

December 17, 2015

Hello,

My name is Jessica Waters and I have lived with epilepsy since I was 11 years old. Since I was first diagnosed I have been an advocate for the epilepsy community and want everyone living with epilepsy to #DareTo live to their fullest potential.

In 2014 I was one of 40 lucky teens living with epilepsy who participated in the Epilepsy Foundation's Teens Speak Up! conference. We learned how sharing our story on Capitol Hill and with local elected officials can advance the epilepsy community's policy priorities at the federal and state level. I've remained actively involved with the Epilepsy Foundation and this past summer I was invited to the White House as part of the Reach Higher Initiative. It was a great experience where I met with dozens of teens who had "beaten the odds" to graduate high school and were getting ready to start their first year of college. The President and First Lady both spoke to us and urged us to continue to work hard and beat the odds. It was a truly inspiring event and I'm happy to say I've just finished my first semester of college and am excited to start my second!



Jessica (Right) at the White House with another teen with epilepsy, Gabe (Left), and Brian (center), a member of our staff.

While I've been able to meet with my legislators and share my story in person, taking action online and sending emails is also incredibly important to benefit our entire community. You've already taken the first step by signing up for the Speak Up Speak Out network and it is your advocacy that has helped the Epilepsy Foundation bring about amazing changes throughout the country during the past year.

One of the biggest advocacy victories this year is the passage of the *Improving Regulatory Transparency for New Medical Therapies Act* (H.R. 639). On Wednesday, November 25 President Obama signed H.R. 639, which will help bring new medications to individuals who need them faster! The Epilepsy Foundation was a big supporter of this bill and our community really spoke up to encourage Congress to pass it, so thank you all!

However, there is still more work to be done. Our community needs to continue to speak up and urge our legislators to support the epilepsy community's policy priorities. Congress is working to finalize appropriations for next year, and we need to encourage them to continue funding epilepsy programs at the Centers for Disease Control and Prevention (CDC) and the National Institutes of Health (NIH). You can learn more and call your legislators at <http://bit.ly/EF16Fund>. Please share this with your friends and family and urge them to sign up for the Speak Up Speak Out list at <http://bit.ly/EFSignUp> so they can join us as we advocate for everyone living with epilepsy.

Thank you all for the work you've done and happy holidays!

Jessica Waters

November 19, 2015

Advocacy Victory to Bring New Therapies to Individuals Faster

On Monday, November 16, Congress unanimously passed the *Improving Regulatory Transparency for New Medical Therapies Act* (H.R. 639). This bill would improve the transparency and consistency of the Drug Enforcement Agency (DEA) review of new Food and Drug Administration (FDA) approved medications and bring these medications to individuals who need them faster. This legislation was a key priority of the Epilepsy Foundation and would not have been possible without the incredible efforts of our grassroots community, so thank you! Please also take a moment to thank your members of Congress for supporting this important piece of legislation at <http://bit.ly/HR639Thank>.

I Am Essential Coalition Urges HHS to Better Define Discrimination in ACA Plans

The Epilepsy Foundation, as a leader of the I Am Essential coalition, joined nearly 200 groups in urging the Secretary of the Department of Health and Human Services (HHS), Sylvia Burwell, to better define discriminatory practices when they issue the final rule regarding non-discrimination in health plans offered in the marketplace created by the Affordable Care Act. Some insurance companies are engaging in practices that impede access to medications and other health care services, negatively impacting many individuals with serious and chronic conditions. You can read more about the coalition and view the latest letter at www.epilepsy.com/ACA.

Experiencing Trouble Gaining Access to or Affording Medications and Specialists? Tell Us!

As part of our work with the I Am Essential coalition we are focused on ensuring that individuals with epilepsy can choose the best health plan for themselves. During this open enrollment season we urge you to look #BeyondPremiums when comparing plans to check that your

specialists and medications are covered. If you've experienced problems on your current plan, please take a moment to fill out our survey at <http://bit.ly/BPSurv> and let us know.

In The States

Rhode Island

On Friday, November 13 the Epilepsy Foundation New England honored Robbie T. and his mother, Lisa Phillips at their Annual Candlelight Dinner. Robbie and Lisa have been outstanding advocates for the epilepsy community, and they have twice participated in the Public Policy Institute and Teens Speak Up! conference to help raise awareness and meet with their members of Congress. We congratulate Robbie and thank him for being an example for all epilepsy advocates.

October 15, 2015

DEA Bill Passes out of Senate Committee

On October 1st, the Senate Committee on Health, Education, Labor, and Pensions (HELP) voted in favor of moving the *Improving Regulatory Transparency for New Medical Therapies Act* (S.481) forward and it now heads to the full Senate for a vote. This bill would bring transparency and consistency to the Drug Enforcement Agency (DEA) review of new Food and Drug Administration (FDA) approved medications. Access to new therapies is particularly important for the one third of people living with epilepsy who experience intractable or uncontrolled seizures, and the many more who experience significant adverse effects from medication. The House of Representatives has already unanimously passed this legislation, so we must now encourage the full Senate to do the same. Contact your Senators at <http://bit.ly/EFDEASen>.

Meet with Your Members of Congress

Earlier this month, Cailin, a past Teens Speak Up! conference attendee, met with Representative Ted Lieu in California to thank him and urge him to support the epilepsy community. Cailin was able to have a face to face meeting with the Congressman and tell him what it is like to live with epilepsy, making her appeals to him very personal. We encourage you all to meet with your members of Congress when they are back in the district. If you need to find your elected officials and their contact information, you can go to <http://cqrcengage.com/efa/home> and enter your zip code where it says "Find your elected officials." Once you've met with them, please send an email to ksu@efa.org letting us know how it went.

In the States

Michigan CBD Bill Passes House of Representatives

On October 7th, the Michigan House of Representatives passed HB 4210 which would allow for the production, regulation, and use of cannabis infused extracts, including cannabidiol (CBD) oil. Michigan already has a medical cannabis program in place, but this new bill will help clarify the law around CBD oil and similar extracts. This important bill now moves on to the Senate where

we will continue to work towards its passage. If you live in Michigan, keep an eye out for an email asking you to urge your Representatives to support CBD access in Michigan.

September 17, 2015

Dear Epilepsy Advocates,

As Congress gets back into session, this is a great time to share with you an update on our advocacy activities in the past year. The Epilepsy Foundation is committed to improving the lives of people living with epilepsy and seizures by improving access to care and incentivizing research and innovation to find new treatments and a cure. We have been actively engaged on numerous pieces of legislation on both the state and federal level with your support through the Speak Up Speak Out network. In Fiscal Year 2015 (July 1, 2014-June 30, 2015) this grassroots community sent more than 10,000 messages to members of the federal and state governments.

