

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

B&B REPORTERS
701 Copley Lane
Silver Spring, MD 20904
[301] 384-2005

AGENDA

	<u>Page</u>
1. Welcome and introduction to PCORI's mission, and patient-centered outcomes research	3 / 9
2. Orientation to workshop objectives, agenda, roles, and rules	14
3. Welcome from the workshop Working Group: What Brings Us Here?	29
4. Opening presentations: Examples of Partnerships in Research and Discussion	42
5. Introduction to Breakout Sessions	111
6. Break into Breakout Sessions	112

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

B&B REPORTERS
701 Copley Lane
Silver Spring, MD 20904
[301] 384-2005

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

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.

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 deBronkhart, 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.

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

B&B REPORTERS
701 Copley Lane
Silver Spring, MD 20904
[301] 384-2005

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

B&B REPORTERS
701 Copley Lane
Silver Spring, MD 20904
[301] 384-2005

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.]

6

7

8

9

10

11

12

13

14

15

16

17

18

19

20

21

22