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Introducing Libby Hoy and PFCC Partners 00:56

*Careful what you wish for. Health equity and participatory medicine depend on the widespread meaningful use of patient family advisors. The trickle of such advisors should be a stream. Unfortunately, even if the supply could meet demand, health care administrators, researchers, entrepreneurs lack skill in making good use of patient family advisors. Libby Hoy leads Patient Family-Centered Care Partners, a small organization with a large vision for improving the quality, safety, and experience of healthcare through the development of authentic partnerships from the bedside caregiving relationship to the boardroom. **PFCC Partners** is committed to collaborating with patients, families, physicians, healthcare administrators, nurses, therapists, social workers and all those invested in improving health care. From one force of nature to another, I'm honored to speak with my hero, Libby Hoy. We started the conversation with Libby introducing herself.*

Libby Hoy: I usually introduce myself as a mom of three grown young men living with mitochondrial disease. I am a patient family advisor from that experience as well as my own lived experience with a stage three salivary gland cancer. Through that perspective, I feel strongly about the value of partnership - partnership with patients and families and healthcare stakeholders across the board to co-design the health system that we all need to work for patients and families; for payers; administrators; and clinicians. And I think that partnership is the way forward in creating that health system.

Health Hats: So, Patient and Family-Centered Care Partners are an aggregation of people who are serving as care partners across the continuum, mostly inpatient? What's the range?

Libby Hoy: PFCC Partners is an organization that contracts with many health systems, federal contractors, measure developers, and research teams to implement the strategy of patient family

engagement. We see patient family engagement as an active strategy for building a person family-centered health system. And through our work with our partners, we were able to start the Patient Family Advisory Network. The [PFA Network](#) is a program of PFCC Partners. As you said, the community of over 600 patient and family advisors who are currently partnering in those areas within hospitals and ambulatory centers, specialty centers, research teams, more recently measurement teams, and even some newer partnerships with payers. So, it's a community learning together - essentially for advisors by advisors.

Patient advocate. Patient family advisor. They differ. 04:30

One distinction important to kind of keep in mind is how we look at the difference between a patient advocate and a patient family advisor. That's important because the roles are distinct. Though they overlap and support one another, both are critically needed. We see a patient and advocate as someone who's shining the light on our gaps in care, our gaps in opportunities for improvement. They say, "Hey, we should be at zero hospital-acquired infections. This is my family's story as to why this is important to me." Those voices are critical in the system. The advisor, on the other hand, is more of a partner in co-designing the solution. Less coming at the partnership with the concept of we need to reduce hospital-acquired infections to zero, which of course we do, and we're all in support of that. More it's partnering at the local level with our local health systems to say how we tackle this problem together. That's the goal. We all want to get there. What can we design together that will be better and beneficial for our patient population, our clinician population?

Health Hats: I like that distinction. With one you shine a light with stories that build emotion, build motivation. With the other, what are we going to do? What are the nuts and bolts of making it happen in real life, whether it's life flow or workflow?

Libby Hoy: Exactly. The other word that I often use for advocates is they bring that sense of urgency. We need to do this now, today. The advisor comes in to figure out exactly how does it happen within the flow locally. The opportunity, too, is to have a hospital or a health center in Mississippi speaking with their patient population and have one in LA County speaking with the department of health services. Those are different populations, not a one size fits all solution, but rather that's the opportunity to co-design solutions more locally.

Health Hats: I like it. I like it a lot. That's a great frame.

From Failure University to PFCC Partners 07:12

How did you come to establish PFCC Partners?

Libby Hoy: I started when my kids were little. I started on a parent's advisory board and made all the mistakes. We were ineffective. We were thrilled if we got to comment on the paint color on the wall.

Health Hats: How many minutes was I ineffective?

