

Opening Statement of Chairman Fred Upton
Energy and Commerce Committee Markup of 21st Century Cures Act
May 19, 2015

We have held dozens of roundtables and hearings on 21st Century Cures, in this room and all across the country; we have learned about the varying challenges facing each family and community, and we have received an outpouring of ideas and support for our shared mission. I'd like to begin by thanking the countless individuals who helped bring us to this moment, at the cusp of a committee vote that will lead to a House vote, a collaboration with our colleagues in the Senate, and ultimately to deliver a bill to the president's desk, and deliver 21st Century Cures to the patients who need them.

Thank you to the staff, too many to name – on both sides of the aisle – who took the meetings, did the research, drafted the language, and sat at the negotiating table to help us develop this incredible product. Thank you to House legislative counsel and the Congressional Budget Office for your tireless efforts and dedication. Thank you to the members of both parties who brought their best ideas, partnered with one another to make their case, and delivered so many of the policies we welcome today. Thank you to the experts, the advocates, and the innovators. Thank you to the regulators, who could have resisted our efforts to bring change, but instead chose to be our partners.

Thank you to everyone here with us, individuals with personal interests and stakes in this legislation, including patients who are at the heart of this effort. Thank you to kids like Max, whose artwork shows that the policy is personal. Max is six years old, and he'll be sitting in the front row tomorrow. Like many kids his age, he loves science, swimming, and Uno. Unlike most, he is faced with the

challenge of a rare diseases – Max has Noonan syndrome. Helping Max is why we're here. Helping my friends Brooke and Brielle is why we are here.

Despite our different backgrounds and interests, every single person in this room has a common goal: we want more time with those we love.

As we sit in this room and discuss the details of this bill, I can't help but think of the patients who are sitting across from their doctors about to get news that will change their world forever.

One of my dear friends likened that moment to being thrown out of a plane without a parachute.

It is not just the disease that makes them feel powerless and vulnerable; the very system designed to help them has not kept pace with scientific advances.

They need the next generation of treatments and cures, but they do not have until the next generation to wait.

They don't care that the timelines, the failure rates, the size and the costs of conducting trials are at all-time highs. They just care they can't get the therapy that might save them. That is why we need 21st Century Cures.

A key provision of this legislation paves the way for critically ill patients to have access to better drugs and treatments.

We have all said too many early good-byes to people we treasure. We have seen families robbed of a parent that will never get to see their child's milestones, like graduation, a successful career, perhaps a family of their own.

In my district in southwest MI, there is a grieving and healing center for children who have lost a parent called "Lory's place". It is modeled after Ele's Place, also in Michigan. Ele Stover, my cousin's daughter, had only 11 months of life before being struck down by disease.

Back home is also where I first met The Champ, Mohammad Ali. Joe Frazier may have been his arch rival. But Parkinson's has been the fight of his life. He became a fierce advocate for more disease research funding. Believe me when people saw him coming down the hall they took notice.

This morning I talked to Lonnie Ali who is cheering on this effort along with her husband. It is difficult for him to speak but he has not lost his voice. She pointed out that it's the depth and breadth of research that gives people with chronic illnesses hope to live another day. She said, "Research means so much to so many. I hope your colleagues will see the light." I am happy to report to her that my colleagues have seen the light, and that's why we are here today advancing this nonpartisan bill.

In this the greatest country in the world, Americans deserve a system second to none. We can and must do better. The time for 21st Century Cures is now.