

everything changed. “Ray came to town, lit it up like a rocket,” Quincy said. “He had it. Whatever it is, Ray had it.” And everyone knew it.

Throughout the fifties, Ray fused jazz, gospel, and blues into a new soul sound. As he put it: “Gospel and the blues are almost the same thing. It’s just a question of whether you’re talkin’ about a woman or God.” [Laughter] And with his touring band, including his iconic backup singers, Raelettes, he recorded some of the biggest hits ever, including “What’d I Say” and “Hit the Road Jack.”

Now, in those days, Black musicians were expected to play in the Jim Crow South. But in 1961—the year I was born—Ray refused to play for a segregated audience in Augusta, Georgia. He was sued for breach of contract, but he continued boycotting segregated venues and became an active supporter of the civil rights movement.

On stage and in the studio, Ray did it all: jazz, R&B, rock and roll, pop. He even helped to bring the country music he loved to a broader audience. But whatever genre of music he was playing, there was no mistaking his singular sound: that virtuoso piano playing that matched that one-of-a-kind voice. Even as a young man, he had the rich, raw honey tone of an old soul. No matter the feeling—whether it was love, longing, or loss—Ray Charles had the rare ability to collapse our weightiest emotions into a single note. And from the tiny clubs in which he started out to the arenas that he eventually filled, Ray was an electrifying per-

former. He couldn’t see us, but we couldn’t take our eyes off of him.

Chart-topping hits, 17 Grammy Awards, a spot in the Rock and Roll Hall of Fame, beating Willie Nelson at chess—[laughter]—his accolades are too many to name. But perhaps his greatest achievement was in showing all of us that it is our incredible diversity of music, a chorus of cultures and of styles, that truly makes “America the Beautiful.”

To see Ray’s legacy, you don’t have to look far. It lives on in the countless musicians he influenced, including the ones here with us tonight. Yolanda Adams. Leon Bridges. Andra Day. Anthony Hamilton. Brittany Howard. Demi Lovato. Sam Moore. Jussie Smollett. The Band Perry. Usher. And we’ve got Rickey Minor conducting the Christian McBride Big Band, using some of Ray’s actual arrangements. And let me tell you, these guys can play anything, and they play it well.

So I’m going to stop talking, because with 17 pieces—the same number of instruments as Ray’s band—this might be the biggest band to ever to play the White House other than the Marine Band. [Laughter] Are you ready? Me too. Hold onto your seats and enjoy the show.

Thank you, everybody.

NOTE: The President spoke at 8:05 p.m. in the East Room at the White House. In his remarks, he referred to musicians Quincy D. Jones, Jr., Willie Nelson, and Usher T. Raymond IV.

Remarks During a Panel Discussion on Precision Medicine February 25, 2016

The Atlantic Senior Editor James Hamblin. I want to get things started by asking you, Mr. President, to kick things off. You’ve been talking about precision medicine since 2005, but a lot of us are still new to it. So could you fill us in on the background and what brings us here today?

The President. Well, this is an incredibly exciting time in medicine generally and the biological sciences. And a lot of this traces back to the incredible progress that we’ve made with

the human genome—oops, I’m sorry, my mike. I’ve got to talk with a mike. [Laughter] We’ve made less progress when it comes to the audio sciences. [Laughter]

Let me start again. This is an extraordinarily exciting time for medicine and the biological sciences, and a lot of this traces back to the work that was done in mapping out the human genome, which was an enormous endeavor. There are some people here in the room who were involved in that process, including our

own head of the NIH, Francis Collins. And at the time, it was enormously expensive for us to do that. With the advance of computers, Big Data, we are now seeing a rapid acceleration in making that process cheaper. It is spurring on a whole new set of understandings about how diseases operate, how the human body, how cells operate, how areas like cancer show that each cancer may be unique, even if it's in the same organ.

And so all these insights promise the possibility of us being able to cure diseases that, up until now, we couldn't figure out. We could oftentimes, with real blunt instruments, treat, but it was very ineffective or, in some cases at least, inefficient. And what we're now seeing is the possibility of us identifying diseases, targeting them, individualizing treatments for a particular patient, and operating with the kind of precision that promises to reduce costs, provide much better care, make our entire health care system much more effective.

