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Proem

Whenever I go to conferences, I prepare two questions to ask people I meet. I don’t always ask those questions, but I like having them in my pocket. It ties the event together; I learn something and listen more than I might have without. Adding the feature of recording more strongly connects me to the interviewees. So, a pleasure to interview twenty-six people in five-minute interviews, although challenging to produce.

Welcome to the third and final episodes created from the Health Voices 2022 Conference. I asked *where do you point people new to advocacy for skills, resources, and research*, to understand trusted sources better. See the previous question episodes in the show notes. People commonly responded with *knowing yourself and your skills* and *not biting off more than you can chew*. I include fifteen of the twenty-six responses to reduce redundancy. I asked the fourth question, *have you heard of PCORI?* As a



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Patient-Centered Outcomes Research Institute Board member, I wondered if anyone would include PCORI as a trusted source. I don't include those responses as 22 of 26 had never heard of PCORI, and only two had any familiarity. Listen through the next fifteen minutes to hear my *Nuggets from the Mine* feature.

Podcast intro 03:27

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.

Sue Rericha 04:00



First, I probably want to find out why they got into advocacy. I'd encourage them to find a platform that they feel comfortable with. Don't bite off more than they can chew. It's easy to get overwhelmed. You want to do all the platforms, all the things. You want to do the politics and policies. The pharmaceutical side, the patient story side. Just pick what you're most comfortable with and just focus on that for a while.

Sharnae Smith 04:33

I usually point them to the [Lupus Foundation of America](#) (LFA). It's because they're well known. They have more resources and connections than I do, so I usually make sure people get my contact information. You may just need somebody to talk to. You may not want to jump into meeting by reaching out to the LFA. You may just want somebody to be a friend. And so I give them my contact information.



Christine Von Raesfeld 04:53



Funny enough, I would point them to [LinkedIn](#). Yeah. And that's because I started out doing a lot of stuff on social media. Facebook was. I started doing Facebook Lives before Facebook Live was a real thing. But I found a lot of negativities, a lot of misinformation, disinformation, and all that stuff over time. And I find that LinkedIn is a good resource for me. These specific things, looking at what companies are working on and actual real facts, right? Are there, and so I tend to tell people, look, if you want to get into advocacy, you have to be on LinkedIn, not social media, but LinkedIn. And find out what these companies are working on, find out what's out there in the future, and just gear your thoughts towards what's there and the potential.

Hetlena Johnson 05:48

First, I would point them to, of course, I'm going to say me. My website, thelupusliar.com. The other main thing I would point them to is not to be reluctant to ask their medical provider or medical partner team for information. Don't hesitate because they don't know what you need unless you ask.



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Brooke Abbott 06:22



Usually at other advocates. Also, I'm big on facts and myth-busting. And as a historian who does research, I will sit with someone and show them how to research something properly. And how to find the foundation on which they want to advocate. I think it's essential because when you first start advocating or when you first get diagnosed, and then you decide you want to advocate or you're a caregiver who wants to advocate, you just want to help, or you just want to find the information yourself. Usually, your advocacy comes from wanting to know how to help yourself. So, I try to help them, and this might sound like a little bit like branding, but I try to help them find their foundation and their platform. What exactly do they want to do? And it could be broad, but they must figure that out first. And then, they can go and find all the resources they need, research the information, and decide if they want to be someone who gives people social tips. Suppose they want to give people information on research and development or legislative recommendations. Like you must know what your lane is. And refine that day-to-day.

Bethany Yeiser 07:41

I love learning more about new clinical trials. Medications are coming out. One is called a [TAAR1 agonist](#). To be specific, it's a different mechanism of action for antipsychotics. It's in clinical trials, and other brand-new medications are coming through. So, I think that's one of the most exciting advances in the schizophrenia field right now. But yeah, if I were to talk to a newbie advocate, I would tell them to share their story. Everybody has to choose if they want to keep it as something in the past or if they want to share it, and every person will make that choice. But as for the people who do want to share, I would encourage them to go for it. Contact your local university or your church, perhaps. Contact [NAMI](#) (National Association for Mental Illness) chapters or other nonprofit organizations. Make yourself available. If this is something you want to do, then create a PowerPoint. I have a PowerPoint presentation I probably used at least a hundred times. And I would also tell them that choosing to advocate is rewarding. And I'm so glad I've done it over the years.



