# *Patient Safety and High Performance Leadership Summit*
# *Issues in Governance, National Collaboratives, and H.I.T.:*
# *Patient Champions: Making Their Voice Mainstream*

## April 27, 2012
## Webinar Transcript

**Charles Denham:** So we're about ready to start. So for our global audience, we'll be starting in about 30 seconds. We have our panel assembled and they're all sitting down.

And we're here at the National Press Club, and for those [who] are on WebEx, you'll only be hearing audio and see[ing] a photograph of our panel. For those [who] want to watch the streaming video, go to www.safetyleaders.org, and if your line is not fast enough, go back to the WebEx. For anyone [who] has interrupted service, we will be editing all of the video of the panels, and word-searchable transcripts will be on the web within about 10 business days. Usually we do it within two days, but we have a whole day of transcripts, so we'll have those there.

And I'm absolutely positive that this panel will be terrific, and I've been waiting for it because it is such an exciting time for us in healthcare. Earlier today we had Jean Moody-Williams, who's in charge of the Quality Improvement Organization through the federal government; and this year, which was just so exciting, they built into the agreements a billion-dollar contract that the QIOs would have to start helping hospitals bring patients into the boardroom and into quality improvement and that they'd have to reach out to trustees, and we think this is the same issue. And our goal, ultimately, is to move from where we're going to be with the panel today to have every one of the people [who] are here, [who] are representing consumers on the board of directors, representing the hospital, and actively governing our hospitals here in America and around the world because this is critical.

So I am so excited about this because I think we're starting to see a tectonic shift in healthcare. I mentioned earlier, in our earlier panels about the physicians, that nine societies declared that there's overuse in testing and imaging and that they want to go up front and say, "We've got to do better care rather than defend the way we've been delivering care, which also means that we don't have to defend the way that we've been interacting with patients."

And so my first person on the panel [whom] I'd like to speak is Regina Holliday, and she's responsible for so many of these jackets, and I'm turning in the Press Club and showing you how she tells her stories with beautiful art, painting them on the back of jackets. And we tried so hard to get Regina and The Walking Gallery in the movie that we are premiering tonight. However, they will be in the next movie. And we thought it was so important that you understand what Regina does, in the current movie, and how she uses art, and that she was a driver [of] a new program called SpeakerLink (www.speakerlink.org), which actually can link consumers to be coming into hospitals and in healthcare.

So, Regina, you've listened to a number panels, you've been painting in the back of the room; what's your reaction? And if you had one message that you wanted to get out globally and to our national audience about patients getting into and being part of and a part of the leadership of what we do in healthcare, what would you share with us?

**Regina Holliday:** The most dangerous thing in healthcare is silos. People think differently, and if you bring multiple ideas and approaches to the same panel or institution, you change things. For instance, I am five feet tall. You might notice my legs right now; they are dangling. It is very challenging for a woman of my height to sit in a chair this tall. I wouldn't have designed this. So when you involve women, patients, children, diverse seniors, all different kinds of people to the table, it starts redesigning everything before we start investing money in it. So that's one element.

The other thing is, I have worked in medicine now for almost four years. And when I first hit this world, I couldn't believe a lot of things. One of the things is, nobody was talking to each other. I made a lot of friends in what's called the HIT movement and I made a lot of friends in the patient safety movement. Guess what? They weren't talking to each other. They were having completely different conversations and also spending money on the exact same thing but not doing anything in concert.

Now, on top of that, within the medical community, the oncologists weren't talking to the people who worked in cardiology. The people who worked in pediatrics weren't talking to the people in senior services. That was within medicine. Then you hit patient communities; guess what? The diabetes community is not talking to the cancer community, who is not talking to the lupus community, who is not talking to all the rest of us. And there's this decision to separate ourselves based on the ideal that medicine is treating separate parts of the body. And guess what? We're one person, we're one people, and if we all start working together and spreading that information, we're going to change the world.

So if there is one number-one thing: get rid of the silos.

**Charles Denham:** And you know, if you study patient safety and we look at the fragmented care at the turn of the century, we didn't have too many specialties, and now we have 300. And we're trying to manage all this information and we are having really fragmented care.

