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Mark Masselli: Welcome to Conversations on Health Care. I am Mark Masselli.

Margaret Flinter: And I am Margaret Flinter.

Mark Masselli: Well Margaret, today is leap day, February 29<sup>th</sup>, and it's a rare day, only comes around once every four years.

Margaret Flinter: Well, that makes it special but it's also another designated day and a really pretty serious one and that is Rare Disease Day today, February 29<sup>th</sup>.

Mark Masselli: I did know that and there are surprisingly some 7000 identified rare diseases which pose a problem. Often they don't get the funding more prevalent diseases get for research so those communities often suffer without treatment breakthroughs.

Margaret Flinter: That's right Mark, and they suffer in part because they are also referred to as orphan diseases meaning that there just isn't that large organized constituency out there advocating for more research or more investment. So the motivation behind this day, as I understand it, is to get the patient communities that suffer from these rare diseases more connected to researchers and to each other in the hope of finding faster routes to cures for the disease. And that is something that today's guest, PatientsLikeMe Founder, Jamie Heywood knows a lot about and we will be talking to him a little bit later.

Mark Masselli: But Margaret, just before we get to Jamie, I wanted to mention that we are at another turning point in the country's move to switching over to the adoption of electronic health records.

Margaret Flinter: And yeah, we are at that next step. The CDC released its next wave of guidelines for a meaningful use of electronic health records. This is Phase II I believe. And adopting these electronic health records we know will reduce medical mistakes, streamline efficiencies and cost but still, we have got that big lag in switching over throughout the country with not yet having hit the tipping point of more than half the practices in the country being on electronic health records.

Mark Masselli: Well they are working on it very hard and the National Health Information Coordinator, Farzad Mostashari who has been on this show last week announced the second phase of meaningful use of the electronic health record and it poses perhaps the biggest challenge. Stage II calls for electronic health record systems to be interoperable, or more simply put, be able to talk to each other, something that just isn't happening enough of.

Margaret Flinter: And Mostashari said that perhaps because of that they are extending the deadline for complying with Stage I. The deadline for switching to electronic health records has been moved from 2011 to 2014. Dr. Mostashari released the proposed rules. Of course they are open for comment for a period of time and for those of you who are interested in details, they are all up on the web and take a look.

Mark Masselli: Meanwhile, Jamie Heywood has been in the frontlines of battling one rare disease ALS, better known as Lou Gehrig's disease, a rare fatal condition that afflicted his brother in 1999. He founded the ALS Therapy Development Institute and has raised the bar on ALS research.

Margaret Flinter: And from that effort, he created PatientsLikeMe, an online personal medical data sharing portal that strives to make as much meaningful information openly available to researchers seeking better cures and better treatments. He thinks it's going to revolutionize how health care is delivered and engaged in by patients of all kinds.

Mark Masselli: But no matter what the story, you can find all of our shows and hear more of us by Googling CHC Radio, and as always, if you have feedback, email us at [www.chcradio.com](http://www.chcradio.com), we would love to hear from you. Coming up our conversations with PatientsLikeMe Cofounder, Jamie Heywood but first, here's our producer Marianne O'Hare with this week's Headline News.

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Marianne O'Hare: I am Marianne O'Hare with this Headline News. Health care reform was a big and sometimes contentious topic this past weekend as governors from around the nation met in Washington. At issue, the Obama Administration's order that states set up state-based insurance exchanges for uninsured residents to purchase health insurance at a reasonable rate. While states like Connecticut, California and Maryland are already up-to-speed on that order, many states, most of them GOP-led, are opting to wait until after the Supreme Court rules on the Affordable Care Act, which will come before the High Court at the end of March with the decision expected in June. Some GOP governors like Dave Heineman of Nebraska is saying they are just going to adopt a wait and see attitude before complying. Meanwhile, all of the controversies springing from conservative measures on things like birth control funding and the Affordable Care Act are creating an uptake in support for President Obama in one formidable sector, women voters. Obama's approval rating on matters like employment and the economy have jumped 10% for him since December among women. Analysts believe issues such as his stance on support for birth control are the underlying factors in the increased approval.

