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Proem



Figure 1: The family

Happy Holidays, family, friends, and colleagues. May the 2024 New Year be infused with wonder, community, and rejuvenation.

I reunited with my friend, [Lisa Stewart](#), at the PCORI Annual Meeting a few months ago. Lisa suggested that she interview me for the new year. When I met Lisa she was Senior Engagement Officer and Health Equity Advisor at PCORI (the Patient-Centered Outcomes Research Institute). Currently Lisa is Principal at Torchlight Engagement Advisors & Leadership Coaching. Her joy lives in connecting ideas, people, and groups for organizations serious about improving the health outcomes of over-burdened communities through health equity strategy implementation and integration, cross-

sector partnerships, impact investing, and capacity-building. We ponder privilege, listening, bitching, travel, family, and music. Hang on.



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Podcast intro

Welcome to Health Hats, the Podcast. I'm Danny van Leeuwen, a two-legged cisgender old white man of privilege who knows a little bit about a lot of healthcare and a lot about very little. We will listen and learn about what it takes to adjust to life's realities in the awesome circus of healthcare. Let's make some sense of all of this.

Why reflect? Accept and look forward.

Health Hats: Hi, Lisa Stewart. Lovely to see you,

Lisa Stewart: Wow. It's lovely to be seen and be here with you. We had this wild and crazy idea that it was time for Danny to be interviewed, right? We're going to turn the tables on Danny. What better time of year as we march into 2024 and start thinking about the life we want to lead and what we want to do differently? I'm thrilled to be in conversation with you anytime, Danny. Anything you want to say?



Figure 2: DALL-E - a color photo of a person looking in a mirror and seeing a black and white younger version of herself

Health Hats: I have mixed feelings about reflection. On my podcast, I start with a proem, a preface. Why do I have the conversation? Why this guest, why this topic, whatever. A reflection at the end, done after production - the interview, the producing, the editing - were there pearls here? Is there one more story to tell? But the reflection is essential even though I'm not really a backward-looking guy.

Lisa Stewart: Tell me more.

Bitch in bursts, not dribbles

Health Hats: Life has ups and downs. It is just the way it is. You can't have an up without a down where everything is flat - no ups and downs. Sounds boring to me. I have a chronic illness, and I'm pathologically optimistic, right? That's my style. Other pathologically optimistic people have taught me that you need to take two minutes periodically and just vent. And do *the life sucks*. *Woe is me* stuff. But mostly I don't want to look back and think woe is me. So that's what I mean by not looking back. Accept what is and what are we going to do now.

Lisa Stewart: Very practical. Do you have a ritual around your two-minute releases?



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Health Hats: It's a good question. The dean of the UMass Graduate School of Nursing introduced me to this idea. She had health problems, and we recognized this optimism in each other. She had breast cancer and surgery and the whole thing, and I had been newly diagnosed with Multiple Sclerosis. She didn't have a watch on, but she looked at her wrist and said, okay, you got two minutes, start now. So I bitched, then she did. It was hysterical. It's tough to bitch for two minutes straight and be creative. You can't bitch and say the same thing over and over. Two minutes is a long time. After about a minute, it's just absurd. So now I have a friend I texted just yesterday; we need a bitch session. She's ready. I did it with my wife a few times, and she's lovely, and it's OK. However, having somebody else who's dealing with whatever insanity is different.



Figure 3: DALL·E - biracial couple laughing, one in a wheelchair looking at their watch

Lisa Stewart: I love how you called out the arc between starting the bitching and then recognizing that there's absurdity in it? The process itself lands back to the word reflection, and out of that, you see the kernels in it.

Catastrophizing, pathological optimist

Health Hats: I was born this way. I didn't do anything to be pathologically optimistic. Maybe because I was the child of Holocaust survivors who are both catastrophizers and pathologically optimistic, I inherited that, whether through genes or learned. And it works for me. My downs are in the middle of the night when I'm lying there, catastrophizing. I know that two things affect my symptoms the most - when I don't drink water and when I'm down. Symptoms are worse. They're just worse. It just is.

Lisa Stewart: Does your optimism, your pathological optimism as you call it, does that ever piss people off, particularly other people who are living with chronic illnesses? Do you ever get any blowback?

Health Hats: No. Really, it's the other way. People think it is so cool that I'm optimistic, and I'm thinking, you guys have no idea. You know what I mean? I think I didn't do anything for this. So many people have depression with whatever they're dealing with. And that's what they're dealing with. I didn't do anything. I have so much going for me. I'm a two-legged, cisgender, old white man of privilege who's pathologically optimistic, and I could count my blessings.

Music, podcasting, grandsons

Lisa Stewart: At the opening, you say what you normally do is record, and then go back, and figure out what the themes are, and then do a wraparound? But you have some idea going into it, what you're trying to impart, what you want to say. What do you want this episode to say?