Michele Nadeem-Baker 08:59



I report for two places I consider the most. They have high credibility when it comes to cancers, which is patient power, an online resource [patientpower.info](#), and the [patient's story](#). And that is also online. I know they're very credible because I followed them. I've tested them. And the people who started them are also broadcast journalists and were trained to be credible, and at least we were, in telling the truth about things. But also, they do this very compassionately. I've been blessed to do this with each of them and for people with CLL [Chronic Lymphocytic Leukemia](#). The [CLL Society](#) is an excellent resource as well. And that is the leukemia that I live with. And they're both very good as well as there are support groups online. You must test and see which one is for you. But when online, social media, for instance, for CLL patients, there's one called the CLL Support Group. Easy to use, very intuitive. And also, I've started a woman's community. And it's called we have one for virtual meetings called [CLL Women Strong](#). The community that's on top of that we started is called [Kicking Cancer in Heels](#). And we found



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similarities between women, how they feel in their lives and how they're changed with any cancer diagnosis. And we, it's about living like in quotes with cancer and living your best life with cancer. So, it's everything around your cancer other than we certainly talk about it, but it's like everything else that happens to you. And we have specialists on about that. We have frank conversations.

Jenna Green 10:50

I would tell them to check depending on what they want to advocate for. Many of us have comorbidities as I do, but I primarily do my public policy volunteer work with the Multiple Sclerosis Society, the [National MS Society](#). So, if it's another person with MS, I tell them to go to the MS Society website. There's an advocacy section and even something as simple as getting started to receive email updates. They'll send you an email when there's information or a legislative bill that they're trying to get, gather support for. You can just fill out your support with the click of a couple of buttons. You don't have to go to the State House and testify to be an advocate. You can do it from your couch, bed, or hospital room. And that, for me, is fantastic, and most organizations have something like that now. So, I recommend going to your main organization and at least signing up for those emails or checking out what resources they have. Of course, Healthe Voices is a fabulous resource. I always recommend they have years of data and information. So the, [Healthvoices.com](#). And you can view past conferences and this conference that we are currently at, which is very exciting.



Kara Beck 12:15



Probably within their community, other people who have been advocating, that's what I do. I watch other people advocating and taking notes, I say, I like what they're doing, or I see them having success with something. And so, if a new advocate would ask, I would say to Watch other people you admire and try to do something similar or spin it for your advocacy. You can always spin it and tailor it to what you are advocating for if you like what someone else is doing.

A word from our sponsor, Abridge

Now a word about our sponsor, [ABridge](#). Record your healthcare conversations with doctors and other clinicians with Abridge. Push the big pink button and record. Read the transcript or listen to clips when you get home. Check out the app at [ABridge.com](#). or download it from the Apple app store or Google play store. Let me know how it went.



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Jasmin Pierre 13:30

So, the first thing that I found when I was researching was NAMI, the [National Alliance of Mental Illness](#). And I honestly feel like that's a perfect place to start because there's a lot of information about mental illness that people don't know about. And many people don't even know that there's probably a NAMI in your city that you can go to and find more resources. So that was one of the first times I felt like I was getting somewhere. So, I would tell a new advocate, like start there. It's important to research.



Alexis Newman 14:02



To other advocates? Just so that they don't feel like they're added by themselves. Because when you're first new at something, you often can feel isolated, or you may not quite belong. So, I like to point them to other advocates within the realm that I'm advocating, which is the diabetes sector. So my platform is Instagram, and also, I've been on many different podcasts and interviews. I'm also a registered dietician, so I write articles in a sense that reporters reach out to me. I give them the information and write articles to get it. And what's your Instagram handle? @ladiellex.

