

PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

TRANSFORMING PATIENT-CENTERED RESEARCH:  
BUILDING PARTNERSHIPS AND PROMISING MODELS

Saturday,  
October 27, 2012

Renaissance Hotel  
1828 L Street, NW, Suite 900  
Washington, DC 20036

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## AGENDA

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P R O C E E D I N G S

[8:30 AM]

1  
2  
3 DR. SELBY: [Webcast video begins at  
4 00:04:40 but audio begins at 00:05:17] -- Research  
5 Institute. I've been here since July of 2011. I  
6 was the first PCORI employee at that time. But  
7 there is quite an interesting history of the  
8 Patient-Centered Outcomes Research Institute before  
9 I arrived and my job this morning is to give you  
10 just a brief history of how we got to be created  
11 and what's happened up to today. From today on,  
12 you're in it with us.

13 So, as many of you know, PCORI was  
14 authorized by the Affordable Care Act, now commonly  
15 called Obama Care. In 2009, early 2010 there was  
16 wide recognition that despite the fact in the US we  
17 spent approximately \$150 billion a year on clinical  
18 and health care research, patients as often as  
19 naught and clinicians as often as naught, lacked  
20 the information that they needed. The practice  
21 decision, the health care decisions were being made  
22 with uncertainty in the absence of good

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1 information. That led to poor outcomes. To  
2 outcomes other than those that patients preferred.  
3 It led to medical errors, as you know, in large  
4 numbers and it led to wasted resources as well.

5           The story goes that sponsors, Senate and  
6 House sponsors had a pretty good idea what they  
7 wanted this institute to do. But they had a heck  
8 of time figuring out a name for it. There was a  
9 lot of interest in the kind of research called  
10 comparative effectiveness research. And the idea  
11 there was, in fact, precisely that. We needed to  
12 do research that was practical. That compared  
13 treatment options that patients and clinicians  
14 faced considered a wide-range of outcomes that are  
15 important to patients and looked for differences  
16 among patients in the ways that treatments work.  
17 So the recognition was that treatments didn't work  
18 the same for everybody. That people were  
19 individuals, that comparative effectiveness  
20 research was supposed to find out what works for  
21 whom.

22           But as most of you, I'm sure know, the

1 notion of comparative effectiveness research got  
2 tied up with the notion of coverage decisions in  
3 that political climate around election time, the  
4 word rationing was raised.

5           And comparative effectiveness research was  
6 just not a name that you wanted to put on a new  
7 institute. Casting about for a name, someone hit  
8 upon the name Patient-Centered Outcomes Research  
9 Institute. Patient-centered care was just taking  
10 off at that time and that sounded good, and I think  
11 the rationale had to be, how could one argue with  
12 research that was patient-centered? And that's how  
13 PCORI got its name.

14           As soon as the Affordable Care Act was  
15 enacted, the Government Accountability Office began  
16 putting the law into effect and they selected a  
17 board. They recruited a board of 21 members. A  
18 multi-stakeholder board from across the country and  
19 I am here to tell you today that the vision of  
20 PCORI is the responsibility primarily of PCORI's  
21 Board of Governors and just to illustrate how  
22 remarkable that board is, two years later they are

1 still on the job, passionately and in a spirited  
2 fashion directing and working with staff to make  
3 the vision of PCORI a reality.

4           So I want to ask those Board members who  
5 are here, and I know there's at least five here, if  
6 you wouldn't mind standing and I would just like to  
7 point out not only who you are, but where you're  
8 from. So I told a lady from Mississippi this  
9 morning that there was another person from  
10 Mississippi in the audience and this is Dr. Gray  
11 Norquist from the University of Mississippi. And  
12 standing right next to Gray is Dr. Debra Barksdale  
13 from the University of North Carolina. Let's see.  
14 It's dark out there. I see a shadow over there but  
15 I swear I can't -- oh that's our Vice Chair Mr.  
16 Steve Lipstein from BJC Hospitals in St. Louis,  
17 Missouri and I told a St. Louisan last night that  
18 Steve was on the Board. Welcome Steve. Hello.  
19 And I know Gail Hunt is out there somewhere.  
20 Although I don't see her right now. Gail Hunt is  
21 from the National Caregiver Alliance based here in  
22 DC. And I know Dr. Harlan Weisman is here. And

1 I'm not sure that I see Harlan. Harlan is --  
2 there's Gail, just walked in. And Harlan Weisman  
3 is from New Jersey and represented when he was  
4 appointed Johnson and Johnson.

5 Anybody else? Have I missed -- Anne, do  
6 you see anyone else?

7 Okay, so those are five Board members and  
8 I just want to say again that it's largely the  
9 Board that took a look at the name, asked itself  
10 what that might mean, and determined, in fact, that  
11 if research is going to be done differently, we  
12 have in fact, have to put patients at the center of  
13 the research enterprise. And that means involving  
14 patients and their family members and also, the  
15 clinicians who care for these patients in every  
16 aspect of the research enterprise.

17 So from identifying the questions in the  
18 first place, to prioritizing those questions and  
19 helping PCORI decide where is the most important  
20 place to go with the limited resources we have, to  
21 reviewing the applications when they come in. So  
22 we need to review applications and make sure that

1 the applications that are coming in, really do  
2 address practical patient-centered questions. They  
3 really do consider the right outcomes, and they  
4 really have a strong likelihood, when answered, of  
5 changing practice.

6 To participating in the research. So we  
7 tell applicant researchers that if they don't bring  
8 patients and other important stakeholders along  
9 with them when they apply for research, they will  
10 not get funded. And we're not talking about  
11 bringing patients along as subjects in this case,  
12 we're talking about bringing patients along as  
13 partners in the research endeavor.

14 We also aim and need to work with patients  
15 and these other stakeholder groups. If we want the  
16 research findings to be disseminated, so to spread  
17 the word, we get the findings and lament is always  
18 that they stood on the shelf for 17 years. The  
19 evidence doesn't get into practice. We think we  
20 can change that if we have patients involved from  
21 the very beginning, helping to guide the research  
22 and then there to disseminate it at the end.

1           So that, in fact, is our plan and we're  
2 glad that you're here with us to help us begin to  
3 put this plan in place. I was speaking with a lady  
4 this morning from New Jersey who told me that no  
5 one she had talked to had yet heard of PCORI, and  
6 so, with your help we will change that.

7           That's all I've got to say other than  
8 thank you so much for being here, for taking your  
9 weekend to come to DC to join us, to hear about  
10 this. We want to lay out the plan as far as we've  
11 taken it. Get your feedback and input and go  
12 forward together. And right now it is my pleasure  
13 to introduce the brains behind this meeting. Our  
14 Director of Patient Engagement, Ms. Sue Sheridan.

15           [Applause.]

16           MS. SHERIDAN: Thank you. Good morning.  
17 Gosh, what an honor to be here with all of you and  
18 this was actually a brain child of Dr. Anne Beal,  
19 who is sitting here in the front of the audience,  
20 and mine when we were sitting at a workshop in Palo  
21 Alto in July, when there was a lot of conversation  
22 about patient engagement and we looked at each

1 other and said workshop. And about two weeks later  
2 we were back in the office and I was in the hallway  
3 and I was talking about how a workshop with  
4 patients in research was my dream and Joe Selby  
5 said, "No, that was his dream."

6           You know, being a researcher, so we saw  
7 were going to bring these worlds together. And  
8 just having the discussion within PCORI, you're  
9 going to meet a lot of PCORI staff here, our  
10 researchers, our support, and just the dialogue  
11 that we have had within PCORI itself, and with our  
12 board. It has created energy within our own  
13 organization and so there has been a momentum  
14 building.

15           So when PCORI's name, Joe mentioned our  
16 name. The Patient-Centered Outcomes Research  
17 Institute. Before I joined PCORI, when I saw that  
18 title, and I come from an advocacy background -- a  
19 patient activist background, I saw this title and I  
20 thought to myself, "Really?" You know, is an  
21 agency really going to look at this patient-  
22 centeredness in a real way? And we believe that

1 patient-centeredness is a transformation of doing  
2 things for the patients to doing research with the  
3 patients. So PCORI intends on modeling that  
4 patient-centeredness in everything that we do.

5 I want to share with you that when I was  
6 with the WHO, we did a survey globally about  
7 patients getting involved in assuring their own  
8 good outcomes. And so, we sent out a big survey  
9 and we asked the patient population of the world if  
10 they wanted to be involved in assuring their own  
11 good outcomes. And, of course, the resounding  
12 response was yes. And then when we said, "How many  
13 of you actually do that or would do that?" The  
14 percentage went way down. And so, the researchers  
15 kind of said to the patient group, kind of, "See.  
16 Patients don't want to get involved." And so, we  
17 kind of pushed the researchers, nothing against  
18 researchers, and we really encouraged them to go  
19 back out and ask the patient population, "What do  
20 you need from the health care system to activate  
21 you and to engage you and to be more involved in  
22 sharing your own good outcomes?"

1           And the resounding response from 59  
2 countries, of hundreds of patients was a simple  
3 answer. And that answer was, "An invitation."

4           So, this is an invitation to you. To help  
5 us build us. I'm going to show you a little video  
6 that was created a PCORI. You're going to see some  
7 of our board members and some of our patients.

8           [Video shown.]

9           MS. SHERIDAN: The first time that I  
10 showed that, it was at Yale, I got so excited that  
11 I told the audience that I wanted to get involved,  
12 and I realized that I already am involved.

13           [Laughter.]

14           MS. SHERIDAN: But it just -- this is an  
15 invitation from us to you. We welcome you. We're  
16 excited about your energy and this is an  
17 opportunity that we have at our fingertips. We  
18 invite you today, we invite you tomorrow, and we  
19 invite you when you go home. Even most importantly  
20 to join us in all of these engagement  
21 opportunities, to touch points that Joe references,  
22 about how we're bringing the patient and

1 stakeholder population in the whole research cycle.

2           We invite you to create processes and  
3 principles in the next day and a half, to help  
4 guide us. We aspire to be the gold standard in the  
5 science of patient engagement and we need you to be  
6 our partners. We invite you to create partnerships  
7 never imagined before. To help improve outcomes  
8 for those of us in the audience, for those of us  
9 back in our communities. And we invite you to  
10 create with us research done differently.

11           So I am excited. Last night the  
12 discussion and the enthusiasm about what's going to  
13 happen in the next day and a half is up to us. We  
14 have an opportunity at our fingertips to create how  
15 research is done in the future in partnership with  
16 patient, caregivers, and other stakeholders to make  
17 a difference in the lives of patients.

18           So with that I am going to pass the  
19 microphone and introduce two of our facilitators,  
20 Marty Hatlie and Jonathan Peck, both of whom I've  
21 worked with in the past. I have -- when we were  
22 dreaming about this workshop and envisioning this

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1 workshop I know the two facilitators I wanted.  
2 They've worked with me in the past here in the  
3 United States making patient groups under the guise  
4 and auspices of HRQ. Jonathan and Marty joined me  
5 in a very courageous journey with the WHO, creating  
6 a network of patients throughout the world founded  
7 on best practices and principles and values and  
8 hope. So I will invite my friends Jonathan and  
9 Marty to take over.

10 MR. PECK: Thank you Sue. Thank you.

11 [Applause.]

12 MR. PECK: Wow. This is just so wonderful  
13 and we're really pleased to be able to work with  
14 you today.

15 What Marty and I are going to be doing  
16 today is getting you oriented and beginning to get  
17 the engagement going. So we'll start with "Why are  
18 we here?" What are the objectives for today and  
19 tomorrow and then we'll take you through the  
20 agenda. So -- go ahead.

21 MR. HATLIE: I'm Marty Hatlie and this is  
22 Jonathan, just so you know the difference between

1 the two of us. And our first objective is to build  
2 partnerships to make patient-centered outcomes  
3 research a reality. We're really excited about  
4 having this group here help PCORI do that.

5 MR. PECK: And last night, I could see the  
6 partnerships already forming and maybe formed.  
7 Second objective, which is we'll be spending a lot  
8 of the time, especially from 11 to the end of the  
9 day is to generate ideas and principles. So,  
10 you're going to be generating these ideas with and  
11 for PCORI.

12 MR. HATLIE: And one of the things we  
13 noticed last night is that there were many people  
14 here who sort of knew each other, so the  
15 dissemination process to invite people here and  
16 invite you to apply went through a lot of different  
17 channels and it was really a tickle for us to see  
18 how many of you got here and knew each other and  
19 began sharing ideas right away.

20 Also, we got a phenomenal response to the  
21 pre-work we sent out and, you know, often you  
22 don't. So we knew you were a really proactive

1 group with a lot of ideas who were eager to be here  
2 and eager to pick up the phone and connect to the  
3 people that we asked you to do that, so thank you  
4 for that and we're really, really eager to get your  
5 ideas.

6 MR. PECK: Great.

7 MR. HATLIE: And capture them and kind of  
8 use them to help PCORI.

9 MR. PECK: Our third objective is to  
10 develop the most promising models in patient  
11 engagement in research. And it's going to be  
12 something -- well, you're going to hear about some  
13 models that will help stimulate your thinking.  
14 You're going to create some models of your own.

