation that would create a national epilepsy awareness campaign to increase the understanding of epilepsy and seizures in the workplace, schools and communities --- making it safer for students, workers and citizens with epilepsy to access emergency care, continue employment, and achieve an education. **Contact your Representative and ask them to co-sponsor House Resolution 298!**

Visit your Representative during the district work period June 11-15. Find your legislators contact information here: [http://capwiz.com/efa/dbq/officials/](http://capwiz.com/efa/dbq/officials/)

**May 10, 2012**

**The RAISE Resolution:** The Epilepsy Foundation continues to strongly support the RAISE Resolution (H. Res. 298) as a first step toward the introduction of legislation that would create a national epilepsy awareness campaign to increase the understanding of epilepsy and seizures in the workplace, schools and communities --- making it safer for students, workers and citizens with epilepsy to access emergency care, continue employment, and achieve an education.

RAISE currently has 57 co-sponsors. Join the Epilepsy Foundation in the push for 100! Check [here](http://www.epilepsyfoundation.org/getinvolved/advocacy/RAISE.cfm/login.cfm) to see if your representative has signed on and ask them to co-sponsor House Resolution 298!
Institute of Medicine Report: On March 30\textsuperscript{th}, the Institute of Medicine released an extensive report on epilepsy, entitled \textit{Epilepsy Across the Spectrum: Promoting Health and Understanding}. The report's findings list epilepsy as the fourth most common neurological disorder, and perhaps most shockingly, that approximately 1 in 26 people will develop epilepsy over the course of their lifetime. The report goes on to make recommendations for bettering the lives of those living with epilepsy, highlighting areas such as health care and services, awareness, and prevention.

To read the report, visit: \url{http://www.iom.edu/epilepsy}

The IOM report on epilepsy is a boost to our advocacy, as the research and solutions included in the report only reaffirm and strengthen the message of the Epilepsy Foundation. Read up, and make sure your representatives know and understand the importance of the IOM's findings!

Policy Conference and Hill Day: April 1\textsuperscript{st} – 3\textsuperscript{rd}, the Epilepsy Foundation held its annual Public Policy Institute (PPI) and \textit{Kids Speak Up!} program. Over 250 participants, representing 34 states and 44 Epilepsy Foundation affiliates, traveled to Washington D.C. for the program. The conference familiarized its attendees with the Foundation's legislative agenda, and trained them on how to be effective advocates. The last day of the conference, April 3\textsuperscript{rd}, was our "Hill Day." All conference attendees applied their training, as they marched up to Capitol Hill, and visited over 200 congressional offices! Though members were on recess, our experts on living with epilepsy went from office to office, meeting with their representatives' legislative assistants, telling their story, fighting for funding, and enlisting support of legislation like the R.A.I.S.E. Resolution and the MODDERN Cures Act.

The conference was a huge success, and we want to thank our advocates for their efforts on the hill, and their commitment to 'Speaking Up! and Speaking Out!' year round.

Federal Funding for Epilepsy Research & Programs: The Epilepsy Foundation continues to push for strong funding for epilepsy programs that are funded by the federal government through the annual appropriations process: CDC Epilepsy program, Project Access at HRSA, and funding from the National Institutes of Health for epilepsy research are our top priorities. During the recent Public Policy Institute (PPI) and \textit{Kids Speak Up} program advocates brought the EF funding messages to Capitol Hill. The timeframe for House and Senate Committee markups on the appropriations bill that funds our programs is somewhat unclear at this time. We expect committee level action in June but do not expect a final bill to be negotiated until after the November elections.

Meanwhile, the failure of a bipartisan Congressional committee to find a solution to the nation's debt crisis has left us with the looming threat of what is known as sequestration. Sequestration is a process by which funds can be "sequestered" by the Treasury and not handed over to the federal agencies to use in order to help pay down the debt. Beginning January 2, 2013, billions of dollars will be sequestered from both defense and non-defense programs. The plan for 2013 will split the burden of cuts, which will equal about $110 billion, between defense and non-defense including some cuts to Medicare and other mandatory programs. Between 2014 and 2021 more funds will be sequestered with a larger portion taken from non-defense programs.

While no one is in favor of the sequestration, finding a better solution is difficult. The Epilepsy Foundation is taking leadership in a coalition of organizations working to find a better solution that is more balanced and is educating Congress about the devastating effects sequestration can have on programs that serve people with epilepsy. House Republicans have introduced a "repeal and replace" bill for the sequestration which the Foundation does not support as it does not offer a balanced approach and would put more of the burden of spending cuts on health, education, employment and disability programs. House Democrats plan to introduce an alternative repeal and replace bill this week that will offer dramatically different spending cuts along with revenue enhancements.
As always, we encourage you to ask your family and friends to join our Speak Up Speak Out advocacy network to show support for these important programs, and be ready to act when Congress votes!