Libby Hoy: In another lifetime, I would love to start Failure University because I have so much content. Anyway, I learned a lot, and what's knowledge if you're not sharing it? I wanted the opportunity to connect. Then I presented at the Institute for Patient Family-Centered Care International conference back in 2006 to about 850 participants, only 37 from California. Half of those were from Stanford. Wasn't happening on the West Coast as much as I wanted to see. So, I started a conference, asked

people if they were interested in a network, and they were. My generous in-laws gave me \$500 for my 40th birthday, and I bought a business license and a box of cards. There we went.

Recognizing success 08:43

Health Hats: Wow. How do you recognize success in this work?

Libby Hoy: That's a great question, isn't it? I would say success is hearing back from our healthcare partners, 'what do the patients and families think of this? Let's run it by them.' That's when we're woven into the fabric. When I hear it, I get it super excited and super motivated. We haven't yet quite gotten to the other success points when patient family engagement and meaningful engagement is prepared for and integrated as an additional voice at the table in a more robust way. That includes a place in budgets. I think hospitals and healthcare systems struggle a little bit, but they do typically come up with some funding for advisory councils and whatnot. Not a lot, but some. Our Federal programs have more room to do that. Our improvement organizations have those budgets released a bit to support that engagement. If the adage is true: put your money where your mouth is, then when patient family engagement is written into budgets, I think that that will be hardwired into the system.

Member / patient advisory panels 10:08

Health Hats: That's big. I remember back to the first member advisory panel that I established. I was Director of Quality Management for a behavioral health managed care company. And I had this awkward moment with my boss about three months after I was hired. He asked me, 'how do you think we're doing?' And I said, 'well, I don't think we're moving as fast along as you want us to.' When he asked what should we do? I said, 'frankly, we need to start with you.' I thought Oh my goodness that was a career-ending statement. But he rose to it and said, 'okay, 7:30 every morning I'm in town, you have half an hour of my time, your agenda.' It was so empowering.

Libby Hoy: Wow Yeah

Health Hats: The first thing that we talked about is that we needed to hear from members and clinicians. His first act was to charge me to establish a member advisory panel and a clinician advisory panel. Then it was, oh my God what do I do? I was a little freaked out. He directed the leadership team, which I was part of, to hear what was learned and do something about it. So, he engaged himself. And then I found in my subsequent roles of similar nature across the continuum is that was unusual. Patient advisory panels were mostly lip service if it occurred at all - more show and tell than redesign.

Building capacity for patient family advisors 12:19

I am intrigued by some of the work that you're already doing. I'm on your PFCC Opioid Task Force. I see that we vary in our ability to be good expert advisers. You ask questions that move the conversation forward in a nonthreatening manner. It seems like part of being CEO of your health is advocacy, as well as, manage, lead, learn, decide. Can you say something about that?

Libby Hoy: I think you're hitting the nail on the head. There are three purposes for the PFA Network. One is capacity raising or skills development. Human beings, professionals or otherwise, have differing levels of capacity. So how do we support one another as a community to develop those skills to strengthen partnerships? We have a very solid core in the core competencies of effective partnerships that we created as PFA Network members. When you're effective, when you're in that room, and you

feel like you're moving that conversation forward, you're asking the right questions or open-ended questions, or you're responding in a way that people can hear and learn. How many rooms have we been in where somebody has a great point and all the passion in the world, but because of the delivery, loses the opportunity to create the message? How do we hone those skills and be effective partners and move our partners? We've got those core competencies to guide us. That's why we're doing a lot of the preparation activities and skills exchange. It's not that PFCC Partners or my team has all the answers. The answers lie in the community. All we're doing is culling the knowledge and the effective strategies and then turning them back out to newer advisors and raising the capacity overall.

Listen. What have you already done? 15:05

Health Hats: Communication is a two-way street. On the other side there's the skill and listening. I spent some time as Vice President for Quality Management in an organization, [Advocates, Inc.](#) Advocates, Inc supports about 23,000 people with disabilities. One of the things that they do amazingly well is there are people that they support at every level of the organization from the board on down. As you can imagine, the people who sit on the different levels, whether it's the board or design or operations; they have varying skills in speaking, in getting their points across. But Advocates is pretty amazing at listening to that. Frankly, I wasn't that good at it when I started. They were able to cull the value in what people were saying that might not seem artful in a formal gathering. Yet it had value. So, it's both the ability to be an advisor, and it's the ability to listen and hear. Do you guys work both ends of it?