Figure 6: Boland van Leeuwen Family

Health Hats: I'd like to reflect on basic things in my life - my health, family, work, and music. These are the big things in my life. They're all going swimmingly. The most exciting thing to me is a centered around music. In my professional life, I am really good at what I do. I'm as good as anybody anywhere, I think. But music, not so much. So, it's the place of humility for me. I really work at it. I play every day. And when I say every day, 320 days a year, unless I'm traveling or so busy with something, I play music. It's the best thing ever. It's one of the things I do with my grandkids - both my podcasting work and my music. And I have a 15-year-old grandson and a 12-year-old grandson. One lives

upstairs, and one lives about eight or nine miles away. They're on my production team. That's just a hoot and a half. My grandson, Leon, who lives upstairs, is an outstanding written word editor. He helps me take the transcripts and turn them into newsletters. And Oscar, who's 12, is an excellent video editor. He coaches me on video editing, and then they're both musical. Oscar spent the night this weekend and pulled out his laptop, opened MuseScore, a composing app, and said, Opa, let's write something. And we worked on a four-bar ditty.



Figure 5: Saturday Afternoon Blues-Funk Band playing at Ryle's Jazz Club before it closed



Figure 4: Danny playing in Cobleskill Jazz Band

Lisa Stewart: I love how you bring all those together.

Health Hats: It's great. I learn a lot from them.

Listening to younger activists

Health Hats: That ties into then to another thing. In my advocacy work and podcasting, I'm an old fart. I'm 71 and on my way out, and I feel like my audience is mostly in their forties, fifties, and sixties and older - veterans in the business. There are a lot of young people out there in advocacy - 25, 30, 40. What are they dealing with? What are their issues? Where do they live and hang out? How do they communicate? Again, this is nice with the grandkids because they're much more

familiar with Instagram and one-minute stuff than long-form. I'm trying to move in that direction.



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Figure 7: Danny's home studio

Lisa Stewart: Are you listening to any podcasts?

Health Hats: I find it hard to create time to listen because I'm full of myself and doing what I'm doing. And listening is another thing to do. With podcasting, I force listening. I just finished doing a series on emerging adults with mental illness. I started with a couple of emerging adults who were in recovery from their mental illness issues, and then parents and teachers—a spiral of sorts to bring in people and include them in my process.

I've also been learning about different groups like [Generation Patient](#), [Students with Psychosis](#), and the [Camden Coalition](#), all places with younger people either supporting people with chronic illness or having chronic illness. I'm trying to become part of those spaces and still learning to do that. If I have a goal for the year, it's listening and contributing to those spaces, which is a hoot.

Connection through video, Instagram, YouTube shorts

Health Hats: Now I'm producing videos and adding short-form material like shorts for YouTube and reels and posts on Instagram. Creating good one-minute stuff is time-consuming. I don't do anything simple. I just can't help it. I'm always learning something new, like adding my music or images. What's my ask? What am I expecting from people? It's not just that I'm putting something out. How do you stimulate people? Once I find where people congregate, I hang out; first, I lurk in different groups.

Generation Patient is international for people in their twenties. I'm 71. So, I asked Sneha Dave, the executive director, if you mind me lurking. It could be creepy, right? She said, oh yeah, sure, we'd love it. We love having you whatever you want.

Impact

Lisa Stewart: I can see how that's invigorating. We need that to bolster us. We have a lot of value to give. I'm putting myself in your category, Danny, but I like recognizing that, so what's their return value?

Health Hats: Yeah, I've had my chance. I can't say that I've had much impact. I've encouraged and celebrated people and initiatives. My work with PCORI is a career capper, an opportunity to influence



Figure 8: My peeps



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things on a big scale. But really, I've had my chance. I don't have a don't care attitude anymore. I was energetic and stupidly creative. We need that young energy. My time is over. People in their thirties and forties now, maybe they can make a difference.

Lisa Stewart: Yeah, but many of us would dispute that you haven't made a significant impact, Danny. And I would even say, just to give the audience some context of how we know each other. One of my earliest memories of you was observing a meeting, an advisory board, or an advisory committee meeting, and I remember. You were cutting through a lot of bullshit, laying it on the line as only Danny can do. And it was like a recognition of you're holding it up. And it's not just that you brought your experience; you rarely speak from an I space. But your hallmark is that you bring the voices of many into the room. You hold it down, and they should feel comfortable that you're bringing them into the room in the best way you can.

Health Hats: Thank you. That's nice. In my PCORI trajectory. One of the things that was important to me was feeling okay, so I am this two-legged, cisgender, old white man of privilege, and here I have a seat. Am I the right person in that seat? What about a woman of color? What about so many other people who don't have the opportunity to sit where I sit? I've gotten feedback, but you have the seat; use it. Just use it. Open the door. Go for it. You are who you are. You can't do anything about that. You're a two-legged, cisgender old white male privilege. You were born that way, and there you are. So, use it. And that was helpful.