Affordable Care Act Hearings: On March 26-28, the Affordable Care Act, President Obama's signature legislation, became a subject of the U.S. Supreme Court. The hearings were to determine the constitutionality of the health care reform. The Epilepsy Foundation joined an amicus brief (friend of the court brief) in support of the Medicaid program expansion under the ACA. This brief was important not only as a defense of the ACA's Medicaid expansion, but also to prevent a precedent that could damage or infringe on other important federal spending statutes, such as the Individuals with Disabilities Education Act (IDEA); Title I of the Elementary and Secondary Education Act, most recently reauthorized in the No Child left Behind Act; the federal foster care and child support enforcement programs; Title VI of the Civil Rights Act; Title IX of the Education Amendments of 1972; and Section 504 of the Rehab Act, which prohibit various forms of discrimination (racial, gender, disability) by entities that receive federal funds. View the amicus brief

The Foundation also joined 30 CEOs in a supportive statement released by the National Health Council released during the week of oral arguments calling on the U.S. Supreme Court to uphold the constitutionality of the Affordable Care Act. You can read this statement here.

While the Affordable Care Act provides services beneficial to many people with epilepsy, and guarantees protection to those with pre-existing conditions, it is structured in such a way that it is not easy to sever each individual piece of the legislation that may be deemed unconstitutional. That means, in the event that a single mandate is found to be unconstitutional, it is then quite possible that the entire legislation will be declared unconstitutional. Arguments were heard from both sides, and the Supreme Court is expected to reach a decision this summer. Stay tuned!

MODDERN Cures Act: The MODDERN Cures Act (H.R. 3497), introduced by Representatives Leonard Lance (R-NJ) and Jay Inslee (D-WA), would accelerate the search for treatment options by removing the barriers that limit medical innovation and by providing incentives to develop new treatments and diagnostic tools that can improve, prolong and, ultimately, save lives.

One such innovation is the continued development and expansion of personalized medicine. We, at the Epilepsy Foundation, support this legislation, as personalized medicine would be a great benefit to the epilepsy community. With diagnostic testing, patients would be better matched to the treatments that would best work for them. Individuals with seizures that are not controlled by drugs or surgery make up approximately 25 to 30 percent of the epilepsy patient population. Even when seizures are controlled, the quality of life for some people with epilepsy is severely affected by the long- and short-term side effects of medication or surgery. Because both the efficiency and side effects associated with specific epilepsy medications vary greatly from person to person, one way to improve epilepsy treatment is to develop ways to predict individual responses to medications.

The MODDERN Cures Act could speed the development of new treatments and diagnostic tools that can improve the lives of people living with epilepsy. Join the Epilepsy Foundation in supporting the MODDERN Cures Act (H.R. 3497)!

Stay Informed: Visit the Epilepsy Foundation Speak Up Speak Out advocacy network for more information, to find the local contact information for your Senators and Representative, and to learn more about our advocacy efforts in Congress and in your state at: http://capwiz.com/efa/home/

December 27, 2011
**Congressional Schedule:** Both the Senate and House are on recess. They are expected to be on recess or in their home states for district work next week through the winter holidays. The House will convene for the second session of the 112th Congress on Tuesday, January 17, 2012; the Senate will convene earlier, but will then recess for state work period until Monday, January 23, 2012. The President is expected to deliver his "State of the Union" address on Tuesday, January 24th.

**Supporting House Resolution 298 - Epilepsy Awareness:** The next few weeks and winter congressional district work period when legislators are back home is a great time to connect with your public officials on epilepsy awareness. The Epilepsy Foundation strongly urges you to participate in Town Hall meetings and other opportunities to meet with your Senators and Representative while they are on recess. **Call the local offices for your Senators and Representatives; ask about meeting with your legislator while they are home. Tell them why epilepsy awareness is important to you, your family, and your community.**

The Epilepsy Foundation strongly supports House Resolution 298 as a first step toward the introduction of legislation that would create a national epilepsy awareness campaign to increase the understanding of epilepsy and seizures in the workplace, schools and communities --- making it safer for students, workers and citizens with epilepsy to access emergency care, continue employment, and achieve an education. **Meet with your Representative and ask them to co-sponsor House Resolution 298!** Find your legislators contact information [here](#).

**Federal Funding for Epilepsy Research & Programs:** Congress finally came to agreement on final spending levels last week for the remaining nine appropriations bills for FY 2012, including the Labor, HHS, Education spending bill. The bill was passed by the House and Senate over the weekend. The Epilepsy Foundation is pleased to report that our CDC Epilepsy Program, our HRSA Project Access, and funding for research at NIH are all level funded based on last year. This is really quite miraculous given that many other programs received cuts and there was a looming threat of across-the-board cuts. While Congress is still debating other critical spending issues such as payroll tax holidays and extensions for unemployment, it's great to have the epilepsy programs funded for the remainder of the fiscal year.

For the next fiscal year, the Epilepsy Foundation government relations staff is busy weighing in with the Office of Management and Budget (OMB) at the White House to secure solid funding in the President's Budget that is expected to be presented to Congress the first Monday in February.

As always, we encourage you to ask your family and friends to join our [Speak Up Speak Out](#) advocacy network to show support for these important programs, and be ready to act when Congress votes!

