

**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/> -- 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/> -- 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> 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>

**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 thrive 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/) <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:** [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>

**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>

***EFA Staff at the HHS Regional Meetings:*** On Tuesday, November 8<sup>th</sup> 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>

**Reminder - Medicare Part D Prescription Drug Plans Open Enrollment:** October 15-December 7. Read more here: <http://epilepsyfoundation.ning.com/profiles/blogs/change-of-plans-medicare-open-enrollment>

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/>

**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 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/>

**September 26, 2011**

**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>

**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>

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>

## **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: <http://www.capwiz.com/efa/callalert/index.tt?alertid=50599751>