From the medical grounds, it appears that flu has been slow to take hold because of all this mild weather. Folks are spending less time cooped up inside spreading that flu bug around. There is another theory for the late start though. This year's flu is genetically similar to last year's showing last year's flu shot may still have a prophylactic effect.

And we know it makes dishes taste tastier but Rosemary may have a positive mental effect as well. A recent study showed those exposed to Rosemary oils in a control group had higher functioning cognition and a slightly elevated mood. How is that for a savory bit of information? I am Marianne O'Hare with this Headline News.

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Margaret Flinter: Today, Margaret and I are speaking with Jamie Heywood, Industrial Engineer, Founder and CEO of PatientsLikeMe, the preeminent online data sharing platform for patients with a variety of diseases. He is also a Cofounder of ALS Therapy Development Institute. Jamie, welcome to Conversations on Health Care.

Jamie Heywood: It's great to be here.

Mark Masselli: Jamie, you launched ALS TDI, the first non-profit biotech company in the world after your brother was diagnosed with ALS better known as Lou Gehrig's disease back in 1998. That quest led ultimately to the founding of PatientsLikeMe which allows patients to openly share their medical data for research. You were not a health care insider but you saw the need for an open research model for accelerating therapeutic research. So what is so different about the model you created?

Jamie Heywood: Well I think in the beginning I came at this from the perspective of Stephen, which is how do I find answers for Stephen. And with the disease like ALS where you are sort of given a death sentence of three years or so, your primary objective is initially to discover a new treatment, something that delays the disease. And I had disadvantage of having an academic father and then working at an institution that was doing basic neuroscience and sort of knowing some of the strengths and weaknesses of the current system. So I kind of did what an engineer does which is to look at the problem and sort of industrialize it and say what are the ways we need to move forward to find a treatment for Stephen, and that's what led to the Institute. And then once Stephen was fairly sick with the disease, we had to manage this very complex disorder at home and I was realizing that most of what I was learning was from other patients and it wasn't necessarily just what to do to treat the disease or manage symptoms but more about how do you live your life with disease well, which is I think where the medical system really falls down, doesn't give that answer. So, PatientsLikeMe sort of came out of an intersection of that quantitative assessment of disease that

relates to discovery and then this need to understand how to live your life as a patient and how that be quantified and exchangeable and understandable.

Margaret Flinter: So Jamie, I think that it really was an incredible innovation that you created because when you started PatientsLikeMe there was nothing like it, there was no portal for patients where they could safely and publicly share their medical data and share with each other, with other people suffering from the same illnesses. And I wonder for our listeners, how do they find their way to PatientsLikeMe, what do they do when they get there, and what are these two pathways of both sharing support with other people and experience with other people that helps them live with it but also sharing their data? What is this data that they share? Maybe you could sort of walk that walk as a patient would today.

Jamie Heywood: Let's say that you are mid 30s and you just got diagnosed with Multiple Sclerosis and you have these weird symptoms of pain and maybe some interference in your ability to see and walk, and you have no idea what's going to happen. And you go and you find a great doctor, and you get a second opinion and you really confirm that you have this process and maybe they put you on the first line treatment and you go home. And the question you ask is, how does this affect my relationship, how does this affect my ability to work, is it going to get worse, is it going to get better, will these problems that I have from taking the drug, these side effects, go away or will they get worse overtime. And you probably asked all of those questions of your doctor and they might have given you pretty good answers from their perspective. But you are home, and you just had a fight with your husband because your sex drive is down and you can't figure out how to connect and relate, and you got to go talk to someone else like you to figure out what's the path, how can you live a great life even with this problem. And you start searching and you find our site. It's not like patients haven't networked and helped each other connect and live, we have always done that through churches and through all kinds of social media. But today, you can find someone just like you, you can find that 36 years old woman who was diagnosed two years ago, had the same symptoms as you. You go through the issues, the dialogue, talk about the consequence of your treatment decisions in that context and because you are sharing everything, you can find and identify that person, and that's where it really comes out. And it's not like there is one simple value, it's that you are in this deep dialogue with the community and you don't know what you need to know and you learn.

