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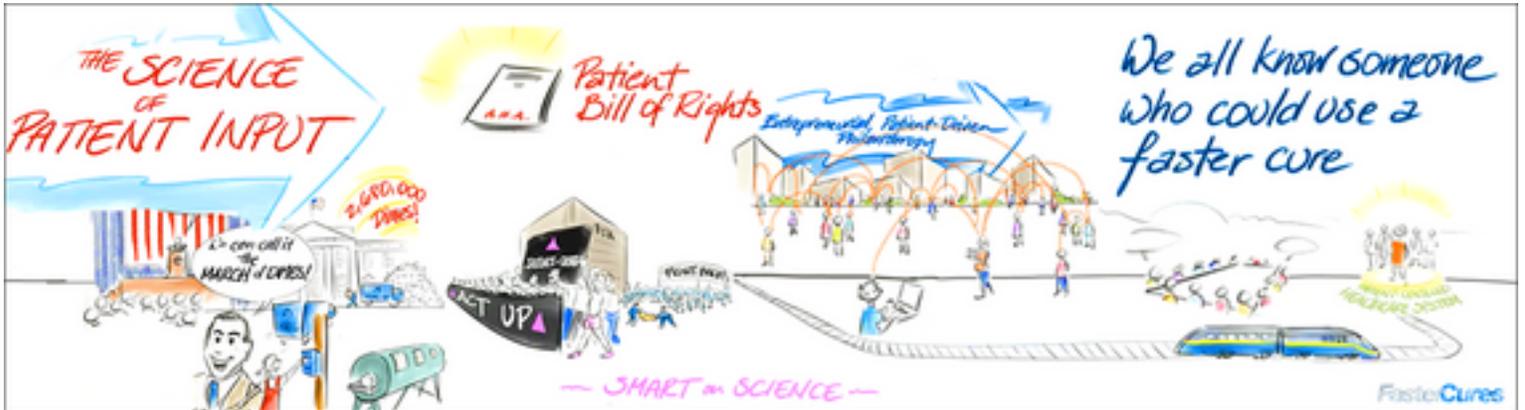


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Patients Are My Co-Pilot

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No longer just passengers, [patients are now co-pilots](#) helping to navigate the future of medical progress. But until recently, the pace of progress has been slow. In some diseases, we still utter the words "we haven't seen a new treatment in decades" with a straight face. *Decades*. Are we seriously accepting this?

I recently heard a TedTalk by Andrew Solomon, "[Depression, the secret we share](#)," where he described the current treatment options for depression as being full of side effects, costly, and appalling all at the same time. But he is so grateful he lives now and not 50 years ago when there weren't treatment options. "I hope that 50 years hence people will hear about my treatments and be appalled that anyone endured such primitive science," Solomon said. Depression, cancer, Alzheimer's, Parkinson's disease, rare disorders - we could say this about so many areas. In fact, the list is long, and where there are treatments they almost always could be enhanced for patients.

We've all heard the dismal statistics: 10,000 known diseases with only 500 treatments. Not great odds if you're a patient. And most

of us are, or will be at some point. At 15 years and over \$1 billion to bring one new therapy from lab to market, we not only have work to do, we actually have an opportunity to do some of it - *now*.

[A perfect storm is brewing - and patient engagement is at its epicenter](#). It's a long, storied history to get us to this point. From the March of Dimes to the Patient's Bill of Rights to the ACT UP movement, patient-driven efforts pushed boundaries that allowed the medical research and healthcare systems to pave new ground.

We are at a turning point once again with the [21st Century Cures Act \(H.R. 6\)](#). Passed unanimously by the House Committee on Energy and Commerce, it sets out to cut through the complexity, bureaucracy, and inefficiency in our over-100-year-old national research infrastructure, and puts in place the resources and tools necessary for our system to catch up to the cutting-edge science happening every day in labs across the country. Most importantly, it gives patients an actual voice and vote in this transformation by proposing the inclusion of patient representatives in nearly every council, panel, advisory board, and body that would be created under the act.