In this update you can read all about the work we have done to ensure that individuals living with epilepsy and other chronic conditions can get access to the medications that their physicians believe are best for them, as well as the initiatives we have supported to ensure that new drugs will get to patients faster and there are ample incentives for innovation in the biotechnology arena. To stress the importance of innovation and how a strong patent system plays into this, Phil Gattone, president and CEO of the Epilepsy Foundation, wrote an op-ed that was featured in Newsweek which you can read at <http://bit.ly/PhilNewsweek>.

To help us increase our influence in the coming year, we are focused on expanding our Speak Up Speak Out advocacy network. Your personal stories, letters, and calls make a big difference as we advocate for expanded access to care and greater research and innovation. If you know someone who is an active advocate for people living with epilepsy and seizures, ask them to join us in the fight by signing up at <http://bit.ly/EFSUSO>.

Thank you,



Angela Ostrom, Esq.
Chief Operating Officer & Vice President Public Policy
Epilepsy Foundation

Access

Timely access to appropriate care and effective coverage for epilepsy medications is a critical concern for people living with epilepsy, because anti-epilepsy drugs (AEDs) are the most common and most cost effective treatment for controlling and/or reducing seizures. Individuals living with epilepsy who experience a delay in accessing their medication due to prior authorization and step therapy requirements, high cost-sharing, medication substitutions without physician and patient consent, and onerous drug monitoring requirements, are at a high risk for

developing breakthrough seizures and related complications, including sudden, unexpected death in epilepsy (SUDEP).

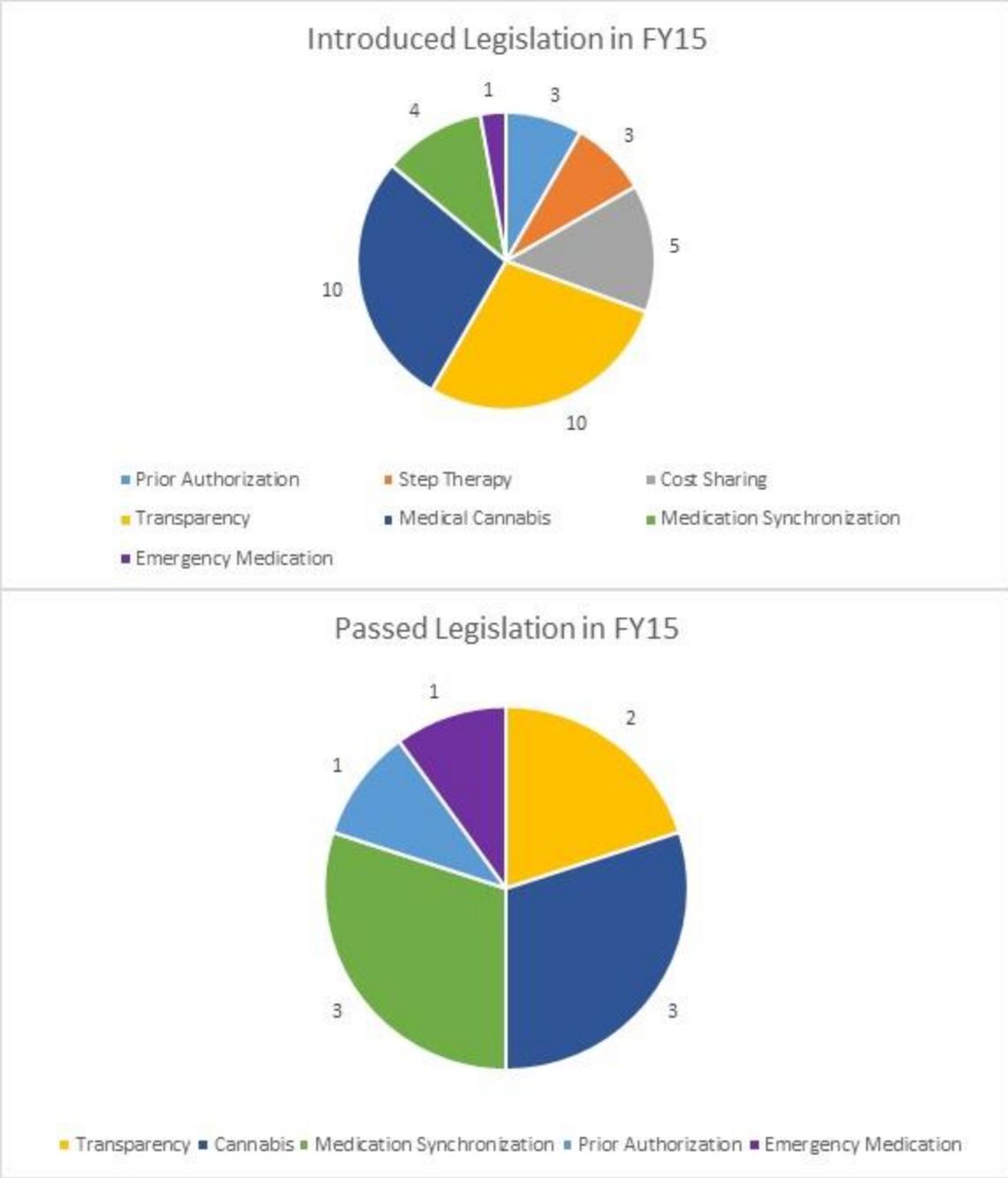
Bringing Transparency to Approval of New Treatments

The Epilepsy Foundation supports legislation in both the House and Senate that would require the Drug Enforcement Administration (DEA) schedule a new therapy within a set timeframe after approval by the Food and Drug Administration (FDA). When a new therapy with abuse potential is approved by the FDA, it is not available for patients until it has been scheduled by DEA in accordance with the Controlled Substances Act. Without an obvious cause or justification, the time period between initial drug approval by FDA and final scheduling by DEA has increased over the years, and new therapies can wait for DEA scheduling for more than a year. Access to new therapies is particularly important for the more than one million people living with epilepsy who experience intractable or uncontrolled seizures or have significant adverse effects to medication, as well as those living with other poorly managed medical conditions. The House version received unanimous support and is now in the Senate. Learn more at www.epilepsy.com/DEA.