Mark Masselli: So it's not anonymous information, it's you really identify who you are and all sort of aspects of your condition. How is that translated and how is that helping out improve outcomes for pharmaceutical companies or other researchers who are engaged in clinical research?

Jamie Heywood: There are two parts to that. First off, you don't have to use your name, in fact most patients don't give their name, but because you are

sharing so much information, ultimately your condition, sometimes where you live, the treatments, we don't want to claim that it's fully anonymous. People don't know who the people are, and if you stay inside the site you are not indexed by the search engines. And you can learn a lot without even sharing anything so you can just come and read other people's information.

The second part, let's just talk about what the sharing experience is like. You mentioned earlier that it was sort of the ability to share your health records. We actually do more than health records. And I think this is one of the misunderstandings about the health system. When I run a clinical trial and I study a disease or a condition, we measure some really quantitative important things that help us understand what your status is. When you do medicine, you don't actually quantify those things. You take notes, you discuss issues but the quantification of the health of the patient is only generally done in clinical trials. And so what we do is we do that quantification. So it's actually an outcome management platform not just a health record.

So you really can, just like a trial, know how someone is. And that's what makes health care become a discovery tool because right now when a pharmaceutical company wants to know if a drug actually helps anyone in the real world, they have to ask a system that does clinical outcomes research and that's what we bring, the clinical outcomes research to the practice of medicine through the patient in a collaboration. We find the real value of the patients is through that triangle of formalizing their understanding of their disease, sharing that and collaborating with their physician to achieve the best outcome, always in a framework that a research enterprise or a researcher, an academic, could learn something from that process of what's your status, what do you do to change it, what was the result of that.

Margaret Flinter: What's your response when people raise questions of privacy and protecting people from what some have called exploitation of using the patients' data?

Jamie Heywood: It's hard to imagine the difference between our society seven years ago, before Facebook, and our society today. We were on the bleeding edge of sort of a new movement which I would sort of call the Community Movement which is to say that we are not all islands, we want to collaborate in ways to create greater shared value. And I think that this shift from seven years ago when doctors were asking us whether it was legal for a patient to share their health information, or the patient literally asking the question was it illegal, to today, where doctors are actively encouraging people to look on the site, is just a change in our culture. You have a right to privacy. But seeking privacy as a goal is really built on healthy societies. And if we limit the circle of the people we care about only to those that live in our neighborhood or in our house or in our family, we are going to have a very unhealthy society.

When my brother was dealing with ALS, he cared about lots of other people with the disease. He had things that could help them. And the idea that the privacy movement would suggest it was a bad idea for him to do so really I think is just an old concept that's gone. I think that today these digital tools are allowing people to sort of follow their human instinct to be parts of the community and make a difference. And we have used privacy or sometimes I would say secrecy as a way of preventing discrimination rather than really fundamentally addressing the question of how do we build a just society that's not based on secrecy but is based on justice. And that's I think the journey we have go through now because technology is going to make it so that we can know so much about everyone, that if we don't figure out how to live together collaboratively with inequality of conditions and other things then we are not going to be able to build a just culture we want to live in.

Mark Masselli: We are speaking today with Jamie Heywood, the driving force behind PatientsLikeMe named one of the 15 companies that will change the world by CNNMoney. You also co-founded HealthDataRights.org. Really you started out with a bold declaration of individual rights in today's social media climate. Talk to us a little bit about that organization and the issues associated with the fundamental right to your health information through all means.

