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Mark Masselli: This is Conversations on Healthcare I'm Mark Masselli.

Margaret Flinter: And I'm Margaret Flinter.

Mark Masselli: Well Margaret we like to focus on issues of human health on this show but animal health can often be a canner in the cold mind and we're watching with some real concern the expanding outbreak of bird flu in the country.

Margaret Flinter: And several strands of avian flu have shown up across the country. Now tens of millions of birds have been destroyed, the turkey population especially hard hit in the Midwest and now egg growers are sounding an alarm.

Mark Masselli: At the moment the outbreak shows no sign of (inaudible 0:34) in multiple poultry species. And it's being monitored very closely by the USDA and the CDC.

Margaret Flinter: Keeping the country's food stream safe and free from harmful pathogens is a vital public health obligation and really an ongoing challenge for these federal agencies including the FDA which of course is test with insuring drug safety as well. Something our guest today is quiet familiar with, Margaret Anderson is the Executive Director of FasterCures a non-profit that's dedicated to improving drug and medical research systems to work faster and more efficiently than they have up until now. She'll talk about how new technologies are poised to accelerate the pace of drug discovery and development.

Mark Masselli: Lori Robertson checks in, the managing editor of FactCheck.org is always on the hunt for misstatements spoken about health policy in the public domain. But no matter what the topic you can hear all of our shows by going to [chcradio.com](http://chcradio.com).

Margaret Flinter: And as always if you have comments please email us at [chcradio@chc1.com](mailto:chcradio@chc1.com) or find us on Facebook, Twitter we love to hear from you. We'll get to our interview with Margaret Anderson in just a moment.

Mark Masselli: But first her is our producer Marianne O'Hare with this week's headline news.

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Marianne O'Hare: I'm Marianne O'Hare with these Healthcare Headlines. Florida Governor Rick Scott sees a state shutdown looming come July 1<sup>st</sup> steadfastly refusing to expand Medicaid in his state. In spite of warnings from the federal government that billions of hospital dollars would be lost to the state as a result. Scott has now sent a memo to all state agency heads making a list of all nonessential expenditures and warning entire agencies could be shutdown as a result. Scott leading a dwindling pack

of state leaders across the country who have refused to expand Medicaid coverage for their residence living closer to the poverty line.

A rite of passage for the over 50 crowd colonoscopies are required screenings and have done much to bring down the death rate from the common form of cancer other than the unpleasant process of the preparation and screening itself under the Affordable Care Act more Americans are seeking screenings because it's covered. The federal government decided to remove another barrier to the screening for some, the cost of anesthesia, some insurers weren't covering that cost. The fed said anesthesia which often a company's called endoscopies must be covered as well.

California's legislatures passed a bill eliminating personal beliefs as a reason for opting out and vaccinating their children. The law restricts families opposed to vaccines for personal beliefs is not reason enough to put their children and the larger population at risk for preventable childhood diseases like measles, mumps and rubella. An outbreak of measles earlier this year sicken hundreds in California.

The South Carolina self-employed republican oppose to the Affordable Care Act found himself on the brink of bankruptcy and diabetes related blindness after a series of strokes caused bleeding in his eyes and his savings were exhausted in the emergency room treatments. It also left him without enough money and without coverage for the surgery required to save his eyesight. Though still opposed to the healthcare law he made a public plea for help. He receive generous donations from an interesting source self described progressives donating thousands to cover his surgery saying they hope he's learned his lesson. I'm Marianne O'Hare with these Healthcare Headlines.

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Mark Masselli: We're speaking today with Margaret Anderson, Executive Director of FasterCures an action tank at the Milken Institute dedicated to removing barriers to medical progress by speeding up the medical research system. She's the past president of the alliance of stronger FDA, is a member of the NIAH National Center for Advancing Translational Sciences. Previously Ms. Anderson was the Deputy Director in the Center on AIDS and community health at the Academy for Educational Development. Ms. Anderson holds a bachelors degree from the University of Maryland and a master's degree in science technology and public policy from George Washington University. Margaret welcome to Conversations on Healthcare.