This is it - our time, the next big chapter of patient engagement and advancing treatments and cures. We can't afford to delay and squabble while patients who need cures lie in wait. This legislation is borne from the spirit of compromise and the tenacity and vision of Chairman Fred Upton, Congresswoman Diana DeGette, and countless others who see this as a chance for our United States Congress to do some of the people's business. It's the right time for 21st Century Cures for so many reasons:

1) Seizing the moment - science is ripe

Our scientific progress is moving forward at a faster and faster pace, and we already have both the understanding of human biology and the advanced technology necessary to tackle questions that previously vexed researchers and drug developers.

The genome has been mapped, many people have electronic medical records, and data about our bodies and diseases are being collected in mass quantities everywhere from doctor's offices to patient registries to our own smartphones. If we don't act now, we risk losing the ability to not only capitalize on our tremendous scientific knowledge, but also to maintain our global leadership in bioscience.

"Complex diseases require complex solutions. Patients can now anticipate earlier access to those lifesaving solutions because 21st Century Cures legislation expands resources, incentivizes creativity, accelerates regulation, and, most importantly, facilitates data sharing across the discovery, development, and delivery of innovative drugs and medical devices."

-- Andrew von Eschenbach, former Director, National Cancer Institute; former Commissioner, U.S. Food and Drug Administration; Senior Fellow, Milken Institute

2) Investing in our priorities

The 21st Century Cures act, also known as "Cures2015," includes critical, sustained funding for the National Institutes of Health (\$10 billion over five years) and the U.S. Food and Drug Administration (\$550 million over five years) that can be deployed as early as FY 2016. That means funding for the best and brightest young researchers, support for risky but promising science, and the capacity-building necessary to pull our national institutions into the 21st century.

"The increased NIH funding proposed in Cures2015 is heroic. Cures2015 would restore the medical research funding that has been lost to inflation and spending cuts over the past decade. Representatives Upton, Pallone, and DeGette have worked together in a bipartisan way to show that Congress can act for millions of American patients and their families. Act for patients, act for NIH, support Cures2015."

-- Pat White, President, ActforNIH

3) Making collaboration HAPPEN

The notion of working together toward aligned goals rings true in the war against a daunting and unyielding enemy: disease. And yet, making collaboration happen every single day does not come naturally in a system built with incentives that undermine teamwork. H.R. 6 cuts through roadblocks to sharing and analyzing the massive amounts of health data generated in research and clinical settings, which is currently locked away in silos across the medical research ecosystem.

"This is a mind-exploding problem, but it's one that we can solve. We've proven over the last decade that scientists know how to work together, and they want to work together, and I think we have to enable that."

-- Anna Barker, Director, Transformative Healthcare Networks, Co-Director, Complex Adaptive Systems Initiative and Professor, School of Life Sciences, Arizona State University; Senior Fellow, *FasterCures*

4) Advancing the science of patient input

What if we actually worked with the patients whose conditions we are trying to improve? What if we learned from the past decades of patient engagement, from the creation of the March of Dimes to HIV/AIDS activism to the launch of patient-focused drug development? What if this was our next big chapter?

"Never before in this country have we had so much scientific potential being impeded by lack of biomedical research funding, inefficient or poorly designed clinical trials, and research and development practices that fail to put the needs of patients front and center. The greatest frustration for me is knowing what we could be doing for patients in this country that we don't do, and not because we don't have the scientific knowledge or technology, but because of bureaucracy, culture, or antiquated practices. The bipartisan commitment to 21st Century Cures sets the course to get cures to patients faster and put our nation back on the map as a global leader in science and innovation."

-- Bray Patrick-Lake, Director of Stakeholder Engagement, Clinical Trials Transformation Initiative; Co-Chair, Advisory

Committee to the NIH Director on the Precision Medicine Initiative

"This legislation makes a bold investment in critical science and research, and builds a framework to better involve and incorporate patients as the top priority throughout the process."
-- Ellen Sigal, Chair and Founder, Friends of Cancer Research

This is an historic moment - with the whole of the R&D ecosystem and the federal government coming together across sectors, diseases, and political parties to fix the system for patients, and improve all of our odds. Who knows when (or if!) we'll have this opportunity again. Disease doesn't wait, and neither can we.

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