

**(Music)**

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

Margaret Flinter: And I am Margaret Flinter.

Mark Masselli: Well Margaret, it's the holiday season, the season of giving, and it seems Congress might be getting into that giving mood.

Margaret Flinter: Well there's give and take going on, that's for sure. Looks like both sides of the fiscal cliff negotiations are giving some serious thought to raising tax revenues on the top 2% of wage earners in this country, something that the GOP had been adamantly opposed to before now.

Mark Masselli: There seems to be some room being made for tax revenue increases and exchange for what could be some cuts to entitlement programs but at least both sides of the aisle are showing more of a willingness to negotiate.

Margaret Flinter: And Congress has until the 1<sup>st</sup> of the year to reach some kind of formal compromise on the budget before we fall off the fiscal cliff and that's when a number of tax breaks for all Americans come to an end. And funding for many programs including Medicare and Social Security are set to see a significant drop in funding as well and that will not make for a merry holiday season for some people.

Mark Masselli: And I have a feeling that Congress will try to get its business done before all of those are upon us. And most economists though warn there will be dire consequences there if they don't reach a settlement before the end of the year, which is up to now seems like a real likelihood.

Margaret Flinter: And in fact, our guest today is very concerned about how those negotiations can affect research at the national level. As the Head of the National Institutes of Health, Dr Francis Collins relies almost entirely on government funds to keep literally thousands of medical research programs going on around the country.

Mark Masselli: You are absolutely right. The National Institutes of Health is the largest medical research organization in the world and is responsible for many breakthroughs in science and medicine as well as generating about seven million jobs in the country.

Margaret Flinter: Dr Collins also led the team that first mapped the human genome and that single extraordinary achievement is poised to have a profound effect on what medicine looks like in the future, and actually, already is having an impact. They are really looking forward to that conversation Mark.

Mark Masselli: And we have another visit with Lori Robertson, Managing Editor of FactCheck.org.

Margaret Flinter: These facts are the gift that keep on giving. But no matter what the topic, you can hear all of our shows by Googling CHC Radio.

Mark Masselli: And if you have comments, please email us at [www.chcradio.com](http://www.chcradio.com) or find us on Facebook or Twitter; we love to hear from you.

Margaret Flinter: And we will get to our interview with Dr Collins in just a moment.

Mark Masselli: But first, here is our producer Marianne O'Hare with this week's Headline News.

**(Music)**

Marianne O'Hare: I am Marianne O'Hare with these Health Care Headlines. Medicaid expansion and the Affordable Care Act, the governors have had their marching orders delivered. Part of the rollout of the health care law includes a provision that each state must expand its Medicaid eligibility to 138% of the national poverty level or \$32000 for a family of four. The move would make several million more Americans eligible for coverage under Medicaid. But the Supreme Court ruled this summer that states can't be required to expand. The federal government will cover 100% of that expansion for the first three years followed by a slow rollback to 90% within 10 years. A number of states have flat-out rejected the move but now some states are coming around saying perhaps they will do a partial Medicaid expansion. The Obama Administration responded this week by saying they would not qualify for federal coverage with only a partial expansion of Medicaid. Nine states including Texas and Florida have said they will not expand, 17 states have said they will, and the rest are still undecided.

And there is a roughly similar split on states setting up insurance exchanges. The online marketplace is being setup for uninsured Americans to purchase health insurance. So far 18 states have said they will setup federal exchanges, 6 have said they will partner with the federal government, and the rest are undecided or defaulting to be federal insurance exchange. Meanwhile as the end of the year draws near, talks to avert a fiscal cliff continue, largely behind closed doors. A private meeting at the White House over the weekend between President Obama and John Boehner did not end with overt open rancor. There is growing consensus on both sides of the aisle there will be some revenue increase on the wealthiest 2% of Americans.