Margaret Anderson: Thank you it's a pleasure to be here.

Mark Masselli: Yeah, and you just got back from the Milken Institutes Annual Global Conference and that's always a great gathering of luminaries and influencers. And I wonder if you could share with our listener some of the more exciting ideas heard at the

conference, and how do they illustrate the overall mission of the global conference as well as the mission of the institute?

Margaret Anderson: It's a gathering that brings together over 3000 of the world's leading visionaries in all different sectors from business and finance to government and that isn't just the United States government but globally. So a lot of discussion about making the world a better place for women and girls. I worked on the medical research track and I would say those conversations were clustered around a few main themes. The elevation of medical research on to the national policy agenda, the second would be the evolution that we've witnessed of patients roles in the healthcare delivery system and research system. Next I would say future of precision medicine, you know, sort of solutions oriented nature of that is really emblematic of the Milken Institutes work and FasterCures and we're a part of that.

Margaret Flinter: I'd like to Margaret maybe focus on your division of FasterCures, it has a specific mission of its own within the context of the larger organization and have this goal to remove barriers to medical progress by speeding up the medical research system. What are some of the great challenge has been and why do you think the time is right for revamping the medical and health research process?

Margaret Anderson: So of the 10,000 known deadly and debilitating diseases that affect the world today, only about 500 of those have effective treatments. We also know that, you know, bringing any kind of a new therapeutic forward from, you know, the beginning of discovery in basic science to the market place it takes on average 15 years over a billion dollars. Just to bring one therapy forward from discovery to patients. So, you know, Dr. Francis Collins who's the Director of the National Institutes of Health will say that the paradox here is we're living in this crazy time where there's a scientific agenda that's catapulting forward with an engine that's kind of running on two little fuel. I really do think that there's sort of this unique moment that we're looking at where the scientific promise is accelerating in a pace that I think is staggering. And we need to make sure the system's ready for it.

Mark Masselli: You laid out some of the ground work of this as sort of infrastructure. Maybe you can talk about this new reality of reduced funding and where opportunities might lie in terms of a collaborative approach in research?

Margaret Anderson: The NIAH has experienced a gradual lost of its purchasing power. They're down almost 25% below where they were in the year 2003. So we have this conundrum here where we are pushing STEM education and we really believe in the power of science but we're starving it essentially. Right now the NIAH only can fund roughly one grant out of six which is about half of what they used to be able to fund. This funding is critical and it's critical because if we starve that scientific enterprise there

will be no cures and treatments to develop. Those philanthropy groups we call them venture philanthropy, out of that venture philanthropy model we've just seen some breathtaking advancements come. So it's powerful capital people call it passion capital but it cannot supplant, you know, the vital role of NIAH.

Margaret Flinter: Well Margaret I wonder maybe just take one more look at this issue of collaboration. We've entered the new arena of genomics and proteomics in the expansion of digital technologies and personalized medicine. But I've seen this kind of parallel wave of innovation around patient engagement certainly through organizations like patients like me and (inaudible 8:43) which is another way of engaging patients. How is this advance in collaboration spurring new kinds of developments in biomedical research?

Margaret Anderson: You know, if you look at the role of patients overtime I would say that role has expanded dramatically in the past 40 years. In the 1980s during the HIV/AIDS, you know, the beginning of the epidemic we witnessed, you know, dramatic transformation of the biomedical research system. And I would argue also healthcare delivery by HIV/AIDS activist. They demonstrated that you can bring attention to a cause but a piece that FasterCures is really try to push forward is that it wasn't just about public disobedience and demonstrations, it was about getting very smart on the science. And by getting smart those activist were able to demand change and get results and we have a paper called back to basics that you can find on our website that will, you know, kind of characterize this evolution.