Libby Hoy: Absolutely. I think it's critical to be a strong high-value advisor. We meet people where they are. To do that you have to listen first. When my boys were young, and we were racing back and forth to new physicians, it took a seven-year nationwide search to get them properly diagnosed. I remember our pediatrician saying with every new physician you meet make sure they ask you what you've done before they tell you what to do.

Health Hats: That's good.

Libby Hoy: That's so simple. But honestly, Danny, that's become my, and our organization's mantra: Ask people how they've tried to solve the problems of readmissions before you come in telling them what to do. Always ask first. Hear and value what people have put into a given issue before you arrived. I don't think any of us on either side of the table has the silver bullet solution to these problems. They were developed over time in a lot of complexity. They're going to unravel over time with a lot of complexity. The foundation of the core competencies is to establish partnerships That's on me as an advisor to come to that relationship as a full partner, which means ask them what they've done before you tell them what to do.

Health Hats: Wow, I like that.

Becoming CEO of your health 18:38

Let's shift now to the individual. You have your health challenges; your kids have health challenges. How did you evolve to becoming the CEO of your health?

Libby Hoy: That's an enormous question. We could spend hours with that. I will say that I started in a place of fear. I started in a place of shock. When my second son was born, he was immediately in trouble, turned blue and whisked away from me. There was shock. I was dropped into this world I didn't

understand or know anything about. It arose from an instinctual mama bear area. I needed to jump in here somewhere. It wasn't easy in the early periods. I trusted the medical clinicians much more than I trusted myself with the kids and bringing them home on all kinds of equipment. I wasn't feeling confident. It was 18 months almost to the day before I held my son without something attached. That was a long, long time. It's this confidence wave - the more you do things; the more I was inquisitive and teachable; the more I got that back from our clinicians. 'You can do this. You can change a PICC line dressing. You can do tube feeding.' You're building these skills with consistent encouragement, fed by my own inquisitiveness. Of course, there were moments of doubt and completely overwhelmed. We continued to move forward. I'm still such a huge proponent of documenting what happened. I used to have these huge notebooks for each of the boys that I would carry to each appointment. It had sections for each specialist and the therapists. It was my own EHR, but paper and binder. Having that all there cleared my head. When I was diagnosed with cancer in 2016, I went back to that. I couldn't manage all of that. We've got to get it out. So, capturing all of that in whatever organizational way you do, empowers you to not feel like you have to have it all in your head. But you are informed. You are keeping up. I think that was one of the biggest ways to manage the enormity of the situation.

[Kids managing and deciding 21:32](#)

Health Hats: How did it evolve that as your boys got older, they took part more and more in their own management and decision making?

Libby Hoy: That that's an interesting question, as well. That was influenced by the fact that they weren't diagnosed. Things were not looking good. Yet we didn't know that things were not going to eventually look good or what have you. It was always in the back of my husband and my mind that we're going to raise them as we had planned to raise them. We're just going to do this other thing as well. So, they were disciplined, and we had expectations of them. From a very young age they were included in the conversation. At two years old, 'where do you want your IV started; here or here? And that evolved. At seven and eight, 'I really can't stand the tape you're using with my IV.' On a child they usually overdo. So, he would make bargains with his nurses. 'If you would tape one or two strips here, I promise I won't touch it.' He engaged. So, I think from a very young age, the expectation was set that they would have voice in the system. At first it was me making space for their voice. Ultimately their care team and themselves making space. I remember as a teenager, Steven asking his GI doctor 'why can't I go snowboarding with a pic line in?' The doctor looked at him. 'I've never been asked that question before.' So, they worked through it. 'Here's the risks: you may dislodge it. Then you're going to have to have it replaced.' He decided he wanted to take that risk and so they worked it all out. Even the simplest pieces of control for a young child or even a young person and young in their diagnosis can be very, very effective in building that capacity.