Advocacy Across the States

The Epilepsy Foundation and its affiliate network across the country remain vigilant on the legislative and regulatory battles taking place at the state level to preserve meaningful access to quality care and treatments for people living with epilepsy and to provide support for epilepsy programs at the state level. The Foundation and its affiliates have been a voice for the epilepsy community at state houses and state agencies on a wide range of issues, including step therapy and prior authorization bills, formulary transparency, drug monitoring programs, and physician directed access to CBD oil for people living with intractable epilepsy. Through expert and patient testimony, public comments and letters, and grassroots letter writing campaigns, we've shared with policymakers the story of people living with epilepsy, their needs, challenges, and achievements. Learn more about our state advocacy activities at www.epilepsy.com/inthestates.

In FY 2015 we were active in 20 states and 28 bills, and a number of regulatory proposals.



Improving Access to Care in ACA Marketplace Plans

As a leader of the I Am (Still) Essential coalition, the Epilepsy Foundation has brought together more than 300 national and state patient and community groups to urge the Department of Health and Human Services (HHS) to eliminate barriers to care in the plans offered by the Marketplace created by the Patient Protection and Affordable Care Act (ACA). We have sent several group letters to the Administration, and have met with leaders at HHS, CMS, and OMB to share our concerns with limited benefits, high cost-sharing, and lack of transparency and uniformity in Marketplace plans. We have worked closely with our affiliates across the country to raise awareness with state leaders and local media about the need to improve access to care.

In the fall of 2014 we launched a survey, part of the #BeyondPremiums campaign, to gather information on access to care barriers faced by the epilepsy community and our findings are informing our advocacy activities at the state and federal level. The Administration has addressed several of the issues raised by the coalition, and we continue to advocate for stronger federal oversight as we await the 2016 plans and now that they have recently released a much anticipated nondiscrimination proposed rule. You can learn more about the campaign and view all the letters at www.epilepsy.com/aca.

Preserving Access to Medications in Medicare

Medicare's Six Protected Classes policy ensures greater protections for six classes of medications, including anticonvulsants for epilepsy. The Epilepsy Foundation joined with many other organizations in opposition to a 2014 proposed rule that would have removed three of the six protected classes. Although CMS has announced it would not pursue the proposed changes, the Foundation continues to raise awareness with Congress and the Administration of the need for the Six Protected Classes and the access hurdles that make it hard for beneficiaries to access medications in a timely manner despite the protected class status. In March 2015 Senator Charles Grassley (IA) and Senator Sherrod Brown (OH) introduced legislation (S 648) to strengthen the Six Protected Classes in Medicare Part D. The Partnership for Part D Access, of which the Foundation is a member, was instrumental in securing the introduction of S 648. In June 2015 the Foundation met with CMS to discuss how utilization management and high cost-sharing stand in the way of timely and meaningful access to epilepsy treatments for Medicare beneficiaries and to explore how CMS can ensure Congressional intent of meaningful access can be realized. Learn more about www.epilepsy.com/medicare.

Removing Barriers to Cannabis Research and Compassionate Access

The Epilepsy Foundation is committed to supporting physician directed care, and to exploring and advocating for all potential treatment options for epilepsy, including cannabidiol (CBD) oil and medical cannabis for individuals with intractable epilepsy. People with uncontrolled seizures live with the continual risk of serious injuries and loss of life. This is why many individuals who have run out of options turn to CBD, and why the Foundation believes nothing should stand in the way of patients gaining access to this potentially lifesaving treatment.

The Foundation has actively advocated in support of several bills to reschedule cannabis and remove CBD from the Controlled Substances Act in the House and Senate, and an amendment to the House CJS appropriations bill to prevent DOJ from interfering with state cannabis program. Since January 2014 the following states passed bills to improve access to medical cannabis ranging from state regulated cultivation, production, and dispensing, to possession-only and study bills: FL, GA, IA, IL, KY, MD, MN, MO, MS, NC, NY, OK, TN, TX, UT, VA, and WI. Learn more at www.epilepsy.com/cannabis.

Research & Innovation

Innovation is of particular importance to the nearly one million people living with epilepsy who don't have their seizures under control and are seeking new treatments and a cure, as well as

many Americans living with complex chronic and rare conditions that are not appropriately managed with current treatment options.

21st Century Cures Advances to Senate

The Epilepsy Foundation supports the 21st Century Cures Act (H.R. 6), which would accelerate the discovery, development, and delivery of lifesaving medical treatments by bringing the nation's health care innovation infrastructure into the 21st Century. HR 6 would strengthen the patient voice in the regulatory environment, increase funding for the National Institutes of Health and Food and Drug Administration, modernize clinical trials; remove barriers to greater research coordination; create incentives for developing therapies for rare conditions; and require the Centers for Disease Control and Prevention to set up a surveillance system for neurological diseases which we believe could include epilepsy. Learn more about our advocacy activity in support of 21st Century Cures at www.epilepsy.com/21stcenturycures.

Patent Reform Could Undermine Investments in New Therapies

At a time when we need to be creating incentives for investment in innovative therapies, Congress is considering a patent reform bill that could make future advances in treating epilepsy and many other complex chronic conditions all too rare. The Innovation Act threatens to undermine patent protection by creating a host of new administrative hassles for those defending their patents in court, which could deter investors and researchers from pouring funds and years into the development of new therapies. A strong and secure patent system that encourages investments in innovative treatments and devices is critical for the millions of Americans waiting for breakthrough therapies and a cure to live their lives to their fullest potential. The Epilepsy Foundation brought together more than 100 organizations on a September 8 letter to the House and Senate Judiciary Committees urging Congress to preserve the Drug Price Competition and Patent Term Restoration Act (commonly referred to as the Hatch-Waxman Act) and the Biologics Price Competition and Innovation Act (BPCIA) as it considers comprehensive patent reform. This builds on our advocacy efforts and a May 21 letter that brought more than 90 groups together in support of strong patents that sustain medical innovation. Learn more about our advocacy in support of strong patents that sustain medical innovation, including an op-ed from Phil Gattone that ran in Newsweek, at www.epilepsy.com/patentsforinnovation.

Medicines in Development for Neurological Conditions Report

The Epilepsy Foundation has partnered with PhRMA on the release of a report on the drug development pipeline for neurological conditions. Scientists around the globe are collaborating to find new or more effective treatments for patients with these complex disorders that attack the nervous system and there are [420 medicines](#) (22 of them for epilepsy) in human clinical trials or under review by the Food and Drug Administration (FDA), these new treatments represent a growing understanding of neurological disorders. View the report and learn more at <http://bit.ly/MedInDev>.