15 MR. HATLIE: Jonathan, one of the things  
16 that I heard as I was talking to the audience, or  
17 not to the audience, but to the participants last  
18 night, is where do our ideas go from here? What  
19 happens after the workshop? And there is a  
20 phenomenal working group that helped put this  
21 together, that's been very front and center for  
22 them. I know it's really front and center for

1 PCORI staff as well.

2           So, I think we'll start with the models  
3 today. We'll learn about the models. We'll see  
4 some models here, but we'll also be able to, you  
5 know, take this input and plug it in a longer  
6 process at PCORI. That includes more workshops for  
7 other stakeholder groups.

8           MR. PECK: And fourth, and in some way the  
9 most important is to form an enduring community.  
10 This is not a onetime event that ends. This is the  
11 opportunity, the beginning of research done  
12 differently and we're going to need your engagement  
13 and that really comes because you form a community  
14 together, an intentional community.

15           MR. HATLIE: Jonathan, if I could share an  
16 anecdote about this because Sue talked a little bit  
17 when she was up on the stage about her work with  
18 the World Health Organization. And at one point in  
19 time when the World Health Organization was getting  
20 behind the Safe Surgery Saves Lives initiative,  
21 they asked us to send a survey out through the  
22 network of patients that Sue had built at WHO. And

1 we got more surveys back than we sent out.

2 [Laughter.]

3 MR. HATLIE: And WHO said how did you do  
4 that? We were expecting three to four percent  
5 response rate. That's what we normally get. And  
6 you returned 150 percent. But it was the  
7 networking. People got the surveys and they sent  
8 it out through their own networks and it was a  
9 really, really exciting thing. So this notion of  
10 community we're catching a wave here, I think there  
11 are a lot of people connecting in a lot of  
12 interesting and different ways and we hope that  
13 will happen here.

14 MR. PECK: So are these objectives clear  
15 to everyone? Anybody have any questions about what  
16 we're here for and how we're going to be spending -  
17 - or what we're going to be doing? Then Marty, why  
18 don't you take us through the agenda today and I'll  
19 pick up and do tomorrow.

20 MR. HATLIE: Okay.

21 MR. PECK: I'm a futurist so I got to do  
22 tomorrow.

1 [Laughter.]

2 MR. HATLIE: Okay. Well, today the first  
3 part of the morning is really -- it's orientation.  
4 We've already started that. We're going to move on  
5 from here to bring Sue back to the stage to bring  
6 the phenomenal working group that helped put this  
7 event together, guided PCORI at every step in the  
8 process.

9 We're then going to show four models.  
10 We've invited researchers who've partnered with  
11 patients or patients who have partnered with  
12 researchers or patient groups that have partnered  
13 with researchers to come up and just kind of tee-  
14 off our thinking, our ideas by showing some  
15 examples. We've got a nice variety of people of  
16 where the research community reached out to  
17 patients or patient groups and some of where the  
18 patients or patient groups reached out to the  
19 research community.

20 So we'll just kind of tee those up and  
21 then we move into a little bit of instruction of  
22 how the breakout sessions will work and then we

1 start our first breakout session before lunch. And  
2 the breakout sessions, I hope this is pretty clear  
3 from your materials, but every participant in this  
4 event is going to have a chance to weigh in on  
5 every topic that matters to PCORI. So the rotation  
6 is really to make sure that no matter what your  
7 first, second, third or fourth priority is, you get  
8 a chance to contribute your ideas and give the  
9 guidance you've got to give.

10           And it's typically a pretty exciting  
11 process. It involves some movement, and so, for  
12 those of you who need help at any time from getting  
13 place to place, please ask. Jonathan or me or a  
14 couple other people that we want to introduce who  
15 are going to be our colleagues today in helping.

16           We go to lunch after the first breakout  
17 session, which is one where we kind of really set  
18 the stage for what will happen. So the first  
19 breakout group, whatever group you're assigned to,  
20 is going to generate the initial ideas and then the  
21 other people that rotate into that topic or that  
22 theme, that session, will be building on those and

1 adding and refining and converging, clustering.

2           So that's the way the day generally will  
3 work, but we're going to take a break at lunch  
4 obviously, we've got to feed you. And during lunch  
5 we're going to have a presentation by Rachael  
6 Fleurence, who is a researcher, about how to submit  
7 a research question. So you saw a piece that we  
8 sent out to you just not too long ago. PCORI  
9 started a process to invite anybody who has got an  
10 experience that they think leads to a research  
11 question to do that and we're going to do a little  
12 exercise around lunch with Rachael, taking us  
13 through how that process works.

14           Come back from lunch and --

15           MR. PECK: Oo-Oo! Don't forget the  
16 computers are out there. So you can actually go  
17 out and submit a research question during the  
18 break. Don't all run out now, but you can go ahead  
19 and you can go right into PCORI.

20           MR. HATLIE: Good, great. Yes, so please  
21 do that. And those are going to be up all weekend,  
22 right?

1 MR. PECK: Yes.

2 MR. HATLIE: So you don't have to do it  
3 during lunch, you can enjoy your lunch, but you can  
4 do it at any time. And it's web-based, there's a  
5 portal so you can do it afterwards as well. This  
6 evening during the cocktail party, for example.

7 Then we do the remaining breakout sessions  
8 through this afternoon. It will feel like a long  
9 day. I mean, we're really going to take advantage  
10 of your coming here and giving us your weekend to  
11 get the best we can out of all of the creative  
12 minds in this room. So it's going to feel long and  
13 if you need to take a break at any point, and  
14 there's not a lot of breaks, honestly throughout  
15 the day. So if you need to take a break for bio  
16 reasons or for personal care reasons or just to  
17 recharge your batteries. We understand that that  
18 will happen and we just invite you to do that as  
19 you can over the course of the day.

20 We do have a couple small breaks here and  
21 there but really not too much.

22 We break right around 5:00, before 5:00

1 and then we come back for a reception and dinner  
2 tonight and that is not required. It's optional so  
3 if you need to rest you can miss that, but I'm not  
4 going to miss it. I think it's going to be great.  
5 Especially based on the reception last night where  
6 you could just see the cylinders firing on multiple  
7 levels, so we hope you'll come to dinner tonight.

8           We'll do a little programming around  
9 dinner also or at the reception around affinity  
10 groups. Last night we kind of -- just to -- as an  
11 icebreaker, asked you to write down some places  
12 that you've lived or where you would like to live,  
13 you know, had your destination wedding at or had  
14 visited or had wanted to visit. But we're going to  
15 ask you to do something similar tonight around your  
16 interests, so sort of your affinities. We have a  
17 process where if there is a group that wants to  
18 form a cluster to talk about something in  
19 particular they could actually write the topic on a  
20 little flag or a little card at a table and cluster  
21 around that table. So it will be exciting to see  
22 how that works out.

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1 MR. PECK: Okay. It should be fun.

2 So tomorrow we're going to start as we  
3 should with breakfast at 7:30, then we'll sort of  
4 move into the welcome. It's going to be a shorter  
5 day, so we're going to actually report out from the  
6 work today. So you will have travelled through the  
7 breakouts, through these five topics and you're  
8 going to be delighted because we have a wonderful  
9 visual report for us here and you can see Patricia  
10 [inaudible] already -- Hi Patricia -- giving us a  
11 visual recording of the meeting. And she's going  
12 to help us, so you're going to go contribute in all  
13 of these breakout topics. You will have a  
14 facilitator who will be synthesizing this and then  
15 reporting back the ideas on each topic, the  
16 principles that we're recognized through this for  
17 patient engagement. And then you're going to have  
18 a chance to make recommendations based on the  
19 learning in each topic.

20 And so, we'll be going through these  
21 reports and recommendation and discussion  
22 throughout the morning. At the end we're going to

1 invite the PCORI Board and leadership to give  
2 feedback on the learning and then we'll hear about  
3 the next steps. We're going to conclude at 12:30.  
4 We'll give you a boxed lunch and the weather  
5 report.

6 [Laughter.]

7 MR. PECK: So that's the agenda. Any  
8 questions on the agenda?

9 [No response.]

10 MR. PECK: You will feel it. Let's just  
11 speak to our rules then.

12 MR. HATLIE: Jonathan, one more thing I  
13 want to mention before we leave the agenda is,  
14 today after the opening presentations, before we  
15 start our first breakout. We'll actually travel to  
16 another floor of the hotel and that is a floor up.  
17 Yes. It's the floor right above us. So that half-  
18 break in the escalator as you came down. And then,  
19 all of the breakout sessions are in the same  
20 corridor. So it will actually be pretty easy to  
21 move from breakout room to breakout room when we do  
22 the rotations, but they're all clustered up on the

1 next mezzanine level.

2 MR. PECK: Okay, so now in the next minute  
3 here's our rules. Show mutual regard and support  
4 for each other. That's a vital rule. Everybody on  
5 board for that one? Thank you.

6 [Applause.]

7 MR. PECK: Respect the limits on time.  
8 This is going to be fast-paced. It means don't  
9 clutch the microphone too long; Marty.

10 [Laughter.]

11 MR. HATLIE: What are you talking about --  
12 I don't see you very often. So it's nice to be  
13 here with you.

14 [Laughter.]

15 MR. PECK: Third, is silence your phones.  
16 If you have a call you have to make or take, step  
17 outside so it doesn't disrupt any of the group  
18 discussions. Are we all on board for that?

19 [Chorus of yeses.]

20 MR. PECK: Put them on stun? All right.  
21 Thank you. Thank you. Quick on rules and then we  
22 can move.

1           MR. HATLIE: Okay. So the rules. I mean,  
2 this is the community that is coming together here.  
3 That's gathering here with a huge emphasis on  
4 patients and caregivers. I mean, the vast majority  
5 of people in this audience are here because of an  
6 experience you have had as a patient and a  
7 caregiver. Seventy-five percent of you was kind of  
8 our goal. We are aware that many of you wear  
9 multiple hats, but that's like a core group for  
10 this workshop. There are other workshops that will  
11 have different percentages of patients and other  
12 stakeholders in it.

13           You're partners and you're educators of  
14 all of us. [Inaudible] energized and are  
15 clustering because you want me to hurry. Other  
16 stakeholders, are here as your partners. Partners  
17 of the patients and caregivers today. PCORI staff  
18 is here en masse, they've been very excited to meet  
19 you and they are going to be our hosts and our  
20 facilitators. Presenters are going to be  
21 storytellers and modelers. Giving you examples of  
22 models. The working group, they obviously put this

1 together but they're also going to be ambassadors  
2 today. We'll introduce the working group if you  
3 need anything over the course of the day, find a  
4 working group member and they will help you get  
5 what you need. And certainly, they are partners as  
6 well.

7           And then PCORI leadership, Joe introduced  
8 many of the PCORI leadership and especially  
9 tomorrow, throughout today, but tomorrow on stage  
10 they will be listeners and reflectors on what  
11 they're hearing coming out of the ideas and the  
12 work that we do in the breakout groups.

13           MR. PECK: Now probably the most important  
14 role for us is to get the microphones to you. And  
15 we have help, Eric Meade is in the back. Eric,  
16 thank you.

17           MR. HATLIE: Natasha Washington. We can't  
18 see in the lights, but she is over here in this  
19 sector somewhere.

20           MS. WASHINGTON: Over here.

21           MR. HATLIE: Hi Natasha. There you are.  
22 Okay.

1 MR. PECK: Thank you Marty.

2 MR. HATLIE: You're welcome.

3 MR. PECK: Sue, back to you.

4 MS. SHERIDAN: Great, I'm back. Thank you  
5 Marty and Jonathan.

6 Marty and Jonathan referenced the working  
7 group. And something that PCORI committed to was  
8 being authentically patient-centered and which  
9 meant we were going to create this event not for  
10 the patients but with the patients. So, given that  
11 charge I reached out to four individual patients  
12 that knew were leaders, four considerably patient  
13 organizations, one of our Board members, and two of  
14 our Methodology Committee members from PCORI. And  
15 we ended up with 11 working group members,  
16 completely different perspectives, which brought  
17 this richness and this challenge to all of us to  
18 create an extraordinary event.

19 I mean, after my first few working group  
20 calls I'd hang up exhausted and wondering why I,  
21 you know, formed it in this way. But I did it in  
22 this way to drive to an extraordinary, excellent

1 event. And so, we're going to take the chance and  
2 you're going to meet all of the working group. And  
3 we're going to all share what brought us here. So  
4 I'm going to share what brought me, Sue Sheridan,  
5 here.

6           What brings me here to PCORI and to this  
7 event is my son Cal. My son Cal suffered brain  
8 damage when he was six days old from his newborn  
9 jaundice and I saw how there were prevention and  
10 diagnosis and treatments that could have been  
11 implemented. So I saw areas in our health care  
12 system that could have been improved. What bring  
13 me here is Pat. My late husband who died at 45  
14 years of age of a cancer that went untreated when  
15 his pathology got filed without neurosurgeons or  
16 physicians ever seeing it. So Pat and Cal bring me  
17 here because I believe that in partnership we can  
18 make a difference. What brings me here is  
19 Mackenzie [phonetic], my daughter, who wishes she  
20 could remember her dad but aspires to be a health  
21 care worker.

22           So what brings me here is PCORI. And what

1 brings me here mostly is hope. I have seen a  
2 witnessed in part of relationships and partnerships  
3 with researchers where we did make change and it  
4 was powerful for me to witness that.

5 So what brings me here is opportunity. An  
6 opportunity that we all have to build a sustainable  
7 architecture for patient-centered outcomes  
8 research. So that's what brings me here. I'm  
9 going to invite our working group members -- we're  
10 not going to go in any specific order, so I'm going  
11 to invite Chuck Bell. Where's Chuck Bell. Let's  
12 start with Chuck Bell. You can introduce yourself  
13 and share what brings you here.