And the key to all this is for us to be able to build up databases. And because all of us potentially could have electronic medical records that voluntarily—with strong privacy protections—we pool together so that researchers, practitioners, scientists can share, we may be able to accelerate the process of discovering cures in ways that we've never seen before.

And our Precision Medicine Initiative has been designed to get all these various building blocks brought together so that the whole is greater than the sum of its parts; so that, for example, the VA, which has been gathering genomic data on a large number of our men and women who have served this country in order to serve them better within the VA system, can they then connect with researchers at a particular university who are focused on a particular disease? And can we use Big Data to accelerate the research process much more rapidly?

Those kinds of opportunities are there. And the good news is, is that over the course of the last year that we made this announcement about PMI, or Precision Medicine Initiative, what we've seen is huge interest from the private sector, from the public sector, from the non-for-profit sector, from the medical com-

munity, from researchers. And today what we're able to announce is that 40 more organizations, or a large number of other organizations are joining us in this process. There are a whole new set of initiatives that are going to help to drive this even faster.

And my hope is that this becomes the foundation, the architecture whereby 10 years from now we can look back and say that we have revolutionized medicine in areas like cancer or Alzheimer's or some of the diseases that cause so much pain and suffering for so many families all across the country. And there's no better place to do it than the United States of America, where innovation and R&D has been the hallmark of driving not only our economy, but the improvements that we've seen in the life expectancy and the quality of life for people all around the world.

Dr. Hamblin. Thank you. I want to go now—[*applause*—]—please. So I want to start by talking about some successes we've had from people on the panel in the realm of precision medicine and then go to some of the challenges that we face moving forward, starting with Sonia. So several years ago, your mother was diagnosed with a rare prion disease and passed away. The disease is known as fatal familial insomnia. You have essentially devoted your life to making that name obsolete. You chose to get tested yourself for the gene. How have you been motivated to be so proactive?

Broad Institute of MIT and Harvard student Sonia Vallabh. It's a great question. I would say deciding to get tested once I learned that my mom had died of a genetic disease and that I was at 50–50 risk of inheriting the same fate, which was midlife onset, very rapid neurodegenerative decline. These diseases are always fatal; they are currently untreatable. Once I had that knowledge in my hand—and these decisions were all made hand-in-hand with my husband Eric, who's here today—for the two of us, the decision to pursue testing and resolve that doubt was clear. We made that decision instantaneously. Because we knew there was no going back to a time before we knew about our risk. So we wanted to know what we were up against.

What I couldn't have predicted is what would happen next. So, as you mentioned, I'd been trained as a lawyer; Eric had been trained as a city planner and engineer. And I don't think either of us went into the test with a vision of how it was going to change our lives one way or the other. But when we came out with that positive test report, my life broke into two pieces. Right—there was before, and there was after.

And what happened after is that we set about trying to learn everything we could about these diseases. And like everyone looking for answers, we started with Google. We started with Wikipedia. [Laughter] We read what we could find on the Internet. We read papers. We called up researchers out of the blue; some of them were kind enough to take our calls. We started attending conferences. We started blogging. And eventually, we changed jobs. And 4 years later, we're both Ph.D. students at Harvard Medical School. And day to day, we work side-by-side in Stuart Schreiber's lab at the Broad Institute in Cambridge. And there we're devoting ourselves to developing treatments for these diseases.

I'm so proud to be doing this. But I have to say we've been just immensely lucky. The Broad Institute has basically adopted us. We have had some brilliant people take risks on us, like Eric Lander, who advises the President on science, sometimes advises us too—[laughter]—amazingly. Amazingly. But even with the best people backing us, there is no guarantee that we will be successful in my lifetime, right? We are running this race day by day, and we still have to see where it takes us.

[At this point, Ms. Vallabh continued her remarks, concluding as follows.]

I think we do ourselves a disservice by clinging to names that obscure the mechanism of these diseases and the things that unite patients with, quote, unquote, "different" diseases that have flown under different names for many decades. So I think of us as patients with genetic prion disease, and I think that is the patient cohort that I identify with. And those are the people who I want to help.

Preventive Medicine

Dr. Hamblin. So once—while you're studying a disease that affects one—a hundred people worldwide, you're also studying this entire mechanism that can tie in to many diseases as people continue to share their data and their experience.