Lisa Stewart: And look that questioning, interrogating, and you know *why me* a little bit. It's what can keep us humble, right? And keep us in the space of asking ourselves, who are we serving? Because in every room I've been in with you, Danny, you are trumpeting loud and clear to get to the community. Like I'm not the community. Like you're, very clear. I am not all communities. We need a footprint, get in, get to those communities.

Health Hats: Thank you.

Lisa Stewart: Hats off to you.

Call to action

I need your help as I expand my audience to younger people in advocacy. I'm doing more in short-form videos. Please help by pointing me to communities of young advocates and the channels and hashtags they use so I can listen and learn. I now have one URL for all channels and media.

<https://linktr.ee/healthhats>, where you can subscribe, access episodes, my website, and social media, and search the Health Hats archive. Your support is appreciated.



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Progressing in music



Figure 9: Still using the harness

Let's talk music. We've intentionally not used the word resolution, but should there be anything that you want to see for your musical development in 2024? You play the Bari sax, right?

Health Hats: I have a teacher I've been studying with for 15-16 years a sax professor from Berkeley College of Music. Great guy. I've taken a leap in basic things like counting to four in the last few years. When I say counting to four, I mean feel four bars, which may sound like when you can't count to four, you get lost, which was my problem, especially in soloing, like I have no idea where I am in the form. So that's something that I accomplished this year. I can count the four. I'm like, it's just so exciting. It sounds idiotic, but it's fundamental, so now I'm trying to play in a Latin band, and it's a very egalitarian group. They are just lovely people. Absolutely lovely. Very warm and



Figure 11: Four bars

interested and forgiving and experimenting. And so what I'm gearing up now is I want to be the leader for a tune, where it's my, I'm like, this is making suggestions about how we arrange it and listen and count people in and who's soloing and, and I've, like purposefully not taken a leadership role in music because I take a leadership role in everything and I can't help it. It's who I am. It was nice not to lead somewhere and have a part of my life where I'm the frontline. However, now I want to introduce the group to a tune. Then I'd like to compose something with my grandsons. They're psyched. Oh my God, I can't believe they want to do this with me. Oscar plays piano and guitar a bit and just got a clarinet. Leon plays piano, and he played trombone for a while, and I think he's interested in saxophone. And they're both into creating music electronically.



Figure 10: Lechuga Fresca Latin Band at Brookline Porchfest 2023

My bari sax is a big horn, which has been an issue for me over the last few years. I can't carry it anymore. It's too heavy, and my back can't take it. Having gear is challenging. But a couple of years ago, Jeff, my teacher, had found this company in Germany that made these stands so that I can put the horn in the stand and either sit or stand and play. The bandmates are my roadies. They're willing to haul my stuff. I recently bought an EWI, a wind

synthesizer that plays like a horn, instead of having a piano that's a synthesizer where you can use different sounds. I've been trying to play it. It's a whole different instrument.



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Progressive condition and music

Health Hats: But I always think ahead about progression. I have a progressive illness, and there will come a time where - maybe there won't - but I'm like, let's face it and prepare. If it doesn't happen, okay, thank you. It's likely, so what am I going to do? I want to keep playing music, so I got something light and different.



Figure 12: EWI Wind Synthesizer

Lisa Stewart: Since you've been playing, your illness has changed.

Health Hats: I've been fortunate as the last four years I've been stable. Thank you, Lord. If I stay like that, okay, I stay like that. But I just don't know. That's the catastrophizing in me. Someday, it's not going to be whether it's from MS or because I'm an old man. I have a primary care doctor who says, you're still an old white man, and you have old white man issues. I'm here to help you take care of your old white man issues. I wasn't born without a prostate.

Lisa Stewart: I have seen musicians very up in age who, at the time, were at a stage in life where they had limited mobility, needing quite a bit of assistance to get on stage with their instrument or get to the keys. You could physically see it as a change. And it all just came through like the aging process.

Health Hats: Look at Tony Bennett with dementia.

Lisa Stewart: Yes. Have you experienced any of that? You may not be physically feeling great, and then you pick up your instrument and have a moment of where you're feeling differently physically in your body.

Health Hats: For me, it's more like my first neurologist when I got diagnosed, and he found out I was playing saxophone. He said he has no treatment that compares to playing the saxophone. I have intercostal involvement, my breathing muscles, and I play this big horn every day. I have dexterity issues. I play this big horn with heavy keys. Music creates new brain pathways, and it's good for the soul. And he says I got nothing. I got nothing that's going to come close. His visit intro was always, have you fallen and Are you still playing the saxophone? For me, it's more long-term. If I go away for two weeks and don't bring my too-big horn, I can tell. It doesn't take long to recover. That's a great thing. It doesn't take long to recover, but it's like moving, playing the horn, and drinking water. Those are the three main things. And indeed, I've been happily married for 48 years, and I have great kids and great grandkids, meaningful work and friends, and all of that.

