

House Energy and Commerce Committee Roundtable
Personal Stories from the Opioid Crisis
“April 19, 2018”

On April 19th the House Energy and Commerce Health Subcommittee held a Round Table entitled, *Personal Stories from the Opioid Crisis*. A webcast of the hearing and opening statements can be found [here](#).

Witnesses included:

- Ms. Kathy O’Keefe, Executive Director, Winning the Fight
- Mr. Gary Mendell, Founder and CEO, Shatterproof
- Ms. Mary Winnefeld, Founder, Stop the Addiction Fatality Epidemic
- Ms. Devon Hott, Director of Operations, Recovery Care Partner
- Ms. Aimee Manzoni D’Arpino, MA State Chair, Addiction Policy Forum
- Mr. Michael Gray, CEO and Co-Founder, Actus Analytical
- Ms. Lisa Daniels, Co-Founder, Jamie Daniels Foundation
- Ms. Gail Smith, Substance Use Navigator, Prevention Plus of Burlington County, on behalf of The Kenny Smith Freedom Foundation
- Ms. Kristen Arant, Peer Support Specialist, Kentucky
- Ms. Paula Peterson, Founding Member, Families Anonymous – Oregon Chapter

Subcommittee Chairman Burgess (R-TX) opened the roundtable by saying that the format would be different than a hearing with a more informal format and no time limits. He noted that the subcommittee is a week away from a major markup of some legislative vehicles, but that the subcommittee thought it was important to hear from people whose lives have been directly affected by this crisis. He said that the process the committee has been going through over the last year has led to 67 pieces of legislation under consideration, but noted that not all of this legislation will be signed into law and that some of it will be consolidated or drop off, but that input from the witnesses is a valuable step in the process.

Full Committee Chairman Walden (R-OR) noted that the committee has been working on this issue for well over a year and will likely markup the legislation next week, finish committee work by Memorial Day, and have bills on floor by early June.

Each witness was then able to tell their personal story. Some of the common themes discussed included:

- Accessibility to MAT
- Need to remove stigma surrounding substance use disorder, mental health, and the use of MAT
- Marijuana as a gateway drug to opioids
- The need for research on the developing brains of children/adolescents and how their brains are affected by things such as marijuana and opioids
- Fentanyl and synthetic opioids
- Patient brokering in treatment facilities in Florida
- Changes to HIPAA

Ms. Peterson noted the need for MAT to be more readily available saying that the longer someone has to wait for treatment, the more likely a person is to relapse. She also noted the need for more

physicians to have the ability to prescribe Suboxone. Chairman Walden noted that the committee is considering legislation looking at these issues.

Ms. Peterson, Ms. O'Keefe, Mr. Mandell and Mr. Gray spoke about the need to remove the stigma surrounding substance use disorder, mental health and the use of MAT, so that people can get the help they need. Mr. Mendell said that a solution to end stigma is to bring mental health and substance use disorder into the health care system like diabetes, cancer, etc.

Ms. Winnefeld spoke about marijuana as a gateway drug for many people and the need to educate to prevent. She noted that the train has left the station, but that there is a need for research to understand about brain development and what happens in the brains of addicts.

Mr. Gray spoke several times about Fentanyl and synthetic opioids and the problems they have created. Chairman Walden said that the committee is taking a multifaceted approach and noted that they have to be careful because if they don't do things right they can make needed medical research on these substances illegal.

Chairman Walden responded to the issues of patient brokering and pill dumping by saying that the Oversight and Investigations Subcommittee has been looking into these issues.

Mr. Mendell said that he would like to see a mandate that every doctor who prescribes opioids follow CDC guidelines for prescribing and that all treatment is evidence based. Chairman Burgess said they have to be careful about the direction they go with legislation because sometimes that can do harm if they don't go in the right direction. He noted that the committee has heard from stakeholders that are concerned about the CDC guidelines and that the issue is not a straightforward one – they are trying to consider a variety of opinions.

HIPAA was raised by numerous witnesses and Rep. Walden noted the controversial nature of bills surrounding this issue. He then asked the witnesses why changing HIPAA is important. Ms. D'Arpino said it is heartbreaking to know her son, who was over 18, was alone when he was brought back to life after an overdose due to the fact that his family was not notified due to HIPAA and his friends didn't stay with him due to stigma. She also noted the importance of services following an overdose, which often are not followed up on if parents or family are not notified. Mr. Grey noted that in a lot of cases someone who overdoses has no competency and needs a support system that is not always available due to the lack of access to medical records or all the information necessary to help that person. Ms. O'Keefe pointed out that HIPAA is not always about privacy between a child over the age of 18 and their parents. She noted that her son's doctor could not discuss his substance use with her, even though he was under 18, because she was not in the room during his exam. Mr. Mendell and Ms. Winnefeld both noted the importance of making this information part of someone's electronic health record. Rep. Griffith (R-VA) pointed out that there may be a legitimate reason for the parent(s) not to know/have access to medical information, especially in cases where parent may be the one that caused the trauma.