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Regina Holliday inspires me because she is a learning dynamo. She takes her skills - painting, connection, spirit, whatever – to catalyze whoever touches someone she has touched. She’s a gift that keeps giving.

Proem 00:46

Regina Holliday, known worldwide for her [Walking Gallery](#), lives in God’s country near the Cumberland Gap, Maryland, close to my old stomping grounds in West Virginia. The Walking Gallery is hundreds of jackets painted by Regina and her artist colleagues. The backs of the jackets tell our stories, our advocacy, and life stories. The painting is free; we supply the jacket. We agree to wear the jacket at conferences and meetings. Advocacy can often be lonely work, swimming upstream. When I spot someone else with a jacket, I know immediately that this is my peap. When I wear my jacket, people come up to me and want to hear my story. I know you’ll be surprised to hear that I have the story ready. The first time I met Regina in person, she blew me away. Her passion was almost more than I could bear. Regina hosts the best conference/retreat going – dollar for dollar, pound for pound. The [Cinderblocks](#) conference is in Grantsville, Garrett County, Maryland, equidistant from Pittsburgh and DC. They are small – 25-50 people – over several days. Regina knows how to blend local action with national policy. I’ve attended four or five of her conferences over the past nine years. I always feel rejuvenated and inspired. My Health Hats logo was drawn by the St. Louis artist, [Danny McGinnis, Jr.](#), while we drove from DC to Grantsville. Please bear with our mediocre connection. Wi-Fi is spotty in Grantsville. The substance is worth the minor annoyances.

Health Hats: Regina, I'm so glad you could join me.

Regina Holliday: Glad to be here.

Health Hats: I miss coming to visit you.

Regina Holliday: I miss everyone who would come. The world of COVID19 is very lonely for many, many folks.

Health Hats: Loneliness is a big deal now. I've been just thinking about you a lot these days.

Enmeshed. Maintain the fire. Keep listening 03:39

As we began our conversation, I started to describe a dilemma I feel as an advocate for equity and inclusion, trying to increase seats at the table of governance, design, operations, and learning in healthcare. Even if we could wave our magic wands and make what we want happen, there's lots of variation in the readiness of professionals and experts to seek and utilize advice and the willingness of people who are experts with lived experience to offer advice. I'm the token patient on several technology and decision support initiatives. What advice do the professionals, whether they're informaticists or clinicians, seek from experts with lived experience that the professionals are willing to hear and act on, and then what does it take for people to be up to speed so they can give good advice?

Regina Holliday: Well, part of the challenge is people who are in the patient space for a long time as a patient voice, often flip sides. They often become professional. They become enmeshed with groups from the provider's side, and whatever application, be it insurance or data or a medical practitioner. They get to the point where they're speaking like that. The tokenism, the challenge is you can become part of the group and lose that reason you're there in the first place. That's one of the challenges.

Health Hats: Losing the outside, looking in perspective.

Regina Holliday: Yes, that happens. So, it's continually working on reigniting their perspective of an outsider is really important. Sometimes that comes through enmeshing oneself deeply in a patient community. That's not necessarily getting invited to those meetings. That could be done online; it doesn't have to be done in person. But you realize how perspective can shift and how code-switching can happen, for instance. So that's part of it.

Regina Holliday: There are other challenges. Caregiving can give you that experience, too, whether you're the primary patient oneself or the caregiver who's deeply empathetic for the patients. Both work if you can put yourself in the other person's shoes. It's continually recreating the fuel that got you where you are in the first place and always identifying with that source. It's one of the reasons I believe change does not happen as rapidly as we would hope it would, positive change. People lose sight of why they got so excited in the first place.

Health Hats: So, what their fire was?

Regina Holliday: What was your fire, and what will get you back to your fire?