Jamie Heywood: Two of us were sitting and talking about how as we were trying to help patients was not allowed. Like there are actually 27 states where as a patient you are not allowed to get access to your labs unless your doctor gives them to you. The idea that someone have information about you that you weren't allowed to have access to just sort of felt wrong to us in this modern world. And we started talking with more people and people really said hey, we really have to write this down. And over about two weeks, literally 100 really amazing individuals wordsmithed these very tight concepts that an individual has a right to a copy of every element of data about their health and if that data exists in a digital form, in the raw form like the MRI file or whatever, they must be made available in that form. And it's so simple but it's not the way the system works. And I think that we need this to enable patients to be the corrective force in health care, the part that makes the health care be honest and transparent.

Margaret Flinter: But Jamie, if I could maybe take you in just a little bit of a different direction for a moment, the whole issue of the off-label use of medication, there are times when pharmaceuticals or treatments have been developed for one condition, tried in something else not yet been through all the rigors of all the research to formally give them approval for use in that case and we call it off-label use. What's the role that your company has played in bringing forward some treatments that may be of benefit to a subset of people?

Jamie Heywood: A lot of medicine is not actually evidence-based. And you could sort of profile the sort of evidence into sort of two categories with a big gray in-between area. So one is you have these large scale formal clinical trials

where you establish beyond any doubt that a treatment is effective for some population of patients. And medicine **operates at** that whole gradient. Obviously, the right thing to do where if you have the good knowledge you should do it, and then strong evidence based. But there is also a great deal in the middle, which is in ALS, in one of treatments is a drug called Elavil that's used to manage excess saliva. And these sort of secondary treatments which do not have formal indications, I mean that's a side effect of Elavil is dry mouth, don't have any evidence for them. And so we have done some work in publishing and demonstrating that and if you go on our website, you can type in a symptom name with your condition and you can learn all the treatments that patients believe helped them with that. And it's belief-based evidence; it's not the formal actual measure change evidence that we are developing that.

The other thing we have done is look at side effects of medicine. So if you look at two drugs for the treatment of fibromyalgia, one is Lyrica and the other is Cymbalta. They have very different mechanisms. But one of the drugs causes significant weight gain. If you are a woman and trying to figure out what drug to take for fibromyalgia and your choices are Lyrica and Cymbalta and you find out that Lyrica will cause you to gain weight every year, you might change your choice or the first choice you make with your doctor. And that information is not obvious, not available so we have done that as well. What I am hoping we can move to is a learning health system where we really do understand that we allow for the development of the treatment collaboratively with the population. We observe and learn what happens in the real world and then the system feeds that back. It's not moral to provide medical care to someone in any real risk situation or any place of ambiguity unless you are collecting sufficient information to guide the next person that goes down that journey. And that's a pretty radical shift to thinking about how we do health care which is it's only about the person in front of you and you protect their privacy as paramount. But to my mind, if my mom has breast cancer and she does an experimental treatment against her mutation that no one else has done, and that information isn't shared, that's as big a crime as not reporting a crime because someone is going to do that and risk their life in the future and you didn't give them a chance to do that on the best information, and we need to really shift our culture to that new model.

Margaret Flinter: It leads me to wonder have you observed, whether it was your intention or not, have you observed advocacy groups or action coming out of the community of individuals on PatientsLikeMe. Has that translated into testifying in Congress or lobbying on behalf of funding for certain diseases, anything that sort of transcends what happened within PatientsLikeMe into a larger context?

Jamie Heywood: The patients are organizing to evaluate whether treatments work. So, in MS they are looking at CCSVI which is this sort of surgery that increases blood flow. People look at diets in fibromyalgia and chronic fatigue. And then they are also looking at treatments in ALS across the board. There is a group that are organizing a petition to force the FDA to sort of be more formal

about its Compassionate Access Policies, and I think we are a platform to that. And then patients just organize together to do specific subtle advocacy issues. They got involved in the stem cell debate, things that really matter to them.