Trisha is a very gifted person [whom] I always love to talk to, and when I say, "Well, let's just have a quick two-minute call," I look at the clock and I go, "Oh, my gosh." The energy that she brings to the dialogue, and her personal experience on how she became a champion for care and help build a network of patient advocates who help me actually in, what, two or three states now, where I found people to help family members get through the healthcare system, as she was building a network and has built a network of advocates … but share your story and why you are able to bring positive fashion after a near-tragedy.

**Trisha Torrey:** Well, I don't want to spend a lot of time telling my story because we'd be here all afternoon, and of course, I can embellish it as much as you'd like me to, Chuck.

But may I just derail this for just a moment to say to you that I've been working in this capacity now for going on eight years, and pardon me if I get emotional over this, but I feel like today is a huge, huge turning point, and you don't have any idea yet the change that you are making in people's minds about how they approach safety and how it's no longer about technology, just technology, or as Regina said, the silos of information. The sociotechno-, whatever that word was you used before, just the fact that you're recombining words is a huge, huge, I mean it's unbelievable and it gives me goosebumps and I thank you for allowing me to be a part of all this and I thank all of you for being a part of it today as well.

**Charles Denham:** Thank you for being here.

**Trisha Torrey:** So my story is just briefly that, in the summer of 2004, I found a lump on my torso that was about the size of a golf ball. I went off to my family physician, who sent me to a surgeon who removed it and explained, "I've never seen anything that looks like this before." And that led to the next three months of me fighting my doctors, fighting, testing, fighting, all kinds of things just to get information because they were telling me that I had subcutaneous panniculitis-like T-cell lymphoma and that my days were numbered, and I was on the golf course. And so somehow there was this disconnect in what I was being told and what the actual reality was.

Eventually, I found a second-opinion oncologist who got me my medical record. Now, this was huge. In 2004, patients didn't ask for their medical record. I just needed to look at them to understand. Well, of course, they were all in med-speak and medicalese. I didn't understand any of it. I literally Googled word after word after word, including deltas. Did you know that you could Google Greek letters?

So I finally came to the conclusion that I didn't have lymphoma. And of course, then the oncologist is laughing at me, like, number one, I was a patient, what was I doing analyzing my medical record? And

number two, they had two labs that independently proved it already based on this biopsy. I eventually found an oncologist who was willing to send the biopsy to the NIH, to Dr. Elaine Jaffe – if any of you know anybody at the NIH – who reviewed this lump and came back and said there was no malignancy. And I've never had any form of treatment. And all these years later, I've never had another lump and I've never had a diagnosis.

And it changed my life. It literally changed my life because not only had my trust – and we've heard that word so many times today – had my trust totally flown out the window with the system that I thought was set up to protect me and take care of me; but the other thing it did was, it cost me every penny of my savings. And at that point I had to ask what on earth had gone on. And because my background was all in marketing and prior to that I had been a schoolteacher, I realized – and spiritually I believe that everything happens for a reason – I had to take my skills and start talking to other people and see if I could get the conversation going about what had gone wrong. Because then I started hearing stories from everyone else.

And so if there were messages that I want to share with all of you today, it's, number one, as we talk about this, let's call it "collision for" a moment, between HIT and patients, we can help. And the gentleman earlier who said he's now got a thousand fact-checkers, that was why we were clapping.

**Charles Denham:** That was great. That was great.

**Trisha Torrey:** I was the fact-checker.

**Charles Denham:** Yeah.

**Trisha Torrey:** You know, had I not checked the facts, what if I'd gone through chemo? What if it had resulted in a lawsuit? I mean, you want to talk about what that would have cost the system, and it already cost me every penny I had. So let us be those fact-checkers; include us.

**Charles Denham:** What a great point, and I think that we're starting to see the tide turning …

**Trisha Torrey:** Absolutely.

**Charles Denham:** … towards realizing that we're not seeing increased lawsuits. You know, what's the threat, other than Warren Buffett's line that I just love, "The chains of habit are too light to be felt until they are too heavy to break."