July 17, 2015

Advocate Spotlight: Jim Ross Fights for Emergency Medication Access

In 2011, Jim Ross and his wife Victoria were preparing for their son Emmett to begin riding the bus to school. While most families are concerned about their child riding the bus for the first

time, Jim and Victoria had an additional worry. Emmett has epilepsy and he could need access to emergency epilepsy medication on the bus. The school couldn't provide a nurse who could ride on Emmett's bus and the Ross family started searching for alternatives so Emmett could ride the bus with his peers. This was the beginning of their advocacy journey to allow trained, nonmedical school personnel to administer emergency anti-seizure medications when a nurse is unavailable.

When Jim and Victoria first embarked on this journey in 2011, they knew very little about the legislative process and how to get a bill introduced and passed. But that didn't stop him and he started reaching out to legislators. Eventually Jim testified before the Public Health Committee and encouraged them to allow individuals other than nurses to administer emergency medications to those with epilepsy. Jim convinced his own Representative Steinberg to introduce the bill. Jim also found a partner in Representative Kim Fawcett who heard his story and wanted to act. Representative Fawcett introduced legislation in 2012 and Jim began working in earnest to get this important bill passed.

This first piece of legislation unfortunately didn't pass, but Jim and his family received great news during the year. The school district agreed to have a nurse ride on Emmett's bus. Even though their own personal fight was now over, they couldn't give up and were determined to change the law to help all families in Connecticut who have a school-age child living with epilepsy.

As Jim and Victoria learned more about the legislative process, they began recruiting grassroots volunteers to help them share their message. Most importantly, they began taking slow but steady steps to work with opponents of their bill. The legislation was again reintroduced in 2013 and 2014, each year the language got stronger and gained more support. But Jim knew ... He pursued a year-long course sponsored by the Council on Developmental Disabilities called *Partners in Policymaking* which he credits with having taught him how to be an effective advocate navigating the complexities of the legislative process.

Jim was eventually able to sit down with leadership in the legislature and the Association of School Nurses who had opposed the legislation in the past. They were able to work together to create a bill that both could support and that would allow trained, nonmedical school personnel to administer emergency anti-seizure medications. With this new partnership, the strength of their grassroots network, and support from the Epilepsy Foundation, Jim and his legislative allies (Representative Fawcett lost her 2014 election) reintroduced their legislation in 2015. The bill again stalled, but Jim and Representative Jonathan Steinberg were able to craft an amendment to House Bill 7023 that was adopted. As HB 7023 moved forward, so did the chance that children living with epilepsy and attending school would have better access to emergency medications. In turned our 2015 was the year, and HB 7023 cleared the legislature and was signed in to law on June 30. Such an achievement wouldn't have been possible without Jim, Victoria, Emmett, and their daughter Olivia. This was a great grassroots achievement that is due to two determined parents. As Jim remarked, "it started with a little boy...and became a much bigger thing."

21st Century Cures Passes House, Goes on to Senate

On July 10, the *21st Century Cures Act* (H.R. 6) passed the House of Representatives by a vote of 344 to 77. H.R. 6 would accelerate the discovery, development, and delivery of lifesaving medical treatments by bringing the nation's health care innovation infrastructure into the 21st Century. The bill would strengthen the patient voice in the regulatory environment, increase funding for the National Institutes of Health and Food and Drug Administration, modernize clinical trials; remove barriers to greater research coordination; and create incentives for developing therapies for rare conditions. H.R. 6 would also require the Centers for Disease Control and Prevention to set up a surveillance system for neurological diseases that could include epilepsy.

We applaud all of the members who supported the *21st Century Cures Act* and encourage the Senate to move quickly on this important legislation to help those living with epilepsy and other chronic conditions. Learn more at epilepsy.com/21stCenturyCures

In the States

Maine Legislature Overrides Veto to Improve Health Plan Transparency

On June 23 the Maine legislature overrode Governor LePage's veto of LD 636, which would improve health plan transparency. Health plans in Maine will now be required to post their prescription drug formularies online in a manner that will allow individuals to search and compare formularies and drug coverage. Health plans will also be required to include information on access barriers like prior authorization, as well as cost-sharing requirements. We applaud the legislature for overriding the Governor's veto to help individuals living with epilepsy and other chronic conditions who need to be sure their medications are covered.

New York SUDEP Bill Passes Legislature

As we mentioned in our last Highlights from the Hill, the New York legislature passed S. 1789 and A. 2359 which would require the medical portion of a death certificate to include a determination of whether the person suffered a sudden, unexpected death in epilepsy (SUDEP). This data is critical to improve our understanding of SUDEP and epilepsy related death and allow us to better identify risk factors and preventive strategies.

However, these bills still haven't been signed in to law and are waiting for Governor Cuomo's signature. If you live in New York, please take a moment to urge Governor Cuomo to sign these important bills at <http://bit.ly/15NYSUDEP>. You can learn more about SUDEP, including how to decrease your risk, at www.epilepsy.com/sudep.

June 18, 2015

House Supports Amendment to Protect Medical Cannabis Patients

The House of Representatives recently supported an amendment to the Commerce, Justice, and Science Appropriations bill that would prevent the Department of Justice from interfering with state medical cannabis programs. The amendment was passed in a strong bipartisan vote of 242 to 186. This strong show of support for medical cannabis programs is an important step towards securing safe and legal access to this promising treatment option.

House to Vote On 21st Century Cures Bill

Congress is considering bipartisan legislation, the 21st Century Cures Act (H.R. 6), which would accelerate the discovery, development, and delivery of lifesaving medical treatments by bringing the nation's health care innovation infrastructure into the 21st century. We expect the House to vote on H.R. 6 soon, so please take a moment and urge your Representative to support this important bill at <http://bit.ly/21stCures>.

In the States

Texas

On June 1st, Governor Greg Abbott signed SB 339 to create a tightly regulated system for the cultivation, production, and distribution of cannabidiol (CBD). We were proud to support SB 339 in partnership with the Epilepsy Foundation Central & South Texas, the Epilepsy Foundation Texas- Houston/Dallas-Fort Worth/West Texas, and C.A.F.E. Texas to bring this treatment option to Texans living with uncontrolled epilepsy.

New York

The New York Legislature has passed legislation (S. 1789/A. 2359) which would require the medical certificate portion of a death certificate to include a determination of whether the person suffered a sudden, unexpected death in epilepsy (SUDEP). This data is critical to allow us to better identify risk factors and preventive strategies. We were proud to work with our New York affiliates to support this important legislation and together we encourage Governor Cuomo to sign it without delay.