Ms. Vallabh. Absolutely.

The President. I know that you're supposed to go next, but I'm going to hijack this—

Dr. Hamblin. Please.

The President. —just for one second. [Laughter] It's—we're in my house. [Laughter] I—but there's something that I should have mentioned that Sonia's story, I think, highlights, and that is, so often, what we label as a health care system is actually more of a disease care system in which the patient is passive, you wait until you get sick, a bunch of experts then help you solve it. And one of the promises of precision medicine is not just identifying—or giving researchers and medical practitioners tools to help cure people, it is also empowering individuals to monitor and take a more active role in their own health.

Now, in Sonia's case, obviously, there's a very particular genetic variant that she's got to worry about. And the extraordinary strength and tenacity that she brings to this makes me really optimistic that she's going to help drive for a cure in this particular area. But for many people who may not have such a clear, specific concern, may still have genetic variants that alter how you think about your blood pressure, your likelihood for diabetes, a whole range of other disease—potential markers that if we get this right, if we do precision medicine well, and we get that information, that data to consumers, gives them the ability to stay healthy for long periods of time. And that's hugely promising.

And it's good for those individuals; it's good for society, generally, because it will save on a whole lot of health care costs if we can prevent diseases from manifesting themselves in the first place.

Sorry to interrupt.

Dr. Hamblin. Not, it's—[laughter].

The President. But it's an important point.

Dr. Hamblin. It's a perfect segue to Howard, who is working not just as a patient advocate, because your own daughter was diagnosed with type 1 diabetes, but in terms of data sharing, you have worked to create a platform for data sharing. And you recently built for your daughter a pancreas, which is especially impressive for someone with no training in the medical sciences. [Laughter] How did you manage that? [Laughter]

Tidepool President, Chief Executive Officer, and Founder Howard Look. No training required. [Laughter] It turns out, I'm a geek dad. And when my daughter was diagnosed in 2011, the first thing I realized was, wow, here are these medical devices, a continuous glucose monitor that measures her blood glucose every 5 minutes, an insulin pump that delivers a deadly hormone which, you walk this tightrope when you have type 1 diabetes of just a little too much insulin and you can have a seizure or go into a coma, or even 1 in 20 people, unfortunately, will die over the course of their lifetime from nocturnal hypoglycemia, or too much insulin while they sleep. And what I realized was we just couldn't get the data out of the devices easily enough.

[Mr. Look continued his remarks, concluding as follows.]

I put one of these together for my daughter. There are many other people who put it together for themselves. And what it means is that she gets those precise doses of insulin in a much safer and much more effective way. So basically, what happened is, by liberating the data from the device, we were able to come up with a much better way to deliver therapy. And I think it just shows the power of engaged patients and how important it is to liberate the data, not just electronic health record data, but also device data, right? Patients with type 1 diabetes shouldn't have to outsmart the very companies that they depend on for these life-saving devices, and I think that's what we've seen the community do.

Dr. Hamblin. And I want to move to Dr. Linehan. You have been for decades doing re-

search in renal cancers. And when you trained as a urological surgeon, there was only one disease, kidney cancer—had the same treatment. And you came in and said that “this isn't working, these are different diseases,” half of which you basically discovered yourself. You were doing precision medicine before it was cool. [Laughter] How—I mean, what led you to that? What was your moment of saying we need—something needs to change?

National Cancer Institute Urologic Oncology Branch Chief W. Marston Linehan. It was very easy in a way. As you said, I'm a urologic surgeon, so if a patient comes to me with a small kidney tumor, we can cure 95 percent of those patients. But if they came, certainly, 34 years ago when we started, with advanced disease, 82 percent of them died within 24 months.

[Dr. Linehan continued his remarks. Dr. Hamblin then asked several follow-up questions, and Dr. Linehan responded, concluding as follows.]

Dr. Linehan. I think every different tumor is—I don't want to say is going to be a fight to the death each one, but just about. I mean, each gene pathway for the different cancers could potentially have a different strategy. So it takes—this is, we say to ourselves and to our patients, this is a marathon, it's not a sprint.