So what we see now are patients and organizations representing patients really being looked at more as partners in, you know, kind of R&D equation. And so you reference some of the groups like patients like me or smart patients. There's a number of these types of groups that are allowing patients to engage in different ways, whether it's by speaking to one another, whether it's by donating their data to larger cohorts of research. And we've seen this in speed FasterCures has a group called the TRAIN network which stands for The Research Acceleration and Innovation Network and it's a group of venture philanthropy groups. And they come together and do best practice sharing. You know, we -- on the list includes groups like the Cystic Fibrosis Foundation or the Michael J. Fox Foundation for Parkinson's research, the list is long. And these groups believe that, you know, they're going to keep their eye on the price of trying to fix their particular disease so they've been doing a lot of resource and best practice sharing through some of the vehicles that FasterCures has created.

So, you know, an example of one of the benefits of one of these groups would be the Cystic Fibrosis Foundation's partnership over a period of time with a company called Vertex Pharmaceutical and this resulted in, you know, a game changing drug which is called kalydeco that really has, you know, propelled forward the science of Cystic

Fibrosis research and, you know, real things that patients can benefit from. So I think what you're seeing now with groups like Patients Like Me is that your -- there are platforms available for patients to share their real world health experiences and data. So I think what we're going to keep seeing is more and more of this democratization of data. And there's a number of efforts that involve sort of public private partnerships between government agencies and not for profits. And it's very exciting because I think we're witnessing what we're going to see I think more rapid adoption of many these different things that we've been talking about.

Mark Masselli: We're speaking today with Margaret Anderson, Executive Director of FasterCures an action tank at the Milken Institute dedicated to removing barriers to medical progress by speeding up the medical research system. She's also a founding board member and past president of the Alliance for Stronger FDA. Margaret you've recently said that in spite of the criticisms often aimed at the FDA and I think we had a couple of those folks here on a radio show. Your work has focused in on how to make the FDA function even faster and more efficiently than it currently does. Tell our listeners more about the scope of the work of the FDA and what can be done to accelerate drug breakthroughs and shorten their research protocols.

Margaret Anderson: So FasterCures as you've said we've made it our policy priority to both advocate for more appropriated dollars as well as looking at some of the specific programs implemented by the FDA. This is an agency that regulates 25% of every consumer dollar and it's just a critical component to bringing safe and effective medical solutions to patients. You know, the FDA has mounting pressures overtime resulting from globalization but they don't have the resources to really go, you know, tracking around and do everything that they would need and want. They also have increasing statutory requirements that are put on them. You know, every time congress asks them to do something new, they're given an extra responsibility but not always the same money to go along with it. In order to make our, you know, drugs come through the process as quickly as possible, industry works with the agency to help fund some of that work. In the last user fee process there were something called the patient focus drug development imitative that was created, it's extremely important to this idea of how do you engage patients more. So they were asked to do 20 disease specific meetings, so that's the beginning and we've been working with the agency and with congress to really try to look at how can we advance that science of patient input. And I will point out that in addition to the development of drugs and therapeutics on the device side there's been a lot of activity where they've really been working on this idea of the qualities of patient preferences and how do you bring that into review decisions. And yeah the FDA's made incredible strides forward. It's a tough agency because they are, you know, asked to be fast and efficient but they're dealing with complex, you know, applications. And, you know, sometimes I think it put between a rock and a hard place where, you

know, the headlines draw attention to something that may have been missed and they, you know, might get conservative after that saying well gee we don't want to have that happen again. So it's a very difficult agency to I think have to navigate through. And Dr. Peggy Hamburg just stepped down as the FDA Commissioner and really did an outstanding job helping to lead them forward. So I always like to say if you ever get a chance to meet somebody who works at the FDA say thanks to them because they have a tough job.

Margaret Flinter: We couldn't agree with you more, but I wonder for our listeners if I could ask you to really try and focus on as you did in a recent piece in the Huffington Post it outline some of the top medical research trends of 2015 that are poised to shift the old paradigm, maybe for our listeners just go through those top ones again. The more promising trends and how they bring about the FasterCures that we're all seeking?