Ryan Williams 14:43

I would honestly just try and point them to influencers, not in the same space as them, that is doing something big and significant. So, like following Mr. Beast or other big YouTubers and seeing what they do. And then, research how they do what they do, and then apply that to the specific category you want to focus on. So, suppose your category is rheumatoid arthritis. In that case, that's cool, but you should see what is potentially working for other people and then see if that inspires you to make content that would resonate with those with rheumatoid arthritis. My platform of choice right now is Facebook groups. I love Facebook groups. I think they're such an important tool to let anybody ask questions. It's not a one-way street. It's a two-way street for information. So, I run the Alzheimer's and Dementia Support group on Facebook. I think it's like the second or third largest, with 30,000 members. And so, you can join that. You can see how the group is run. It's very hands-off. I hardly do anything in that group. I just help make sure it's a safe place for communication to take place. And I let everybody else ask whatever questions they need.



Andrew Schorr 16:04



I have a website, [patientpower.info](#). Helps, and I recommend some others. I try to help them identify the providers that are knowledgeable about what they have. Because a key source, obviously, for health information for people is a knowledgeable healthcare team. Because you want to get well, you need treatment. There are many other issues—affordability, living with quality of life, side effect management, and a million things. But first, I try to help people identify who the doctors primarily are, who are leaders for what they've got are, and ideally, to connect with them even as a second opinion. So even if you live in a very rural or remote area, can you somehow be in contact with the leaders for what you have so that your treatment plan and your diagnosis are accurate? Your treatment plan is on track with hopefully state-of-the-art medicine. Then the next step, of course, is affordability, which is a big thing



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now related to treatment. What are the resources to help you, depending on your financial situation? Are there foundations? Is there an advocacy group? If you're in the clinical trial, is there assistance to be in the clinical trial? So, it varies, but I think it starts with who's knowledgeable in treating you or advising your doctor on what treatment you should have.

Howard Chang 17:45

When it's tech, I don't understand. I go to my kids.



Rachel Star Withers 17:48



I always say start with what you know. Writing books might be good for you if you're good at writing and blogging. If you're just good at speaking and connecting with people, maybe you want to volunteer work and go to different centers. If you're already always on TikTok Instagram and you're good with tech stuff, a video might be your option. Too many people try and dive into the deep end, and they get overwhelmed. You were just trying to cover all the bases. Just start with what you know and branch out. Thank you.

Reflection 18:22

Fun, eh? I love the passion and diversity of people with lived experience. I especially liked Ryan's outside-your-bubble response to find good examples of advocacy in arenas in which you are unfamiliar. I resonate with Brooke's comment about showing newbies how to research. Bethany's suggestion about creating a PowerPoint for yourself worked for me. I have evolving resources as I keep clarifying what I'm about and what I offer. I think the mission statement. Mine is to *learn with people on the journey toward best health*. I appreciate that people offer themselves as resources. I often talk with newbies about how to create trust in themselves. I mention creating, documenting, and feeding your network. Feeding a network means responding when asked to help and replying on social media. People are more likely to respond to you if you've responded to them. I introduce people to PCORI and the Society for Participatory Medicine. Howard's statement, when it's tech, I go to my kids is spot on. For me, it's my grandkids.



Nuggets from the mine 19:55

I recommend following the [Knowledge for Caregivers](#) podcast, practical tips from Kathy, a geriatric nurse, on how to help your aged loved one. I use practical tips with my own family to help navigate the caregiving role. Ten to fifteen

minutes episodes range from activities of daily living (dental, showering, cooking, home modifications, driving), assisted living, power of attorney, conflict, pain management, case managers, and medical marijuana. Quite a broad spectrum. Practical, practical, practical. Check it out.



Podcast Outro 20:55

I host, write, edit, engineer, and produce Health Hats, the Podcast. Kayla Nelson provides website and social media consultation, and we both create video trailers. Joey van Leeuwen supplies musical



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support, especially for the podcast intro and out. I play bari sax on some episodes alone or with the Lechuga Fresca Latin Band. I'm grateful to you, who have the most critical roles as listeners, readers, and watchers. See the show notes, previous podcasts, and other resources through my website, www.health-hats.com, and my [YouTube channel](#). Please subscribe and contribute. If you like it, share it. See you around the block



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