14 MR. BELL: So, I'm with Consumers Union,  
15 the publisher of Consumer Reports Magazine in New  
16 York. And we're an organization that cares about  
17 value for money and consumers and patients need  
18 information that we can trust. And so, we're very  
19 interested in the outputs of PCORI, because we  
20 think that will advance the welfare of consumers.  
21 We want safe, affordable, and effective care for  
22 every consumer that's out there. And we're also,

1 as a National Consumer Organization, interested in  
2 contributing the resources we have to build this  
3 community and to help it succeed. We operate a  
4 project called the Safe Patient Project. I think  
5 some of our folks are here today, people on the  
6 ground working for safer care. We have a big  
7 mailing list and we're going to try to bring more  
8 consumers and patients to the table and build a  
9 really rich community. So we're thrilled to be  
10 here and look forward to working with you.

11 MS. SHERIDAN: Okay, Perry. Where is  
12 Perry?

13 MR. COHEN: I have my speech all written  
14 out so I don't go over time.

15 I was diagnosed with Parkinson's more than  
16 16 years ago, so I've had a long journey on the  
17 advocacy road. I first lobbied Congress for  
18 greater funding for scientific research at the NIH  
19 like a lot of advocates do. Then in 2000 I was  
20 selected a patient representative for Parkinson's  
21 at the FDA. I organized the Parkinson's Pipeline  
22 Project in 2002 to give a voice to patients

1 interested in the regulatory process.

2 Now we are lucky to have PCORI, who are  
3 rapidly becoming champions for activation and  
4 empowerment of patients as we learn together how to  
5 do truly patient-centered research and medical  
6 care. Thank you.

7 MS. SHERIDAN: Thank you Perry. And Sara  
8 van Geertruyden is right next to Perry.

9 MS. VAN GEERTRUYDEN: Thank you. My name  
10 is Sara van Geertruyden, I'm here on behalf of the  
11 Partnership to Improve Patient Care. The  
12 partnership was created back when Congress started  
13 rumbling about creating a comparative effectiveness  
14 institute, and so, our organizations that are part  
15 of our coalition are organizations that had an  
16 interest in advocating for the creation of an  
17 institute and they used the words patient-centered  
18 a lot and looked at doing research that focuses on  
19 what patients need and what patient preferences  
20 are. And so, you see those terms woven into the  
21 legislation that created PCORI in large part  
22 because of the activities of PIPC.

1           Tony Coelho who is the chairman of PIPC is  
2 an epilepsy patient, a former Congressman, and a  
3 disabilities advocate. And he stated in a writing  
4 that he did for Health Affairs awhile back, "If the  
5 health reform law is implemented correctly, the  
6 most important stakeholders in health care,  
7 patients, will have a key role in the effort to  
8 fill gaps in evidence and identify the most  
9 effective treatments. They will have an equal  
10 voice in determining what questions researchers  
11 will study and equal input into how research  
12 findings will be communicated to the public."

13           So for us, and for PIPC, and from myself  
14 and Tony, we are very excited and appreciate, Sue,  
15 your efforts to put this together.

16           MS. SHERIDAN: Thank you. And we have  
17 Regina right there. Let's hear from Regina.

18           MS. GREER-SMITH: Good morning. My name  
19 is Regina Greer-Smith. I started -- I learned  
20 about PCORI in July of this year, and I'm just so  
21 excited about being here. I think I've died and  
22 gone to heaven. Just to think that someone would

1 even consider having patients as peers with  
2 researchers.

3           Who do I represent? I think I represent  
4 my mom who has dementia. My nephew who died from a  
5 medical error, he was actually dumped. I think I  
6 also represent or try to bring a voice to  
7 underserved and diverse patients. I have had the  
8 honor to work at Cook County Hospital and some of  
9 my colleagues are here now. And I'll just tell a  
10 real brief story.

11           I used to leave the parking lot, walk to  
12 my office, and you see an amazing mosaic of diverse  
13 patients whose families' countries of origin are  
14 all over the world. So hopefully, it's my hope  
15 that being here with all of you wonderful people,  
16 that we can recognize them as patients. Honor them  
17 and really represent the needs and hopes of their  
18 participation and research.

19           MS. SHERIDAN: Thanks Regina. Where's  
20 Gail? Gail Hunt.

21           MS. HUNT: Good morning. I'm Gail Hunt.  
22 I'm the head of the National Alliance for

1 Caregiving. We're the people that do most of the  
2 national research around family caregiving. You  
3 know, how many caregivers there are? What tasks  
4 they do? What's the impact on work? What's the  
5 impact on caregivers health? So we do all that  
6 sort of research that some of you may have used and  
7 if you haven't, if you ever need it, if you just go  
8 to our website, there it is.

9           But the other role that I play, is being a  
10 Board member for PCORI and one of those Board  
11 members as Joe said, who was around from the  
12 beginning before there was a Joe, before there was  
13 a Sue, before any of those people. So we actually  
14 have been working really hard to get PCORI started  
15 and I think this meeting is one of the meeting that  
16 will put right on the right path and I'm very  
17 excited to see all of you here.

18           Thank you.

19           MS. SHERIDAN: Thank you Gail. Linda  
20 Kenney.

21           MR. PECK: I was wondering where you were.

22           MS. KENNEY: Thanks. Hi. I'm Linda

1 Kenney and they asked me what brought me here and I  
2 was going to say Sue. She asked. I came. It's  
3 that simple. You know you build relationships in  
4 this work that, you know, when people reach out you  
5 make yourself available. But I'm here because I  
6 almost died of a medical error in 1999.

7           Actually, it wasn't really a medical  
8 error. I say that just to get at it quickly. But  
9 the bottom line is the impact that it had on my  
10 family, on myself, and the staff involved was  
11 devastating and there were no support mechanisms in  
12 place, so I vowed to change that. So that's what I  
13 do. But recently I've been an add-on, you know, a  
14 check the box. They've already done the research  
15 project for a state-wide coalition and "Oh yeah, we  
16 need a patient." So I get added on.

17           And then I have comments, and then they  
18 say, "Oh it's already done." So, this idea to me  
19 is brilliant and I'm hoping that even some of your  
20 ideas I can bring back at a state level to say,  
21 "You know, they're starting to think about this  
22 differently" and hopefully that can help make

1 change in my state, too. So thanks for being here  
2 and I can't wait to meet you all.

3 MS. SHERIDAN: Great. Thanks Linda.  
4 Reggie James.

5 MR. JAMES: Hi, I'm Reggie James. I'm  
6 with Consumers Union, the policy arm of Consumer  
7 Reports. Chuck kind of described some of the work  
8 that we're doing, but I wanted to describe just one  
9 little aspect. He mentioned our Patient Safety  
10 Project. That stems out of a change in our work.  
11 Of course, Consumer Reports, we have the  
12 laboratories. We test products and we report on  
13 them. But we were kind of doing a lot of what the  
14 [inaudible] system does. We were the experts. We  
15 did this. We reported on it. We lobbied as  
16 experts. The change was engaging consumers in the  
17 advocacy work that we were doing. We started doing  
18 that 10 years ago and it makes a phenomenal  
19 difference.

20 So, I know there are several people in the  
21 room here that have been doing work with us and the  
22 effectiveness of our work as increased multifold,

1 but it also changes how we think about what we do.  
2 So, we really, really support the mission of PCORI.  
3 It's a really cool thing. I wish it happened in  
4 every single policymaking arena that governs every  
5 single consumer issue, not just health care. But  
6 health care is a great place to start because it's  
7 so important.

8 I saw one of the quotes of a person here  
9 who shared one of the reasons why they thought this  
10 was so important and I really, really loved it and  
11 wanted to read it. It says, "If designing health  
12 care is like planning a party, professionals have  
13 been treating it like a surprise party."

14 [Laughter.]

15 MR. JAMES: "What is really needed is for  
16 patients to be part of the party planning  
17 committee." I loved that.

18 [Applause.]

19 MS. SHERIDAN: Thank you Reggie. Angela,  
20 I'm not sure where you are sitting. Angela Ostrom.  
21 Oh, she's not here. Well, we'll thank Angela for  
22 her participation in the working group. Kristen

1 Sloan. Is Kristen here? From the National  
2 Partnership for Women and Families.

3 MS. SLOAN: Hi, good morning. I'm Kirsten  
4 Sloan. I'm with the National Partnership for Women  
5 and Families and I'm delighted to be here today.  
6 The National Partnership has been through its  
7 campaign for better care incredibly active in  
8 building a deeper bench of very experienced  
9 consumers to serve on governing boards and patient  
10 advisory councils and making sure that we're really  
11 getting -- building a much more enthusiastic effort  
12 towards patient collaboration and patient  
13 engagement. Thank you.

14 MS. SHERIDAN: Thank you Kristen. And we  
15 also have three members that couldn't make it that  
16 I wanted to thank. Mary Tinetti and Ethan Basch  
17 who were on all of our conference calls, who helped  
18 create some of those questionnaire exercises that  
19 you participated in. Again, thank you for that  
20 energy. They are on the PCORI Methodology  
21 Committee.

22 And then Dave deBronkhardt, who is known by

1 many "e-Patient Dave." And he did send me, he was  
2 on his way to Europe, he sent me a message to read  
3 to you. So I will do that. His message is, "Do  
4 good work. I wish I could be there. I've heard  
5 from several people who are attending. This is  
6 important. We are the advisors on behalf of all  
7 the other patients. We are bending history. Be  
8 wise and strong."

9           So that is our working group. I thank and  
10 applauded the working group. It took all of their  
11 effort to create this. So, we're going to move  
12 from recognizing the working group and what brought  
13 us here, and move into the four different models.  
14 I would like to welcome the presenters to the  
15 stage.

16           And we're going to listen to what brought  
17 them here and four different models of patient-  
18 researcher partnership or how patients are getting  
19 involved in research, and they come from all over  
20 the United States. We're very lucky to have all of  
21 them. And I am not going to read their bios, so  
22 I'm going to invite you to look at their bios in

1 your packet.

2           And it is my great pleasure to introduce  
3 the first researcher-patient partnership. Gosh, I  
4 believe I am starting with Vinny and Kris. Is that  
5 the first one?

6           MR. HARTLIE: It doesn't matter.

7           MS. SHERIDAN: Okay. I am pleased to  
8 introduce Maret and Ned. They are from  
9 Northeastern Colorado. I am from Idaho so we  
10 connected when we were on the phone. You know,  
11 thinking about the mountains and the Wild West.  
12 And that we're all headed to Washington, DC where  
13 we had to dress up like grownups. And I really  
14 appreciated their story. It was very human. It  
15 was community-based. A really nice model on how  
16 they've worked with researchers. I understand  
17 they've given presentations before and they're  
18 considered rock stars.

19           So I welcome the rock stars from  
20 Northeastern Colorado.

21           MS. FELZIEN: So we're not quite sure how  
22 to manage the technology here, so we're going to

1 try this and see if it works.

2 Well, good morning everyone. My name is  
3 Maret Felzien and this is my husband Ned Norman.  
4 Can you hear me okay.

5 [Chorus of noes.]

6 MS. FELZIEN: I'll move up. How about  
7 that? So we are really excited to be here, to be  
8 in DC. All of the presidential candidates are in  
9 Colorado, so this is great for us. And we're  
10 really honored to be talking to such an interesting  
11 group. A little intimidated, and thanks Sue for  
12 that.

13 [Laughter.]

14 MS. FELZIEN: We just want to tell you our  
15 story about how we do research differently. So,  
16 Ned and I believe that we are experts. Thank you  
17 very much. We are experts at understanding our  
18 community. We know what people are concerned  
19 about. We know what they need and want in our  
20 small towns, in rural eastern Colorado. We learn  
21 these things because we're at the schools, the  
22 coffee shops, the tractor and implement

1 dealerships, and the grocery stores and we're  
2 listening and we're talking and we're one of the  
3 community members.

4           We also know how information moves through  
5 our rural community. We know who moves it. We  
6 know what drives it. We have the pulse on  
7 Northeastern Colorado. We are experts in our  
8 community, just like you are experts in your  
9 community. We have come to realize that this kind  
10 of culturally relevant knowledge coupled with just  
11 natural community enthusiasm and "go get 'em"  
12 attitudes is what makes this an authentic and  
13 potent resource for research.

14           And when you pair our energy and our  
15 knowledge with the research, then the health of our  
16 community can be improved. So, we have seen it  
17 happen and we're going to tell you that story.

18           MR. NORMAN: So as Maret mentioned, she  
19 and I are both members of the Community Advisory  
20 Council for the High Plains Research Network. And  
21 HPRN is a practice-based research network that  
22 encompasses all of eastern Colorado. It is a

1 geographically-based network that includes a 33,000  
2 square mile area. Almost -- about three time the  
3 size of Maryland. And the network includes every  
4 clinic, every practice, every doctor, every nursing  
5 home, every public health department within that  
6 large area. And HPRN seeks as its mission to  
7 translate evidence-based knowledge into practice in  
8 a way that's relevant to a rural setting.

9           And this research network had been  
10 established for about six years when Dr. Jack  
11 Westfall, the director, heard the call to action  
12 for community-based practice research and knowing  
13 very little how to do this, he jumped right in.  
14 And as we go through this talk, we're going to be  
15 using the word "community" a lot and we use that  
16 interchangeably with the word "patient," which  
17 seems to be commonly found here.