**Essential Health Benefits:** A final push for your input! The Epilepsy Foundation is interested in what you believe are essential benefits. We are asking you to share your story about what healthcare and access is important to YOU by sending an email to the Secretary of Health and Human Services. Your response will be shared with HHS and the White House; and it will help us as we advocate for health care reform implementation that provides for the needs of the epilepsy community. For more information read our [Advocacy Rx](#) blog.

**Restraint and Seclusion:** Senator Tom Harkin (IA), Chairman of the Senate Health, Education, Labor and Pensions Committee, introduced the Keeping All Students Safe Act, a bill to protect students from ineffective and dangerous seclusion and restraint practices in schools. The Epilepsy Foundation supports this legislation to establish federal minimum standards to limit the use of restraint and seclusion in schools. The Keeping All Students Safe Act (S. 2020) is the Senate companion to H.R. 1381 that was introduced in the House in September. Both bills aim to establish federal minimum standards. The Epilepsy Foundation believes it is critical to protect children's health and safety in schools and that these bills will provide guidance and support to states by limiting, but not banning, the use of restraint and seclusion. The legislation would require states to develop policies and procedures for the use of restraint and seclusion and permit this extreme practice only in
emergency situations where there is a threat of danger or injury. The bills would provide grants encouraging states to provide training for school staff. Read more about this legislation and all bills we support here.

**Health Reform – Resources you can use:** As we approach 2012 and more action on implementation of the federal health reform law, we wanted to share the following links to resources from the government and other organizations will help explain important changes to health insurance.

- [www.healthcare.gov](http://www.healthcare.gov) – Federal Web page for resources on health reform and health insurance needs
- [www.consumerreports.org/health/insurance/health-insurance.htm](http://www.consumerreports.org/health/insurance/health-insurance.htm) -- Online guide from Consumers Union on major marketplace reforms under the new health reform law
- [http://healthreform.kff.org/](http://healthreform.kff.org/) -- Kaiser Family Foundation Health Reform Source online publication
- The following link offers state specific information on health insurance laws, coverage, programs, and consumer issues: [http://healthinsuranceinfo.net/getinsured/](http://healthinsuranceinfo.net/getinsured/) -- Georgetown University Guide on Health Insurance

**Stay Informed:** Visit the Epilepsy Foundation *Speak Up Speak Out* advocacy network for more information, to find the local contact information for your Senators and Representative, and to learn more about our advocacy efforts in Congress and in your state!

**November 26, 2011**

**Congressional Schedule:** Both the Senate and House are in session this week. They are expected to be on recess or in their home states for district work next week through the Thanksgiving holiday.

**Supporting House Resolution 298- Epilepsy Awareness:** November is National Epilepsy Awareness Month, we encourage everyone to use this month to bring special recognition to epilepsy awareness and **support House Resolution 298.** Your member of Congress recently received a "Dear Colleague" letter from Representatives Steny Hoyer, Jo Ann Emerson, Dan Benishek, and Ed Perlmutter along with a special note from the Foundation's champion and Interim CEO, Tony Coelho urging them to sign on as a co-sponsor for House Resolution 298.

**Act Now!** Please urge your member of Congress to sign the "Dear Colleague" letter and become a cosponsor of H. Res 298. It's simple and easy! You can send a message directly to your Member asking for their support at: [http://capwiz.com/efa/issues/alert/?alertid=56113596](http://capwiz.com/efa/issues/alert/?alertid=56113596) Consider personalizing your message by adding your own story about living with epilepsy. To learn more about National Epilepsy Awareness Month and how you can participate, visit our resources here: [http://www.epilepsyfoundation.org/getinvolved/neam/index.cfm](http://www.epilepsyfoundation.org/getinvolved/neam/index.cfm)

**Federal Funding for Epilepsy Research & Programs:** Congress has begun the process for approving the annual appropriation bills for FY 2012 through a series of "mini-buses" (packages of 3 bills each). The Epilepsy Foundation supported the Senate level funding for the Food and Drug Administration that was included in the first mini-bus that Congress is considering. The Foundation believes that it is essential that the FDA be well funded in order to adequately perform its job of approving new drugs and therapies for epilepsy and other health conditions. This first mini-bus will also include a second Continuing Resolution (CR) to keep all other programs funded into mid-December. The current CR expires on November 18.

The Labor, Health and Human Resources, Education appropriation bill will be part of the final mini-bus to be addressed by Congress. This bill will include funding for programs that are important to ensuring the safety and health of people with epilepsy. We support maintaining the current funding levels for the CDC Epilepsy program ($7.8 million) and for the Project Access epilepsy program at HRSA ($3.7 million). FY 2012 began on October 1, 2011. At this time the prospects are good for continued funding at current levels for the CDC and HRSA epilepsy programs. Your voices and explanations about how these programs help people with epilepsy to
thrives in your towns and cities has been heard by the congressional appropriators. We encourage you to ask your family and friends to join our Speak Up Speak Out [http://capwiz.com/efa/mlm/signup/] advocacy network to show support for these important programs, and be ready to act when Congress votes!

**UPDATE**

**Super Committee & FY 2013 Budget:** The Epilepsy Foundation staff reacts to Super Committee's lack of agreement on submitting a proposal to Congress.