**Trisha Torrey:** Ooh, that's a good one.

**Charles Denham:** And you know, those chains of habit are pretty hard to break.

**Trisha Torrey:** Yeah.

**Charles Denham:** We talk about – I'm one up for time though. I just want to make sure, because we have a longer panel …

**Trisha Torrey:** Okay.

**Charles Denham:** … we'll come back to you Trisha, but …

**Trisha Torrey:** Okay.

**Charles Denham:** … Mary and Ellen, you both are nurses. This panel is about our patients. This is about the patients. It's about the dialogue that we just heard. Our nurses feel like they're hostages at the table. They would like to give more information. Many of them want to have the patients to be more a part of it, but the three of us separately have had this conversation of how they feel unempowered by the

leadership [who] are leading up at the hospital to be more fully engaged with patients in a more equal way, and they would love it but they are afraid.

What advice – let's go to Ellen and then Mary because we've heard …

**Ellen Canepa Brzytwa:** Mary is [inaudible].

**Charles Denham:** Okay. Mary, go ahead.

**Ellen Canepa Brzytwa:** [inaudible]

**Charles Denham:** Okay.

**Mary Foley:** I think [inaudible] done a lot of research on this subject, and I think would offer the audience some insights …

**Charles Denham:** You're being a good trustee.

**Mary Foley:** I am.

**Charles Denham:** You should be the hospital trustee. She was governing. Go.

**Mary Foley:** And I know Ellen had some really great points to make, so I won't step on that. So I'll respond to what nurses are thinking and feeling as best as I can as a previous front-line nurse, chief nurse, safety officer, and now a researcher in the area of quality and safety in hospital care. And this is not just about hospitals. Our health systems need to be safe whether you're in the community clinic or in post-acute care, and if you're lucky you'd never make it to the hospital, but all of our health systems need to be safer.

Nurses are struggling, and I think it's a reality that there's a production model in place in many settings. I resonated with the Lucille Ball funny moment of trying to stay ahead of the chocolates coming out of the chute, and there was even a quote in there saying, "Nurses dread the moment where they say 'do more with less.'" Resource allocations …

**Charles Denham:** And, you know, I wrote that in because I've shown that 25,000 people and every nurse …

**Mary Foley:** That's right.

**Charles Denham:** … is laughing and then kind of like …

**Mary Foley:** Yeah.

**Charles Denham:** … they laugh and then they get sad.

**Mary Foley:** That's right.

**Charles Denham:** Yeah.

**Mary Foley:** So, you know, nurses are struggling with this productive model and are trying to keep abreast of all the technology, the latest meds, the equipment, the EHR that isn't working well, the barcoder that's broken today, the electronic record that nobody really taught everybody how to use. I mean, I thought the points about good HIT and not-so-good HIT implementation was very important for folks to hear, particularly those buying these systems and putting them into place. So they are struggling. They do want to be active caregivers and partner with patients. And I think they're just looking for the

ways to learn how to do that. I said this earlier but I'll say it again, we're told [to] be patient-centered, but we're not really explained or shown the way on how that is actualized.

**Charles Denham:** And they really do want to create a …

**Mary Foley:** They do.

**Charles Denham:** … dialogue.

**Mary Foley:** Yeah.

**Charles Denham:** The dialogue we heard, two people say, "We want to have dialogue, fragmentation, bring it together. We can be an active fact-checker."

I'm going to go now to Ellen, and we've talked numerous times about figuring out how we can create a track for nurses to get on boards because they know what we're hearing here and people in the community don't. And if we could get a nurse on every board in America, things would be different …

**Ellen Canepa Brzytwa:** Change everything. I will tell you that.

**Charles Denham:** … if they were listening. It really would.

React to that and, you know, we've talked about that and that's an important issue.

**Ellen Canepa Brzytwa:** I think most people don't realize that there're only about seven percent of boards of trustees in the United States that have a nurse on board. And I would urge our listeners and certainly anyone in the audience to join the trend of adding a nurse expert on the board.

Now, when I speak with people about this they'll often say to me, "Oh, well, we have a nurse on the board. The CNO is the nurse on the board." And I say to them, with all due respect, that a CNO on the board is not going to turn Dr. Toby Cosgrove and say, "Dr. Cosgrove, I don't think you're correct on that."