Digital Health Records/Medical Research

Dr. Hamblin. So the question that raises in my mind, then, is how does that not become an exorbitant cost when pharmaceutical companies need to move away from a drug that can treat many people to drugs that are treating small groups of people, just as a matter of scale and production, research and development?

The President. Well, what the doctor is identifying, I think, is the fact that we're just in the infancy of all this. We're just beginning to understand at the molecular level, at the genetic level, what exactly is happening in various diseases.

And the goal of the Precision Medicine Initiative is to figure out how to break down some

of the structural or institutional barriers that prevent us from making the big leaps over the next several years. So I'll just give you a couple of examples.

With respect to being able to map out what's happening with these different diseases and what are the genetic similarities, what are the differences, why are some people doing okay with it, why are people not, the more samples we have, the more data we have, the more we're going to be able to learn. Part of the problem we have right now is, is that every patient's data is siloed: It's in a hospital here, a hospital there, a doctor here, a lab there. And so the goal here is, if we can pool and create a common database of ultimately a million people that's diverse so that they have a lot of genetic variation, we can now take a disease that may be relatively rare, but because we have a pretty large sample size and start seeing patterns that we might not have seen before.

But a couple things that requires: It requires, first of all, us understanding who owns the data. Right? And I would like to think that if somebody take—does a test on me or my genes, that that's mine. But that's not always how we define these issues, right? So there's some legal issues involved.

In terms of the model that we use for health records that, hopefully, will be digitalized more and more, companies help hospitals keep and collect that data. And they should get paid for that. It's—they're building software; they're building an infrastructure. On the other hand, we don't want that data just trapped. So if I am sick and voluntarily I want to join with other people who have a similar disease than mine and donate our data to help accelerate cures, I've got to be able to work with the electronic health record companies to make sure that I can do that easily. Right? And there may be some commercial resistance to that that we have to talk about, although we're seeing some terrific participation now—and that's part of what we're announcing—of those companies in terms of helping that happen.

There's privacy issues. We've got to figure out how do we make sure that if I donate my data to this big pool that it's not going to be

misused, that it's not going to be commercialized in some way that I don't know about. And so we've got to set up a series of structures that make me confident that if I'm making that contribution to science that I'm not going to end up getting a bunch of spam—[laughter]—targeting people who have a particular disease I may have.

And so across the board, what you're—what we're trying to do is just make sure that all the various players in the health care system, including the researchers themselves, are invested in us building this broader capacity. Because this can potentially also change how we do research. Right now what happens is, the best researchers and the best universities, oftentimes they're kind of hoarding their samples—

Dr. Hamblin. No.

The President. —because—apparently—I'm not a researcher, but that's—[laughter].

Ms. Vallabh. Never too late, Mr. President. [Laughter]

The President. Yes, good point. It's a good point. I don't think I'm as smart as you are, so—[laughter]—the transition may be difficult, but—

Mr. Look. You could try software. [Laughter]

The President. Right. But my understanding is, is that the basic model of research at universities is having your samples, that's really valuable because that's how you get grants. And on the other hand, if we've got a million samples that are accessible to researchers from all across the country and all around the world, and they're all able to at least shorten the lines of inquiry and collapse them so that they can eliminate those things that are less likely to work and pursue those things that are more likely to work before you start getting into the more detailed aspects of the research, that ends up being a cost saver.

Now, you're identifying one last point, which is something that we're—we've got to have some big brains out here figure out, and that is the economics of treatment. Because right now, if you have a big, blockbuster drug, it may work really well for this individual, not so well for that individual. In the aggregate, it

works pretty well, and as a consequence, it gets prescribed a lot and the drug company can make a lot of money. If it turns out that we start knowing that it really works well for you, but it doesn't work well for Francis—Francis is no longer buying it—[laughter]—and we now have a smaller group of potential customers, and so there may be some pause in terms of making that investment.

And what we have to be able to do is to think about—much in the same way that we have to think about vaccines, and right now we're working—we just had a meeting about Zika, where we actually think there's a promising pathway for diagnostics and vaccines on this. It's not a real complicated virus, apparently, but how do we figure out a production cycle that makes sense. We're going to have to make some decisions.

