

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 the 12/10/12 edition of the publication Politico. See the letter here:

<http://www.epilepsyfoundation.org/getinvolved/advocacy/positionstatements/upload/NonprofitCommunityCharitableDeductLtr-Dec2012.pdf>

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 at this balanced approach. We expect more action by Congress after the November elections. 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>

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 yeas 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>

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> .

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 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.

August 15, 2012

100 Cosponsors of the RAISE Resolution (House Resolution 298) & Counting: On Friday, August 3rd, 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> **Congressional recess will end for the House on September 10th. 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>

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

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 June 18-29. 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/>. Find more ways to support the RAISE Resolution here <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/>

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](#) to see if your representative has signed on and ask them to co-sponsor House Resolution 298!

Institute of Medicine Report: On March 30th, the Institute of Medicine released an extensive report on epilepsy, entitled *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: <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 1st – 3rd, the Epilepsy Foundation held its annual Public Policy Institute (PPI) and [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 3rd, 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 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 <http://capwiz.com/efa/mlm/signup/> 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/>