Iowa

The Iowa Legislature has sent SF 510, a patient literacy and transparency bill, to Governor Branstad for approval. This bill would make health plans more transparent and help individuals navigate the appeals process. The Epilepsy Foundation and the Epilepsy Foundation North/Central Illinois, Iowa, & Nebraska have encouraged Governor Branstad to sign this important bill to ensure that comprehensive, easy to understand drug coverage information is available for Iowa residents, making it easier for all individuals, especially those living with complex chronic conditions like epilepsy, to make informed decisions when selecting a health plan. If you or someone you know lives in Iowa, please take a moment to contact the Governor at <http://bit.ly/IASF510>. You can also read the letter to Governor Branstad at <http://bit.ly/EFIowa>.

May 21, 2015

Senators Gardner and Wyden Introduce CBD Legislation

On Wednesday, May 13th Senators Cory Gardner (CO) and Ron Wyden (OR) introduced the *Therapeutic Hemp Medical Access Act of 2015* (S. 1333), which would remove therapeutic hemp and cannabidiol from the Controlled Substances Act so that people living with epilepsy and uncontrolled seizures can gain access to this treatment option. This bill is a companion bill to H.R. 1635, introduced by Representative Scott Perry (PA). We strongly support this and other compassionate access legislation to help protect individuals in states with medical cannabis and

lift federal barriers to research on the connection between cannabidiol, cannabis, and epilepsy. You can read more and urge your Senators to support S. 1333 at www.epilepsy.com/cannabis.

I Am (Still) Essential Campaign Urges Secretary Burwell to Review 2016 Plans

On Thursday, May 15th the I Am (Still) Essential campaign sent a letter to the Department of Health and Human Services (HHS) Secretary, Sylvia Mathews Burwell, urging her to conduct a thorough review of the 2016 plans and reject those that do not comply with new patient protections included in the most recent Notice of Benefit and Payment Parameters for 2016. More than 215 organizations, including 18 Epilepsy Foundation affiliates, spoke with a united voice and urged the Secretary to transparency and improved access to care in ACA plans by rejecting discriminatory practices such as high patient cost-sharing and excessive use of prior authorization and other medical management techniques. The Epilepsy Foundation is a leader of the I Am (Still) Essential campaign. Read the letter and learn more about the campaign at www.epilepsy.com/aca.

Epilepsy Foundation Sends Group Letter to Congress to Protect Patents and Innovation

Today, the Epilepsy Foundation and a diverse group of more than 90 national and state advocacy organizations sent a letter to the House and Senate Judiciary Committees. The letter urges Congress to maintain a strong patent system that encourages investments in medical breakthroughs. Patent protections can accelerate the discovery and development of new therapies and devices that individuals with epilepsy and many other complex, chronic conditions need to help them live their lives to the fullest potential. Read the letter and a statement from our CEO at www.epilepsy.com/patentsforinnovation.

In the States

Iowa

The Iowa Legislature has sent HF 632, an insurance bill to the Governor for approval. The bill would require insurance companies respond to all prior authorization requests within 72 hours, improving access to care and health outcomes for Iowa residents living with epilepsy and other chronic conditions. The Epilepsy Foundation and the Epilepsy Foundation North/Central Illinois, Iowa, & Nebraska have encouraged Governor Branstad to sign this important bill to ensure that Iowa residents can access the medication they need in a safe and timely manner. If you or someone you know lives in Iowa, take a moment to urge Governor Branstad to sign HF 632 at <http://bit.ly/IAHF632>.

Minnesota

The Senate version of the Health and Human Services (HHS) budget includes language that makes limits prior authorization makes the process more transparent. These changes would speed up the prior authorization process and allow Minnesota residents to access the medication they need in a safe and timely manner. If you or someone you know lives in Minnesota, take a moment to urge your representative to support the inclusion of language improving the prior authorization process as they work on a compromise budget bill at <http://bit.ly/MNHHSBA>.

Texas

On Tuesday, May 19th the Texas legislature passed SB 339, which would create a tightly regulated system for the cultivation, production, and distribution of cannabidiol (CBD). We have supported this legislation in partnership with the Epilepsy Foundation Central & South Texas; the Epilepsy Foundation Texas – Houston/Dallas-Fortworth/West Texas; and C.A.F.E. Texas. SB 339 now heads to Governor Abbott and we are hopeful that he will sign the bill and bring this treatment option to Texans living with uncontrolled epilepsy.

Wisconsin

The Wisconsin Senate is considering legislation, SB 138, which would improve transparency in health plans offered in Wisconsin's insurance marketplace created by the Affordable Care Act (ACA). SB 138 aims to increase transparency and access to vital information about qualified health plans, including online availability of prescription drug coverage and formularies, creating a more understandable and consumer-friendly experience for individuals searching for the treatments they need. If you or someone you know lives in Wisconsin, take a moment to urge the Wisconsin Senate to support SB 138 at <http://bit.ly/WISB138>.

April 23, 2015

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 April 12th through 14th.

Representatives from 33 states and 36 affiliates participated in a day and a half of learning and advocacy training that culminated with a great, but rainy, Hill day on April 14th. 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 more than 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/EFYOS>.

We would like to spotlight Abby, one of the great teens who was at the conference who has been featured in her local paper. You can read her story at <http://bit.ly/EFTSUGW>.

Reps. Griffith and Blumenauer Introduce Compassionate Access Act to Lift Federal Barriers to Cannabis Research

On Tuesday, April 14th Representatives Morgan Griffith (VA) and Earl Blumenauer (OR) introduced the Compassionate Access Act (H.R. 1774), which would move cannabis out of Schedule I, remove cannabidiol from the Controlled Substances Act, and remove federal barriers to research on cannabis. By rescheduling cannabis this legislation would help protect patients in states with medical cannabis programs and lift many federal barriers that stand in the way of

researchers studying the potential benefits of medical cannabis. Please take a moment to urge your Representative to support H.R. 1774 at <http://bit.ly/HR1774>.

In The States

Florida

On Tuesday, April 7th the Epilepsy Foundation of Florida (EFOF) honored six Florida lawmakers with the Champions of the Heart award for their individual efforts to help Florida residents and families impacted by epilepsy. Champions of the Heart honorees included Senators Jeff Brandes, Rene Garcia, and Denise Grimsley; and Representatives Katie Edwards, Matt Gaetz, and Matt Hudson. These elected leaders were chosen for their support for preserving epilepsy resources and promoting new treatment options for individuals living with epilepsy. We applaud all legislators who work in support of the epilepsy community.

