(Music)

Mark Masselli: This is Conversations on Health Care. I am Mark Masselli.

Margaret Flinter: I am Margaret Flinter.

Mark Masselli: Margaret, the holiday seasons are upon us and our best wishes for happy and healthy New Year to all of our listeners. And you know as we forward, we are always very optimistic but looking back it was not so merry of a year for a significant sector of our population.

Margaret Flinter: Well, that's for sure Mark. NPR and the Kaiser Family Foundation just released their poll of the long term unemployed and not only are they unemployed, they are also uninsured. More than half, more than 50% of folks unemployed for a year or more are without health insurance. And Mark, that absolutely fits with what we are hearing from so many colleagues in health care, people have been putting off routine and preventive dental and medical care but now they are putting off even really necessary urgent care.

Mark Masselli: That's right. In that poll, 56% of the folks admitted to putting off necessary health care in the past year because they simply couldn't afford it and we know so many people are borrowing from family and friends to pay for basics like food and shelter, their physical and mental health have declined during their unemployment, pretty sobering statistics I would say.

Margaret Flinter: And all good reasons for every one of us to find it in our hearts to share generously however we can during this holiday season with those who have less and we wish for a better economy in the New Year. But as 2011 ends Mark, there were some exciting developments out of Washington where they were holding the mHealth Summit last week. We had some colleagues down there reporting back all week and I think my personal favorite was your ability to use the cell phone as an EKG with the promise that you might even be able to use it as a defibrillator not far down the road.

Mark Masselli: Well that should work for me. I keep my cell phone in my shirt pocket all the time. And the wireless technology is exploding in health care and there were hundreds of new apps unveiled at the summit designed to facilitate patient health outcomes. They are focused in on streamlining communications between patients and health care providers, between home and office and in the field. Margaret, we are all part of this new apps generation or apps economy they are calling it.

Margaret Flinter: They are, and a potential big impact on the economy. I am hearing reports that widespread use of mobile health technology might shave 5%

off current health care cost in this country. 5% off of three trillion, that sounds somewhere between impressive and almost unbelievable.

Mark Masselli: It's a big number. And all of that engages patients in their own health and health care. We have got a great guest today who is in the forefront of patient participation, Dave deBronkart, better known as e-Patient Dave. He is the Founding Member and on the Board of the Directors of the Society for Participatory Medicine. He is also a well-known blogger and speaker on topics of e-patients.

Margaret Flinter: And we are delighted that Dave can join us today. And remember, no matter what the story, you can always find all of our shows and hear more about us by Googling CHC Radio.

Mark Masselli: And as always, if you have feedback, e-mail us at www.chcradio.com, we would love to hear from you. You know Margaret, today we introduce a new producer Marianne O'Hare who we are happy to have join us and we also want to wish Loren Bonner a fond farewell. She served us so well and is off to do some work with Martha Stewart. Isn't that exciting?

Margaret Flinter: It's very exciting. We are looking forward to getting some tips from her.

Mark Masselli: And now Headline News with Marianne O'Hare.

(Music)

Marianne O'Hare: I am Marianne O'Hare with this week's Headline News. The battle continued this week on Capitol Hill to enact another temporary fix to the Medicare reimbursement formula but final resolution is still in doubt. While the House passed a payroll reduction bill that would also restore Medicare reimbursements for doctors over the next two years, Senate Democrats and the Obama Administration are poised to block the measure due to methods by which the Medicare reimbursement would be paid for. Both doctors and hospitals are facing a 27% cut to their reimbursement schedules on the first of the year if Congress doesn't enact a funding measure. In a report released this week, it was announced that 2.5 million more young adults are covered now by insurance since the passage of the Affordable Care Act. The rise in health care coverage for 19 to 25 year olds surpassed the expectations of the Obama Administration. It's a direct result of provisions in the Health Care Reform Bill; young adults could stay on their parents' policies to age 26. In health care news, a recent study showed that women who were diagnosed with breast cancer had smaller tumors if they had higher levels of vitamin D in their system. The study also found that after three years, the breast cancer patients with higher Vitamin D levels had a dramatically lower incidence of recurrence. Working moms, stay-at-home moms, who is happier? A recent study showed that women who work part-time rank

happier than their at-home counterparts. The study showed part-time working moms of even small children had a happier outlook and less depression than moms who stayed at home with their children. Now back to Mark and Margaret.

(Music)

Mark Masselli: Today, Margaret and I are speaking with Dave deBronkart, also known as e-Patient Dave. He is the Founding Member and on the Board of Directors of the Society for Participatory Medicine in addition to being a well known blogger and speaker on the topics of e-Patients. Welcome Dave.

Dave deBronkart: Thank you very much.

Mark Masselli: We hear the term Participatory Medicine brought up often these days in health care but the term e-Patients may be less familiar to our listeners. Can you tell us what an e-Patient is and how you became one?