Margaret Anderson: Absolutely so, you know, we did this every year to understand what's been going on, what -- you know, what's the chatter out there and it's very gratifying because we have the opportunity at FasterCures to work with the entire biomedical research ecosystem, and listen to a lot of the bright innovative thinkers. We tend to be pretty spot on about what's hot and what do we need to be, you know, thoughtful about. And I would say that, you know, the theme going forward has been collaboration which we've talked about a bit today. There is also been this theme of a bipartisan quest for cures, so there's 20% free cures initiative that I reference is a remarkable opportunity, it's been led by chairman Fred Upton but really in partnership with congress women Diana DeGette. And both of them have, you know, deep expertise in understanding complex issues related to biomedical research and I think that if they can be successful and pushing this forward it has to go into the senate and, you know, ultimately be signed at the law. But if they can be successful I really think it shows the American public that Washington can get something done that Capitol Hill, you know, it's serious about advancing things important to the nation. Is it going to be easy? No, and it, you know, they've released at first a 400 page draft and then it went to a 200 page draft and now it's back to 300 pages, it's a lot. But as we've been speaking throughout the show these issues are not easy, if they were easy they would have been fixed already.

Margaret Flinter: Exactly our philosophy.

Margaret Anderson: Right so, you know, there's also another theme as this increased practice of venture philanthropy, I think that everyone will see more and more evidence that these groups are the little engines that could, they are fund raising their bottom line every year. They're, you know, through all of those means the walkathons but they are targeting that capital very specifically. And they can take risks with that money that's a

little bit different than, you know, some of the sort of, you know, bread and butter we got to fund these particular science project.

Mark Masselli: Sure.

Margaret Anderson: So I think that's another area. I want to talk about that increased focus on patient engagement and the science of patient input. I think what started out as I mentioned about the HIV/AIDS activist, it started out in terms of advocacy but it's a scientific discipline now. And it's really looking at how can you accommodate patient needs and preferences and put them into a process of developing, regulating and delivering therapies. And I think there's a, you know, a growing community of people who are focused on it, trying to figure it out and we have a specific program that's been looking at benefiting risk as well as value and coverage which I think is another really hot area that we're all seeing headlines about this. You know, looking at the cost of, you know, our therapeutics. So as we've talked about getting a drug approved by regulators it used to in some ways be the finish line, you know, if you got FDA approval yay okay that means patients can have access. That's not such a certain proposition anymore, you now have to demonstrate the value to patients. And so FasterCures is working with a lot of those disease foundations because they have concrete data about their patient populations. So they're able to say the introduction of this particular product completely change the paradigm of how these people are living their lives, they're going back to work, they're, you know, productive members of society now without symptoms. So they can show the value proposition. Patient groups will be playing an increasingly critical role and closing the gap between the evidence that regulators need to just approve a product. And then the evidence and information that payers are going to need to make their decisions.

Mark Masselli: We've been speaking today with Margaret Anderson, Executive Director of FasterCures an action tank based at the Milken Institute which is dedicated to removing barriers to medical breakthroughs by accelerating the pace of research. You can learn more about her work by going to [FasterCures.org](http://FasterCures.org) or you can follow her on Twitter at [@MargaretAinDC](https://twitter.com/MargaretAinDC). Margaret thank you so much for joining us on Conversations today.

Margaret Anderson: Thank you so much, I appreciate it.

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Mark Masselli: At Conversations on Healthcare we want our audience to be truly in the know when it comes to the facts about healthcare reform and policy. Lori Robertson is an award winning journalist and managing editor of [FactCheck.org](http://FactCheck.org) a nonpartisan, non-profit consumer advocate for voters that aim to reduce the level of deception in US politics. Lori what have you got for us this week?