Wealthy, healthy and wise. How does American's health stack up? Well the short answer, we are living longer but sicker with more chronic disease. 27% of Americans are obese; 28% lead sedentary lives and smoking rates are highest in

Southern states like Mississippi and Louisiana. There is some good news though on the childhood obesity front. Rates are showing a slight decline in certain targeted areas. New York City has reported a 5% drop in childhood obesity with the program deployed in a number of preschools and elementary schools. Rates are also dropping in Philadelphia, Los Angeles and Anchorage Alaska. While the numbers are small, it does suggest a reversal of a 30 year trend. I am Marianne O'Hare with these Health Care Headlines.

### **(Music)**

Mark Masselli: We are speaking today with Dr. Francis Collins, Director of the National Institutes of Health, which is the world's largest supporter by biomedical research. Dr. Collins is a physician-geneticist who led the human genome project which achieved its goal of mapping the human genome in 2003, and is author of *The Language of Life: DNA and the Revolution in Personalized Medicine*. Dr. Collins is an elected member of the Institute of Medicine and the National Academy of Science. He was awarded the Presidential Medal of Freedom in 2007 and received the National Medal of Science in 2009. Dr. Collins, welcome to Conversations on Health Care.

Dr. Francis Collins: And it's a pleasure to be with you, Mark and Margaret.

Mark Masselli: Well the National Institute of Health is responsible for so much including thousands of research studies pertaining to medicine and health. And the mission of NIH is to seek knowledge about the nature and behavior of living systems and applying that knowledge to enhance health, length of life and reduce the burdens of illness. So can you share with our listeners some of the broader aspects of health in America and what are the really important health issues that need to be addressed?

Dr. Francis Collins: Well first, let's point out that we have made a lot of progress when you look over the last century, the ways in which medical research has taught us about what are the causes of illness and what we could do about it, we have come a long way. Human longevity in the United States has been increasing about one year every six years for last 30-40 years and now stands at age 79. And you can look at certain causes of serious illness or premature deaths that are actually diminishing quite significantly. It happens slowly enough, maybe people don't notice but heart attack deaths are down by 60% of where they were 40 years ago; deaths from stroke is down by 70%; HIV/AIDS which used to be a death sentence is now associated almost to the normal lifespan; and even cancer, which we still have a lot work to do on is dropping in its cause of death about 1% every year, which is progress.

What are the big challenges now? Gosh, it's a very long list. But certainly areas of particular need and scientific excitement would include cancer, Alzheimer's disease, obesity and diabetes big threat of course to our nation because of the

epidemic we are encountering here of that condition and all of its consequences, HIV/AIDS we have a chance to actually end that epidemic which is a bold thing to say but I think we could see a path forward to that, or something like Autism which is frustrating and growing in its frequency and need to understand it and come up with better inventions. So our plate is very full. At the National Institutes of Health we have programs in all of those disorders and many others trying to find answers.

Margaret Flinter: Well Dr. Collins, I really appreciate you are leading with that good news and optimism and I do think people don't realize the progress we made in reducing deaths from heart disease and so many other things as you have said. And you personally have had the opportunity to lead in one of the most transformative breakthroughs of the modern medical era, the complete mapping of the human genome. It took 13 years and \$4 billion which your team did in 2003, and just 10 years later we have gotten the technology down to where a person could choose to have their entire genome sequenced in a day for maybe \$1000. So here we are on the threshold of the ultimate tool for clinicians I think who seek to provide true personalized medicine. Tell us about the promises and the challenges and maybe the limitations to genomics and transforming the way health care is practiced in not too distant future.

Dr. Collins: Well the genome is the instruction book for human biology. It's that wonderful information molecule called DNA with all of the letters that make up each of our instruction books. About three billion of them in fact is the human genome and mine and yours are about 99.5% identical. By having not only sequence that first reference genome but now having a huge amount of information about differences and how they associate with disease risk and a lot more about how the genome actually functions, we really are in a position to be able to do some pretty interesting things. And one area is the ability to use information about your DNA along with your family history to predict what you are at risk for in the future and to give people a chance to practice more individualized preventive medicine instead of one size fits all.