Health Hats: Learning by doing. That seems so common sense. There's such a range whether it's the organization or the activist, the advisor. There's such a range of events and capabilities. I guess the goal is to align as much as possible and grow. That's what you were saying at the beginning about was partnerships. The individual and the community are kind of similar.

[Engagement without policy. Ineffective. 24:40](#)

Libby Hoy: We have an interesting way of looking at that. We look at two sides of the scale: Engaging in my care or my children's care is something that happens within the clinical context. It happens between

the clinician and the individual. It requires good communication. We know a lot about what that engagement looks like. But that also requires policy behind it that provides the physician enough time to have those conversations. It requires a system set up so that bedside rounding occurs, and we are all informed. That engagement must have this other piece that is organizational design and improvement. That's the advisor role. In our minds, one without the other is unsustainable. If we don't have the policies that support this, it falls apart. If we have advisory councils, but they're not impacting the clinical environment so that every patient and every family member can engage, then that's not sustainable. We see them very much connected and needed in both areas.

For example, my mom-in-law was in a well-known health system following a stroke a few years ago. I was impressed with the nurses and the clinical staff, and they engaged my in-laws in the conversation, engaging us in the conversation. As we were getting closer to discharge, I said could we look at a list of the medications? Grandma had been on a couple that worked well and a couple that didn't work so well. We wanted to make sure we knew which ones were which. I wanted to start helping Grandpa get used to the medications and what was going on. Our nurse said, 'of course.' She'd been so engaging the whole time. 'Let me run to the nurses' station and get it.' She came back and said, 'I was reminded that our policy is we can't give the medication list until you go home until discharge.' And I said, 'you realize that's not congruent with the whole hospital stay, right? We've been working together this whole time. It's not going to help us prepare.' And she said, 'I know. It's our policy. We can't do it.' She said, 'here's the computer on the wheels. I suddenly have to go to the bathroom. I'm gonna leave this right here and I'll be right back.' She very sweetly left so that we could copy the medication list. I thought, 'why are we doing this to our staff? This individual was encouraged and taught by the organization to engage patients and families and came up against a policy that didn't allow her to do that. She didn't have the autonomy to override that system. That was a light bulb moment for me. We can't pick a side and only focus on one. We must do both.'

Health Hats: When you look at complex organizations with complex systems with inevitable failure, the way you minimize failures is to allow for sensible workarounds.

Libby Hoy: Yes.

Health Hats: Here was a place where she did a sensible workaround. She had that kind of creativity. It was unnecessary to exercise that creativity muscle at that moment - a crazy-making story.

Libby Hoy: Early on, maybe the early nineties, I remember doing a presentation to a hospital administration and saying, 'Isn't this great. Your patients and families can show you things that you don't see in your organization. For instance, all the workarounds on the second floor. I can tell you all the ways your staff workaround. It seems so stupid now, not surprising, they were less than excited about my presentation. I thought it was helpful, but I didn't see the context.'

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Preserve natural development. Pediatric and geriatric. 30:29

Libby and I next shifted from discussing decision-making with children to decision-making with older folk, pediatrics to geriatrics. I asked Libby if she could apply the same principles to both populations.

Libby Hoy: It's a great question, as all your questions are. It's two ends of the same spectrum. We're doing work with the [National Institute on Aging](https://www.nia.nih.gov/) on a few different research projects, embracing the geriatric research space. The geriatricians so much remind me of the pediatricians. They have this natural understanding that you're going to have to work with the family as a unit. It's not about an individual. I don't know why we wait for either end of the health-life spectrum. It should be available to every patient and family member. I always kept in my mind with the kids when they were little was to preserve their natural progression, their natural development, to the extent possible at all times. We looked at every decision through the lens of is this going to limit their natural development. Are the tradeoffs worth it to will it risk their natural development? I see the same with the older populations. Is it preserving their life trajectory, which includes death? Are we preserving that natural human development to the degree that that individual wants it? You bring up such a good point. Natural family development should be preserved. The more that we can move the culture to considering that the better opportunity we have to preserve that natural human development. So, I do see it as the same. How it gets expressed in the geriatric population may be a little bit different, but the need for family, however you define that, is there and the natural development should be preserved.