Iowa

On March 30th, the Iowa Senate Ways and Means committee sponsored S.F. 484, which would establish safe and legal access to medical cannabis for Iowa residents living with epilepsy and other debilitating conditions. Iowa's current CBD law has not improved access to CBD as a treatment option for uncontrolled seizures because it does not allow for state-regulated cultivation of cannabis for producing and dispensing medical cannabis treatments. To read our letter in support of this important bill, go to <http://bit.ly/EFIowa>.

Maine

The Maine Senate is considering two pieces of legislation which would improve transparency and limit step therapy. SP 229 would make prescription drug coverage and formularies more understandable and consumer-friendly for individuals searching for the drugs they need, whether they are reviewing their current health insurance plan or comparing new ones. SP 103 would limit the use of step therapy to ensure that people with epilepsy and other chronic conditions have access to the right medications in a timely manner and also limit costs for those who have completed the step therapy requirements for non-preferred drugs. Both of these bills are important to help those living with epilepsy in Maine get appropriate and affordable care as easily as possible. To read our letters in support of these important bills, go to <http://bit.ly/EFMaine>.

New Hampshire

On Tuesday, April 21st the New Hampshire Senate Health and Human Services Committee held a hearing on HB 476, which would add epilepsy and other chronic conditions to the list of qualifying conditions for New Hampshire's medical cannabis program. The hearing was well attended by individuals in support of the bill and we are hopeful that it will receive a positive vote in the committee soon.

New York

The New York legislature is considering two bills which would that would benefit epilepsy research. A. 2359, introduced by Assembly Member Brindisi, and S. 1789, introduced by Senator Griffo, would require the medical certificate portion of a death certificate to include a determination of whether the person suffered a sudden, unexpected death in epilepsy (SUDEP).

This data is critical to improve our understanding of SUDEP and epilepsy related death and allow us to better identify risk factors and preventive strategies. If you live in New York, take a moment to urge the New York legislature to cosponsor A. 2359 and S. 1789 at <http://bit.ly/EFNYSUDEP>.

Rhode Island

The Rhode Island House of Representatives is considering legislation, HB 5605, which would limit the use of step therapy to ensure that people with epilepsy and other chronic conditions have access to the right medications in a timely manner. It would also bring clarity and transparency to the step therapy process and limit costs for those who have completed the step therapy requirements for non-preferred drugs. To read our letter in support of this important legislation, go to <http://bit.ly/EFRhodeIsland>.

March 24, 2015

CARERS Act Introduced in the Senate

Senators Cory Booker (NJ), Rand Paul (KY), and Kirsten Gillibrand (NY), have introduced legislation to lift federal barriers to research on cannabis and CBD, and protect individuals in states with medical cannabis programs. The Compassionate Access, Research Expansion and Respect States (CARERS) Act (S. 683) would move cannabis to Schedule II and to remove cannabidiol (CBD) from the Controlled Substances Act. For individuals experiencing multiple seizures every day, cannabis is a treatment option they would like to consider with their care team when other options have failed. Medical use of cannabis has been legalized in 23 states and the District of Columbia, and people living with uncontrolled seizures have reported beneficial effects and reduced seizure activity when using medical cannabis, especially CBD oil. Urge your Senators to support the CARERS Act at <http://bit.ly/EFS683> to facilitate research on cannabis and help the epilepsy community gain safe, legal access to this treatment option.

DEA Scheduling Bill Passes House

Thanks to the advocacy of the epilepsy community, on March 16th the House of Representatives passed the Improving Regulatory Transparency for New Medical Therapies Act (H.R. 639), which would bring transparency and consistency to the Drug Enforcement Agency (DEA) review of new Food and Drug Administration (FDA) approved medications. The bill now moves to the Senate, and we will continue to advocate for passage of this important legislation and need your help! Access to new therapies is particularly important for the one third of people living with epilepsy who experience intractable or uncontrolled seizures, and the many more who experience significant adverse effects from medication. Urge your Senators to support H.R. 639 at <http://bit.ly/EFSenDEA> so safe and innovative treatments can get to people living with epilepsy in a more timely and predictable manner.

Senators Introduce Legislation to Preserve Six Protected Classes

On March 4th Senator Charles Grassley (IA) and Senator Sherrod Brown (OH) introduced legislation (S 648) to strengthen the Six Protected Classes in Medicare Part D. Epilepsy medications are part of the protected classes in the Medicare program and the Epilepsy Foundation has strongly supported steps to maintain this important patient protection. The Six

Protected Classes help to prevent forced medication switching which can lead to serious consequences, like breakthrough seizures. The Partnership for Part D Access, of which we are a member, was instrumental in securing the introduction of S 648. Read our letter in support of this important bill at <http://bit.ly/EFS648>.

Epilepsy Foundation Joins Letter to Extend CHIP Funding

We joined more than 1,500 national, state, tribal, and local organizations in a letter urging Congress to provide a four-year funding extension for the Children's Health Insurance Program (CHIP). For nearly two decades, CHIP has been an essential source of coverage for families, ensuring access to high-quality and affordable health care for children. It is important that Congress acts quickly to ensure that there will be no interruption in coverage for the more than 10 million children enrolled in CHIP. You can read the letter at <http://bit.ly/CHIP2015>.

In The States

South Dakota

On March 12th South Dakota Governor, Dennis Daugaard, signed legislation (SB 118) to improve health plan transparency for all plans offered in South Dakota so everyone, especially persons living with complex chronic conditions can select a plan that they know covers their medications and specialists. Read our support letter at <http://bit.ly/EFSDakota>.

Illinois

The Illinois legislature is considering legislation (HB 3605) which would limit the cost of drugs offered in the state's ACA Marketplace to help those living with chronic conditions set a predictable and more affordable budget for their health care needs. HB 3605 would cap a single drug to \$100 per month for silver, gold, and platinum plans, and \$200 for bronze plans.

Maryland

The Maryland legislature is considering legislation (HB 990 and SB 834) which would limit mid-year formulary changes, prohibit discriminatory benefit design, and ensure that new medications are reviewed quickly for possible addition to health plan formularies. Making these changes would improve access to care for those living with epilepsy and other chronic conditions. Read our joint support letter at <http://bit.ly/EFMaryland>. If you're a Maryland resident ask your legislators to support HB 990 and SB 834 at <http://bit.ly/EFMDAccess>.

Virginia

On February 26th Virginia Governor, Terry McAuliffe, signed legislation (HB 1445) to provide an affirmative defense to those living with intractable epilepsy who possess cannabidiol oil (CBD) with a written certification from a physician. This is an important step forward in protecting patients with epilepsy, but we urge the Virginia legislature to establish a full medical cannabis program when they reconvene next year to help ensure people living with epilepsy have safe, legal access to this treatment option.