I think another area where genomics is already having an impact is the ability to predict for an individual who has a particular disorder where treatment is needed what's the right drug and what's the right dose for that person. And a lot of that is determined by differences in DNA, and we can measure those and make better predictions. We call that pharmacogenomics, which is a lot of syllables but I think you get what that's about and there is now more than a dozen drugs for which it's recommended that if possible you have that kind of analysis before the drug choice is made. Maybe though the place where genomics is furthest along in terms of its impact on health is cancer. Cancer is a disease of the genome. It comes about because of misspellings in genes somewhere that causes cells to grow when they should have stopped. But every cancer is different, that's what we are learning and so the one size fits all approach to breast cancer or prostate cancer doesn't look like it's the right answer now either. If we could actually

identify for each individual what's driving their cancer and then pick from the list of more targeted drug therapies what's the right mix for that person, we would probably be on the path towards much better outcomes and less toxicities.

Mark Masselli: So Dr. Collins, I really love your simple description of that we have the instruction book. What are the challenges and the opportunities again, and I want to go back there, is there anything we are on the precipice of a revolution in the way that we treat certain disorders, and also, is there some concern that once people think we have the instruction book that we will get to these answers right away?

Dr. Collins: Well, we do have to be careful not to oversimplify or imply that answers are immediately at hand. The genome is an incredibly complicated instruction book and we are still learning how to read it. And certainly although I talked about cancer a minute ago in terms of our ability to do individualized diagnosis of what's driving a particular tumor, we still have way too short a list of interventions available; we have to work very hard in what you would call translational science to take the discoveries about what it is that causes cancer and connect those up. There are a few instances and we all can tell dramatic stories of people who had far advanced cancer where everything seemed to have failed and then the cancer got analyzed and they had an Achilles' heel sort of finding that oh my gosh, if you just try that drug, which you never would have thought of for that tumor and maybe you will get a response and people suddenly find, wow, that tumor is melting away; six months later the person is back at work. We all have stories like that but we need more of them.

I guess another area where the whole idea of genomics is starting to play a big role in is to try to figure out what's going on with children with birth defects or other kinds of unexplained difficulties in childhood. And once in a while, you have a dramatic result. I will tell you one about a pair of twins from Texas who had their DNA sequenced to try to find out why these twins were having this progressive neurologic disease that seemed to be threatening to shorten both of their lives fairly dramatically by the time they were teenagers. And what was discovered was a glitch that was immediately clear what was going on. They were missing an enzyme that was necessary for their bodies to make a particular neurotransmitter. That could be supplemented actually in their diet and they are both now remarkably vibrant healthy young people which is pretty amazing from a kid who was considered unlikely to make it to her 18<sup>th</sup> birthday.

Margaret Flinter: You know Dr. Collins, you talk about there being five Ts to medical research and that includes the technology, talent, threat and telling stories. And I think--

Dr. Collins: I just told a story.

Margaret Flinter: You just told a story that will permanently stick with me because it's a very compelling story, which is why they are so important. Tell me about the transition. Is this really about how we get the knowledge of what was accomplished in that specific instance into practice and disseminated throughout the health care community? Maybe you could talk a little bit about that and how that works on a policy level at the NIH as well.

Dr. Collins: Sure. So translation generally means taking the basic science discoveries about how life works and how disease occurs which are pouring out of the laboratories that NIH supports. And making sure that those don't just sit there but they actually get moved into new ideas about diagnosis and devices and therapeutics and actually provide benefit to patients in the clinic as quickly as possible because that can be a very long slow process and the failure rate can be very high. That means trying to identify what the bottlenecks are and they occur all the way along depending on which technology you are trying to move forward.

Mark Masselli: We are speaking today with Dr. Francis Collins, Director of the National Institute of Health, which is the world's largest supporter of biomedical research. Dr. Collins is a physician-geneticist who led the human genome project. He was awarded the Presidential Medal of Freedom and received the National Medal of Science for his groundbreaking work in genomics. Dr. Collins, I want to pull the thread a little on the conversation you were just having about the value proposition that NIH provides for our country and look a little behind the scenes at the business paradigm that supports the research and walk us through a little bit about the struggle that NIH is always facing but perhaps now more than ever.