Lori Robertson: Well we recently looked into whether marijuana is a gateway drug as New Jersey Governor Chris Christie claimed and saying that he would crack down on marijuana sales and use in states that legalized marijuana for recreational use. It turns out the science on this topic is far from settled, there are correlations between marijuana use and other drug. But there is no conclusive evidence of causation that using marijuana causes the use of other drugs.

Studies have found that those who smoke marijuana are more likely than those who don't to use other drug. The correlation is there, but there's not evidence of causation that smoking marijuana causes one to use other drug. In 1999 report from the Institute of Medicine said exactly that, marijuana use 'Typically precedes rather than follows the use of other drugs.' But the Institute of Medicine said it doesn't appear to be the cause of serious drug abuse or even the most significant factor in predicting drug abuse.

We spoke with spoke with an expert at the national institute on drug abuse which is part of the national institutes of health who told us the scientific community was still debating this complicated issue which has been contentious over the years. For more on the studies that have been conducted on this topic see our website at [FactCheck.org](http://FactCheck.org). I'm Lori Robertson.

Margaret Flinter: [FactCheck.org](http://FactCheck.org) is committed to factual accuracy from the country's major political players. And is a project of the Annenberg Public Policy Center at the University of Pennsylvania. If you have a fact that you'd like checked email us at [chcradio.com](mailto:chcradio.com) we'll have [FactCheck.org](http://FactCheck.org)'s Lori Robertson check it out for you here on Conversations on Healthcare.

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Margaret Flinter: Each week, Conversations highlights a bright idea about how to make wellness a part of our communities and to everyday lives. Disease from unclean water cause more deaths in parts of the world than all forms of violence including war. And of the 30,000 people who die every week from unsafe water and lack of sanitation 90% are children. At any given time up to 30% of the tens of thousands of wells across the African Continent can be out of commission. And sometimes they never get repaired.

Robert Lee: Yeah sometimes they have trouble like collecting funding and managing that well in order to pay for the (inaudible 22:34) and the labor to install it. And a lot of times there's no valid stable infrastructure in place that they could reach out to if they need (inaudible 22:42)

Margaret Flinter: Robert Lee is the Director of Special Programs at Charity Water an innovative non-profit, privately funded in a way that every dollar donated goes directly to building and maintaining wells. He says they decided to rig all the wells with GPS



markers and special sensors that send a message to a command center when a well is starting to malfunction.

Robert Lee: So this is usually a community hand pump well, so we have -- make a (inaudible 23:06) that will last a really long time. So the battery don't need to be replaced, and then I have (inaudible 23:12) to be able to detach from the data what's really going on. The hope is that this is the actual support system that they would need. We're putting a phone numbers for them to call on the water plant we're giving them training, motorcycle tool and yeah enabling them with a combination of infrastructure as well as technology through the sensors that a building be electronic tablet survey systems as well as (inaudible 23:38) so that they could be able to manage their staff as well as other repairs that come in.

Margaret Flinter: Often within days a trained well repair person is dispatched to the broken well. Which in many cases is the well that provides the only clean water for an entire community. And in Africa alone people mostly women and girls spend an estimated 40 billion hours a year collecting and transporting water to their villages.

Robert Lee: And the stakes of it are like women aren't able to take care of their (inaudible 24:07) children are able to go school.

Margaret Flinter: Charity Water's alert system puts the pumps back in action supplying not only clean water for drinking and sanitation but for small local farms as well which feed entire villages and provide a source of income for the farmers. Charity Water, building thousands of wells across Sub-Saharan Africa deploying a digital alert system to warn of a well's malfunction and sending help to repair it. Ensuring that clean water continues to flow into a community, now that's a bright idea.

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Margaret Flinter: This is Conversations on Healthcare, I'm Margaret Flinter.

Mark Masselli: And I'm Mark Masselli, peace and health.

Female: Female: Conversations on Healthcare broadcast from the campus of WESU at Wesleyan University. Streaming live at WESUFM.org and brought to you by the community health center.