So the nurse trustee brings a different voice. She can or he can translate things. And I think the two things that a nurse trustee brings are, one is, they see care through the eyes of the patient because they are educated to be the patient's advocate. They are the most involved with the patient, minute to minute and hour to hour. And in terms of quality and safety, they are the icon for quality and safety working with that patient and family.

**Charles Denham:** We believe this is so important that we're starting a training program for nurses to track into governance because we think it's really important. We think that even governance advisors, knowing how to work with a board, they rarely go in this area and then they don't understand the vocabulary and the business approach, and yet …

**Ellen Canepa Brzytwa:** No.

**Charles Denham:** … it's just like learning another specialty.

**Ellen Canepa Brzytwa:** And …

**Charles Denham:** Let me go …

**Ellen Canepa Brzytwa:** I just wanted …

**Charles Denham:** Yeah.

**Ellen Canepa Brzytwa:** … to make one comment about you heard the physician trustee this morning. Nurse's physicians that move over to being a trustee, they have the similar learning curve issues. They know the business, hopefully, but they have to learn a different culture in a boardroom, the business side, and so on, but there are efforts to move and to transform people in a boardroom …

**Charles Denham:** So we have 1.6 million nurses in America, and globally, just, you know, do the math, of how many are caregivers. We see them hostages at the table where they'd like to have the dialogue but they feel constrained by the legal issues, the business issues, and the production issues.

Lygeia, tell us what your role is at the Office of the National Coordinator and how that intersects with the patients and bringing the patients into this IT moment.

**Lygeia Ricciardi:** So I'm at the Office of the National Coordinator for Health IT and I run our Consumer eHealth Work. It's very exciting that we had a program for the first time which launched last fall which is specifically about bringing consumers and patients into this push to develop Health IT and encourage its adoption around the country.

As I see it, our role is not to lead this effort *per se* but to harness the energy to catalyze the change that's already going on, both as a result of changes in the healthcare system, like payment reform, but also some of these outside forces that we're seeing, patients like Trisha and like Regina, who have become very activated, and certainly nurses who believe in this viewpoint, but also technology changes. The world is radically different today from what it looked like five or 10 or 20 years ago in terms of technology. I mean, as an example, look at that screen over there. We're looking at a tweet screen. That wouldn't have been there two years ago, never mind five. And so the rate at which technology is changing is really impressive and that it's constantly shifting our landscape in a way that moves us toward greater patient engagement and empowerment politically and in their own health and healthcare.

So our job – my job, as I see it, is to harness some of those energies, make partnerships, catalyze, and let this all kind of bloom forward in a way that really benefits patients and the …

**Charles Denham:** And really to put a sharp edge on it, you know, our demographics are our destiny. The people [who] are on that stream are becoming the caregivers of those of us [who] are aging, and we're expecting democratization of information. They don't understand lack of access, and they understand why wouldn't there be a health exchange where I could see what it cost for the operation …

**Lygeia Ricciardi:** Right.

**Charles Denham:** … and then the guides' outcomes and process measures. And why wouldn't they? They do it for restaurants. You know, I take my smartphone and I know everything about that. Why don't I have that in the *U.S. News & World Report*? Why isn't that, you know, right here and …

**Lygeia Ricciardi:** Yeah.

**Charles Denham:** … helping guide me to it? And they will become the new payer, ultimate payer because they're going to be caring for the elderly. My wife does a wonderful job caring for my mom and helping her through the process, and she's much more wired than what we would be five or ten years ago.

Because of time, I want to come to Nancy, and I want to take a totally separate issue, Nancy, because you and I have had a history together. I think that another part we don't talk about is when we lose a family member, when a harmful event occurs and this big body of patients and families who would like to come and help hospitals. We know that the Quality Improvement Organizations now are given the charge to do it. We know that the progressive hospitals are doing it. We know that it doesn't increase lawsuits. You don't hear of the train wrecks that everyone's afraid of. It doesn't happen.