Dave deBronkart: It's funny because I was one long before I knew the term exists. The 'e' stands for empowered, engaged, equipped, enabled, some people are saying educated about evidence sort of a pick your own e thing. The term was invented by a doctor named Tom Ferguson who coined this term e-Patient and he started spotting individuals who were beginning to do the things that he anticipated. One of the people he spotted was a guy named Gilles Frydman who had founded www.acor.org which is a network of list of plaintext simple mailing list for people with different cancers. I ended up joining that. It turns out it's the best source of kidney cancer information in the world. Another one he spotted was my primary physician Danny Sands, who in 1997 wrote the first published guidelines for how to do doctor-patient email effectively. And so when I had my cancer adventure in 2007 and recovered, the following year Dr. Sands invited me to go on this annual retreat with this band of Internet crazies. And I read their manifesto called the e-Patient White Paper and immediately spotted myself in those pages because the behaviors that were described there just matched what I had done. Though I did have a blog, in fact my first post on that blog was four years ago today and I had called it the New Life of Patient Dave and I just renamed myself e-Patient Dave.

Margaret Flinter: Dave, you have been a champion and a crusader really in this e-Patient movement and in opening up access for patients to specialists, to each other for support but also just access to your own data. And one outcome you experienced that you found was that the data might not always be as accurate as it should be and some of that, and I notice it's getting into a bit of detail, but for our listeners I think this is important. You found that the data being used to describe people, reflect people is their claims data, the data that people select for billing purposes more than the data that might be in the chart itself and more specific and more accurate. How have your worked to correct this and why is that important to our listeners?

Dave deBronkart: Well it's funny because my career and then this whole thing of me being thrust into being an international keynote speaker and blogger on health care, I knew nothing about any of this until I got sick and then I didn't really know anything about it until after I got better and started studying it. But my career has been in high-tech where we do things with data. Most, not all but most, Electronic Medical Record Systems in hospitals and doctors' offices have been cost justified by the ability to bill insurance not by the ability to create a good record for us. And it turns out, without getting too geeky here, it turns out there are numerous reasons why the data that you need for insurance billing is not the data that you need for good accurate medical picture of your health. So the first thing I think it's important for people to understand is that your billing records are different from your clinical records, the real medical information, and unfortunately, the billing records are more likely to be automated than your real medical records, which are likely to exist in paper or just in a really un-computerized pile of text. And the reason this is important, and I would encourage everybody, your hospital may tell you otherwise but you are entitled under law to get a copy of your medical record. It may take, they are allowed to be starchy and take 30 days or even 60 to give it to you and in some States they are allowed to charge ridiculous amounts of money but you can get at it and those rules are changing.

Mark Masselli: That's a very interesting point. And you know under the Affordable Care Act there is an initiative in all the States to develop Health Information Technology Exchanges so providers can put their information out there and other providers can access them but more importantly patients can access them. Have you been working on those or been a resource to those authorities as they think about the issues? There are lot of the 'inside the beltway', do you opt into this or opt out. But I want to talk more about the bigger picture of really trying to push out access to people's medical information whether it's their primary care provider, a specialist, or the hospital; how do you see this movement developing and how are you helping inform it?

Dave deBronkart: I am a child of the '60s. I came to Boston, the college from Minnesota in the middle of the protest years, the consciousness raising about feminism and civil rights and in any movement like that there is this awakening phase. As I say, consciousness raising like oh, I didn't realize that was going on, I didn't know there was anything there to pay attention to. So I mean I myself when I got sick five years ago _____ 11:30 when I discovered I was almost dead, I just presumed that everything about doctors and hospitals was perfect. And I was saved by magnificent doctors at a magnificent hospital, no question about that, but I had no comprehension of how poor most of the computer systems are to support them. Today, it's not possible for instance for a commercial airliner to take off with its flaps in the wrong position. There was a day when that sort of mistake would cause a fatal crash. Today, that's been engineered out of you just can't do that anymore. Well, protections like that don't

exist in the hospitals to keep doctors and nurses from making honest mistakes. So I advocate two things. First of all, I advocate for us the patients, the consumers, whatever you want to call us to be responsible and take an active role in helping make sure that the information is as good as it can be. And I also advocate for physicians to open their minds and hearts to realize that it's not pointless to get that kind of help from somebody who hasn't been in the medical school. Now I am fond of saying that I am not a doctor, I didn't even know I was sick I couldn't have diagnosed myself and so on and yet, when I looked at my radiology reports you don't have to be a doctor to notice that for instance one of my X-rays identified me as a 53-year-old woman. Now why with a clearly male name attached to it somebody could have put 53 year old woman in radiology report, I don't know how that can happen but the point is you may be more able as a consumer and you may benefit more as a physician from having the patient actively involved in improving the quality of the medical record.

Margaret Flinter: You know Dave, we often talk about training the next generation on the show and look at areas where we need to really improve the training of physicians and nurses and other health care professionals to accomplish our goals. But this area around the engaged patient, the e-Patient as we describe it, the use of information and electronic communication might be just one area where the current generation of people who are training actually come to this de novo with this as a skill set. What's your work been or your connection been to students of the health professionals and what's your sense for how they will carry this into their future careers? Are we looking really at a new generation that comes to this philosophy and this set of activities naturally?