Health Hats: I'm trying to work through how I could have been more effective moving my parents along in this being CEO of their health process. Having said that, it didn't matter what I thought. My opinion about what they should do but you know that, and a buck and a quarter would have bought you a Pepsi. Who cares what I thought they should do they weren't ready? Right And there's I know that sometimes I've thought with my kids well they're not ready. So, a decision might be I would give them two choices that were both acceptable to me and then let them decide. Then we got to the stage where I thought that was a crazy decision that they were making and now what am I going to do with that? I want them to be making decisions for themselves and it wasn't run across a busy street without looking. It was a decision that this didn't make sense to me.

Libby Hoy: I wonder if it's helpful to think about especially with parents. I lost my mom young, so I didn't get this chance with her too much. Although we did talk end of life before she passed. I wonder if it's helpful to think about and this was always my mom's way of approaching life was process over product. Pay attention to what's available. Pay attention to what's going on and don't worry so much about the outcome. So, I think sometimes that the [five wishes](#) and all of these wonderful templates that we have push people too fast too soon when it's not an isolated conversation. It's more of a you know so I imagine when you're parenting your kids, you're providing guidance all along and then you're hoping that those decisions get put onto the framework of all that you've taught. You're not just turning them loose on the world at 16 hoping they figured it out. When we really pay attention to the process and the conversations and relationships that leads up to those, I think that can be really helpful in getting us

both to where we have a mutual understanding. Don't get me wrong I think five wishes is a fantastic conversation starter and the conversation project we've got lots of great tools to help us have those conversations, but we still have to have those conversations and have that framework in the context of the individual's life.

The teachable spirit 36:11

I kept coming back to intertwined cords of patient family advise and policy practice change. One without the other seems disheartening and, frankly, a waste of precious time. Libby and I returned to the core competencies of PFCC Partners.

Libby Hoy: At the top of our core competencies is the teachable spirit.

Health Hats: Okay, say more.

Libby Hoy: The teachable spirit is a term that came to us from a gentleman named Chi who was an adviser and came to one of our early skills exchanges. He sat quietly in the back of the room with a group of boisterous people. And at the end of the four hours he said, 'this all comes down to committing to entering this partnership with a teachable spirit.' When I asked him to explain he said, 'as advisors we have to come to this partnership knowing there's lots we don't know about running a healthcare system or being a clinician. But those organizations don't know about being a patient in that organization. So, when we commit to a teachable spirit, we're committing to the fact that what we build together will be far greater than what either of us could have done apart. That's exactly I think what you're looking for that's what we look for in partners: a teachable spirit.'

Health Hats: We're back to the beginning. How have you tried to become more patient engaged already? I'm putting it a little differently than we talked about it when we started. But instead of my ideas about what they should do, it's what have you done so far and how has that worked might be a good approach?

Libby Hoy: Exactly. Because that's a primary activity of having a teachable spirit. That's you emulating what you want to see in this partnership If you're going to move forward with it

Health Hats: Thanks for taking the time to chat with me I look forward to seeing you in a week.

Libby Hoy: Yes. So fast

Reflections 38:41

The audience of my Health Hats activism are people who help other people: advocates, advisors, activists, policy makers, informaticists, researchers, clinicians, caregivers, case managers, and more. People who help other people make their way in our healthcare system for best health. The gist of my mission is learning. Learning to make choices, learning to communicate with each other, learning to support each other, learning to share what works. At the heart of my mission is health equity: equal opportunity for best health. All this rests on the catalytic relationship between people use the healthcare system and those who manage it, study it, pay for it, control it. Libby Hoy's Patient Family-Centered Care Partners delivers key services to advance the number and effectiveness those relationships. Thank you for this important work.