But there are two groups. There's an A group and a B group. There's the A group [who] are going through Kübler-Ross stages of grief. They're going through denial, anger, depression, bargaining, and acceptance. They're going through these stages, and when they're going through that, they really …

Nancy, after Pete died and we got together, we together went through A and B, right? We went through the times when you were angry, when you hurt, and when telling the story made it feel better; but we also went through the times when reliving the story really hurt and it opened up an old wound and it made it harder, and it's happened with Sorrel King, who's in our movie. It happened with Sue Sheridan in our movie. And it has happened with Steve Rel in our first movie. And it happened with you. Now we need to have sensitive care.

Some of the greatest hospital organizations in the world are in this room today, and they can really help us study how to help with A and B because I see A and B in a room. We've seen this at a national meeting two years ago where people fuss because the A group undergoing the healing process thought that the other group "didn't care that my daughter was killed." And the B group said, "Look, I'm set to go serve, but we've got to be positive." "Yeah, but my daughter or son was killed." And we need to be sensitive because this is a psychological emergency.

And I think when Pete died, you went through both A and B in a wonderful way that led to lives saved all over the country because of the talks that we gave together and that kind of thing. But help put a finer edge on that for us to understand what it is to be in that state.

**Nancy Conrad:** Well, I suppose one of the most important things that you and I worked on together, and there were many, was disclosure. And those three pieces of it tell me what happened, tell me what you're going to do so it won't happen again, and could you just say you're sorry. Then you don't have to go through all of this because you're working together to transition close to hospital environment so they're listening and they've taken the leadership to disclose, and that's huge. And that helps the victim – God, I hate even using the word – but it helps the person who gets left behind to understand that at least the hospital is taking responsibility, there's some leadership here, that they're going to import a system so this won't happen again, and that really takes the whole thing to a whole different level.

**Charles Denham:** So it would be improper to talk about any event, which I won't. I'm going to talk hypothetically though.

Nancy, if there had been an NTSB report that said, "Here's how this kind of circumstance from the experience you had a report could have been written," or I know Dennis Quaid, who really wished he could be here – he's on a movie set and he's flying all over the globe, and he really wished he could be here – but he says that if a report had been written 11 months earlier about the accident in Indianapolis, it wouldn't have happened to his twins. And why didn't one happen after his accident with his twins? Because it happened again, and it happens again and again.

Would that have been a healing thing for you to know that, would that have been a healing thing that would happen to Fred, to know that a report prevented the suffering that occurred to you, Regina?

**Regina Holliday:** [Inaudible] speaker did it specifically for that reason. That if you're not going to create a report for us, we'll just go and talk all over the nation …

**Charles Denham:** You're going to see the report?

**Regina Holliday:** … and create our own report.

**Regina Holliday:** Right.

**Charles Denham:** And in some cases, a painting.

**Regina Holliday:** Yeah.

**Trisha Torrey:** Yeah, that's absolutely true.

And this is the other thing that I was going to say earlier and that is that for any of us who have been harmed by the healthcare system, and, you know, I talk about any harm, what I hear from patients, and I hear from dozens of them every month who have suffered something; or I hear from their family members, every one of them wants to know that someone will be better off …

**Charles Denham:** Absolutely.

**Trisha Torrey:** … eventually because [of] what they have suffered. And if somebody can say to them, "You know what, you telling that story will influence somebody else's life in a very positive way," then forgiveness begins, healing begins.

**Charles Denham:** Healing begins.

**Trisha Torrey:** And bringing those people into your boardroom – you know, I've written about the sixth stage of grief, which I called proactive survivorship. Those are the people who've been through the five stages and now take whatever it was that took them through that into a positive for other people. The best example I give is the Mothers Against Drunk Driving. You know that mother, whoever she was, was a proactive survivor. That's the sixth stage. Those are the people you want in your boardroom because they will make an incredible difference.

**Charles Denham:** So now – applaud. Absolutely. We should applaud that. Good job, Trisha.

So what, are there good stories? Are there good stories of bad event, patient advocate getting involved, translating into positive impact, and giving meaning to harm? And I think that Jenny is an example of that because Jenny, every other Saturday morning, 7:00 o'clock Pacific Time, Jenny and about six or seven of us are on the phone talking about what we could do to create moments like this moment here. Jenny is a co-author of medical articles, more than one. And that's why it says author at the bottom on the movie. And Jenny has been an advisor to HRSA. And I know Paul Moore is here from HRSA, and I know the head of the agency is a wonderful person [who] was hoping to be here as well, Mary Davenport.

