



Highlights from the Hill

September 2016

In this Issue:

- Epilepsy Foundation of Florida Shared Navigator Experience at HIV/AIDS Conference
- House Committee Passes Legislation that Preserves EMS Agencies' Ability to Administer Scheduled Medications in Emergency Situations
- Urge Congress to Oppose Attempts to Erode Disability Rights Guaranteed by the ADA
- Epilepsy Foundation Joins Amicus Brief related to Title II of the ADA
- Patient Community Reacts to Proposal for Assessing Value of Medications

Epilepsy Foundation of Florida Shared Navigator Experience at HIV/AIDS Conference



Monica Gonzalez, Ines Mosi, from the Epilepsy Foundation of Florida, and Natalie Keen, from The AIDS Institute, speak at the ACA Implementation Seminar at the US Conference on AIDS.

On September 16, the Epilepsy Foundation of Florida shared their experience as a navigator for individuals and families seeking to purchase health insurance in the marketplace created by the Affordable Care Act (ACA). The affiliate has been a navigator since 2014 and has helped 10,000 people gain and maintain access to care. The presentation was part of a conference focused on implementation of the ACA.

House Committee Passes Legislation that Preserves EMS Agencies' Ability to Administer Scheduled Medications in Emergency Situations

On September 20 the House Energy and Commerce Committee held a markup to consider a number of public health bills including the *Protecting Patient Access to Emergency Medications Act of 2016 (H.R. 4365)*, bipartisan legislation that would amend the Controlled Substances Act to allow paramedics and emergency medical service professionals to continue to administer

controlled substances to patients in emergency situations. We are pleased to see that the House Energy and Commerce Committee passed the bill unanimously by a voice vote. [Click here](#) to view our support letter.

Urge Congress to Oppose Attempts to Erode Disability Rights Guaranteed by the ADA

The House Judiciary Committee recently passed legislation, the *ADA Education and Reform Act of 2015 (H.R. 3765)*, which would weaken protections for individuals living with a disability by making it easier for businesses to avoid complying with accessibility requirements under the Americans with Disabilities Act (ADA). The changes proposed in H.R. 3765 undermine the promise of the ADA by shifting the burden for ADA compliance from business owners to people living with disabilities. The bill would require a person living with a disability to provide written notice to a business that has not complied with ADA, kicking off a long timeline for compliance, despite the ADA being the law of the land for more than 26 years.

The House is expected to vote on the *ADA Education and Reform Act of 2015* this month. Congress needs to understand the critical role public accommodations requirements created by the ADA play in the lives of people living with disabilities. Urge your member of Congress to reject additional barriers for the disability community and vote against the *ADA Education and Reform Act of 2015* to ensure we preserve the rights guaranteed by the ADA. The ADA passed with strong bipartisan support and leadership and it is important to maintain these protections for all! [Take Action!](#)

Epilepsy Foundation Joins Amicus Brief related to Title II of the ADA

Recently the Epilepsy Foundation joined an amicus brief along with Paralyzed Veterans of America, National Federation of the Blind, and ten other disability rights organizations in the case of *Ivy, et al. v. Morath*. The plaintiffs sued the Texas Education Agency (TEA), which oversees the administration of driver education courses in the state, alleging violations of the Title II of the ADA and Section 504 of the Rehabilitation Act. Plaintiffs allege that TEA, which allows private entities to operate driver education courses, failed to ensure course accessibility to young adult deaf drivers. TEA argues that it is not liable because the agency only provides licensure and regulation of the driving schools -- not driver education courses. TEA further asserts that there was no agency or contractual relationship between TEA and the private entities. The U.S. Court of Appeals for the Fifth Circuit (Texas, Louisiana, and Mississippi) agreed with TEA's argument and ruled against the Plaintiffs. The Plaintiffs asked the Supreme Court to review the case.

While the U.S. Department of Justice (DOJ), through its Solicitor General, opposed the Supreme Court taking the case, DOJ informed the Court that it believes that Texas is liable under Title II for the inaccessibility of the state's private driver education schools. Through the amicus brief, disability rights organizations make a legal argument about the circumstances under which state and local governments should be held accountable for discriminatory activities of private entities. The brief was filed on August 30, 2016 and can be read [here](#).

Patient Community Reacts to Proposal for Assessing Value of Medications

On September 12, the Epilepsy Foundation joined more than forty other groups in public comments submitted by the Partnership to Improve Patient Care (PIPC) to the Institute for

Clinical and Economic Review (ICER) in response to their Value Assessment Framework. PIPC shared the patient community's concerns that each person in need of care, especially people living with chronic conditions, has highly specific care needs and as a result a one-size-fits-all value model is not a sustainable framework for wellness. The letter included a number of suggestions for modifications that would yield a more patient focused framework. You can read PIPC's full letter [here](#).

Creating a Pathway to FDA Approved CBD Therapies

The Epilepsy Foundation is bringing together the epilepsy community to advocate for changes to state scheduling laws that would allow therapies derived from cannabidiol (CBD) and approved by the Food and Drug Administration (FDA) to become available to patients in a timely manner. Therapies derived from CBD show promise for people living with uncontrolled seizures and rare epilepsies. Despite FDA approval, states would need to implement changes to state scheduling laws for these therapies to become available in the state, even if the state has a medical cannabis program. Without changes to the state schedules, people would not be able to access and seek insurance coverage and reimbursement for FDA approved therapies derived from CBD. We've begun reaching out to states agencies and legislatures to raise awareness of this issue so we can begin to implement changes to state law to ensure timely access to FDA approved therapies in the future. [Check out our website](#) to read our FAQ and learn more about this issue.