We had continued to meet with members of the Super Committee who are busy working on a proposal to cut the nation's deficit by $1.2 trillion. The Committee must submit a proposal to Congress by December 23 but must have the plan ready to be evaluated for how much savings it really creates by November 23. The Epilepsy Foundation continues to educate members of the Super Committee about what programs are essential for those living with epilepsy and how we cannot afford to decimate programs such as Medicaid and Medicare, important health research funding for the National Institutes of Health, or critical CDC and HRSA education and employment programs that provide the safety net and supports people need in order to go to school, work and live in their communities.

Read more about how the Epilepsy Foundation is weighing in with this committee on our advocacy eblog here: [http://epilepsyfoundation.ning.com/profiles/blogs/what-is-so-super-about-that-committee](http://epilepsyfoundation.ning.com/profiles/blogs/what-is-so-super-about-that-committee)

**Health Reform Law & the US Supreme Court:** On Monday, the United States Supreme Court announced it will hear challenges to the Affordable Care Act during this year's court term. The date for hearings of challenges to the constitutionality of this law has not been set, though it is expected to happen around March. The Court would then make a decision and issue an opinion by its adjournment in late June. The Foundation will report on issues to be discussed and progress of this case as more is known.

**Essential Health Benefits:** The Epilepsy Foundation is interested in what you believe are essential benefits. We are asking you to share your story about what healthcare and access is important to YOU by sending an email to the Secretary of Health and Human Services. Your response will be shared with HHS and the White House; and it will help us as we advocate for health care reform implementation that provides for the needs of the epilepsy community. Link to alert: [http://capwiz.com/efa/issues/alert/?alertid=55474501](http://capwiz.com/efa/issues/alert/?alertid=55474501)

**EFA Staff at the HHS Regional Meetings:** On Tuesday, November 8th Bill Murphy, Director, State Government Relations for the Epilepsy Foundation attended the Region I, Department of Health and Human Services (HHS) listening session on the Affordable Care Act's Essential Health Benefits in Boston. This was one of nine public listening sessions the Department is holding across the nation to hear comments from regional, state, and local stakeholders on essential health benefits. Well over one hundred individuals representing diverse stakeholder groups attended. These included, various state agency representatives, patient and patient advocacy groups, providers and employer groups from the New England area. HHS emphasized that the listening sessions are preceding a formal period of comment during which individuals and organizations may submit written comments to the Department.

On behalf of the Foundation, Bill offered brief statements urging that the definition of Essential Health Benefits not be so narrow as to limit access or prevent newer treatment options from being included; that access to the full range of treatment options be included and covered; that the pharmacy benefit in particular not allow for restrictive policies such as "fail first" or "step therapy" with the final decision for treatment being left to physician and patient; and that patient and patient advocates be included from the beginning in the design and evaluation of Essential Health Benefits.

For more information read our Advocacy Rx blog at: [http://epilepsyfoundation.ning.com/profiles/blogs/what-is-essential-to-you](http://epilepsyfoundation.ning.com/profiles/blogs/what-is-essential-to-you)

Visit the Epilepsy Foundation *Speak Up Speak Out* advocacy network for more information, to find the local contact information for your Senators and Representative, and to learn more about our advocacy efforts in Congress and in your state at: [http://capwiz.com/efa/home/](http://capwiz.com/efa/home/)

**October 26, 2011**

**Congressional Schedule:** The Senate is on recess while the House is in session this week.

**Supporting House Resolution 298 - Epilepsy Awareness:** As we approach November and National Epilepsy Awareness Month, we encourage everyone to support House Resolution 298 by sending a "Letter to the Editor" to your local newspaper by clicking here and by contacting your Representative to ask them to cosponsor epilepsy awareness House Resolution 298. Share your personal story with your member of congress and newspaper. Tell them why epilepsy awareness is important to you, your family, and your community. It's quick, it's easy and it's a great way to educate the public while asking for support for House Resolution 298 to increase epilepsy awareness! This resolution does not require any federal funding while raising epilepsy awareness nationwide.

**Federal Funding for Epilepsy Research & Programs:** For the upcoming 2012 Fiscal Year (FY) and in 2013, the Epilepsy Foundation encourages Congress to continue programs that are important to ensuring the safety and health of people with epilepsy. We support maintaining the current funding levels for the CDC Epilepsy program ($7.8 million) and for the Project Access epilepsy program at HRSA ($3.7 million). FY 2012 began on October 1, 2011. At this time the prospects are good for continued funding at current levels for the CDC and HRSA epilepsy programs. Your voices and explanations about how these programs help people with epilepsy to thrive in your towns and cities has been heard by the congressional appropriators.

The full Congress now must pass an appropriations bill. Rather than pass one large bill (an omnibus appropriation) several spending bills are being packaged together in a few smaller bills (mini-buses). The outcome may be level funding or across the board cuts could be applied. A current continuing resolution (CR) is funding the federal government through November 18. If Congress cannot finalize an appropriation bill that time, another CR would have to be passed. With the upcoming holiday of Thanksgiving the pressure will be on to pass another CR which would likely keep federal programs funded until Christmas.