Jenny, you know, you've been able to turn the negative energy into positive energy, and you are kind of one of those behind the scenes comfort person to others [who] have gone through the event. Has that had meaning for you to take what happened to you and to other people to have impact on others and would you recommend that?

**Jennifer Dingman:** Oh, yeah. I highly recommend that. I've been counseling with folks who experience medical error and other outcomes that were poor through healthcare, either through loss or injury to themselves or a family member; and through the years I've connected many people together with other like-minded people and they have developed great relationships. For one, a child was lost by one mother. I put her in touch with another mother who lost a child in a similar way. That second mother convinced her to have a second child, and it was able to help her heal; so little things like that are really, really important.

But most importantly is, I've learned so much from all of the people I've counseled through the years. And we go through experiences from the cradle to the grave in healthcare, but we also go from the cradle to the grave starting with our primary care physician all the way through anything that we do, anything specialty that we receive, and it is imperative that patients and families be part of the big picture, that they're true partners, that they're able to communicate freely and not be afraid to talk about things with their providers. And it's important that we have a well-rounded group caring for each patient in this country, particularly with our aging generation that we have right now and others taking care of them. We can no longer depend on the healthcare industry to do everything for us. We must educate ourselves.

[Inaudible] an issue and it is – Chuck has taught us all that it's good to get information through to people by telling stories.

I'm going to tell a story on two people [who] are here in the audience, and that is, I attended a meeting of 300 executive nurses in the state of California, and they are brought together to look at all the same issues that we are. And one of the major sessions was led by Mary Foley, Dr. Mary Foley; and instead of standing up and giving data to these 300 nurse executives, she brought Karen Curtiss to give a presentation similar to what we are hearing about, and Karen also is a national speaker. She had three family members with cascading incidents and went through the stages of grief, anger, and acceptance and took her experience. And she stood up and gave a presentation about all of this and then announced a book that she had written called *Safe & Sound in the Hospital*. And this is a checklist for family members and caregivers of patients, and it's practical. It's things that every single patient and caregiver should know about to work with the nurses on quality and safety.

At the conclusion of her speech, one of the nurse leaders stood up, and people were just breathless at what she described, and this nurse stood up and said, "On behalf of all of the 300 nurses here in this session, we apology to you and your family for what happened to you," and people were in tears. And I think it was a very powerful message, instead of having Dr. Foley give statistics. But anyway, so I stood up, moved by this, and of course you can tell by being shy and quiet, and said that I really wanted to harness all these nurses to help get more nurses on boards and also to work more closely with patients with a true partnership, not partnership for patients, partnership with patients.

**Mary Foley:** And the reason I could do that, the reason I had no doubt about the right thing was having worked in this kind of partnership with patients and families and health leaders and policy leaders to make the difference happen. So it was natural for me because I've been on these panels and been a partner with talking and folks here on those Saturday calls, but more importantly telling the stories and it was a natural, and so I'm really proud that this is a patient and family partnership.

**Charles Denham:** So what I want to conclude with is come back to Nancy. Had Nancy not stood up at the podiums all over … podia all over the country …

**Unidentified Speaker:** Podiaitis.

**Charles Denham:** … podiaitis – and declared this disclosure issue, the pain of disclosure, I wouldn't have been as motivated to work on a national quality forum disclosure practice, and then we wouldn't have written an article that you two and all of you were involved in that actually was the evidence that pushed it over the line and it all started there, just like The Walking Gallery all started here. And people don't realize how catalytic these things are. So I'd like all of you just to help me thank this wonderful panel to know that this is not a token panel, this is tomorrow, because I think we're at a point where this is the new leadership that we're going to have that's going to be the pull-through because our system is broken.

**Regina Holliday:** [Inaudible]…conference that she was bringing a patient with her. She just did it.

**Unidentified Speaker:** She just did it.

**Regina Holliday:** So you do that too.

**Charles Denham:** Thank you very much. That was a great reminder. Thank you, guys. So we'll take five minutes and we'll start our next panel.