Health Hats: I'm susceptible to what you're describing. Being that I'm a two-legged, cisgender white man of privilege wearing all these hats and I'm the token representative on initiatives, I'm susceptible to that. Recently the most successful that I've been is when working with a group to figure out what input only patient-caregiver experts could provide - people with lived experience. In the project I was working on with chronic pain management was to formulate an ask: this is what we're looking for, information about, or advice about. I kept going to the group I was working with. Are we asking this because we need the advice and we're going to use it? We went to a group of people at the [PFA Network](#), Libby Hoy's group. We had a call together, and we laid out a little background and then we laid out the question and then they responded. It was fabulous because the advice we got was very useful, able to implemented and incorporated into the design of what we were working on. That felt really good to me. But man, it was a shit load of work. On the other hand, as a quality management professional, before I

retired, we would have patient advisory councils. It was hard for that not to be show-and-tell. We had a group of people that we could bring along and help them learn about parts of the business. Then they would share their perceptions about the business or the service. We could put that together, but that was also a shitload of work. You just can't have coffee and donuts and meet once a month and think that there's gotta be value out of it.

Regina Holliday: No. You need more than that. One of the places I was most excited about how they incorporated the patients was [Bellin Health](#) in Green Bay, Wisconsin, because they enmeshed patients in every working group. I don't know where their program is at this point, but when I was there, I very excited to see that they had gone beyond the patient-family advisory council and had fully enmeshing people in all the different working groups. Regular Joe Schmo is on the EMR working group. That was exciting because you bring in that voice of non-jargon.

Health Hats: Yes. Regina, one of the things that I so admire about you - there are several things, but the one I'm thinking about this minute - is how involved you are in your community. When I come for your conferences, the pulse that you seem to have on the community that you live in and your ability to work with clinicians and government officials and citizens of the town or the city. You bring that all together. There's something different about that. I operate more on the federal level. You operate on the neighborhood level. Where I see you shine is on the local level. What do you think about as you're bringing all that together?

Regina Holliday: It's important to listen to all sides, all the time. For instance, my Facebook feed is filled with every view, and I don't delete people. I listened to all of them. Everyone has value. On one topic, they may very much disagree with you. But then there's another topic where you guys are very aligned. It's important to read and listen to people about what they're struggling with. What's making them angry or upset or happy. I find that people get in bubbles way too easily, where they're not listening to anybody, but their peer group, only people who they agree with, only people they work with. That's dangerous because then they start creating policy thinking that's the way the world thinks. There's a whole bunch of people who don't think like you at all. So, it's also getting down to the core of this problem. A lot of people don't take enough time to talk to someone and develop enough of a relationship to find the core of the problem. Often when a person is noncompliant, which is a popular term within healthcare. They're not getting their prescription correctly. And they're not taking their drugs on the right date the way they're supposed to, because they can't see the label because their glasses are out of date. They need new glasses. But they can't afford new glasses. Then you have to know where you can get glasses. Oh, the Lion's Club will buy you glasses. Then they don't have transportation to get to Walmart, which is the cheapest place to get the glasses. They need transportation to get there. Lion's connection to pay for it. They got the glasses. Now they're taking the drugs correctly. It's a lot of steps to get to the core.

Health Hats: I see. So, you're a listener and you're a connector.

Regina Holliday: That's what I do. I listen. Okay, so would this be a solution? But sometimes it's not, so then I listen more for what's below that.

Enmeshed with community 15:17

Health Hats: Grantsville recognizes you as a resource. You didn't just wave your magic wand and become that. How did that happen?

Regina Holliday: When I first moved to this area, I started going to so many different meetings. I joined Rotary; I started going to County Council, of course, volunteering at the thrift shops. Every way that I can make sure I was communicating with every facet of society, from the well-to-do, Chamber of Commerce mixers to people at every economic level of the community, so that when a problem arises, you have a resource. This person needs this, and they can help. In a rural community, this is incredibly important because nothing's advertised. People come here, and where do you find apartments? You have to know somebody. It's different for folks who live in cities where things are advertised.

Health Hats: I'll bet you also need to know somebody.

Regina Holliday: You need to know somebody.

Health Hats: But I get your point though. You joined. You participated. Then you were recognized as somebody who would do the work. When you identified problems, you had a network of people you could call on to help solve that problem.

Regina Holliday: Correct.

Eureka, the Walking Gallery 17:20

Health Hats: I didn't meet you in the local scene because you live in Grantsville, and I live in Boston. I met you on the national stage with your Walking Gallery. And I don't know where I met you first. There's probably HIMSS (Healthcare Information Management Systems Society) or something, and you were painting these jackets, and I thought. So that's where you've been more on a worldwide stage. The jackets are beautiful, but the jackets to me - I would go places and I would see other people with jackets, and I would know, okay, these are my peeps. I better get to know them because Regina has vouched for them by making a jacket. You created a lot of energy for people to get together and solve whatever problem they're trying to address.