18           MS. FELZIEN: So how did we get recruited?  
19 How did Jack recruit us? Just as Sue mentioned or  
20 one of the working groups mentioned today, when  
21 someone calls and you're part of their group, of  
22 course, you step up and say yes. And so, he did

1 the exact same thing. He's like, "Hmm, I want to  
2 create -- I want to gather community members to  
3 help me guide the research. How am I going to do  
4 that?" Well, he picked up the phone and he started  
5 calling people that he knew. And it went something  
6 like this: "Hi. I've got this crazy idea.  
7 Something about guiding and influencing my  
8 research, I'm not sure what it's going to look  
9 like, will you try it?" It was that hard.

10 But what we found is that when given this  
11 invitation, had we not heard that this morning  
12 already, that the curious will come. And in fact,  
13 they will even say yes and probably stick around  
14 for a really long time. Those who don't get it,  
15 they'll say no thank you, but they'll also leave  
16 behind someone else's name and say but I know  
17 somebody who will be interested and they will be  
18 your next round of people to ask.

19 So for us, our Community Advisory Council,  
20 we're just made up of normal people. We're not the  
21 stakeholders of our community. We're not mayors  
22 and bank presidents. We don't own businesses.

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1 We're not the shakers and the movers of our  
2 communities, we're not researchers. We're not  
3 involved in the world of health care except as  
4 consumers.

5           However, we are dental hygienists and  
6 hardware store managers, and high school students,  
7 and retirees and people involved in the education  
8 of rural Colorado. Ned, in fact, is a cattle  
9 rancher. A city-born cattle rancher, how about  
10 that? I'm a junior college instructor and fourth  
11 generation wheat farmer. But, as a group we speak  
12 together, we representatives of our large rural  
13 expanse of a community. We don't speak for a  
14 specific town. We don't' speak for a specific  
15 clinic, we don't speak for a specific health issue.  
16 We speak for the community-at-large and we try to  
17 tap into all of those needs and interests.

18           So coming together for our first meetings,  
19 whew, man. They were a feeling out process on both  
20 sides. Nobody knew what to expect of the other.  
21 The researchers thought, "Oh, we'll give you  
22 structure. You must need to be organized. This is

1 how we do this kind of work. We need bylaws and we  
2 need memorandums of understanding and we need  
3 mission statements. And the community looked at  
4 them like they were absolutely crazy. This is not  
5 how we get stuff done. And in fact, one gruff dry  
6 land farmer who is a retired educator stood up, I  
7 mean he physically got himself out of his chair and  
8 he said, "Listen Jack. If we're going to do  
9 something and it's going to be about improving the  
10 health of our community, then I'll stay. But if  
11 this is just going to be about talk and you're  
12 going to waste my time. I'm gone."

13 So that's the only memorandum of  
14 understanding we've ever needed and it's been nine  
15 years.

16 [Laughter.]

17 MS. FELZIEN: So, of course, those first  
18 meetings were really interesting. We didn't know  
19 anything about research. There was this disconnect  
20 between the community about what we were supposed  
21 to do. And as a community, when we're activated  
22 and we hear a good idea what's the first thing we

1 want to do? We want to get to work and we want to  
2 do it now. But research is different. The  
3 timeline is really slow. This is a big machine and  
4 it moves in a different way. So this caused a  
5 natural tension, this is something that we've had  
6 to learn over the years.

7           Additionally, this is nine years ago.  
8 There was no clear model to follow. There was no  
9 one out there who had taken a very large expanse of  
10 a region and brought together people and tried to  
11 say "we're going to cover all of the interesting  
12 areas for us to follow," we had to figure it out on  
13 our own.

14           But our relationship with the researchers  
15 grew and now the research is truly a partnership  
16 and we are not a focus group. We do not just give  
17 our rubberstamp of approval on like "Yeah, that's  
18 a good idea. Please move forward." Instead, we  
19 are completely and integrally entwined with the  
20 research that's going on in Eastern Colorado.

21           MR. NORMAN: So the question now is what  
22 do we do? You know, how is our research done

1 differently with our involvement and maybe the  
2 other question is why do we keep coming back and  
3 doing it?

4           Well, we've been at this for nine years  
5 now and we've been involved in a number of  
6 projects. Some of these projects were born of  
7 ideas that came completely from the Community  
8 Advisory group, that we suggested. In fact, there  
9 is a master list that started early on in the  
10 process. One of these is our Eye on Health  
11 Project, which is a health awareness project using  
12 PhotoVoice, to engage fourth graders using high  
13 school mentors. Other ideas have come to us from  
14 HPRN and were the result of them finding projects  
15 that were fundable and bringing them back to us and  
16 showing them that our community had a need and that  
17 money was available.

18           And this was really important, it was one  
19 of first crash courses in the world of research and  
20 how that process works. Other ideas have come to  
21 us from other researchers and hospitals who have  
22 wanted to come to HPRN and do partners with us to

1 get access to our area. And there are times when  
2 we won't allow that to happen.

3           There was one example where National  
4 Jewish Hospital had a health initiative that was  
5 already put together. They had the materials.  
6 They had a 1-800 number. And they came and  
7 presented it to us and we turned them down. And we  
8 looked up and the HPRN staff was sort shocked at  
9 the table, shock and awe. And they were shocked  
10 that we had refused them outright. And at the same  
11 time they were awed at our ability to protect our  
12 community and shepherd projects through it the way  
13 we thought was appropriate.

14           And we've always respected the fact that  
15 they didn't argue with us. They accepted that.

16           So, our council is fully involved with the  
17 projects that we do from designing and implementing  
18 the research. We evaluate, explain data, we  
19 present at conferences. We do everything. I'm  
20 going to skip that story.

21           MS. FELZIEN: So there's a lot of things  
22 on the horizon for us and Marty is giving me your

1 time's up, and you know, as community members and  
2 storytellers, we could talk all day. We have lots  
3 of things going on. Research started a long time  
4 ago, continues through. We're seeing projects that  
5 we have done in Northeastern Colorado move to the  
6 Southeastern corner. We're seeing a project that  
7 we've done in Eastern Colorado move into the urban  
8 community and being tried there. So the research  
9 that we're finding is sustainable. It's effective.  
10 It's something that can be picked up and shared  
11 with other communities, allowing communities to be  
12 involved and patients to be involved.

13           And we are excited to share those with you  
14 as we move throughout the day, because we've got  
15 lots we can talk about. So the last thing I want  
16 to say, hold on a minute. So why do we keep coming  
17 back?

18           We keep coming back because the research  
19 is fun, this is a community member talking. It is  
20 fun. It's challenging. It's mentally stimulating.  
21 But it really does affect the health of our  
22 community-at-large and for these reasons we keep

1 coming back. So, thank you.

2 [Applause.]

3 MR. PECK: Yes, please. And you'll get a  
4 chance later to talk a little bit. First I want  
5 you to talk to each other at your table. And just  
6 talk for a few minutes about what you really like  
7 about this model, because you are going to be  
8 sneaking your ideas into these breakouts. So share  
9 with each other what you heard that you really like  
10 that you'll want to build on for patient  
11 engagement. We'll give you a few minutes.

12 MR. HATLIE: And by a few, Jonathan means  
13 two.

14 [Table discussion.]

15 MR. HATLIE: Okay. Jonathan, I think it's  
16 time for us to --

17 MR. PECK: So, when I went to Maret and I  
18 said, Maret, that's so wonderful, and she said, but  
19 I have so much more to say. And I know all of you  
20 do too, but we're going to ask you, stimulated by  
21 this first model, that you bring the noise level  
22 down, that you turn your attention forward, and I

1 know you're engaged. That's great.

2 You want to hear about another model, so  
3 Sue?

4 MS. SHERIDAN: Okay, thank you. I hope  
5 that the discussion was energizing. It is my honor  
6 to introduce Dr. Vinod Bhutani and Kris Schulze. I  
7 have journeyed with both of them for the past 12  
8 years through the research partnership that Vinny  
9 and Kris are going to talk about, and so I'm very  
10 proud to be on stage with both of them, and thank  
11 you for coming.

12 MS. SCHULZE: Thank you, Sue. And, again,  
13 when Sue calls, we come.

14 So, I'm going to share our story of the  
15 power of partnership and collaboration with Parents  
16 of Infants and Children with Kernicterus, or PICK.

17 My piece in this story started a bit over  
18 14 years ago with the birth of my son, a nine and a  
19 half pound, full term, very healthy newborn. And  
20 within that first day he had developed newborn  
21 jaundice. By the time he left the hospital two  
22 days later, his jaundice was worsening and we were

1 told to keep him in the sun and follow up with our  
2 doctor for a well-baby visit two weeks later.

3           When we arrived on day ten, he had a  
4 bilirubin test, which, of course, we had no idea  
5 even existed or that there was an objective  
6 measurement for how severe jaundice could be, and  
7 we found ourselves in the NICU for the weekend  
8 receiving phototherapy.

9           Four months later, we discovered that our  
10 son had kernicterus, which is brain damage caused  
11 by severe newborn jaundice. Kernicterus, for my  
12 son, means that he has severe athetoid cerebral  
13 palsy, he is unable to sit on his own, he is unable  
14 to walk, he is unable to feed himself, he is unable  
15 to get a drink of water on his own, he is dependent  
16 on others for all basic cares and will be for the  
17 rest of his life. Had he had a one dollar blood  
18 test before we left the hospital and had received  
19 the appropriate treatment, he would have been just  
20 fine, we would have had a different journey that we  
21 would be on today.

22           When Justin was two years old, or just

1 after he was two years old, a coworker spotted a  
2 USA Today feature story on a young boy that looked  
3 a lot like our son -- there's Justin right there --  
4 and as I read the story of Cal Sheridan, Sue's son,  
5 I realized that we were not just an isolated case.  
6 We had already connected with two other families in  
7 the Minneapolis-St. Paul area whose kids had  
8 kernicterus, even though we kept repeatedly being  
9 told that kernicterus no longer happens in our  
10 country. By the end of the day that we saw the USA  
11 Today article featuring Cal Sheridan's story, we  
12 had connected with Sue and we found out that there  
13 was going to be a symposium on newborn jaundice and  
14 kernicterus the following weekend in Chicago.

15           So, six of us moms showed up in Chicago  
16 that weekend, dropped everything and made it  
17 happen, and a seventh mom soon joined us whose  
18 newborn baby had just been diagnosed with  
19 kernicterus in the Chicago-area, and PICK was born.

20           We connected with amazing, courageous  
21 doctors, Dr. Bhutani being one of them, and never  
22 underestimate the powers of moms on a mission. We

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1 realized at that point that a lot of babies were  
2 falling through the cracks of the medical system  
3 and developing very preventable disabilities and we  
4 needed to do what we could to work with the medical  
5 researchers and medical community to make it stop  
6 so that we would have healthy newborns.

7           And that was our main focus early on, is  
8 how do we prevent this from happening. By the time  
9 we left Chicago, we had plans in place for not only  
10 our nonprofit organization of Parents of Infants  
11 and Children with Kernicterus, or PICK, but we had  
12 plans in place to meet four months later at the  
13 University of Pennsylvania in Pennsylvania  
14 Children's Hospital for our first system-wide,  
15 consumer-centered workshop to meet with our  
16 representatives from the CDC, from NIH, from the  
17 Health and Human Services, and from the Joint  
18 Commission on the Accreditation of Healthcare  
19 Organizations, and we moms mixed ourselves up  
20 around the table and were able to share our  
21 stories, and by the time we left that meeting and  
22 we asked who was going to do what by when, and

1 trust us, we moms had a very short timeframe in  
2 which action was going to happen, we had a plan  
3 going forward.

4           Within several months we had Sentinel  
5 Event Alert had been issued on the reemergence of  
6 kernicterus and kernicterus was also listed as a  
7 never event and then several years later the APP  
8 ended up changing their treatment guidelines and  
9 standards for the treatment of newborn jaundice.

10           So, in a very short time, a small group of  
11 moms came together with amazing researchers and  
12 started connecting those dots and connecting the  
13 stories along with the research to change how we  
14 treat newborn jaundice in our country.

15           With that, I'm going to have Vinny share.

16           DR. BHUTANI: Thank you. So, we met Kris  
17 and Sue in Chicago. We had been working on a video  
18 to put together to define some of the effects of  
19 newborn jaundice that affects almost all babies who  
20 are born in the U.S.

21           And I put the video together from the  
22 clips that the families had sent to us, I did not

1 know the families then, but one of the things that  
2 we did was as you put the clips together and made  
3 the video, we decided to invite the moms at the  
4 luncheon of this video for education.

5           At the front row of the audience sat seven  
6 moms, and I was sitting across the dais as this  
7 video played, and as I looked across, the tears  
8 were there, the pain was there, but what was most  
9 apparent was a silent rage the emanated from these  
10 moms, and that had a powerful impact on those of us  
11 who were at the dais, because we felt that here  
12 were lives that had been thoroughly changed because  
13 of an inability to detect or prevent something that  
14 had been eradicated many years ago.

15           This was a journey that began about 13  
16 years ago and since then, as you heard, with the  
17 leadership and the support of the moms on a  
18 mission, that we embarked on an effort to gather  
19 evidence, bring about change, bring about change in  
20 the communities of physicians who are taking care  
21 of babies in the U.S. as well as abroad, and I'm  
22 happy to report that their effort on the CDC

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1 website, if you click on newborn jaundice or the  
2 word kernicterus, you will see a portfolio of  
3 teaching materials in four different languages for  
4 moms or moms-to-be, prepared by us as a  
5 partnership.