Dave deBronkart: I would just love to have the chance to participate in medical education because you hit the nail on the head. I blogged last month about something I stumbled across from Max Planck, the magnificent physicist from a 100 years ago, who said something, I don't have it in front of me for the exact wording, but it's something about new scientific truths are not adopted because people change their minds, new scientific truths are adopted because the old **farts** die off and a new generation comes along that wasn't raised with the old erroneous view. So here is a tangible example of that. At conference after conference and on blog after blog, I have heard physicians say, I am not doing email with my patients unless there is an insurance billing code for it. But a year and a half ago I participated in my hospital's Lean Quality Improvement Workshop and we had an interesting mix of people there. There were case managers, attending physicians and a bunch of kids I could say fresh out of medical school and for them it's like what do you mean not to email, of course I will do, that's how you talk to people. And so, indeed if we can connect with students in the school and find ways that will be acceptable in the culture of medicine to connect them to the idea of the engaged patient, really there is no telling what may be possible.

Mark Masselli: This is Conversations on Health Care. Today, we are speaking with Dave deBronkart, also known as e-patient Dave. And I want to pull the thread a little on that the culture of medicine. Certainly, the Internet has become available and information's more accessible to individuals at a click of a button. But if you look at the younger generation of people out there, social media is the way they communicate; they actually aren't emailing, they are on their Facebook or in fact they are texting and the like. What do you see the role that social media is playing in all of this around engaging and activating patients?

Dave deBronkart: Well, if you want to talk about activating patients to connect with each other that's a whole different game than doctor-patient communication. I personally think that it's a good idea for doctors and patients to have that care relationship in an Electronic Medical Record system so that it's all archived in one place. But on the other hand, the aphorism that I have heard recently is social media talk about medicine but don't practice medicine. So you have for instance two doctors who spring to mind, in fact three, who do this brilliantly. There is Wendy Sue Swanson who is a pediatrician and a mother in Seattle. Her Twitter name and Facebook page are Seattle Mama Doc. Then there is Jeff Livingston in Texas but his identify is Mac OB/GYN. He says that by putting out good information to his patients, most of whom are young women who are on Facebook, but putting information out there by being where they are, he sees them making better choices and having better results. And this is in that manifesto that I mentioned earlier that Tom Ferguson was working on when he died and his kin finished afterwards.

One of their seven preliminary conclusions was as much as possible health care should take place on the patient's turf, be where the patient is. In every other industry, they know that being located, especially in retail, being located where people already are is how you get better results. And then the third physician doing social media, and there are others who will kill me for not mentioning them, forgive me, third one is an orthopedist named Howard Luks. He decided that he would like to converse with people on his blog with videos so he just switches on his webcam, records five minutes of discussion about a topic. And just to show how this sharing of technologies can work, I said, you know Howard, that's great that you have these YouTubes on your blog but the words you said can't be found by Google. And so he found a cheap transcription service so now he records the video and then takes the text and pastes it in so that it works out both ways. So at a deeper level what's changing here, I was trained years ago as a structural thinker to deconstruct a situation, look for how is value flowing from point to point, how do people or players in the ecosystems who have a need how do they go looking for it and how do they connect with that resource. What's happening here is that you could say 50 years ago, all ability to create value in medicine resided with people who had been to medical school, the access to information in the libraries, the ability to do diagnoses, the knowledge of available treatments and so on, and so many of those things including the skill of a brilliant care-giving or physician or nurse are still true. But it's no longer true that the only

access to useful information and the only access to good medical advice comes from your local physician. Now that can seem threatening to some people but it does no good to just feel threatened and stick your head in the sand, the question is how do you adjust. People like Wendy Sue Swanson, Jeff Livingston, Howard Luks are becoming participants in that new information ecosystem, they are putting information out there for others to find and they go out and they look for information as well.

Margaret Flinter: Today, we have been speaking with Dave deBronkart also known as e-patient Dave, a Founding Member and on the Board of Directors of the Society for Participatory Medicine. He is also a well known blogger and speaker on the topic of e-patients. Dave, thank you so much for joining us on Conversations today.

Dave deBronkart: It's been a real pleasure. Thank you so much.

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

This week's bright idea recognizes that a range of factors including the built environment can determine health. Mercy Housing California, a non-profit development company, decided to collaborate with the City of San Francisco as well as community-based organizations on a project that would combine development and health. Their plans include transforming the city's largest public housing community, Sunnydale. It consists of 800 units housing 1700 people on 50 acres of land but most residents live in poverty, there is no grocery store, and violence is pervasive. The revitalization of Sunnydale is part of HOPE San Francisco Initiative to reinvent distressed public housing communities and is San Francisco's largest anti-poverty collaboration in decades. The housing units will be redeveloped into a mixed income community with a life center for fitness, family programming, a health clinic, educational facilities, green space grocery stores and a farmer's market. In addition, developers are working with researchers at the University of California to collect baseline data on the social and physical needs of the residents so that their health and well-being can be measured overtime. Last spring, after several months of community meetings with Sunnydale residents, a master plan for the revitalization of San Francisco's Sunnydale neighborhood was finalized. Recognizing the impact that community development can have on health, uniting a city and bringing hope to underserved populations, now that's a bright idea.

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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