And this is where Senator Lamar Alexander, who is taking great interest in this—this is going to be part of the legislative process that we've got to think about. Are there ways where the Government says we step in—not to pay for every drug, but there may be areas where we subsidize drugs that are really effective for a small group of people, and there ends up being some cross-subsidies with other drugs, we create markets. There's a whole bunch of complicated questions that we're going to have to answer.

The point though—the final point I'll make is, over the long term, we can save a lot of money, rather than make this more expensive, if every drug we prescribe actually works. [Laughter] If the doctor with his kidney patient knows that this is not going to work, and that's not going to work, he's not going to be wasting a huge amount of time, effort, surgery, et cetera, on a path that's less likely to succeed. He's going to be saving money and focusing entirely on those pathways that we know are going to work.

Opioid Addiction

Dr. Hamblin. Can I piggy-back on that and note that CDC announced last month that 47,000 Americans died in 2014 of drug overdoses, the majority of which were opioids. That

number has doubled since 2000. Do you see a role for precision medicine in addressing that, what they're calling an epidemic?

The President. Well, it's a complicated question. Part of the problem that we have with the opioid epidemic is that, in 85 percent of rural communities, we don't have mental health or drug treatment facilities.

So I want to make sure people understand, precision medicine is not a replacement for making sure people have just basic health care. [Laughter] And we have to make sure that that's still in place. But we don't yet know the genetic basis for addiction, for example, in ways that we may discover 10 years from now or 15 years from now. And so it could end up having an impact.

I think, short term, the opioid problem really has more to do with the fact that a lot of people don't have basic health care. They put off getting help on pain management. The easiest way to do it initially is just to get some pills; the pills run out, and then, sadly, it turns out that heroin is a cheaper way to refill your prescription and people are getting hooked.

So I think that's actually a different category of problem. But what it does speak to is the fact that the more we know about how to treat a particular problem, the more effectively we treat that problem; over time, the more efficient and cost-effective the health care system will be.

Medical Regulatory Reform/Medical Research

Dr. Hamblin. Can I turn to Sonia and Howard, who are—this will be my final question—talking about barriers to sharing. You've both been very open advocates for donating data. What has—how do you encourage people to donate data and feel safe about it and understand the importance? And what are the barriers to people feeling safe about that going forward?

Ms. Vallabh. I think it continues to be a challenge, in the sense that we've come a long way. I'm so grateful to the people behind GINA and the people who are working to make sure that people with genetic variants like mine don't fear discrimination. But they still do, and

I hear from patients all the time who are really concerned about even letting their PCP know that this disease runs in their family.

[*Ms. Vallabh continued her remarks, concluding as follows.*]

Ms. Vallabh. In rare diseases, every person who comes forward to participate is like a quantum leap in the amount of data we have. So I hope that we keep working on the sort of legal framework behind celebrating patients who come forward, and I think we're headed in the right direction.

[*Mr. Look made brief remarks, followed by Dr. Linehan, who concluded as follows.*]

Dr. Linehan. And over the years, our approach has always been the same: that you shouldn't be surprised, the progress people can make working together if you're not quite so concerned about who gets credit for the work. And I think that—[*applause*]. And that's always—you get so tied up, and then—but we all think, those of us in science or those clinicians all think, why did we go in this field in the first place? It was to help patients. And then, you got involved in all these things about promotions and who knows what—publications or something. But the leadership comes from the top. The good news is, we have great leadership. The leadership comes from the top. And I think we can change the culture. It's going to take a little bit of that, but we can do it.

The President. And just—[*applause*]^o—one of the charges I've given all the Federal agencies working together on this is looking at the regulatory framework we have that was designed for another era of medicine and making sure we update it. And that's where I think the work that we do with Congress can be very important here. And there's good bipartisan support for how we think about this.

So, for example, we've got a new FDA Commissioner, Robert Cardiff [Califf].^o Congratulations, Doctor. But the FDA traditionally has

thought about protecting the public health in terms of, these are medical devices, and these are drugs, and there are certain categories, and here's certain protocols that we go through. And when it comes to gathering data, disseminating data, making sure it's accurate and valid, figuring out how it's communicated to the patient or the individual who's interested in it, sometimes, we're fitting square pegs into round holes, and we may have to reconceptualize how we think about this to open up this space.