Regina Holliday: I needed the Walking Gallery purposely hard to join. I didn't vouch for people. What they did is vouch for themselves. So you don't get to be part of this unless you work at it. You had to be willing to mail a jacket. You had to do a lot of steps to part of the Gallery. There's no economic barrier. Anyone can join. You gotta have this jacket. You've got to be willing to put your story out there. You gotta be willing to be real and authentic. You've got to have a social media voice, and these are steps, and some people can't join the movement because they won't do the steps. And then there's no painting on their back. This person may not be the person that you would have put their energy out there. Interestingly, people walk away.

Health Hats: It is interesting. How did you get the idea of doing it? What was the germ?

Regina Holliday: First of all, it began with the paintings I did about my husband back in the summer of 2009 and his medical journey. Those were large scale murals. You do large scale murals outside in temperate weather. I did three of them between the late spring to late summer of 2009. Then it got cold in Washington, DC. You cannot paint murals when it's cold. You can't do that work. I had a lot of Twitter

friends, and that's where we, you and I, first met I'm pretty sure it was Twitter. It gets confusing, but it's just like, it's the Society of Participatory Medicine, or Twitter, but either way, I've met a lot of people on Twitter. I met a woman, Jennifer McCabe. She was going to the American Medical Association meeting that year and realized she was invited to participate, but no patients were. Patients were not invited. They were not in the room. There was no representation of them. So, she suggested I paint my husband and my story, our story on the back of her jacket that she was going to wear every day of the event. There were three jackets she had wanted to be painted. They were all focused on data access because that's my core mission and advocacy: real-time data access. She wore them, and people saw them. And then Ronny from Google Health wanted one. Again, it was my story on his back, but about Googling healthcare data. Then there was another woman, [Chiara Bell](#), working for a company Careticker, which was caregiving. It was me, a caregiver, and my husband on her back about caregiving. We called them art jackets, and they were all small-scale murals. They were out there public – not private, not second a wall in a museum, but out there speaking to the common man. Then I went to this [Kaiser Permanente Center for Total Health](#) opening event with my friend, Ted Aton. When I got in there, I said, 'Ted, this is going to be a great space for a gallery show.' He's like, 'Oh no, this is a giant smart wall.' They can't because he'd seen me do one gallery show event, [Clinovations](#), with big canvases. I said, 'No, no, no, no, no. It's not going to have canvases. It's going to be on jackets. But the jackets are now going to be about a person's life. It's their life. And they'll be telling their life story. We'll walk around the room and learn about each other and text, that's an amazing idea.' We had to get clearance from Kaiser Permanente, and it took a little bit to get clearance. Then we had one month to get as many jackets done as we could. So, thirteen other artists and I painted for a month, and we managed to get 56 jackets done. That started the Walking Gallery.

Health Hats: There are 500, 600 jackets now?

Regina Holliday: I've got to look at my numbers now, but there's way over 500 at this point.

Health Hats: They're worldwide?

Regina Holliday: We're in 16 countries. And at this point, we have 48 artists painting.

Health Hats: Really? I had no idea it was that many.

Regina Holliday: It's one of those things that a person can join if they would like to paint a jacket for themselves or another, telling their story. The one thing I request is that they accepted donations towards the creation of it. But not you're not buying it. You cannot buy a jacket; it's not for purchase. That's hard for some artists to understand. The paintings are a co-mission, not a com-mission. We are working together. My artist's vision: your story to create this piece will create advocacy, hopefully, policy change. That was hard for a lot of people to understand. In part, we do that because then people who work in the federal government can be part of the Walking Gallery. These jackets have no value.

Now a word about our sponsor, ABRIDGE.

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the app at abridge.com or download it on the Apple App Store or Google Play Store. Record your health care conversations. Let me know how it went!"

Seminary, calling, mitzvah 25:13

Health Hats: What do you see for your advocacy in the near future?