Lisa Stewart: You just named it Danny, like the recipe *for success*.



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Figure 13: Santiago de Compostela

Travel with abilities in Costa Rica

Health Hats: Another thing that's been big for my wife and me is travel. We've done the Camino, a pilgrimage in Europe, a couple of times. Last year we went to Costa Rica. The interesting thing about Costa Rica is that it's not an accessible country. It's mountainous, it's rural. But everywhere you go, somebody is tuned in to disabilities and thinking about how to help you. The idea that a country was aware of that as a national thing is. It was fascinating.

Traveling with a disability is such a hoot on so many levels. When sitting in a chair and traveling, you see many behinds and many kids.

I like different perspectives and problem-solving. What am I going to do? How am I going to handle this? What can I do? It's fun to see the world that closely: hiking or riding or whatever. We decided a couple of years ago that travel is our priority. Are we going to upgrade the bathroom or travel? Travel.



Figure 14: Riding my chair in the Honk Festival

Travel with abilities in the US

Lisa Stewart: Yeah. Hands down. I'm with you. What do you think is the difference though? You pointed to this ethos that happens in the people. What's different in this country?



Figure 15: Juve Acuna

Health Hats: Tourism in Costa Rica is a huge business. And Juve, our guide, was the grandfather of disability travel in Costa Rica. I lucked into that relationship. He started stuff, and then the government took it over. They have a certification process for guides. They think about equipment, sites, and safety. But what's here? This is a country that thinks a lot about itself. And not so much others. I'm making a gross generalization here. Personal support is uneven. There are still plenty of really helpful people, and usually all you have to do is ask and people help. But it varies a lot. And so that was interesting because it made me realize that we all need help. And somebody with disabilities needs a particular kind of help. Very different kinds of help. There's a whole constellation of kinds of help people need. I think institutionally, we're not oriented to helpfulness, or we don't see, we're oriented to money, we

don't see how helpfulness pays, maybe because it's got a long tail. We're more of short-term gratification. So, I don't know.

Lisa Stewart: It'll be interesting as you travel the world to continue to pick up those differences. In contrast, I'm wondering if one ingredient is discomfort with difference.



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Words of wisdom

Health Hats: Any words of wisdom from you?

Lisa Stewart: Words of wisdom. I'm drawing a blank. I wish you a fantastic 2024, Danny. To recap, on your list of things you want to pursue and will make happen in 2024, they fall on the space of the things you love the most. Family, traveling, music, learning, and being around younger generations and an activist, to be an activist in the way you do best. Sounds great.

Health Hats: All right, have a lovely holiday. Best to you and your family.

Lisa Stewart: You, too.

Reflection on Advantage

So, life is good, crazy good. I couldn't ask for more. The word for the year is **Advantage**. Ten takes on advantage

In every adversity there lies the seed of an equivalent advantage. Robert Collier.

I've been blessed with the opportunity to express the views of black people who otherwise don't have access to power and the media. I have to take advantage of that while I'm still bankable. Spike Lee

Why is it that if you take advantage of a corporate tax break you're a smart businessman, but if you take advantage of something so you don't go hungry, you're a moocher? John Stewart

I feel like I'm a creative, and I want to take advantage of that. Lil Peep

One advantage of marriage is that, when you fall out of love with him or he falls out of love with you, it keeps you together until you fall in again. Judith Viorst

I think that has to do with my awareness that in a sense we all have a certain measure of responsibility to those who have made it possible for us to take advantage of the opportunities. Angela Davis

There's only one life. There's no repeats. You only get one life, and you gotta take advantage of it. Victor Cruz

There may be an evolutionary advantage for schizophrenia genes during famine. Feng Zhang

My only advantage as a reporter is that I am so physically small, so temperamentally unobtrusive, and so neurotically inarticulate that people tend to forget that my presence runs counter to their best interests. Joan Didion

The advantage of being eighty years old is that one has had many people to love. Jean Reno



Podcast Outro

I host, write, and produce Health Hats the Podcast with assistance from Kayla Nelson and Leon and Oscar van Leeuwen. Music from Joey van Leeuwen. I play Bari Sax on some episodes alone or with the Lechuga Fresca Latin Band.

I buy my hats at [Salmagundi Boston](#). And my coffee from the [Jennifer Stone Collective](#). Links in the show notes. I'm grateful to you who have the critical roles as listeners, readers, and watchers. Subscribe and contribute. If you like it, share it. See you around the block.



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