When—I mentioned researchers earlier. Well, part of the reason that people are worried about getting credit is because research dollars and grants flow in the direction of who gets credit. And so rethinking how we design—the NIH and other agencies redesign their grant-making to encourage collaboration rather than siloing, that's going to be important. Right?

So there's going to be a whole range of areas where we may need new safeguards, there—for example, in terms of privacy and security of the data that's being disseminated. There may be other areas where we need to break down regulations that might have applied and made sense in another era of medicine, but aren't going to apply now. And that's the kind of evaluation that we're doing.

Because ultimately, this is going to be successful because everybody in this process starts rolling in the same direction. This won't work unless we have the private sector coming up with innovation. And that includes the drug companies, and that includes manufacturers of—ultimately, something that's just tracking your heart rate may be able to track a whole bunch of other stuff that is giving you a constant flow of information on a daily basis to keep you healthier.

We want to encourage that kind of innovation, and we don't want to have bureaucracy stand in the way of that. On the other hand, we also know that there's going to be possibilities for abuse, and really making sure that we have private sector providers, researchers, doctors,

^o White House correction.

academics, Government officials, agencies all figuring out what's the basic architecture and having an open mind about continually updating it, modifying it, it—if we get this right now—and this includes, by the way, the Cancer Moonshot that Vice President Biden is initiating, because a lot of the progress is going to be in this same space, making sure that we're all working in the same direction. If we do that, I'm confident that, at least for Malia and Sasha's generation, they're going to be able to make progress in ways—and live healthier lives in ways that we could not imagine.

Dr. Hamblin. That's all our time, can we get a round of applause for the panelists?

NOTE: The President spoke at 11:25 a.m. in the South Court Auditorium of the Dwight D. Eisenhower Executive Office Building. Ms. Vallabh referred to her husband Eric Minikel; Stuart L. Schreiber, director, Broad Institute Center for the Science of Therapeutics; and Eric S. Lander, Cochair, President's Council of Advisers on Science and Technology. She also referred to the Genetic Information Nondiscrimination Act (GINA). Mr. Look referred to his daughter Katie.

Remarks on United States Efforts To Combat the Islamic State of Iraq and the Levant (ISIL) Terrorist Organization at the Department of State *February 25, 2016*

Good evening, everybody. I just met with my National Security Council as part of our regular effort to review and intensify our campaign to destroy ISIL. And I want to thank Secretary Kerry for hosting us and for his leadership of American diplomacy, not only in the Middle East, but around the world. Secretary Carter and Chairman Dunford updated us on our military campaign, and Brett McGurk, my Special Envoy to our coalition, helped lead a review of our overall strategy.

At the outset, I want to say again that this remains a difficult fight. The situation in Syria and Iraq is one of the most complex the world has seen in recent times. ISIL is entrenched, including in urban areas, using innocent civilians as human shields. Even in places where ISIL has been driven out, it leaves behind utter devastation: communities in ruin that need to be stabilized and rebuilt, which will take years and tremendous international resources. Because, certainly in Iraq, they're hard pressed to come up with everything that they need to rebuild, and in Syria, the regime there still is not constituted in such a way that it is investing in civilian populations.

Countries, communities, and groups that agree on fighting ISIL in the short term often don't agree on broader, long-term goals. Indeed, the fight in Syria is not only a civil war,

but it's also a proxy war between regional powers, reflecting deep sectarian and political rivalries. Russia's intervention and airstrikes have reinforced the Asad regime and made a humanitarian catastrophe even worse. And the entire world has been horrified by images of starving Syrians, including children, reduced to near skeletons.

So this is a tough situation with a lot of moving parts. And as a consequence, I want to thank John for his tireless efforts, along with his team, to reach a cessation of hostilities in the civil war. None of us are under any illusions. We're all aware of the many potential pitfalls, and there are plenty of reasons for skepticism. But history would judge us harshly if we did not do our part in at least trying to end this terrible conflict with diplomacy.

If implemented—and that's a significant "if"—this cessation could reduce the violence and get more food and aid to Syrians who are suffering and desperately need it. It could save lives. Potentially, it could also lead to negotiations on a political settlement to end the civil war so that everybody can focus their attention on destroying ISIL. And that's why the United States will do everything we can to maximize the chances of success in this cessation of hostilities. At the same time, I want to make totally clear that there will be absolutely no cease-fire