Legislation (HB 1942 and SB 1262) that would improve the prior authorization process is awaiting Governor McAuliffe's signature after passing the legislature. The bills would help

improve access to care for those living with epilepsy and other chronic conditions by requiring Virginia's health plans to comply with clear guidelines for a more patient-centered process. We urge Governor McAuliffe to sign this legislation before the deadline on March 29th. Read our support letter at <http://bit.ly/EFVirginia>.

Join the Capitol Crusaders

The Epilepsy Foundation's Advocacy Department has created a team for the National Walk for Epilepsy. Join the Capitol Crusaders at <http://bit.ly/CapitolCrusaders15> and support us in our fight to improve the quality of life for people living with epilepsy and their families!

February 19, 2015

Legislation Would End Scheduling Delays at DEA

Congress recently reintroduced bipartisan legislation, *Improving Regulatory Transparency for New Medical Therapies Act* (H.R. 639 & S. 481), which would bring transparency and speed up the Drug Enforcement Agency (DEA) scheduling process once a new therapy has been approved by the Food and Drug Administration (FDA). These bills would allow safe and innovative treatments to reach patients in a more timely and predictable manner, while preserving DEA's role within the scheduling process. H.R. 639 has already been marked up by the House Energy and Commerce committee and is headed for the House floor. Urge your members of Congress to support these bills at <http://bit.ly/EFDEA2015>. Learn more about improving access to new therapies at www.epilepsy.com/DEA.

Epilepsy Foundation Supports EEOC Lawsuit

The Equal Employment Opportunity Commission (EEOC) recently filed a lawsuit against a few large employers with onerous employee wellness programs that EEOC deemed were in violation of the ADA. The Epilepsy Foundation supports workplace wellness programs that improve employee health and lower medical costs, and which are designed and implemented in such a way that they do not penalize employees or otherwise violate their rights under the Americans with Disabilities Act (ADA), and comply with requirements under the Affordable Care Act (ACA) and the Health Insurance Portability and Accountability Act HIPAA. The ADA protects employees with disabilities from being forced to disclose medical information unrelated to their ability to do their jobs. The EEOC's enforcement actions to safeguard this right, in cases where steep financial penalties were used to force such disclosures, are important to the patient and disability communities and are consistent with the law.

The Senate Health, Education, Labor and Pensions (HELP) Committee recently held a hearing on employee wellness programs, partly in response to a lawsuit filed by the EEOC, and the White House has expressed some concern with the EEOC lawsuit.

The Epilepsy Foundation joined patient advocacy and disability rights organizations in a letters to the EEOC in support of the lawsuit, and to the White House in support of the EEOC. The Foundation also submitted a letter to the Senate HELP Committee expressing our concern with

employee wellness programs that violate the nondiscrimination provisions in the ADA. You can view the letters at <http://bit.ly/EFNondiscrimination>.

President's Budget Request Signals Support for Research and Programs at HHS

On February 2nd the President released his budget request for Fiscal Year 2016, which marks the start of the federal budget and appropriations process. The Department of Health and Human Services (HHS) has release their "Budget in Brief" outlining how the President's budget request would support major initiatives at HHS. According to the "Budget in Brief" the National Institutes of Health (NIH), and several institutes including the National Institute of Neurological Disorders and Stroke (NINDS), as well as the Centers for Disease Control and Prevention (CDC), would receive significant increases in funding, signaling investments on the work these two agencies carry out is important to the Administration. To read the "Budget in Brief" go to <http://bit.ly/EFBIB16>.

In The States

Transparency

The Epilepsy Foundation supports proposals that would improve transparency requirements for health plans. Persons living with complex chronic conditions know they must select a plan that covers their medications and specialists, but obtaining the information they need to confirm if their drugs and specialists are covered, and the costs or restrictions associated with these benefits, is often unavailable or incredibly time consuming to acquire. Several states are considering legislation to address lack of transparency by requiring that plans provide a complete and update-to-date formulary and provider network information using a standard template, often available online, as well as information on restrictions, such as prior authorization or step therapy requirements, and on cost-sharing and out of pocket costs. Below is a list of states considering transparency legislation supported by the Epilepsy Foundation:

- Arizona is considering SB 1420
- Hawaii is considering SB 301
- Iowa is considering HF 349
- Minnesota is considering SF 934
- Nebraska is considering LB 531
- South Dakota is considering SB 118
- Virginia is considering HB 1339

Prior Authorization

The Epilepsy Foundation supports proposals that would create a patient-centered and streamlined prior authorization process, to ensure individuals have timely access to the medication they need, including standard forms that can be submitted electronically and requirements that insurance companies respond to urgent prior authorization and all other prior authorization requests within a set timeframe. Below is a list of states considering prior authorization legislation supported by the Epilepsy Foundation:

- Virginia is considering HB 1942 and SB 1262. Take action at <http://bit.ly/EFVAPA>.
- Minnesota is considering SF 934

Cost-Sharing

The Epilepsy Foundation supports proposals that would limit high cost-sharing for epilepsy medications, the most effective seizure control treatment option for most individuals living with epilepsy. High co-pays and co-insurance can make it hard to afford lifesaving medications, leading many people to skip doses or not fill their prescriptions at all, and resulting in preventable seizures and medical complications, along with lost wages and productivity, not just for the individuals living with epilepsy but also their families and communities. Below is a list of states considering cost-sharing legislation supported by the Epilepsy Foundation:

- Kentucky is considering SB 31 and HB 146. Take action at <http://bit.ly/KYCopay>.
- Illinois will consider legislation this session

Connecticut Considers Improved Access to Emergency Medications in Schools

The Connecticut General Assembly is considering legislation (HB 6288) that would improve access to emergency seizure medications in all schools and school activities by allowing for the administration of emergency seizure medication by trained, non-medical personnel when a school nurse is not available. Children living with epilepsy should have access to the full range of school and school-related experiences in the least restrictive environment, and allowing trained, non-medical personnel to administer emergency seizure medication for a child experiencing a life-threatening seizure would be a first step. If you're a Connecticut resident urge your Representative to support HB 6288 at <http://bit.ly/CTHB6288>.