Regina Holliday: Seminary classes. I took my first, and I have three intensive classes coming up later this month. I'm part of a track for later in life-learners. I'm 48 now. I'm ancient. I was very gray during COVID, and I reached out to my beautician. I said, okay, I can get box color and color my hair, or you could just give me the stuff that I need, and I'll do it myself. So, you won't get in trouble.

Health Hats: Oh, that's funny.

Regina Holliday: It was so bad, my mother-in-law was staring at my head every day that I would see them to bring groceries. 'you look so old.'

Health Hats: Seminary, what will you do with that?

Regina Holliday: In the Evangelical Lutheran Church of America, of which I am a member, we have over six hundred vacancies on pastors, especially vacancies in rural communities. So, when we lost our pastor in 2017, I was on the call committee to try to find a new one. And we just got a new one in May. It took from November 2017 to May 2020 to find a pastor. During that time, I felt called to offer my services. It's a long process just to get approved for candidacy. You have to have psychological examinations and turn all these things in, and it's a long process, but I got approved. So now I'm in seminary classes. Why? Like I explained to them when I was beginning this, I'm already on God's mission. I am already a servant of God. I'm already doing mission work. I consider a lot of what I do an act of faith that some folks would call a mitzvah. I do this because it is what is good and right. I'm adding another layer to what I'm already doing. I'm not going to stop what I'm already doing. They said, 'that makes sense. You are driven and called to do something to make it better.' You never know.

Health Hats: You're one of the most driven, inspiring people I know. I'm glad we're friends, and I'm glad that I see you from time to time, but I like watching you. I like knowing what you're up to because it's inspiring. I like that you take people under your wing, and you mentor them. You encourage people to grow and give back. You're pretty remarkable in that way.

Regina Holliday: Well, thank you, Danny. It's something I try at all times to do. I've had mentors in my life that made a significant difference to me, and I hope that I can, in some small way, do the same thing for other people.

Health Hats: What should I be asking you that I'm not.

Covid, masks, gardens 29:35

Regina Holliday: With all the crisis that's going on right now, I think a lot of people are very stressed out, very anxious. There's a lot of backlash in my community. Our local County Commissioners mandated masks. The State of Maryland recommended them. Not required, but recommended. Now it's mandated. There's some backlash on that because they're hard to breathe in.

Health Hats: I just made it back in time for this call because I went for an MRI. I needed a brain scan for my Multiple Sclerosis. I had to wear a mask in that tunnel. My goodness, horrible, hard to breathe. I was a little claustrophobic, and it was deafening. I struggled to breathe with that stupid mask. Anyway. Have you had many infections where you are?

Regina Holliday: No. A total of six cases in our County until recently.

Health Hats: 20,000 people in the County, if I remember correctly?

Regina Holliday: 28,000. We only had six cases until they tested in a nursing home. That gave us seven more cases. It looks like all of them came from potentially one staffer that didn't live in our County. Our numbers are very low. Our economy, like most of the United States, has been struggling greatly.

Health Hats: Garrett County was struggling before?

Regina Holliday: Yes. A lot of people have gardens here already. It was already hard. It's just become harder.

Health Hats: Well, honey, I gotta go.

Regina Holliday: Oh, okay. Well, this was great.

Health Hats: It is lovely to talk to you, and you know that I think about you regularly, and we communicate one way or the other. And I look forward to the day I can hug you.

Regina Holliday: Well, I'm very hopeful for next year, because next year is the 10th anniversary of the Walking Gallery.

Health Hats: Alright, well, I'll want to come. Yeah. Cool. We'll take care of yourself. I love you.

Regina Holliday: Love you, too.

Reflection 33:19

I feel tension in patient-caregiver advocacy and engagement. On the one hand, networking, bridge building creates connection, influence, trust, and sustains the fire, the passion in often lonely work. Yet, advocacy and engagement are about something – action, policy, problem solving. Our communities need so much - accessible healthcare, equitable life, information to make choices. We, mortals, have limits – our eyes are bigger than our stomachs. We have to pick our battles, select our minimum viable audience, while taking care of ourselves. Regina Holliday inspires me because she is a learning dynamo. She takes her skills - painting, connection, spirit, whatever – to catalyze whoever touches someone she has touched. She's a gift that keeps giving.