After the FY 2012 appropriations are finalized, there still may be funding cuts that endanger epilepsy research and programs for the next fiscal year (2013). Additionally, if the Joint Special Committee on Deficit Reduction (a.k.a. the Super Committee) cannot reach its goal of funding savings of $1.2 trillion cuts can be made to all discretionary programs. The Foundation's government affairs department will continue to monitor this and work to support full funding of these important programs and research. We encourage you to ask your family and friends to join our *Speak Up Speak Out* advocacy network so that we have a strong response when these important bills are acted upon by Congress.

**Education:** Congress has begun the process to reauthorization of the Elementary and Secondary Education Act (ESEA). The first steps have taken place in the Senate with a draft bill by Senate Health, Education, Labor and Pensions (HELP) Chairman Tom Harkin (IA). This draft bill was negotiated by Chairman Harkin and HELP Ranking Member Michael Enzi (R-WY), and makes a number of changes to the existing law known as No Child Left Behind. The Senate Health, Education, Labor and Pensions Committee held a two-day markup and approved the legislation with a bipartisan 15-7 vote. This draft bill is a compromise that removes some of the most controversial provisions of No Child Left Behind law -- particularly those that related to math standards that many believed most schools would fail. The bill now requires states to adopt "college and career ready" standards and accountability systems in order to receive federal funding. We are pleased that the legislation emphasizes the inclusion of all students, while we share concerns of others in the disability community that accountability standards must include the needs of students with disabilities and that teacher qualification standards must be strong. Next steps for this draft bill include a full committee hearing the second week of
November. Chairman Harkin is aiming for a full Senate vote before Thanksgiving.

The Epilepsy Foundation works to support the ESEA bill through the Consortium for Citizens with Disabilities Education Task Force. We have supported recommendations to improve the bill. The Foundation is also hopeful that an amendment will be introduced to include limiting the use of restraint and seclusion in schools (see H.R. 1381 Keeping All Students Safe Act) and has spoken with Senator Harkin's staff and other members of the Senate Health Education Labor and Pension Committee requesting the inclusion of this amendment.

Medicare Part D Prescription Drug Plans Open Enrollment: October 15-December 7. Read more here.

Combating Autism Reauthorization Act: The Senate passed the Combating Autism Reauthorization Act of 2011 (S 1094/HR 2005) by unanimous consent. The bill was signed into law by President Obama. Passage now assures that federal support for autism, research, services and treatment will continue uninterrupted for another three years. Approximately 25 percent of individuals with autism will develop epilepsy. This is why the Epilepsy Foundation supported the reauthorization to increase treatment and evidence-based interventions for individuals on the autism spectrum. This program provides for (1) the surveillance and research program for autism spectrum disorder and other developmental disabilities; (2) the education, early detection, and intervention program for autism spectrum disorder and other developmental disabilities; and (3) the Interagency Autism Coordinating Committee.

You can find up to the minute status on this recently passed bill and other legislation supported by the Epilepsy Foundation http://capwiz.com/efa/issues/

CLASS: The Epilepsy Foundation was a strong supporter of the Community Living Assistance Services and Supports (CLASS) Program that was created as part of the Affordable Care Act (health care reform legislation). We believe that this program will help people with epilepsy secure access to long term care insurance which will help them to maintain independence and improve their health. Unfortunately, a report from the Department of Health and Human Services (HHS) announced that HHS does not see an "immediate path forward for the CLASS program." It is unclear how this will impact implementation and the White House has tried to clarify that they are committed to continue work on the CLASS program. This report has given a voice to those in Congress who were opposed to health care reform and/or this voluntary long-term care insurance program. The House Energy and Commerce Committee has scheduled an oversight hearing on CLASS, the Epilepsy Foundation is following this issue and may take action with Congress or the White House in support of the CLASS program. You can find more information on the coalition that is working to implement the CLASS program, Advance Class', website.

Super Committee & FY 2013 Budget: The "Joint Special Committee on Deficit Reduction" or "Super Committee" continues to meet. As previously reported, if this committee cannot find budget cuts of at least $1.2 trillion, across-the-board cuts to defense and domestic discretionary spending will be enacted. The Epilepsy Foundation continues to share our message with members of Congress that major cuts to Medicaid and discretionary health spending could be devastating to those most in need, endanger our advances in epilepsy research, and prevent support for much needed epilepsy programs -- all investments that can save money and improve health outcomes in the long-term. If the Joint Committee or Congress fails to act by December 23, 2011, there would be automatic across-the-board cuts, split 50-50 between defense and non-defense spending (including Medicare) matching the dollar amount of savings needed that was not achieved. Social Security and Medicaid would be excluded from those automatic cuts. Read more about how the Epilepsy Foundation is weighing in with this committee on our advocacy eblog here.