Dr. Collins: Yeah it is now more than ever, and I think we all understand why that is given the fiscal stresses our nation is facing with the ballooning deficit and the need to do something about that. Yet at the same time if you were looking for a way to dig the economy out of the difficulties it's in, you would probably want to search for investments that are known to have a return. And in that regard, when you look at biomedical research, as many have now done, this is not only the best investment for advancing human health, it's also one of the very best investments you can make in the economy. People have looked at that and have come up with some pretty staggering numbers. The NIH supports directly about 488,000 jobs but when you consider all the ways in which that supports what goes on in small businesses, biotech and pharmaceutical industry, we are probably talking more like 7 million jobs that are directly related to what NIH puts their funding into. And on top of that, people have done the calculations on return on investment and it's clear that every dollar spent on biomedical research returns more than twofold in just one year in terms of the local economy and 85% of our dollars go out to grants to our nation's finest universities in all of the 50 states. So that's where the economic benefit occurs.

I will give you one startling example of how the return can occur. You mentioned the genome project a little bit ago and that's something I am fairly proud of in terms of how it turned out. But somebody recently looked to say off that \$4 billion that was spent over 13 years what have we gotten so far as far as economic return. And they calculated like a year ago that it already added up to \$796 billion in just the US. So, even accounting for inflation, that came to 141 to one return on investment. It is serious right now in terms of how those decisions play out particularly in terms of one of those five Ts you mentioned which is talent. I am particularly worried about young scientists who are just getting started who are full of ideas and creativity at a time where science has never had more potential than right now and yet their chances of getting supported by NIH are at historically low levels and could plummet to almost unimaginably low levels which would make it very difficult for many of those young scientists to keep going.

Margaret Flinter: Dr. Collins, it's always (16:56 inaudible) one of the not as well-known as it should be treasures of the United States. How the research agenda is set for NIH and the leadership of NIH in setting the research agenda is important to all of us across the country. So perhaps you could share a little bit of your thoughts with us on that.

Dr. Collins: It's very much an ongoing discussion that we have almost every day around here. About half of NIH research dollars go into basic science which is not targeted towards developing a direct advance in medicine and the other half is focused on translation or on clinical research where there really is that intention, and our mission encompasses both of those activities. But factored into that is public health need. So we pay attention to what are the disorders that are causing the greatest amount of morbidity and mortality and where are the scientific opportunities to make advances in those areas and then we try to place our bets in that regard. But we can't do just that or we would neglect rare diseases. At the same time, by studying rare diseases we often learn things. And the whole thing is actually supported by the best peer review system in the world where any grant that comes to NIH that has to be reviewed by experts who look at it and say, what's the promise here or what would happen if this actually worked, what's the likelihood it's going to work. That is the main reason why NIH has been so successful over these many decades is that we have absolute rigor in terms of how we decide what we fund.

Mark Masselli: Dr. Collins, this year NIH opened up a new division, National Center for Advancing Translational Science. So it seems to me that you are doing from the translational research hopefully to the transformational breakthroughs in primary care but then back to the transactional work that happens in the day-to-day settings in primary care or other places. So walk us through that cycle and tell us a little bit about the impact that you are having on those hospital and clinic practices.