Utah May Limit Access to Medications in the Medicaid Program

The Utah Legislature is considering legislation (HB 156) that would limit access to epilepsy medications in the state's Medicaid program, by removing their current protected class status. The Epilepsy Foundation strongly opposes policies intended to restrict access to physician-directed care that unnecessarily prolong ineffective treatment, especially for vulnerable populations like those served by the Medicaid program. Limiting access to medications for epilepsy patients impacts not just the individuals living with epilepsy but also their families and communities. Patients with epilepsy who experience a delay in accessing their medication are at higher risk for developing preventable seizures, which lead to significant medical costs and

complications, including accidents, emergency room visits, and hospitalizations, along with lost wages and productivity. If you're a Utah resident urge your Representative to oppose HB 156 at <http://bit.ly/UTHB156>.

Medical Cannabis

The Epilepsy Foundation is committed to supporting physician directed care, and to exploring and advocating for all potential treatment options for epilepsy, including cannabidiol (CBD) oil and medical cannabis. People with uncontrolled seizures live with the continual risk of serious injuries and loss of life. If a patient and their healthcare professionals feel that the potential benefits of medical cannabis for uncontrolled epilepsy outweigh the risks, then families need to have that legal option. Nothing should stand in the way of patients gaining access to this potentially lifesaving treatment. Below is a list of states considering cannabis legislation that the Epilepsy Foundation has supported:

- Virginia is considering HB 1445
- Hawaii is considering HB 321

Join the Capitol Crusaders

The Epilepsy Foundation's Advocacy Department has created a team for the National Walk for Epilepsy. Join the Capitol Crusaders at <http://bit.ly/CapitolCrusaders15> and support us in our fight to improve the quality of life for people living with epilepsy and their families!

January 16, 2015

New Congress brings New Opportunities

January 3rd marked the start of the 114th Congress with 73 new Members of Congress coming to D.C. There are 13 new Senators and 60 new Representatives, which presents a perfect opportunity for the epilepsy community to reach out to share our stories and educate new Members about issues important to those living with epilepsy. To find out who represents you in Congress go to <http://capwiz.com/efa/dbq/officials/>.

Epilepsy Foundation Seeks Greater Protections in ACA Marketplace Plans

As part of the I Am (Still) Essential campaign, the Epilepsy Foundation and 32 affiliates joined nearly 300 national and state patient organizations on a December 19th letter to HHS Secretary Burwell in response in a recently proposed rule for ACA plans. The letter highlights some of the positive changes proposed by HHS and suggests additional patient protections that could improve meaningful access to quality care. The Epilepsy Foundation also submitted a detailed comment letter on the proposed rule. You can view the letters at www.epilepsy.com/aca.

There is Still Time to Enroll in an ACA Marketplace Plan! Look #BeyondPremiums When Considering Plans

The Epilepsy Foundation has been actively advocating with HHS Secretary Burwell and other agency staff about the need to improve access to care in ACA Marketplace plans, especially for people living with chronic conditions like epilepsy. As we continue to advocate for increased access to care, **we want to hear from you about any challenges you've faced this year when trying to gain access to and affording the medications and specialists you need.** Are your medications covered by your plan? Have you faced high out-of-pocket costs for them? Did you have to switch medications or specialists because they were not covered by your plan? **We have created a survey at <http://bit.ly/EFSurv> to capture this information, which will make it easier for us to raise awareness with federal and state officials about the need to look #BeyondPremiums and improve access to care in ACA Marketplace plans,** especially for people living with chronic conditions like epilepsy.

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

In The States

State Legislatures are Starting Up

Many of the state legislatures are getting under way, and there will be many new bills introduced which could impact the epilepsy community. We are working with our affiliates throughout the country to monitor legislation and advocate to improve the lives of those living with epilepsy. Be on the lookout for action alerts urging you to contact your legislators to share your story, because it is a great way to support the epilepsy community's policy priorities.

Oklahoma and Nebraska Challenge Colorado's Marijuana Legalization

In a complaint filed with the Supreme Court on December 18, 2014, the states of Oklahoma and Nebraska claim that Colorado's Amendment 64, which permits the use and regulation of marijuana within the state, "is contradictory and obstructive to the CSA [Controlled Substances Act]".

Oklahoma and Nebraska argue that the legalization of marijuana in Colorado has placed a burden on law enforcement to control the increased amount of marijuana crossing into their borders. They argue that the passing of Amendment 64 by Coloradoans has "created a dangerous gap in the federal drug control system" and allows marijuana to flow into their states. In a [press release](#), Colorado's attorney general, John Suthers, stated that the lawsuit has "no merit" and is rather an issue of "non-enforcement of federal laws regarding marijuana."

This complaint was filed directly with the Supreme Court which handles all lawsuits involving two or more states. Cases between states are rare and in the past have mostly included boundary disputes and water rights issues. A case involving the burden placed on other states as a result of the legalization of marijuana in one state would set a new legal precedent.

Some legal experts fear that a ruling in favor of Oklahoma and Nebraska would have dangerous implications on the already weakened limitations of Congressional authority set by a previous case, [Gonzales v. Raich](#), which expanded the scope of Congress' power to make marijuana illegal. Permitting this lawsuit would also allow one state to interfere with the policies and laws enacted by citizens of another state, an action which could also have implications on a state's constitutional right to implement its own laws. If there is a ruling in favor of Oklahoma and Nebraska, we do not believe that there would be any immediate impact on states with medical cannabis programs, but it could set a precedent for challenging these laws and impacting patients' access to medical cannabis.

The complaint filed by Oklahoma and Nebraska can be found here:

<http://sblog.s3.amazonaws.com/wp-content/uploads/2014/12/Neb.-Okla.-original-suit-vs.-Colorado-12-18-14.pdf>

Share Your Zip, Share Your Story

With a new Congress and many state legislative sessions kicking off in early 2015, we are preparing to bring the epilepsy community's voice to elected officials and decision makers across the country. We want to engage you in our advocacy efforts, and call on you to share your powerful stories and to ask your representatives to support the epilepsy community's policy priorities. But we cannot do that if we don't know where you live and who represents you! When you share with us your address, our advocacy tool identifies your Member of Congress and state representatives, and this makes it very easy for you to take action on Foundation alerts by sending a letter to them, and for us to send you federal and state updates that are relevant to you. Members of Congress, and State Senators and Representatives want to hear from their constituents, and the best way for us to ensure we can connect you to them is by having your address attached to your record in our advocacy network. You've joined the network, now share with us your address so we can better serve you, and you can join us as we make the voice of the epilepsy community heard across the country and in every community. Please take a moment to check your profile at <http://bit.ly/SUSOUpdate> and add your address if it's not already on there. We won't share this information with outside parties or for non-advocacy purposes.