Visit the Epilepsy Foundation Speak Up Speak Out advocacy network for more information, to find the local contact information for your Senators and Representative, and to learn more about our advocacy efforts in Congress and in your state at: http://capwiz.com/efa/home/
Supporting House Resolution 298- Epilepsy Awareness: The Epilepsy Foundation has two new outlets to gain co-sponsors for H. Res 298 – 1. A letter to the editor; and 2: A sign-on letter to use at schools. Now is the time to Speak Up and Speak Out – we are hoping that House Resolution 298 will pass by November for epilepsy awareness month! Join epilepsy advocates nationwide in sending a "Letter to the Editor" to your local newspaper, by clicking here. Send in your letter to local media and share your personal story about why epilepsy awareness is important to you, your family, and your community. It's quick, it's easy and it's a great way to educate the public while asking for support for House Resolution 298 to increase epilepsy awareness! This resolution does not require any federal funding while raising epilepsy awareness nationwide.

For students and families, we are providing this sample letter to use at your school. Ask your friends, your class, your teachers, and your principle to join you in raising epilepsy awareness and exercising civic activism by sending this letter to your Member of Congress!

Federal Funding for Epilepsy Research & Programs: For the upcoming 2012 Fiscal Year (FY), The Epilepsy Foundation encourages Congress to continue programs that are important to ensuring the safety and health of people with epilepsy; we have supported maintaining funding for the CDC Epilepsy program ($7.8 million) and for the Project Access epilepsy program at HRSA ($3.7 million). FY 2012 begins on October 1, 2011. There is good news from the Senate appropriations subcommittee -- the CDC epilepsy program and HRSA programs received level funding for FY 2012.

However, the full Congress must pass the appropriations bill, and there is a possibility that all outstanding appropriations could be combined in one large continuing resolution (CR) for FY 2012. This could result in support for the level funding or some across the board cuts. A new continuing resolution (HR 2608) passed the House along mostly party lines, 219-203, but has dim prospects in the Senate. With few days remaining in the fiscal year, there is pressure on Congress to act before an anticipated early recess next week. The House spending bill would fund the government through Nov. 18. Whether through large CR or individual appropriations legislation, funding could be in danger for the next fiscal year (and that budget process will begin soon in early winter). The Foundation's government affairs department will continue to monitor this and work to support full funding of these important programs and research.

Make sure you are ready to Speak Up and Speak Out when legislation is moving by joining our grassroots advocacy network here!

Super Committee & FY 2013 Budget: The "Joint Special Committee on Deficit Reduction" or "Super Committee" held its first meeting on Thursday. This committee is tasked with finding ways to reduce the deficit by $1.5 trillion by November 23, and is made up of 12 Members from both the Senate and the House (with an equal number of Republicans and Democrats). If the Joint Committee or Congress fails to act by December 23, 2011, there would be automatic across-the-board cuts, split 50-50 between defense and non-defense spending (including Medicare). Social Security and Medicaid would be excluded from those automatic cuts. Read more about how the Epilepsy Foundation is weighing in with this committee on our advocacy eblog here: http://epilepsyfoundation.ning.com/profiles/blogs/what-is-so-super-about-that-committee

UPDATE! Combating Autism Reauthorization Act: The Senate passed the Combating Autism Reauthorization Act of 2011 (S 1094/HR 2005) by unanimous consent. The bill is now off to President Obama and he is expected to sign it. Passage now assures that federal support for autism, research, services and treatment will continue uninterrupted for another three years. Approximately 25 percent of individuals with autism will develop epilepsy. This is why the Epilepsy Foundation supported the reauthorization to increase treatment and evidence-based interventions for individuals on the autism spectrum. This program provides for (1) the surveillance and research program for autism spectrum disorder and other developmental disabilities; (2)
the education, early detection, and intervention program for autism spectrum disorder and other developmental disabilities; and (3) the Interagency Autism Coordinating Committee.

You can find up to the minute status on this recently passed bill and other legislation supported by the Epilepsy Foundation here.

**Lifespan Respite:** The Epilepsy Foundation joined in support of the National Respite Coalition's statement to the Senate Health, Education, Labor, & Pensions Committee on the Lifespan Respite Program. Epilepsy Advocates long advocated for this program that was authorized by Congress in 2006, though no funding was given until 2009. The program is authorized at $94.8 million for FY 2011, but has never received more than $2.5 million in any of the fiscal years 2009-2011. For FY 2012, the President has recommended $10 million as part of the Administration's Caregiver Initiative.

**Health Care Reform:** Recently a federal appeals court has issued conflicting decisions on health reform's constitutionality – one dismissing a challenge to the law and another opening the door to future challenges once the law takes effect. At issue this and many other challenges is the individual mandate to purchase health insurance or face a tax burden if declining to purchase coverage (there are financial supports if affordable coverage is not available). Ultimately, the United States Supreme Court is expected to decide the issue of the law's constitutionality; and the only question now is whether this will happen next year or after the 2012 elections. You can follow issues related to health care reform implementation at: http://www.healthcare.gov/

Visit the Epilepsy Foundation *Speak Up Speak Out* advocacy network for more information, to find the local contact information for your Senators and Representative, and to learn more about our advocacy efforts in Congress and in your state at: http://capwiz.com/efa/home/