Dr. Francis Collins: So sure, the center you mentioned, National Center for Advancing Translational Sciences or NCATS is a new arrival on the scene but NIH has many other investments in this space. But there are all kinds of other places along this long complicated failure-prone pipeline from an idea to a new therapy that's been widely accepted where we aim to try to knock down barriers. You really like to know when you are contemplating giving a new drug to somebody for a disease that desperately needs a new treatment is the drug going to be safe. And the way we traditionally have done that has been using small animals and large animals and hoping they would predict human toxicity. But we all know it's not that reliable. We are working with the Department of Defense namely DARPA, they are wild and crazy group of bioengineers, to try to develop bio chips loaded up with human cells derived from this new stem cell technology that allows you to develop those from any individual representing liver or kidney or heart or brain and to be able to assess in a much more realistic situation is this drug going to be safe or toxic for that individual. This is going to revolutionize the way we both develop drugs and test them for safety in the next 5 years, this notion that once you have developed something that looks like a good intervention, you have got to be sure it works in the real world. I am on the board of the Patient-Centered Outcomes Research Institute PCORI, which is a new enterprise supported by the Affordable Care Act which has as its mission trying to develop research protocols to figure out what really works in the real world and let's be sure that we are asking the patients whether they agree and not just checking to see what the measurements are in the laboratory. And that's going to be I think a major entry into this space. They are trying to provide primary care physicians with useful information that they can act upon and be confident it's going to apply in their environment.

Margaret Flinter: We have been speaking today with Dr. Francis Collins, Director of the National Institutes of Science, the world's leading supporter of biomedical research. Dr. Collins led the team that first sequenced the human genome and is the recipient of the National Medal of Science. Dr. Collins, thank you so much for joining us today on Conversations on Health Care.

Dr. Francis Collins: It's been a pleasure. Thank you.

Mark Masselli: At Conversations on Health Care, we want our audience to be truly in the know when it comes to the facts about health care reform and policy. Lori Robertson is an award-winning journalist and managing editor of FactCheck.org, a nonpartisan, nonprofit consumer advocate for voters that aim to reduce the level of deception in U.S. politics. Lori, what have you got for us this week?

Lori Robertson: Well, Mark and Margaret, we recently looked at claims about the Affordable Care Act from a group called Americans for Tax Reform. The group made the claim that under the law employers must offer preventive coverage that includes abortion. But that's not true. The law does require that insurance plans



sold on state-based exchanges cover preventive care but the states are the ones that decide what that preventive coverage is. Some states already have banned abortion coverage beyond exception for rape, incest or danger to the life of the mother and 20 states have banned insurance companies from offering plans that cover abortion on these state-based exchanges. Other states will allow plans to cover voluntary elective abortion but the law then requires those states to offer one plan on the exchanges that doesn't cover abortion. In other words, the law doesn't require plans to cover abortion. In fact, what it requires is that state-based exchanges include at least one insurance plan that doesn't. And that's my fact check for this week. I am Lori Robertson, Managing Editor of FactCheck.org.

Margaret Flinter: 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 would like checked, email us at [www.chcradio.com](http://www.chcradio.com). We will have FactCheck.org's Lori Robertson check it out for you here on Conversations on Health Care.

### **(Music)**

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

One in six people in the world lacks access to drinking water or basic sanitation and statistics show that diarrhea is the leading cause of death for these populations. In Africa, the numbers are staggering, with 46% of the residents of Sub-Saharan Africa having no direct access to clean water. In 2005, artist Tracy Hawkins went to Tanzania to see what she could do about it. Clay pot water filtration has been around for several hundred years, where simple clay pots lined in the bottom with silver oxide can remove up to 99% of the impurities from most water sources but no one had undertaken a dedicated program to produce and distribute these pots. Tracy founded the Sing'isi Pottery Project and began making the pots with local artisans in this region of Tanzania. She and her team were able to get a factory built so that they could increase production. The project has served multiple communities and continues to expand. Independent researchers have determined the system to be safe, effective, and the best part, the health of entire communities has been improved significantly once each village resident is provided with a clay filtration system. The pots are inexpensive to produce, easy to handle and the factory has also created jobs for local residents. They have since changed the name of the organization to Safe Water Ceramics of East Africa. A simple easily manufactured solution that improves access to water for a community, one that improves health, well-being, and economic conditions at the same time, now that's a bright idea.

### **(Music)**

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

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

Conversations on Health Care, broadcast from the campus of WESU at Wesleyan University, streaming live at [www.wesufm.org](http://www.wesufm.org) and brought to you by the Community Health Center.