6           And more importantly, in the chapters of  
7 the books that pediatricians read now, as well as  
8 in practices that they are governed through the  
9 guidelines of perinatal care, the screening for  
10 newborn jaundice now is the standard of care.

11           It took a while, it took a lot of effort,  
12 but it was driven by the engine that is the passion  
13 of the moms generated with that silent rage, and  
14 now we need to keep our promise.

15           MS. SCHULZE: Just to wrap up quickly, we  
16 wanted to talk a little bit about what our next  
17 steps are. Unfortunately, we still continue to see  
18 and get contacted by families who have kids who  
19 have fallen through the cracks of the medical  
20 system or find themselves with kernicterus. The  
21 wonderful thing about technology now is that we're  
22 starting to connect with families from around the

1 world, so as we get families from Nigeria who've  
2 discovered that they have a child with kernicterus,  
3 we're able to put them in touch with other families  
4 in Nigeria or families from Brazil are connecting,  
5 families from India, from Great Britain, there are  
6 families from around the world who are not only  
7 using the PICK resources that were developed along  
8 with the Centers for Disease Control, but also are  
9 coming together on our Facebook groups and our  
10 listserv and through our website to be there for  
11 one another, to have that support, and guidance,  
12 and hopefully, figure out, as Vinny mentioned, we  
13 had a three-pronged approach of partnership,  
14 prevention, and promise.

15           Right now, our main area of focus is going  
16 to be moving forward on how to do more research to  
17 create the future these kids deserve and how do we  
18 make their lives better and make sure that they  
19 have full, happy lives, have the technology they  
20 need, and all the supports they need to have full  
21 lives.

22           And I think that's about it. So, thank

1 you.

2 [Applause.]

3 MR. PECK: Okay. Kris, Vinny, thank you  
4 so much.

5 Take a few minutes and talk with each  
6 other about what in their model that you really  
7 like that you want to build upon as we go to the  
8 break.

9 [Table discussion.]

10 MR. HATLIE: Okay, Jonathan, I think we've  
11 got to move on. Do we have time for comments?

12 MR. PECK: Okay, it's a good thing I'm  
13 from New York; I don't think it's rude to  
14 interrupt. If you can, this was wonderful, I can  
15 see you're primed. Let's hear another model.

16 MS. SHERIDAN: Thank you, and I must share  
17 that if Ned and Maret were rock stars, Vinny and  
18 Kris, I think, were the Olympians, and now I'm  
19 going to introduce a super hero now, Ben Heywood,  
20 who is going to share a really creative model and  
21 I'm excited that he's going to expand our thinking  
22 about how patients can really get involved in

1 research.

2 MR. HEYWOOD: It's very easy to meet that  
3 expectation. Thank you guys for having me here.  
4 It's really, truly, and honor.

5 So, I think I'm on the stage because 13  
6 years ago my brother was diagnosed with Lou  
7 Gehrig's Disease and -- sorry, it's always --  
8 unfortunately, he passed away six years ago, but I  
9 want to talk a little bit about our family's  
10 journey and what we've done, because I think it  
11 sheds a lot of light on this topic, and what's  
12 possible when you really let patients in and engage  
13 them deeply.

14 So, you know, I think this idea that when  
15 patients are diagnosed and when my brother got  
16 diagnosed, we don't have research questions; we  
17 just have questions. We want to know, what will  
18 help me get better, what can I expect. I think  
19 particularly in spaces where, you know, like Lou  
20 Gehrig's Disease or illnesses in children where  
21 there are not great answers, we quickly become --  
22 the question is, well, we realize that there isn't

1 answers to these questions. And not only are there  
2 not definitive answers, there's not data to  
3 actually make -- to guide even partial answers to  
4 this.

5           And so, you know, and this sense of  
6 urgency is really acute for someone like my brother  
7 who was diagnosed at age 29 and our family. So,  
8 what happened? So, we as a family did a few  
9 things. My brother Jamie -- Steven was my brother  
10 who passed away, but my brother Jamie and our  
11 family started a nonprofit biotech called the ALS  
12 Therapy Development Institute, and it's running  
13 today. We actually have raised about \$70 million  
14 for that, and I say that as a top line just to give  
15 a sense of the scale, but not because that's what  
16 we want to do.

17           What they tried to do -- it's a nonprofit  
18 biotech doing really hardcore in vivo drug  
19 discovery and they really tried to take apart this  
20 disease at scale using a preclinical mouse study  
21 model.

22           They've actually run 30,000 mice through

1 that lab in the last ten years, just to give you  
2 the sense of scale.

3           Now, what's interesting about what they  
4 did in terms of this discussion is it's not just  
5 about clinical research that we can bring people  
6 into the fold; you can bring it in at any stage of  
7 the environment. They had a completely open  
8 research model, all of the research in their  
9 pipeline and their knowledge network that they'd  
10 developed to do this task was on the web and  
11 available for patients.

12           Their Laboratory Information System, their  
13 real-time LIM System of the mouse studies, was put  
14 live to the web, blinded, but live to the web in  
15 real-time so patients could engage and understand  
16 it and know about it.

17           So, you can really let people into the  
18 process early.

19           So, the other thing we did is Jamie and I  
20 started Patients Like Me, and what Patients Like Me  
21 set out to do was to actually begin to bring  
22 together patients to allow them to tell their

1 story, but actually tell it in a way that we can  
2 begin to capture the data about what happens to  
3 them because, you know, every patient has a story.  
4 I think these stories are too often not heard, but  
5 I think more importantly these stories aren't  
6 turned into meaningful information, because it's  
7 not just a story that every patient has, every  
8 patient has a deep understanding of how their  
9 illness is affecting their body, their mind, their  
10 lives, and I think we need to begin to capture  
11 that.

12           And there is no system today to capture  
13 that in a comprehensive sort of global patient  
14 view. So, what we did is we started Patients Like  
15 Me. It's a community of patients coming to the  
16 web. They come primarily to find answers, to share  
17 their experiences, and to learn from the experience  
18 of others, but what we help them do is we take  
19 those stories and we turn that into qualitative  
20 data, so we take their experiences and we give them  
21 patient reported outcomes and we give them  
22 structured Q&A to allow them to actually begin to

1 track and tell their story and paint the picture of  
2 the longitudinal course of their illness in their  
3 disease.

4           The scientific jargon around that is we  
5 try and help them create what we call a phenotype  
6 engine on our inside, which we want to understand  
7 fully the phenotype of that disease and our  
8 illnesses.

9           So, where are we at today? I mean, we  
10 started this about eight years ago. Again, you  
11 know, we have about 160,000 patients in this  
12 network across 1,000 different diseases. We're  
13 definitely much stronger in a few communities, you  
14 know, you talked about your community. We started  
15 in ALS. One of our next early communities is MS.  
16 Those are some of our strongest ones. We actually  
17 have about 5 percent of the U.S. MS population on  
18 the site.

19           You know, just from the scientific side of  
20 this, it is a clinical research platform. We have  
21 published 25 papers in peer-reviewed journals over  
22 the last four years, so we are engaging in the

1 scientific research. We have an amazing science  
2 research team, but actually I think more  
3 importantly, and again, about letting patients into  
4 a transparent research process, we publish all of  
5 our data in real time, live, so we have data on  
6 over 10,000 treatments in our system.

7           Now, that's not just pharmaceuticals, that  
8 is prayer, that is nutraceuticals, that is, you  
9 know, pets, that's the whole range, but actually  
10 all of that data is reflected back live. We have  
11 actually over 8,000 symptoms in side effects  
12 reports, again, reflected back live, and patients  
13 can slice and dice that data to make it meaningful  
14 for a patient like you, and that goes back to the  
15 evidence problem, right, so obviously in  
16 traditional research we want to get to the perfect  
17 standard of randomized placebo controlled trials,  
18 but the reality is, patients with these illnesses  
19 are making decisions, and I would rather them make  
20 them with some data than no data.

21           And we can learn which of that data, as  
22 long as we cycle back the learning into the system,

1 we can continue to improve and understand and  
2 ultimately get to the right answers for a patient  
3 like you.

4 I think there's a few headwinds that I  
5 think this group can make a big difference on. I  
6 talked about patient reported outcomes, that's a  
7 big part of what we do on our side. I think there  
8 are a few interesting headwinds there and I'm  
9 excited to see -- we've been doing this a long time  
10 at Patients Like Me. I'm excited to see this group  
11 and I'm excited to see the energy around this in  
12 other arenas too of both policy research and  
13 patients.

14 One is that there's still a skepticism  
15 about the validity of the patient's experience in  
16 research. There just fundamentally is, and  
17 obviously I'm saying this to this crowd, they don't  
18 believe that, but when you get out there, you will  
19 find it, and that's a headwind that we, as a group,  
20 can really make a difference on.

21 Two, I think, as we begin to design  
22 measures in research, I think it's important that -

1 - and this is something we focused on in the  
2 beginning is, those outcomes, those measures, those  
3 understanding should help a patient drive their own  
4 individual care, and then we can aggregate that up  
5 and learn how that affects the system. Let's not  
6 measure patients to figure out how to change the  
7 system, let's help them change the system through  
8 their understanding of their own illness and their  
9 own experience.

10           So, I think this group is really well  
11 positioned.

12           So, you know, we're supposed to talk about  
13 what's distinctly different about what we do -- I'm  
14 sorry, talk about how we incorporate patient  
15 engagement in the process. Well, we're a website  
16 where patients come and participate. Engagement is  
17 our research process. We don't have anything to do  
18 if our patients aren't engaged and aren't  
19 participating and so, you know, it's funny, one of  
20 the things -- highlights that was exciting, I was  
21 just talking yesterday with our head of product and  
22 he said, we just ran the experiment where we said -

1 - when patients join, we ran -- we put them into  
2 the sort of the charts that show the data as  
3 opposed to the sort of stream of what updates in  
4 what the community is doing and we found that  
5 patients much more rapidly engage both in the site  
6 ultimately in giving and tracking their data when  
7 we give them the access to the community as their  
8 first step.

9           And so, that's amazing for us because it  
10 means we're going to get more engaged patients,  
11 more ability to work with them to answer tremendous  
12 questions. That's not a research question, per se,  
13 as we might think about it in this room, but  
14 actually when engagement is the center of the  
15 research, that's a very, very important thing for  
16 us.

17           Just a couple of great, quick anecdotes,  
18 early on, this relates to the PRO story -- topic I  
19 was talking about, we had a patient, Kathy Wolf,  
20 who was an ALS patient, and the PRO we used on the  
21 side, the patient reported outcome we use on the  
22 site is called the ALS Functional Rating Scale. It

1 sort of goes from -- it's a progressive disease and  
2 the end point of it, because it was designed for  
3 trials, was ventilations or death.

4           And so this patient was on a vent and she  
5 was like, well, I want to continue to understand  
6 how my progress and share that experience, she  
7 doesn't want the line to flatten out an event  
8 that's still meaning to where she is and how she is  
9 engaging in life. And so we actually worked with  
10 her to design an extension to that rating scale  
11 called the FRC extension, you know, we did the  
12 traditional PRO development process with our  
13 research team, but working directly with her we got  
14 it down to four questions, and now she can actually  
15 track and engage with that data and that meaning  
16 and actually convey her experiences after  
17 ventilation, because the PRO is designed for  
18 endpoints in trials, which the pharmaceutical  
19 company only cared about that endpoint, but then,  
20 you know, understanding it past that is something a  
21 patient cares about.

22           I think it's a really powerful way to

1 think about engaging researchers.

2 I'm getting down to 28 seconds here, so --  
3 what am I excited about? I think, you know, one of  
4 the things we're trying to do is figure out how to  
5 make this -- we are a for-profit company, because  
6 we believe to scale this we really need to actually  
7 align the patient's interest with the financial  
8 interest of the system, so we are trying to bring  
9 together patients, industry -- primarily  
10 pharmaceutical companies today -- and nonprofits --  
11 I swear only 30 more seconds -- and we also are  
12 working on a project we're not announcing yet, but  
13 I think a very exciting project where we're going  
14 to be able to help with the rapid, I think,  
15 development and deployment of patient reported  
16 outcomes in the next year, and I think -- the other  
17 thing is I think we're embarking on a really, I  
18 think, interesting dialogue about the dissemination  
19 of results to patients and where they can get them  
20 in the process, because patients want answers  
21 sooner. You talked about that tension, and the  
22 question is, what happens if you allow them in

1 sooner and how does that affect the research  
2 fundamentally.

3           And I think you'll see over the next few  
4 weeks here a very interesting dialogue starting  
5 around that and I'm excited to have everyone  
6 participate.

7           Thank you.

8           [Applause.]

9           MR. PECK: Thank you. Before you process  
10 this, I have an announcement. The hotel is opening  
11 Internet access to everyone at the workshop and the  
12 access code is internet, all lower case.

13           Okay. Take a few minutes and talk about  
14 what in this model that you've just heard you  
15 really like that you're going to bring into the  
16 other groups.

17           MR. HATLIE: And Ben, I think, has one  
18 more thing to say --

19           MR. HEYWOOD: Real quick, I apologize, I  
20 have to run home for a family event that was  
21 already preplanned, but I do have a colleague here,  
22 Sally Oaken, who is an amazing clinical nurse, who

1 works on our research team, so she is here for the  
2 whole conference, so if you have questions about  
3 Patients Like Me or my story, she is a wonderful  
4 colleague over here.