**August 23, 2011**

**Congressional Recess Edition**

**Call to Action: Visit Your Legislators at Home**

Congress is on recess until after Labor Day. From funding for epilepsy research and programs to raising awareness about epilepsy, there are so many issues at stake. The Epilepsy Foundation strongly urges you to participate in Town Hall meetings and other opportunities to meet with your Senators and Representative while they are on recess. Call the local offices for your Senators and Representatives; ask about meeting with your legislator while they are home. Find your legislators contact information here: http://capwiz.com/efa/dbq/officials/

The Epilepsy Foundation encourages Congress to continue programs that are important to ensuring the safety and health of people with epilepsy; we have supported maintaining the funding for the CDC Epilepsy program ($7.9 million) and for the Project Access epilepsy program at HRSA ($3.7 million). We also continue to garner support for House Resolution 298, this resolution looks to increase epilepsy awareness in the federal agencies; it does not require any federal funding. **Join our efforts; meet with your legislators in your area!**

- Tell your Senators and Representatives that federal funding for critical epilepsy public health programs at the Centers for Disease Control and Prevention (CDC) and the Health Resources and Services Administration (HRSA) as well as research at the National Institutes of Health (NIH) is important to you.
- **Ask your legislators to support strong funding for epilepsy research and programs in the Labor-HHS appropriations bill.**
- Ask your Representative to **support House Resolution 298** - This resolution does not require any federal funding.
• Ask your Senators to **support the soon-to-be introduced RAISE Act** (Raising Awareness and Insight into Seizures and Epilepsy) in the Senate. This is legislation to create a national epilepsy awareness campaign to increase the understanding of epilepsy and seizures in the workplace, schools and communities --- making it safer for students, workers and citizens with epilepsy to access emergency care, continue employment, or achieve an education.

Visit the Epilepsy Foundation **Speak Up Speak Out** advocacy network for more information, to find the local contact information for your Senators and Representative, and to learn more about our advocacy efforts in Congress and in your state at: [http://capwiz.com/efa/home/?CFID=336208&CFTOKEN=21644457](http://capwiz.com/efa/home/?CFID=336208&CFTOKEN=21644457)

**August 2, 2011**

**Debt Limit Bill Agreed to by Congress and Signed by President Obama**

On August 2, 2011 President Obama signed into law the Budget Control Act of 2011 a deal negotiated among congressional leaders and the White House. Epilepsy Foundation staff closely monitored the negotiations and weighed in with our message that budgets and deficits should not be balanced by severely cutting or eliminating programs and services for people with epilepsy and other chronic health conditions and disabilities. The final deal increases the debt ceiling by $900 billion immediately with a second increase of $1.2 trillion to $1.5 trillion later in the year. The size of the second increase will be determined by Congress. A "Super Committee" comprised of 12 Members from both the Senate and the House and an equal number of Republicans and Democrats is currently being appointed to determine how to reach the $1.5 trillion goal. The Super Committee's work will begin September 23, 2011 and must be completed by December 23, 2011. This committee can consider deficit reduction strategies that include revenue increases as well as reforms of entitlement programs such as Medicare, Medicaid and Social Security. A trigger mechanism has also been built into the plan. If Congress does not enact at least $1.2 trillion in deficit reduction by January 1, 2013, automatic cuts across the board, known as sequestration, would be triggered with half of the cuts coming from defense spending and half from non-defense discretionary spending and Medicare providers (not Medicare beneficiaries). Social Security and Medicaid would remain exempt from cuts.

While the bill makes no initial cuts to Medicaid, Medicare, Social Security or Food Stamps, new spending caps have been set for discretionary spending from fiscal year 2012 through 2021. **Discretionary spending includes programs important to the Epilepsy Foundation such as research funding at the National Institutes of Health (NIH), the Centers for Disease Control and Prevention (CDC), the Health Resources Services Administration (HRSA), education, employment and many other programs that impact the lives of people with epilepsy.** The caps established in the law are lower than those originally agreed upon by Congress and may impact funding for programs that people with epilepsy depend on in the coming years. We will not have more detail on FY 2012 spending for epilepsy programs until October.

**July 26, 2011**

**Prescription Drugs & Bioequivalence – Comments to the Food and Drug Administration**

The Epilepsy Foundation joined the American Epilepsy Society, American Academy of Neurology, International League Against Epilepsy, and the National Association of Epilepsy Centers in joint comments to the Food and Drug Administration (FDA) Pharmaceutical Science and Clinical Pharmacology Advisory Committee. Collectively, our organizations represent a broad spectrum of the patients, providers, and researchers who seek to serve the health and welfare of the nearly three million Americans living with epilepsy and their families. This advisory committee is exploring the issue of bioequivalence in prescription drug products. We have previously expressed concerns with medication substitution and antiepileptic drugs to this committee. **The joint comments** reinforced the steps that this Committee and the FDA have taken over the past year to address bioequivalence, and specifically the recognition by the FDA that this is an area of key concern within
the epilepsy community. We applauded the steps the FDA has taken to address the Committee's recommendations from April 13, 2010. The supporting epilepsy organizations encouraged the FDA and the Committee to incorporate a definition of narrow therapeutic index (NTI) or critical dose drugs that allows for the inclusion of AEDs; and supported the FDA in funding research that will best address the bioequivalence concerns for AEDs and epilepsy patients.