Mark Masselli: Jamie, one of the initiatives to make patient data more accessible is the Blue Button Initiative. Talk to us a little bit about that initiative and why are other data sharing systems not working as effectively.

Jamie Heywood: I mean I think the Federal Government has really done a great job of leading here. The VA Blue Button with Peter Levin, Todd Park, Farzad Mostashari, Aneesh Chopra have really pushed for and defined this data liquidity in health care in a really important way and it's very exciting. Registries really matter and we are building a lot more and the NIH is investing a ton in that. But they are still building them in such a way that they can only allow 20 or 100 researchers to access the database because they contain genetic data which is mostly fingerprints and identifiers, right. It's a little bit like it's the beginning of the personal computer age. I don't think anyone can really imagine that normal human beings that are not epidemiologists or clinical researchers want access to data and when high school students can do genetic studies on disease, we will live in this different world and I think the promise is just really complicated leap across that gap and no one has done it. It's that's why those organizations (20:28 inaudible) matter to me because they are starting that leap. Oh and the Creative Commons, which has got an organization called Science Commons that has developed a thing called Open Consent where if a patient consents then their data can be used by anyone. Think of the irony of that. Until 2011 there was no document that a human being could sign that would allow anyone in the world to do research on their information. I mean that's just so insane.

Mark Masselli: Jamie, we like to ask all of our guests this final question. With all of your hopes and connections, when you look around the country and the world, what do you see in terms of innovations and who should our listeners at Conversations be keeping an eye on?

Jamie Heywood: Sweden has been doing some really amazing work with registries over the last decade. And medicine in Sweden has moved from being sort of this formal research process model to this specialists really operating these registries and collaborating to make the country's health better and every individual with that condition. They are lowering costs, but they are not even trying to do that. What they are really doing is they are just taking better care of people and that's a model to my mind I think that we help make possible more broadly. A country's wealth is not so much how much money it has but its how much health it has because health drives everything. It drives how successful your children will be in the world economy. We have to start viewing health as a strategic asset and building an economy around health care that maximizes that. My parents are in their 70s. I want them to be here for my kids for a long time and I want a model that allows me to invest with them in that making a healthy



fulfilled long health span. And that's what I think things like Sweden and registries and platforms like ours make possible.

Margaret Flinter: Today, we have been speaking with Jamie Heywood, Founder and CEO of PatientsLikeMe, the preeminent online data-sharing platform for patients with a variety of diseases. Jamie is also the co-founder of the ALS Therapy Development Institute. Jamie, thank you so much for being with us on Conversations today.

Jamie Heywood: It's been a pleasure.

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Margaret Flinter: Each week, Conversations highlights a bright idea about how to make wellness a part of our communities and everyday lives.

Mark Masselli: One of the directives of the Obama Administration's Health Care Reform Act requires pediatricians and health insurers to begin screening kids for obesity, a condition afflicting one in three American children. The problem, what to do with those children who are identified as being overweight or obese? It's tough enough for adults to lose weight even with multiple programs at their disposal. There are relatively few programs available to overweight children and their families that aren't expensive or hospital-based. UnitedHealthcare has teamed up with the YMCA to create a program for community based weight loss sessions for kids and teams, launching the pilot program in Providence, Rhode Island. The kids, accompanied by a parent, joined in a group session that are fun but also informative. Kids are educated about the calorie counts of food, learn about Body Mass Index and the importance of exercise on a daily basis. At the end of the 16 week program, the overweight kids lost an average of 3.5% of their body fat, and the bonus, the parents and the rest of the family often lost weight too. The pilot program is inexpensive, kid-directed and life changing. And with follow up as part of the program, these kids know they will still be challenged to keep up with healthy lifestyle changes. Helping kids tackle obesity cheaply, and in a community setting that works for kids and their families, now that's a bright idea.

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Margaret Flinter: This is Conversations on Health Care. I am Margaret Flinter.

Mark Masselli: And I am Mark Masselli, peace and health.

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