5 MR. PECK: Thanks, Ben.

6 [Applause.]

7 MR. PECK: Okay, take a few minutes and  
8 we'll interrupt.

9 [Table discussion.]

10 MR. HATLIE: Okay, I think we're going to  
11 -- we have one more presentation that we're going  
12 to share with you if I could have your attention,  
13 please.

14 MR. PECK: Okay, he's asking politely.

15 MR. HATLIE: I'm going to get up in a  
16 chair. Okay, we have one more presentation and  
17 then we will have 15 minutes for a little bit of  
18 Q&A or a little bit of comment on the presentations  
19 you've heard, so we'll get that interaction going,  
20 but right now we're going to ask Sue Sheridan to  
21 come back up to the stage and introduce our last  
22 presenter.

1 MS. SHERIDAN: Thank you, Ben, that was  
2 fabulous. Our last presenter is Janice Bowie, and  
3 I'm going to introduce her as the Saint in that  
4 when we connected on the phone to talk about her  
5 passion and her dedication to improving healthcare  
6 in disparate populations, it was really moving and  
7 I can't remember how long we spoke, but it was a  
8 powerful story that she shared when a community  
9 actually came to the researcher, so it was a little  
10 different model than what Ted and Maret shared.

11 And so this is a community recognizing and  
12 confused why their county suffered from some of the  
13 worst outcomes and they approached Janice and so  
14 I'm going to introduce Janice Bowie, and hear her  
15 story.

16 MS. BOWIE: I'm going to apologize in  
17 advance for my voice. I don't usually sound like  
18 this and I have not been on the presidential  
19 campaign trail, although I think I might, could do  
20 as good a job as some of them. Maybe that's not  
21 so true.

22 Before I get started with my portion of

1 the presentation, we have a short video from my  
2 community partner who could not be here today  
3 because the National Association of Colored People,  
4 the NAACP, is having its meeting this weekend as  
5 well and so in lieu of Childlene Brooks being able  
6 to be here, we have a short video clip.

7 I understand it doesn't come through very  
8 clearly, so I'll do my best to try and fill in the  
9 gaps.

10 [Video shown.]

11 QUESTION: Childlene, why would you reach  
12 out to the Hopkins Center for Health Disparities  
13 Solutions? Also, what motivated you to do so?

14 MS. BROOKS: Dr. John Ryan, the former  
15 health policy director for the Talbot County Health  
16 Department approached me to [inaudible] and the  
17 fact that Talbot County ranked number one  
18 [inaudible] breast cancer and colorectal cancer.  
19 We began looking at ways to disseminate information  
20 into the community and to [inaudible] issues. The  
21 initial presentation was to the Talbot County  
22 NAACP.

1           Dr. Ryan knew about [inaudible] and he's  
2 tied to the Eastern Shore, because he attended the  
3 University of Maryland Eastern Shore, he also knew  
4 about [inaudible] work with health disparities and  
5 he gave me his contact information and asked me if  
6 I would call him and I called him and spoke to him  
7 in 2008. And at that time he suggested several  
8 approaches to include professional [inaudible]  
9 assessment to clarify and define the problems in  
10 the county and he [inaudible] to identify and  
11 catalog [inaudible] stakeholder to the community.  
12 [Inaudible.]

13           [End of video.]

14           MS. BOWIE: Thank you. So, what I'd like  
15 to first do is to acknowledge my colleagues, the  
16 NAACP and the Talbot County Health Department,  
17 which is on the eastern shore of Maryland, as you  
18 can see in the slide. I also want to acknowledge  
19 that our work is collaboration through the Hopkins  
20 Center for Health Disparity Solutions, which is led  
21 by Dr. Thomas LaVeist and other colleagues, and one  
22 of my colleagues here who has been working with

1 some of the PCORI team is Cheri Wilson, and it was  
2 through Cheri's efforts with PCORI that we were  
3 asked to share our story.

4           So, Talbot County is a very interesting  
5 case because they contacted us. The Maryland State  
6 Health Department issues a report annually on the  
7 state of the health of Marylanders and Talbot  
8 County, located on the eastern shore of Maryland,  
9 there are other neighboring counties and the  
10 neighboring county to it is Caroline County, and  
11 they couldn't understand why having similar  
12 demographic characteristics in terms of population  
13 size, in terms of socioeconomic status, and even in  
14 terms of racial and ethnic mix, why did they have  
15 very serious health outcomes that were not apparent  
16 in the Caroline County.

17           So, they contacted us. The NAACP placed a  
18 call, as you could maybe not hear in Childene's  
19 comments, was that Dr. LaVeist had trained at the  
20 University of Maryland Eastern Shore and people  
21 knew of his work and knew of the center at Hopkins,  
22 and that is how this occurred.

1           So, we, during the conference call with  
2 them, began to look at the demographics in the  
3 counties. We met with them over the phone, and  
4 what we learned was that, yes, they have similar  
5 demographic characteristics, they even have a  
6 similar age distribution, but you will see in this  
7 next slide -- you can see -- hopefully you can see  
8 -- yes, that you can see the different -- the  
9 similar age distributions across each of the  
10 cohorts from 18 to 34 and 65 years of age and  
11 older.

12           And then in this next slide you'll notice  
13 in the educational levels that the Talbot County  
14 group, which is -- and this is broken up by Talbot  
15 County whites and blacks because the county is  
16 largely white and black even though there is an  
17 emerging and growing population, like in many other  
18 places, of Latino residents.

19           And then the third bars represent  
20 Maryland, and what you can see from these bars is  
21 that the Talbot County population fares a little  
22 bit better than Caroline County for both income and

1 education level, so you can see the education  
2 levels here, slightly few more high school  
3 graduates and slightly more college graduates in  
4 Talbot County. Similarly in terms of higher  
5 incomes being represented in the Talbot County, and  
6 this is among the African-American populations.

7           So, what was most striking for us is that  
8 when looking at excess mortality, we could see that  
9 the blacks in the county compared to the whites,  
10 had a greater excess death rate, so the mortality  
11 was 64.5 percent compared to that mortality in  
12 terms of 20 percent in Caroline County and 30  
13 percent at the state, so you can see it's a huge  
14 excess mortality and excess mortality represents  
15 mortality that's over and above what you would  
16 expect to see in terms of similar or comparative  
17 population groups.

18           Similarly, we could see that there was  
19 also excess in terms of all-cause mortality ratio,  
20 meaning that, when that ratio is above one, that  
21 you would see, again, that the Talbot County  
22 residents -- black residents in Talbot County were

1 faring worse than all others.

2           So, what happened is that as a result of  
3 this -- and then this bar also sees -- if you  
4 notice where -- and the read is the African-  
5 American group and then the yellow are the whites,  
6 and if you look at Talbot County, which is marked  
7 at the bottom highlighted in yellow, you can see  
8 this disparity in terms of mortality.

9           Similarly, you can see these are all the  
10 counties in Maryland followed by the whole state,  
11 which is in red, and the U.S., which is in the blue  
12 or white marked bars, and you see where Talbot  
13 County fares.

14           So, of all the counties, compared to the  
15 State of Maryland and compared to the U.S., that  
16 there's a 60, almost 65 percent excess mortality.

17           So, of course, if you were a member of  
18 this county, you would be somewhat concerned about  
19 what's going on. And so, again, when we met with  
20 the county, we thought, well, maybe must be  
21 something wrong with the data. And so, what that  
22 led us to do was to go back and try to rerun the

1 numbers, and in fact, we did see that these numbers  
2 were actually accurate. And when you think about  
3 the behavior of medical conditions, we could see  
4 that there were large rates of all of these  
5 conditions going on in the county, that there was  
6 greater smokers, that there was disparity in terms  
7 of cancer screening rates, that people -- fewer  
8 people were having their cholesterol checked and  
9 when you really looked at hypertension, it was  
10 really off the charts.

11           So, as it typically is, when researchers  
12 go to a county, they take our pictures, as opposed  
13 to taking everybody's pictures, but this is Dr.  
14 LaVeist in our first community meeting, and as you  
15 can see, Hopkins looks at racial health disparities  
16 in Talbot. I would have had a different lead  
17 story, but -- and we had 35 community attendees  
18 from the Chamber of Commerce to clergy to the  
19 school of nursing, the head of the hospital  
20 association, average citizens, just an entire group  
21 -- just a very mixed and diverse group of people  
22 who met.

1           We went back again, we had another  
2 community meeting. This time, I'm in the paper and  
3 I try very hard not to be in that picture, but as  
4 it is.

5           So, what I want to really say about this,  
6 because it fits very nicely with what all of my  
7 other co-presenters have said in terms of their own  
8 personal stories, what's most important in the work  
9 that I do, I've been involved for a long, long time  
10 in community-based participatory research, and we  
11 go from patients to consumers to communities, all  
12 of us are representing patients at an individual  
13 unit and we represent each other collectively as  
14 communities and as populations.

15           And what I think is important in the work  
16 that we try to do is to understand that that  
17 process has to involve communities in defining  
18 their own problems and expressing their own  
19 concerns versus how professionals, being the  
20 experts in deciding what those problems are. The  
21 work takes a long, long time, as has been pointed  
22 out by many of the other presenters, and that

1 decision making rests collectively. It's not the  
2 decision of any one entity.

3           And finally, that our goal is not only in  
4 terms of changing health outcomes, but changing the  
5 capacity of people who are making those decisions,  
6 because if we are not building capacity, then at  
7 the end of the day, we really have not moved the  
8 agenda forward in the ways that we think we should.

9           I'm out of time and you will have these  
10 slides. We are still working. We have  
11 applications that are pending to continue our work,  
12 and I want to thank each and every one of you for  
13 putting up with my voice, and I really appreciate  
14 the work that you do.

15           MR. PECK: Thank you.

16           [Applause.]

17           MR. PECK: Okay, thank you. Should we  
18 take a few minutes to let them say what it is on  
19 this model at the tables and then we're going to  
20 have a group conversation between you at the tables  
21 and our wonderful panel.

22           So, go ahead and take a few minutes just

1 to talk about what you like about the Talbot County  
2 work.

3 [Table discussion.]

4 MR. PECK: If we can now, we want to see -  
5 - Marty and I have mics, will travel. So, if  
6 you've got something that you'd like to share with  
7 the panel that came out of your discussions at the  
8 table, it could be something that you want to share  
9 that you like or a question that you have about how  
10 they did it. You know, each of these speakers had  
11 a half hour presentation they condensed into ten  
12 minutes for us, so if I can end this conversation  
13 at the table, if I can just get you to forward it  
14 here, we want to center it up to the front. We  
15 only have them for a few minutes.

16 MR. VAN LEEUWEN: Oh, I'm Danny van  
17 Leeuwen. I really -- when I came to this  
18 conference, I was thinking, you know, there's  
19 something wrong with the model of research itself  
20 that, you know, as my neurologist says to me, I  
21 know a lot about populations, none of it relates to  
22 you. You know, we still have to make decisions.

1           So, to hear you say, from the Patients  
2 Like Me angle, you know, that we as patients need  
3 information to make decisions right now, and  
4 research is like this really long process that's  
5 about populations and it gets so narrow to qualify  
6 as a research project and gets really specific, and  
7 so it doesn't necessarily help me make treatment or  
8 lifestyle decisions.

9           So, what is it, you know, in your  
10 experience with what you were describing in your  
11 work with Patients Like Me, so how does -- I guess  
12 it's both, how do we move it forward so that people  
13 can use information to make decisions, but also so  
14 that it's more accepted? I guess.

15           MR. HEYWOOD: You know, the definition  
16 today of clinical care of medical evidence is the  
17 randomized placebo controlled trial, right, which  
18 is the gold standard and is a very, you know,  
19 useful piece of medical evidence, but it doesn't  
20 always relate to a patient like you and it's not  
21 always available, right, about 15 percent of  
22 medicine is practiced on that kind of evidence,

1 right.

2           So, the question is, how do we begin to  
3 allow evidence on the spectrum of quality to drive  
4 decision-making? We make decisions in our lives  
5 every day with imperfect information, except  
6 specifically in medicine, right, but the reality is  
7 people do make those decisions on imperfect  
8 evidence, so what we need to do is begin to talk  
9 about what's the quality evidence, why am I making  
10 it, and how does the quality of the evidence relate  
11 to the decision-making at that time.

12           And I think -- but the other thing that's  
13 really important, and this is what our system is  
14 not set up to do, is we need to then capture that  
15 experience and that experiment that happens with  
16 that physician and that doctor in real time and  
17 feed it back into the learning network so that we  
18 can -- that model can get better and better.

19           I mean, there's a great article in the BMJ  
20 about parachutes and no one's ever decided that,  
21 you know, double blind placebo controlled trials --  
22 people should use parachutes, but when you jump out

1 of an airplane, you know you should use one, and  
2 when we first started jumping out of airplanes with  
3 parachutes they had a nasty adverse event rate of  
4 about 1 percent, right? Today, there's zero or  
5 almost zero adverse event of jumping out -- I mean,  
6 near zero, and we didn't do that through this type  
7 of research that we traditionally talk about. We  
8 just looked at it, learned, learned and learned,  
9 and the system got better and knocked that out.

10           So, I think we really do need to rethink  
11 it and I don't think any of the clinical  
12 infrastructure or informatics infrastructure we  
13 have today is designed to do that, and we're trying  
14 to -- I mean, that's what we're trying to build  
15 outside the system.

16           MR. HATLIE: So, Ben, you talked about the  
17 headwind, and that's Danny's question too. What  
18 piece of advice would you have? I mean, how did  
19 you fight that headwind? Did you stand up and  
20 scream? Did you go to media? I mean, I know what  
21 the kernicterus moms did, they basically got a  
22 meeting, did an action plan, and said, we're out of

1 time, let's go.

2 I don't know what your strategy was.

3 MR. HEYWOOD: Well, so one strategy -- I  
4 mean, I mentioned, our family both started a  
5 nonprofit and this for-profit, is I actually do  
6 fully think that you need to think about the  
7 financial incentives and aligning them to this  
8 cause, right? I mean, if this cause about putting  
9 patients in the center of healthcare is not  
10 incented in the system directly, then it's not  
11 going to -- I mean, we live in a capitalist  
12 society, and so we really need to really align it,  
13 and so, you know, the questions need to flow  
14 through the patients, what we're talking about,  
15 getting it to flow, but actually, ultimately, on  
16 some level, the money needs to flow through the  
17 patient directly in a very different way than it  
18 does today.

19 MR. HATLIE: Okay, great. Thanks. I hope  
20 that's helpful.

21 [Applause.]

22 MR. FARBSTEIN: I'm Ken Farbstein and we

1 have some really smart people at our table, but  
2 we're unclear, still, on the specific way that the  
3 partnership research model worked for several of  
4 the speakers.

5           So, Ben, for Ben, you know, patients like  
6 me, we get that, but for the others, like  
7 specifically, what were the steps of the research  
8 and, you know, what's the recipe, like, you know,  
9 first we did this and then we did that and then we  
10 did that, and so forth? I'm sorry, but we're kind  
11 of unclear on that.

12           MS. FELZIEN: is there specifically  
13 someone you want to have answer that or just jump  
14 in?

15           PARTICIPANT: [Off microphone.]

16           MS. FELZIEN: So, we have steps and a  
17 method and we stumbled upon it, and it looks like  
18 this. Either the community brings an idea forward  
19 or the researchers bring an idea forward, and then  
20 of course you need money, and so you have to go,  
21 you have to dance this dance about, well, where's  
22 the money, what's fundable?

1           When money is available and there is a  
2 research project that we are able to move down the  
3 path with, then the process works like this for us:  
4 the idea is pitched, long before the money arrives,  
5 the community says, wow, we like that, we see the  
6 need for that, or the community says, I'm not so  
7 sure, but talk to us more, or something. And  
8 eventually there's buy in.

9           Then the community has to go through a  
10 pretty rigorous education process when we are going  
11 to embark on some sort of research program, and we  
12 call it a boot camp of sorts where we bring in  
13 someone who's an expert in whatever it is the field  
14 that we are learning about, so next week we are  
15 going to have a boot camp on behavioral mental  
16 health. We have been working on hypertension,  
17 we've worked on asthma, we've worked on colon  
18 cancer.

19           So, each one of those topics we've had a  
20 two to three hour CME level, so, where a  
21 professional could go and get credit for attending  
22 this seminar, that's the level seminar that we

1 receive as the community. Then that allows us to  
2 process this information. Now we understand, we  
3 have the language, we can talk fluently with the  
4 research community, and we can work shoulder to  
5 shoulder, but we can also continue to keep this  
6 information and make it relevant for our community.

7           That then starts us on this path of, okay,  
8 so now we understand, what are the salient points?  
9 Who are we trying to target? What are the research  
10 questions? And the community is involved in each  
11 one of those steps.

12           Then depending on what the research  
13 project is, there may be a lot of effort in  
14 creating some messaging and some materials and, you  
15 know, how do we get this information out, how do we  
16 put out an implementation process, how do we put  
17 out an intervention, how do we disseminate -- you  
18 know, get this out there, and able to collect the  
19 data.

20           Once that is going, then it's the research  
21 team that collects the data. That's their job;  
22 that's not ours. But that data always comes back

1 and we help evaluate it, we help to explain it, and  
2 then ultimately in the end we help to present it  
3 and author papers and then bring it right back to  
4 the community and say, this is what we learned and  
5 this is what we can do with it now.

6 Does that help?

7 PARTICIPANT: Thank you, Maret, that's  
8 terrific.

9 MR. HATLIE: We've got only time for a few  
10 more questions, so -- we've got --

11 DR. GOESCHEL: Very quick question here.  
12 Chris Goeschel from Johns Hopkins. I'm a nurse and  
13 I'm a health services researcher and very quickly  
14 would like to say, two years ago I sat at a  
15 research conference with the NIH for two days where  
16 there were qualitative and quantitative researchers  
17 and at the end of the conference one of the  
18 quantitative researchers really said, I still don't  
19 know why I'm here because you're not a researcher,  
20 you don't do randomized control trials.

21 I'm having déjà vu all over again because  
22 what's happening here is the missing piece, that we

1 need to have the session where people understand  
2 that without patients as the center of this, we  
3 aren't really doing research, so I applaud the  
4 efforts.

5           But my question is, we had four wonderful  
6 models, but there are no doubt thousands of them  
7 out there, so the planning that went into this, and  
8 I don't know if it's a question for you, Sue, or  
9 for throughout the day, how are we going to share  
10 what's happening so that the people who are thirsty  
11 for this -- I mean, I'm taking notes as fast as I  
12 can -- but the people who are thirsty for this, my  
13 research colleagues, who want to know how to  
14 connect with patients and families because they've  
15 never done it need to know how. And you need to  
16 teach us, and so that's kind of where the ask is.

17           MR. HATLIE: Chris, if I can just respond  
18 to that. I mean, the answer is in this room, so  
19 there's going to be a lot of people here -- and  
20 we're going to spend most of the rest of the  
21 conference just generating those ideas from you and  
22 then trying to harvest them and feed them back much

1 in the way that Maret mentioned, so you can refine  
2 them and help us put together the strategies to  
3 make it happen.

4 MR. PECK: And remember, this is just the  
5 beginning. Question here or comment.

6 MS. WISE: Hi, my name is Leslie Wise and  
7 I actually work for Biomet, which is an orthopedic  
8 medical device company, so I kind of have a  
9 different hat, and as I'm listening to the  
10 conversation, all these thoughts are flying through  
11 my head because obviously industry does most of the  
12 research or at least funds most of the research,  
13 and as we talk about the random control trial,  
14 which is what is required of us to get FDA  
15 approval, so, while that model, even to me, seems  
16 not to be relevant, it's required of us.

17 But we do have new tools, we have  
18 registries, we have real world data, we have claims  
19 evidence, we have lots of evidence that -- and  
20 we're now beginning to understand that some of that  
21 evidence needs to include the patient's voice, but  
22 I do think it's important for patients, clinicians,

1 and industry to partner and collaborate around how  
2 we can change the paradigm of research so that the  
3 questions that get asked, the ways they get asked,  
4 and even the ways that intervention -- because as  
5 he stated earlier, it's 17 years between the  
6 knowledge to where it's applicable in the clinical  
7 environment. That's way too long.

8           You know, some of our loved ones won't be  
9 here 17 years later, so how do we shorten that  
10 time? And that's about us all collaborating to  
11 make that process, that regulatory process more  
12 user friendly because even though the evidence is  
13 there, it doesn't mean that we could always use the  
14 intervention sort of legally or, I don't know if  
15 that's the right term, but you guys know what I'm  
16 saying.

17           I think that that's going to take  
18 everyone's mindset to shorten that time and make  
19 that information available in a real way so that we  
20 change the lives of real people.

21           MS. BOWIE: So, if I might respond to  
22 that, Marty. Thank you for your question and

1 comments and what I think is also important is to  
2 understand that there has to be a value shift. I  
3 think in this room we're probably preaching to the  
4 choir, but I think that as part of that choir our  
5 responsibility is to go back in to share with  
6 others. We are those mechanisms for dissemination.

7 I am involved in a research study that is  
8 trying, for the first time, to use a participatory  
9 approach and it's a study on Duchenne, which is a  
10 form of muscular dystrophy for boys, and their life  
11 expectancy is relatively short. And my role on the  
12 study is to make sure that there is fidelity to the  
13 partnership process, so there is industry, because  
14 most of those studies are done by pharmaceutical  
15 companies, there are bioethicists, there are  
16 clinicians, there are researchers, there's the  
17 March of Dimes and other advocacy groups.

18 And when we had our first meeting I said,  
19 well, where are the parents? Where are the  
20 patients? And so now our research team includes  
21 parents and patients and none of us are experts.  
22 What's required is that we each listen to each

1 other and that the decision-making process is a  
2 collaborative one and so I think it's the  
3 beginnings, but we have a ways to go, but I think  
4 that there has to be a value shift. Industry has  
5 to be willing to be at the table and to listen as  
6 much as we, as researchers, have to be at the table  
7 and be willing to relinquish control and to think  
8 about different kinds of research study designs.  
9 Yes, absolutely, we know that that's the gold  
10 standard for, you know, for getting drugs approved  
11 and getting interventions approved in many cases,  
12 but it's not the be all and end all.

13 MR. PECK: So, we have one more, and we  
14 may have time for one more, but if we can keep  
15 questions and comments -- answers --

16 MR. HATLIE: Jonathan, I'm going to take a  
17 moment, though, and highlight something about Kris  
18 and Vinny's tour that they didn't highlight. Vinny  
19 talked about the silent rage of the moms that were  
20 just outraged that this could happen to their kids.  
21 One of the ways they channeled that was in a  
22 timeline. They went into meetings with researchers

1 with a timeline, and it was short. It's here's  
2 what we expect, here's when we'd like you to have  
3 it done, and the researchers responded really,  
4 really fast.

5 So, think about things that you could do  
6 as people. I mean, you could bring a timeline to  
7 the mix. And it can be faster than 17 years.  
8 Thanks.

9 MS. PRICE: My name is Carol Price and I  
10 think Ben touched on something talking about  
11 economics, but I think there's still a piece that  
12 has not been talked about that needs to be brought  
13 up, and that is the whole paradigm that's within  
14 this country of how universities operate and how  
15 research is done and that deals with researchers  
16 doing research to maintain their labs, to get  
17 tenure within universities. How are we going to  
18 change that paradigm so that when I do research  
19 grant reviews, I stop seeing research one on one  
20 side of the country, the same research being done  
21 on the other side of the country, and the  
22 researchers not talking together?

1 [Applause.]

2 DR. BHUTANI: So, if I may just add to  
3 that and to the other previous comments, I think  
4 the story that families bring to us, which is what  
5 they brought to us, and have researchers understand  
6 the value of the quality of the data, not the  
7 quantity of the data, is key. That's a lesson I  
8 learned from PICK, and it happened with having to  
9 deal then and translating the stories to the  
10 headwinds that I was dealing with from the  
11 establishment.

12 I mean, we had to challenge the American  
13 Academy of Pediatrics, JCAHO, AHRQ, CDC, I mean,  
14 all the experts were versed in the traditional  
15 model of research of randomized control trials.  
16 These families did not fit into randomized control  
17 trials, there were not enough patients, they were  
18 not on the radar screen.

19 So, the element here was to bring this  
20 into a dialogue, into a national dialogue, and  
21 unfortunately, part of the national dialogue takes  
22 in the medical/legal arena, which is not the right

1 arena.

2           The arena is an open, transparent system  
3 and it is for the universities and for the families  
4 to demand it. We need to do it together and I hope  
5 we can find a mechanism to do so, but I think it  
6 can be done.

7           MR. PECK: I'm going to experiment. We've  
8 got three mics and what we're going to do is ask  
9 you to just put your question out -- put your  
10 question out, put your question out, no comments,  
11 speeches, and we'll give the panel a minute to --  
12 or a couple minutes to respond, and then we're  
13 going to move so we can prep you for the next  
14 session, which is where you'll all really get to  
15 put your ideas out.

16           So, you're on first, sir.

17           MR. BIGGERS: Hi. My question is quick.  
18 I'm Greg Biggers. I'm a patient caregiver and I'm  
19 associated with three organizations Invoke Health,  
20 Genetic Alliance, and Genomera. I appreciate the  
21 humility that you all brought with your stories in  
22 just telling us your stories rather than trying to

1 give us advice or preach to us, but you do have  
2 experiences, and sue this morning talked about  
3 needing to create a sustainable architecture in  
4 what we're doing.

5           And so, I want to ask most or each of you  
6 to give us just one or two sentence advice about  
7 how can we scale this level of participation in  
8 research.

9           MR. PECK: Thank you. Next question, sir.

10           PARTICIPANT: There have been a number of  
11 comments on working with industry and financial  
12 incentives and I think it is evident that what is  
13 cost effective to the institution is not  
14 necessarily cost effective to the patient, and the  
15 question would be is the role and the value of  
16 value based purchasing in realigning those  
17 incentives through financial incentives so that  
18 cost effectiveness is now tilted in the favor of  
19 the patient, and we have -- our organization has  
20 written a study on this which was recently  
21 published in the Journal of Nursing Scholarship,  
22 and it's something I think is just imperative for

1 an area of research. Thank you.

2 MS. WILLIAMS: Hello. I'm Pamela Williams  
3 and I'm at the Medical University of South  
4 Carolina, and for those of us that have -- are  
5 already in the path of engaging the community in  
6 true partnerships and empowerment, my question is,  
7 to all of you, but especially the PICK group, what  
8 are the social media features that you've found to  
9 be the most successful in channeling the rage and  
10 creating the sustainable architecture? What social  
11 media has worked the best for you?

12 MS. SCHULZE: For PICK, we have used a  
13 listserv, which we started probably about 10 or 11  
14 years ago. It would be a wealth of material for  
15 researchers to go through and see all of our  
16 discussions on what medications might be working,  
17 what kind of therapies might be working, is  
18 auditory neuropathy, which is one of the features  
19 of kernicterus, you know, does it work to have  
20 cochlear implants or are hearing aids going to work  
21 or FM systems? There's just so much material  
22 there.

1           I think the sustainability part is really  
2 difficult for organizations like PICK. We are a  
3 parent, volunteer organization. We have very  
4 little funding, almost none existent. I mean,  
5 whatever time we have, is spent caring for kids who  
6 have severe disabilities. Some of us are working  
7 full time on top of that, and in our spare time we  
8 do what we can to keep our nonprofit going.

9           So, there are a lot of pieces there for  
10 engaging patients in how do we support patients to  
11 be able to come to the table. It takes time. It  
12 takes having other people care for your kids while  
13 you're off doing this. It's a lot of pieces there  
14 that we need to think about and truly engaging  
15 people with that financial piece of it also.

16           And also with the social media piece, you  
17 know, it's our listserv. Right now we have an  
18 Effectuated by Kernicterus Facebook group that's  
19 specifically for parents, along with our Facebook  
20 page for the broader public, and our website.

21           So, those are key pieces. We use Survey  
22 Monkey a lot to get quick feedback from parents

1 too.

2 MR. PECK: Thanks. In just a couple  
3 minutes, let's pass the mic down, you've heard  
4 questions, and give a response to whatever you  
5 think you can add.

6 MR. HEYWOOD: Well, I would just touch on  
7 the question about granting -- and I think you  
8 emphasized, but even going a little bit more, sort  
9 of aggressively. I mean, I think those who hold  
10 the dollars can enforce change in the system and I  
11 think an important part is having sunshine is huge,  
12 having the grants be public, having the data be  
13 public, in positive and negative versions of it.  
14 Don't let research be funded that people can't  
15 learn from. Just flat out and stop.

16 MS. BOWIE: I want to say similarly that  
17 the most important way to get your efforts  
18 sustained, one, is to make sure that they do get  
19 published and not published just in the peer review  
20 literature, but it has to be published in places  
21 and ways in which it gets to the intended  
22 beneficiaries.

1           The second thing that I wanted to also say  
2 is that I think when you build the capacity, you  
3 know, whether you're coming in as a parent, as a  
4 volunteer, as a community member, as a patient, as  
5 a caregiver, as a researcher, when you're building  
6 that capacity from within, that helps lead to  
7 sustainability.

8           When we don't do that, when we're not  
9 coming together and doing this collaboratively,  
10 then, you know, we really can't take -- it seems to  
11 me that then when things go wrong, then we're  
12 responsible for that.

13           I feel that we have to work collectively.  
14 Resources are thin everywhere and the best way to  
15 do this work is to bring all of those limited  
16 resources together and try and work through this.  
17 And yes, it does take time, but, you know, we can't  
18 get weary in well doing.

19           DR. BHUTANI: So, if I may add, is as an  
20 academician what I've learned from my working  
21 relationship with PICK is, number one, do the right  
22 thing, number two is in form the society, and

1 number three, really make an effort to change  
2 lives. Now, that is something we can ask all of  
3 ourselves to be able to do through the final medium  
4 that is of a value to a researcher, and that is a  
5 peer review publication.

6           How many parents or families or patient  
7 representatives are there on the editorial board of  
8 national journals? Is there anybody on the New  
9 England Journal of Medicine or Lancet? All right?  
10 We want to be able to know if the research that has  
11 been reported has actually changed lives and does  
12 it inform society?

13           I think if we can set that standard, then  
14 the granting will come and the money will flow.  
15 It's not the flow of money, it's the flow of  
16 knowledge. Knowledge flows from our patients to  
17 our providers, not the other way around.

18           [Applause.]

19           MR. NORMAN: A simple thought from a  
20 fairly simple person. You know, I started this  
21 project just trying to help my small rural  
22 community, very simple. And then through the work

1 that we've done, we've gained a little bit of  
2 access into this world, which amazes me, and now  
3 I've learned enough to know that we can't just stop  
4 people from being -- from going farther than here,  
5 people like us. Through Maret's involvement in  
6 some other committees that have come off of our  
7 group work, she's getting to the point where she is  
8 able to review proposals and help bring the  
9 community voice to the granting portion of this so  
10 that hopefully that way we can change how money can  
11 flow more towards patient oriented ideas.

12           So, we just need to keep bringing people  
13 up, somehow, and get them farther and farther up  
14 and higher up, like you were saying, in the  
15 journals.

16           MS. FELZIEN: And I want to address -- and  
17 that actually leads in nicely -- I want to address  
18 your question about the paradigm shift of changing  
19 how the university research machine works. And,  
20 you know, money is there to change this paradigm  
21 and through the clinical and translational science  
22 awards, the universities are seeking really, really

1 large money -- what's it, in its 10th year -- and  
2 part of that involves community engagement. There  
3 has to be a community engagement piece to this.

4 PCORI has caused, you know, this amazing  
5 ripple effect throughout the states, but the -- so  
6 there's this momentum and this buzz, however, what  
7 we find is it's not the community side that's on  
8 the -- we know we're in the dark and we'll rise to  
9 the challenge and we'll learn, but really the issue  
10 is the research side, and all of the sudden the  
11 pressure is out there. You need to do research,  
12 you need to have community engagement, you need to  
13 have patients involved also, and they really don't  
14 know how.

15 And the guide needs to be there. In  
16 Colorado we've done a few things and I can share  
17 that later, but that's where the education needs to  
18 start. If we can get researchers immersed in  
19 community, think about that, then the community can  
20 become immersed in the research.

21 MR. HATLIE: And we have a breakout group  
22 on matchmaking, so perfect timing. One more

1 comment. I guess you're up again. But should we  
2 give a round of thanks?

3 [Applause.]

4 MS. SHERIDAN: Thank you. I was just  
5 going to comment before I leave the stage. What a  
6 remarkable demonstration of passion, of courage, of  
7 the power of partnership, like Kris said. You have  
8 all -- you're identifying opportunities that we  
9 want to define and make recommendations to PCORI  
10 over the next few days, so, thank you, panel, and  
11 you will be, I think, asked lots of questions while  
12 you're here.

13 Meanwhile, I'd like to -- you can go join  
14 the gang. Let's give them another applause.

15 [Applause.]

16 MS. SHERIDAN: This storytelling that we  
17 heard this morning and the importance of bringing  
18 patients and researchers together, I want to  
19 announce that PCORI is capturing your stories at  
20 this event. We have a videographer here. I've  
21 been asked to -- many of you know this already, but  
22 in your breakout area session, in room eight and

1 nine, we'll be right around the corner from where  
2 you're breaking out, we will be pulling you aside  
3 and asking you to share your story so PCORI can  
4 capture your stories and share this out there and  
5 continue this momentum.

6           And so, moving on to the breakout  
7 sessions, it's my pleasure to introduce my boss,  
8 Dr. Anne Beal, who is the Deputy Executive  
9 Director. She and Joe, talking of passion and  
10 courage, had the courage to hire me and they have  
11 the passion to see this vision through that we've  
12 been developing.

13           So, Anne is going to share with you our  
14 breakout sessions and the various touch points of  
15 engagement, that we call it, so we can all really  
16 dig in this afternoon and develop those to make  
17 recommendations tomorrow.

18           So, Anne?

19           DR. BEAL: Thanks, Sue.

20           So, good morning. I have to say, as I've  
21 been walking around, it's just been thrilling to  
22 see the energy in the room and to actually hear an

1 idea, that as you heard Sue and I talked about last  
2 July, really coming to fruition.

3           One of the other things that I noticed as  
4 I was watching the webcast is that as a lot of  
5 people were getting up, behind them I saw a number  
6 of PCORI staff, so all scattered throughout the  
7 audience and listening to the conversation is our  
8 PCORI staff, so I'm very thrilled to see them.

9           So, as Sue mentioned, this is an idea that  
10 really started as we've been trying to ask  
11 ourselves, how do really meaningfully engage  
12 patients in the work of PCORI? One of the things  
13 we like to say is that we take the P in PCORI very  
14 seriously, that this is just not a name, but it is  
15 really part of what it is that we want to do.

16           And so as we start to look at other  
17 experiences, one of the things that we discovered  
18 is that there's been a lot of work on patient-  
19 centered care, and what we're hearing a lot today  
20 is that there's actually a lot of experience in  
21 terms of patient advocacy, but we really started to  
22 ask ourselves, what is the paradigm, then, for

1 patient-centered research and how is that  
2 different, how is it the same, how does it build on  
3 the experience that already exists in terms of  
4 patient-centered care.

5           One of the things I often remember,  
6 because I am a health services researcher, is that  
7 I once was at a conference where someone said that,  
8 you know, the data that we see are really the story  
9 of peoples' lives with the tears removed, and what  
10 that means to me is what we're seeing here are not  
11 just these esoteric numbers, what we're seeing here  
12 is the actual impact on peoples' lives from the  
13 work that we're trying to do, and the data is  
14 really telling the story of people, and so when we  
15 talk about a patient-centered paradigm, it really  
16 is understanding that these are not just numbers on  
17 a wall, but each number, each observation  
18 represents a person.

19           And so really understanding that and the  
20 outcomes that are really relevant to patients is  
21 something that's very important to us. And so as  
22 we were starting to think about, okay, so what is

1 it that we want to do at PCORI and how can we  
2 really be patient-centered, we said, well, let's  
3 ask the patients, let's ask them how we can do our  
4 job best.

5           And so that's really one of the major  
6 outcomes that we're looking for today is guidance  
7 from you all and guidance from folks who are  
8 watching us as we're webcasting, to really help us  
9 be patient-centered in our approach.

10           So, as we think about it, as a research  
11 institute, there are essentially four activities  
12 that we engage in. So, first is asking research  
13 questions. Are we asking the right questions that  
14 are really meaningful to you and that are really  
15 going to impact care? And so, one of the breakout  
16 sessions is focused just on that area.

17           The second thing that we do as researchers  
18 or as a research institute is engage in actual  
19 conduct and review of research, and so the other  
20 breakout session is really going to be focused on  
21 this engagement of patients in a meaningful way,  
22 which is something that we've heard about quite

1 frequently in terms of really partnering with  
2 patients in research.

3           The fourth area, and the fourth activity  
4 that we have as PCORI is on dissemination. So,  
5 we've heard a lot of discussion about we can no  
6 longer tolerate the 17-year gap between getting new  
7 information and then getting it into practice. And  
8 so, as we're thinking about then, what are going to  
9 be the activities that PCORI is going to engage in  
10 in terms of trying to reduce that gap, then how do  
11 we do that in a way that really engages patients in  
12 a meaningful way.

13           And then, lastly, one of the things that  
14 PCORI is holding -- we're holding ourselves  
15 accountable for, is that we don't want to do  
16 research for research's sake. We don't want to do  
17 research that's just going to help someone get  
18 promoted or get tenured. We want to do research  
19 that is having an impact, and at the end of the  
20 day, only the patient community is really going to  
21 be able to tell us if we are having that desired  
22 impact.

1           So, part of our assessment in terms of  
2 whether we're having the desired outcomes will come  
3 from the patient community and what we want to hear  
4 is what are the best practices. What are the  
5 things that we should be putting into place now to  
6 be able to collect those data and collect that  
7 information as it comes out?

8           So, there are four breakout sessions that  
9 really tie to what we call our four touch points in  
10 terms of what it is that we do, but the fifth area  
11 is also related to the fact that we're interested  
12 in thinking about how can we bring researchers  
13 together with patients, and not patients as  
14 subjects, but patients as partners.

15           And so we're thinking about what are some  
16 of the promising practices that we could  
17 potentially develop around matchmaking and bringing  
18 people together so that if you are a researcher on  
19 the East Coast and are interested in working on a  
20 project with someone on the West Coast, then we're  
21 able to do that, and fortunately we now have  
22 capability through virtual organizations and

1 through virtual capability to be able to do that.

2           So, this is one of the ideas that we're  
3 exploring, but we want to hear from you what are  
4 some of the promising practices around that.

5           So, when you go out, you're going to see  
6 that there will be instructions to go up to the  
7 five different breakout rooms, and if everyone  
8 looks at their card, you're going to see that you  
9 have been assigned to a group, and so this is  
10 really very straightforward. Go out of these doors  
11 and then go to the left, and what you'll see is  
12 then there's the escalators that we all had to come  
13 down in order to get down here, all the breakout  
14 rooms are upstairs.

15           And so what we're going to be doing is  
16 asking people to provide time within each of the  
17 breakout areas to be able to provide us with  
18 feedback on those five areas, and then there will  
19 be time in between to move to the different rooms,  
20 then to be able to make sure that we have an  
21 opportunity to hear from you on all five areas.

22           So, look at your numbers, follow the

1 instructions that are outside, and then we'll be  
2 looking forward to hear from you.

3           Is there anything else that we need to  
4 tell them right now? All right, so be upstairs --

5           [Whereupon, the PCORI workshop concluded.]

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