Epilepsy Foundation public remarks to FDA advisory committee.

**Epilepsy Awareness – House Resolution 298**

The Epilepsy Foundation continues to garner support for House Resolution 298. Affiliates have been leading this effort in writing letters to their House members. House Resolution 298 seeks to boost epilepsy awareness in the federal agencies; it does not require any federal funding.

We have issued a Speak Up Speak Out call to action and advocates across the country are joining to ask for support of this important public awareness initiative. Join in our efforts to have every member of the House of Representatives as a cosponsor this important awareness statement – take action and call your Representative today: [http://www.capwiz.com/efa/callalert/index.tt?alertid=50636546](http://www.capwiz.com/efa/callalert/index.tt?alertid=50636546)

The Epilepsy Foundation strongly supports House Resolution 298 as a first step toward the introduction of legislation that would create a national epilepsy awareness campaign to increase the understanding of epilepsy and seizures in the workplace, schools and communities. Nearly 3 million Americans have epilepsy, yet epilepsy and seizures remains largely misunderstood by the public.

The Epilepsy Foundation is particularly concerned about the lack of epilepsy awareness among educators, employers, medical professionals and first responders as they often come into contact with someone having a seizure. This lack of understanding can have a serious impact on the access to communities, treatment, employment or education for people with epilepsy.

The Epilepsy Foundation is grateful for the leadership and support of Representatives Jo Ann Emerson (MO), Ed Perlmutter (CO) and Dan Benishek (MI), who introduced House Resolution 298. Please take time to contact your Representative today!

**Comparative Effectiveness Research**

Dr. Vera R. Jackson, President and CEO of the Epilepsy Foundation Metropolitan Washington presented comments at the Patient-Centered Outcomes Research Institute's (PCORI) Board of Governors meeting this week in Washington, D.C. Dr. Jackson advocated for CER that includes a goal of using real-world research, values individual patient outcomes and quality of life, and resists the urge to create a "one size fits all" medical decision for all health conditions. She encouraged the Board to continue to use a transparent process for feedback and to improve upon its outreach to patients and the public.

Tony Coelho, Chairman of the Partnership to Improve Patient Care (PIPC) was recently published in *The Hill* discussing the ways in which the Patient-Centered Outcomes Research Institute (PCORI) could greatly impact the future of health care. As a patient with epilepsy, Tony understands the importance of the comparative effectiveness research trials, as well as, the important role that the PCORI Board plays in ensuring the successful and objective transmission of patient-centered CER. You can read this news story here: [http://www.improvepatientcare.org/news-media/tony-coelho-little-known-board-could-have-big-health-care-impact](http://www.improvepatientcare.org/news-media/tony-coelho-little-known-board-could-have-big-health-care-impact)

**Medicaid**

**Meetings with White House Staff:** The Epilepsy Foundation joined in nationwide efforts to support Medicaid programs and to combat cuts proposed during ongoing budget negotiations. On July 13, 2011, the Consortium for Citizens with Disabilities (CCD), chaired by Epilepsy Foundation Senior Director of Government Relations, Donna Meltzer, was invited to bring two families to the White House to share how
Medicaid funds have supported their family members with disabilities. The families met with Melody Barnes, the President's Domestic Policy Adviser, and Jeffery Crowley, Senior Advisor on Disability Policy, at the White House to discuss the important role Medicaid plays in the lives of millions of Americans. The families did a wonderful job articulating the real impact Medicaid cuts would have on the lives of real people. Valerie Jarrett, Senior Advisor to the President, wrote an article for the White House blog regarding the visits. The article contains a link to the stories of individuals brought in by CCD as well as other organizations. Video of the interviews of the CCD families will be posted online soon. The Epilepsy Foundation also signed onto an ad in Roll Call, a Capitol Hill newspaper, which highlights the need to retain Medicaid funding for those who need it including people with epilepsy and other disabilities.

**Speak Up Speak Out Alert to White House:** As the White House and congressional leaders look for ways to trim federal spending, Medicaid is squarely on the chopping block. The Epilepsy Foundation and other advocacy groups are deeply concerned that the proposed Medicaid cuts will jeopardize the health, independence and quality of life of people with disabilities and seniors. Medicaid is a true lifeline for many people living with epilepsy; estimates show that 18% of people living with epilepsy rely upon Medicaid.

The President has conveyed a willingness to identify $100 billion in Medicaid savings. This would mean less federal funding for already cash-strapped states, likely forcing state governments to reduce reimbursement rates and cut services. This proposal would also eliminate the enhanced Federal Medical Assistance Percentages (FMAPs) used in determining the amount of Federal matching funds for State expenditures for assistance payments such as Medicaid.

The President needs to hear that there is strong opposition to arbitrary reductions to the Medicaid program and strong support for measures that contain costs while promoting the health, independence and civil rights of seniors and people with disabilities.

Advocacy groups nationwide, including the Epilepsy Foundation, are urging people to call the White House to protest the President's willingness to cut $100 million of Medicaid money as part of a debt reduction plan. Join in this effort by sharing the SUSO alert on your website and taking action today: