

Techtopia with Chitra Ragavan

Episode 7: Vanessa Slavich and Pete Kane

Chitra Ragavan:

For nine years, Vanessa Slavich took a traditional reactive, whack-a-mole approach to manage her battle against a rare and aggressive tumor, working with highly specialized doctors in various treatment silos. Frustrated with the outcomes, this year, Slavich is taking a new, more proactive, and strategic approach. She's using her career in technology startups as a model for turbocharging her research and treatment options in a unique way, which she describes in a recent post in Substack called *The Startup Body: Managing My Healthcare Like a Boss*.

Chitra Ragavan:

Hello, everyone. I'm Chitra Ragavan, and this is Techtopia.

Chitra Ragavan:

Vanessa Slavich is taking a strategic approach to combat her rare tumor in collaboration with Pete Kane. He's Founder and Executive Director at Research to the People, a nonprofit biomedical research initiative based in San Francisco. Research to the People helps patients co-lead and direct new research and treatment options for their conditions. The group is creating a bold new model for patient-centric treatment and giving voice to patients who are grappling with rare and complex diseases.

Chitra Ragavan:

Slavich and Kane are both here today to talk about their collaboration and how it represents a milestone for the future of personalized medicine. Vanessa and Pete, welcome to Techtopia.

Vanessa Slavich:

Thank you for having us.

Pete Kane:

Thank you.

Chitra Ragavan:

Vanessa, tell us when and how you first found out about your tumor and what kind of tumor it is.

Vanessa Slavich:

I found out about it in 2011. I had just started working at Square. It was an early startup back then, and I was actually at my friend's graduation, and the chair was hitting my back in a very particular way. And I remember shifting back and forth and being like, "Man, this chair sucks." And then my friend looked at my back, and she's like, "Oh, you have a little bump."

Vanessa Slavich:

And I ended up getting a biopsy, and they found out it was what's called a desmoid tumor. It's also called aggressive fibromatosis, and it's a rare tumor. You're more likely to get struck by lightning than have this tumor. There's about 900 cases per year in the United States. And it basically is part of my connective tissue so it's everywhere in my body, but it's considered locally aggressive in that it likely won't show up in my foot or my brain. It'll probably always be somewhere near my back. But in the last 10 years, we haven't found a really effective treatment option.

Chitra Ragavan:

What was that like to know that you had a tumor that was rarer than being struck by lightning. That must've been quite a shock.

Vanessa Slavich:

I think the optimist in me is like, "Wow, I'm so special and unique. I'm really one of a kind." And then actually at one point, so part of the reason I'm working with Pete now is we've done quite a bit of genetic testing in this time period, and we've never found the traditional molecular markers of a desmoid tumor.

Vanessa Slavich:

So I've had one doctor tell me, "It looks like a desmoid and smells like a desmoid, but we can't actually prove it's a desmoid."

Vanessa Slavich:

And I even got a biopsy a month ago, and they tested it again. It came up with the same conclusion and so there's a possibility that my tumor is also a rare one in the world of desmoids, and so I could be one of a kind which, intellectually, is really fascinating and working with Pete... I told him this week, the innovation side of this I love, and it's like, "Wow, this is so interesting." And then I'm like, "But it really sucks." So I'm really curious about it, but it's also really pretty overwhelming.

Chitra Ragavan:

I guess the startup, techie geek in you really appreciates it, but at an emotional level, it packs a punch, doesn't it?

Vanessa Slavich:

For sure.

Chitra Ragavan:

Now, you've given the tumor a nickname. Tell us how that came about and why you call it what you do.

Vanessa Slavich:

So my tumor is called Ursula which is funny because my fiancé used to date someone named Ursula, so that's a complex name, but I actually named her a long time ago when I found out that the way desmoid tumors kind of react is that they don't invade in that it wouldn't show up in my blood as I was kind of explaining, but they push, and they have tentacles. So there's no...

the idea of clear margins is kind of nebulous, partly because it's part of the connective tissue. And so it's kind of this evil thing that's very hard to die or very hard to kill, and it has tentacles.

Vanessa Slavich:

And so I started getting this image of Ursula from the Little Mermaid, and it just felt fitting. And then after a pretty massive surgery I had in 2018, it came back in three places. And so now, Ursula has her little eels and it just... the metaphor keeps going, but I actually met another desmoid patient probably five years ago, and she also named hers Ursula for the same reason. So I feel like it's quite fitting.

Chitra Ragavan:

That's interesting. Now, it's rare, but very aggressive at a local level. And it's not a cancer, right, but it acts like one, and it's typically treated by cancer doctors.

Chitra Ragavan:

What kinds of treatments have you had to date? I mean, this has been going on for a long time, hasn't it?

Vanessa Slavich:

Yeah, like I mentioned, 10 years. So depending who you ask, it'll be classified as cancer or not. As you mentioned, technically, it doesn't metastasize, so in a typical sense then, you wouldn't consider it as cancer, but I had one doctor tell me it's actually worse because it's part of my connective tissue which is everywhere.

Vanessa Slavich:

And so my treatments, as you mentioned, are all cancer centers. I get treated at UCSF, Ohio State. I'm now being treated at MSK in New York as well.

Vanessa Slavich:

And the treatments I've had to date, I've had surgery twice. I've had an operation called HIFU, which is High-Intensity Frequency Ultrasound, which they basically hack an MRI bed and shoot laser beams at your back which I did twice. And then I did two months of radiation, had a really massive surgery in 2018 where they took half my lat out and part of the spinal processes and then put a big skin graft, basically the size of a sheet of paper, over everything. And then it recurred after that which then came back in three places and then it pushed through the skin graft, so now I have an open wound and then since then, I've been on three different types of chemotherapy. And we're looking at kind of really interesting... there's a lot of progress in this space. And so we're looking at more localized chemotherapy options where the same chemo compound could be put directly on the tumor instead of systemically throughout my entire body.

Vanessa Slavich:

So that's some of the possibilities in the future, but then with Research to the People and all these different doctors I'm working with now, we're considering basically vaccine-type technologies and gene therapy, and there's a lot of other new innovations that could be potential treatment that's in the future.

Chitra Ragavan:

So you said in your piece that you were taking a fairly traditional approach to managing your treatment and care, and you likened it to or contrasted it with hair care. Can you give us that analogy and explain what the change has been in how you manage your care?

Vanessa Slavich:

So for a long time, so I also used to race at Ironman Triathlons and be super active. And actually while I was getting radiation, I did an Ironman. It's like, I was just kind of like, "Cool. Let's go." And so I tried to compartmentalize it, basically put Ursula in a box and live my life, and so I was still working at startups and crazy hours, and I did research in a refugee camp in Tanzania. And at the time, I was on chemo and struggling walking and my hair is falling out. So it's like, I've definitely tried to live my life, despite all this happening in the background.

Vanessa Slavich:

And I used the hair metaphor. I have an amazing hairdresser. I've been going to him for almost 10 years. And he has helped me... basically, I go to him, and I'm like, "Hey, I've actually, quite a few times, wanted to look like Taylor Swift." I just think her hairstyles have been lovely over the years, and so I'm like, "This photo of Taylor Swift." And then he's like, "Cool," and then he just does it, right? And he cuts it, he cleans it, he styles it. He does everything, and I don't have to think about it.

Vanessa Slavich:

And I've wanted that from the medical doctors and field in that I have my oncologist, and I just want to go to him and be like, "This is what I'm noticing," and then we talk about the scan, and we're like, "Cool. This should be your treatment." I'm like, "Great." And that's what I want, but that is so far from reality.

Vanessa Slavich:

And this is not a fault of the doctor, right? It's just a part of the complexity of the system, but B, the way the medical institutions are set up right now and kind of the medical industry, at least in the US, is it's all around silos and specialties. And the patient is the only connection between all these different doctors.

Vanessa Slavich:

And so in one regard, it's really empowering that I can make decisions and navigate my care, but am I equipped to do that, and how do I actually navigate when one specialist is telling me A and another specialist is telling me B. And I'm really trying to get clarity, not consensus. And I think the default is you kind of get into a world of consensus. Well, if three out of four doctors recommend that I get chemoembolization then maybe I should get chemoembolization where, in reality, that might not be the best option for me, especially when I don't have data to clarify what that path should be.

Vanessa Slavich:

So we've been flying blind. It literally feels like you put your finger in the air, and you're like, "It feels warm today. It's like, "Can we measure it? Can I tell you what's the temperature outside?"

Vanessa Slavich:

I kind of started with all of my treatment at UCSF with one doctor, and then I went to MD Anderson in Texas and Ohio, and then I was kind of triaging decisions, as I mentioned, looking

for consensus. And then, now it's a totally different approach in that I recognize that I just need to drive the process. And Pete has definitely helped a ton with this mindset and the team at Research to the People.

Vanessa Slavich:

And so instead of waiting to be told what to do or what my options are, it's doing a lot of independent research, deciding what data we need, having an independent team. We have weekly stand-ups, et cetera, and so we're kind of... we have our own, actually, three-part strategic plan, and I'm tapping into these different institutions and doctors that align to my plan.

Vanessa Slavich:

And so kind of going back to the hair metaphor, then, it's a totally... I'm not going to one doctor or one hairdresser for a plan. I'm coming up with my own and tapping into the resources that I need to execute on it.

Chitra Ragavan:

So Pete, tell us a little bit about yourself and why you founded Research to the People.

Pete Kane:

Hi, so the organization actually had quite a runway to become what we are today. In short, what we're doing right now is working with patients with the most challenging cases where they're in rare cancer or rare disease and really, patients that are, like Vanessa, who've been on nine lines of therapy and still trying to figure out what is going to work for them. And especially... and Vanessa's case is especially unique because it hasn't been able to be clinically diagnosed as a desmoid tumor.

Pete Kane:

Our program got started in 2017. And back in the early days, we were a community group that was doing a lecture series about how AI has been used in healthcare. And we had just some of the smartest people showing up on a monthly basis to our lecture series in the Bay Area. I was really eager to do more with the wonderful folks who were showing up.

Pete Kane:

So I had had the idea to get a dataset from a hospital or something that we could work on as an open source community project. I call up the hospitals that I knew and said, "Hey, do you have any rad data that we can hack on as an AI community group?" And every hospital said, "No."

Pete Kane:

So approximately around the same time, I met Onno Faber who is now a quite well-known patient and founder in the Bay Area. And Onno has a rare condition called NF2, neurofibromatosis type two. He had his tumor sequenced at the Broad Institute so he had exceptional data for his tumors, and he was dissatisfied with the current clinical options for NF2 and was seeking alternative routes.

Pete Kane:

So Onno and I decided to host a hackathon where we bring together a bunch of scientists, interdisciplinary scientists across AI, bioinformatics, biology, and computational biology and get

everyone in the same room and release his genetic data to the group and see what more could be done or what new avenues could be presented for Ono and Ono's case.

Chitra Ragavan:

And so how did that then lead to Research to the People as an organization?

Pete Kane:

So after the first event, there's 150 people that showed up at Google in San Francisco to work on Onno's case. And the energy in the room, all the cues was... it was more amazing than we could ever have predicted. The energy that it created was phenomenal. Folks were... the passion that the scientists came to the room with and being able to work with a patient and contribute to a patient case was... it cued us in that we were onto something really important and really, really big. And we shifted our entire organization to replicate what we had done with Ono for other patients.

Pete Kane:

And the second patient we worked with was actually a participant who helped analyze Ono's tumors in the first case. Bill Paseman, he approached me afterwards and said, "Hey, I have a rare kidney cancer. Can you do the same thing for me?" And so we embarked on getting sequencing for Bill's tumors and replicated the same type of event.

Pete Kane:

And since then, we've worked with two other patients, so four patients in total, and currently, we are working with four patients in 2021.

Chitra Ragavan:

So you're working on a small scale, but the results and the model could be broadened out, do you believe, on a large scale?

Pete Kane:

I believe it can be expanded quite a bit. Whether or not this work can truly scale to the masses is TBD. I think that there's going to be a lot of technology innovation that comes out of our group. Frankly, there already has been a lot of technology innovation that has come out of our group or where our group has been a connecting point for scientists who go on to work on collaborations together or in some cases, start businesses together, startups.

Pete Kane:

I think we're really focused on being low volume and going really deep with one patient versus trying to tackle a larger space right now.

Chitra Ragavan:

What's your background, by the way? Tell us a little bit about yourself.

Pete Kane:

Well, I studied Chinese language and literature at the University of Minnesota, and then I embarked on a long healthcare entrepreneurship journey. Started a number of healthcare startups, started a healthcare technology community based in Minnesota. And then when I got

to the Bay Area, I just defaulted to the community building side of what I was interested in, and that's the foundation of this group.

Chitra Ragavan:

Did you say you started by learning Mandarin? Is that what you said?

Pete Kane:

Yeah, I did. Yeah.

Chitra Ragavan:

So there's a story here about how you went from Mandarin to healthcare research.

Pete Kane:

I don't know. I studied Chinese language and literature in school. I mean, I have three Chinese adopted sisters, and so it made sense. But in terms of career, I wanted to do... I wanted to be in healthcare and technology.

Chitra Ragavan:

That's great. So how does it work? Say, let's take Vanessa and Ursula, and she's hit a dead end in her treatment or not entirely satisfied with the how it's being managed, how to find the state-of-the-art research because it's such a rare condition. What happens next, Vanessa, when you found Pete somehow? How did that happen, and then how did you guys end up deciding to work together?

Pete Kane:

I mean, Vanessa can talk a little bit about how she found out about our organization. The first thing that we do when... we have a patient application process, and we recently implemented a system where the new patients to our program are selected by the previous patients that have gone through our program as a committee because the past patients know exactly what makes a good case and a good patient for our program. We end up working extremely closely with the patients, and in most... in a lot of cases, it becomes sort of a full-time position where the patient is working alongside with us every step of the way.

Chitra Ragavan:

That's great. Vanessa, how did you find Pete?

Vanessa Slavich:

It was in December. I was looking... I was doing some research and just recognizing that I needed a new approach and kind of what other options are out there, and I read an article about the last case they worked on, the woman named Leila who was the founder of Samasource. And just hearing about the approach, I was kind of curious, and then I read their website, and I applied using a Google form which I remember being, "Wow, that's so interesting for the medical field." I was like...

Vanessa Slavich:

And then, literally, it was a Sunday night and then an hour later, I got a response being like, "Let's do a call." And I was like, "Whoa, this is very different than any other kind of medical

experience I've had." And Pete and I had a call, and then we talked about going on a bike ride when he was in town, and it just felt exciting.

Vanessa Slavich:

And when we started talking, I think one of the things Pete's downplaying a bit, but his strength is really the interconnection between understanding how the hospitals work and what the doctors' motivations are and what the patient needs are and what the nonprofits and the funders. He kind of sits at the intersection of all these different organizations and can translate.

Vanessa Slavich:

And so for me, he's speaking, "We're going to do this hackathon. It's going to be open source. We're going to get more"... I'm like, "Cool. Got it. All of the above." But then when talking to doctors, it's like, "We're going to have a patient deep dive. You're going to have access to X and X data. We're going to do the sequencing."

Vanessa Slavich:

And so in talking with him, he was speaking my language and kind of understanding where I was at. And I was like, "Absolutely, this sounds amazing." And I knew that it's just something that I wanted to put my energy towards.

Chitra Ragavan:

So what does the Goodbye Ursula strategic plan look like in this new sort of startup scenario with your hackathons and your Slack channels and your weekly stand-ups, and you've got a team you've put together. Tell us what it looks like and how it's different than traditional sort of relationships with doctors and all of that.

Vanessa Slavich:

So our team is currently eight people, and it's cross organization and institution. And that's just the core kind of working group that we meet weekly and have meetings with all different experts.

Vanessa Slavich:

And then the strategic plan is a three-part phased approach. So the first part is shrinking the current tumors and hopefully, kind of eliminating to some degree. And then once my back is flat, and we have kind of that situation under control, there's going to be a different team of experts that come in to help actually close the wound. And one of the doctors thinks we can actually do it in a way that's cosmetically appealing as well as going to stay closed and resolved.

Vanessa Slavich:

And then the third part is what's our long-term suppression strategy? In the last five years, at least, nothing has been able to stop the growth. It'll shrink, and it'll grow off something or recover from a surgery and then it'll come right back. And so it's been this yo-yo for the last five years.

Vanessa Slavich:

And so we need some sort of systemic treatment modality, not that I necessarily need to be on it forever, but we need to explore what the options are and kind of understand at a root level what's driving the growth again because we haven't found the traditional markers or mutations

which may be there, but if we do find that in the research, then it could point to different clinical trials that I could be part of, for example.

Vanessa Slavich:

So part one, shrink, part two, close, part three, long-term strategy.

Vanessa Slavich:

And then there's kind of the core working group, but then we're tapping into different doctors and organizations based on the treatment needs or kind of the different findings at each phase. And so as part of this whole plan, there's collecting all of the data. So we had a big meeting with about 10 doctors on Monday, doctors and scientists, working through what is all the data we want to collect which is about, I think, 15 different kinds of sequencing-type tests. And then once we get all that together, organizing this hackathon of sorts or this kind of patient deep dive experience. We're deciding if it's remote or in person, given COVID, and then actually presenting the findings to teams of doctors, including my doctor to help them navigate decision-making and help me find treatment options.

Chitra Ragavan:

So I'm curious to know what are the biggest obstacles both you and Pete confront in this type of approach? I mean, one thing I'm thinking of who's paying, right? How do insurance companies react? Is this different in any way? And you've got this huge team and is there... I mean, just tell me what are the intricacies of getting somebody to pay for this stuff and then other obstacles that you might find?

Chitra Ragavan:

Vanessa, do you want to go first?

Vanessa Slavich:

So, as part of the program, I haven't actually paid anything yet which is also quite amazing that Pete's been able to do a lot of this bootstrapped. But Pete's working on a separate kind of longer term fundraising plan for Research to the People.

Vanessa Slavich:

But as far as my data sequencing, we're reaching out to the different companies like Oxford Nanopore to see if they would donate the data. And then in exchange, have a case study for how the data is used. But then also doing fun things like familiar, I work in crypto, and we're creating an NFT inspired by Ursula, and so that could potentially help fundraise for not only myself, but for the cohort, for Research to the People and so looking kind of fun, innovative ways to also bring more awareness to the program because I do think as this program scales, there's going to be a lot more opportunities for people to kind of understand and kind of embody the patient-led research approach. And so I do want to share this program and all the amazing things that it's already done for me with the broader tech community.

Chitra Ragavan:

What does the NFT or non-fungible token look like? What is it?

Vanessa Slavich:

So it's still a work in progress. It's actually a woman's name, the artist's name is and she has some really innovative ideas. I have a pretty massive scar on my back and so relate it to ecosystems and potentially something related to Ursula, so it's going to be some sort of physical body work.

Chitra Ragavan:

Sounds great. You mentioned your back and in your piece, I think in your earlier piece about "Ursula, the Origin Story," you talked about how you had massive surgery on your back and that you really couldn't bear to look at your back for almost a year. So there's a... you're very strong and positive, but I see there's this huge emotional component in dealing with an adversary that just won't go away. What's that been like?

Vanessa Slavich:

Been hard, for sure. I've definitely gone through my own spiritual journey and in relation to Ursula where, initially, I just wanted to get back to life. And so when I was getting radiation, I was feeling really fatigued, and my back was getting really fiery, and the skin was breaking down, and it was emotionally taxing.

Vanessa Slavich:

And so I planned a funeral for Ursula, and it was Little Mermaid themed, and we ate fish, and it was like, "See ya," and at the time, she wasn't gone. She was shrinking. And so it made me feel like I had something to celebrate.

Vanessa Slavich:

And so that helped, but that was kind of... I was like, "Once you're over, just need to get this over and be done with." And over time, I've just kind of moved into acceptance that maybe it's not going to be over. Maybe it'll never be over. I don't know. But grateful for today and grateful for this life and just trying to kind of take it as it comes and not overthink it. And in the process and especially the last five years, I've really moved a lot more to acceptance.

Vanessa Slavich:

I read a book called The Book of Joy with Archbishop Tutu and the Dalai Lama. And they talked about the difference between finding a cure, but still being healed. And I may never have a cure, but I can still find healing. And so that's been a big focus for me is just how do I heal through this process, both physically and mentally and emotionally?

Chitra Ragavan:

And Pete, I'm sure that one of the big things you offer in addition to all of your expertise around the healthcare system is sort of this ability to support patients like Vanessa in their journey as they tackle these very rare conditions.

Pete Kane:

Working with patients is incredible. Vanessa has been absolutely amazing.

Chitra Ragavan:

How do you see this, potentially, in terms of the future of precision and personalized medicine at this incredible genetic and molecular level, and where do you think this can lead in the future? Pete, what do you see as your vision for this?

Pete Kane:

It's a really special place in time where we have more data types coming online, especially in the research-grade data coming online and more and more algorithms being developed to provide personalized insights on this data. And I think the patients like Vanessa and the patients that are sort of more advanced and taking more ownership of their care really realizing that there's a lot more data out there that you can get.

Pete Kane:

I mean, if you read the research, there's incredible things happening on the research level that just aren't really accessible at the clinical level. The number of cancer patients that aren't getting sequenced is still quite high.

Pete Kane:

And one of the biggest things that people should realize is that there's a huge delta between what's available through the clinic in terms of sequencing and what's available at a research level in terms of sequencing and other data generation.

Pete Kane:

So part of the genesis of our program is generating research-grade data for a patient and then bringing that data to the researchers who are experts in that data and seeing what more we can uncover and provide insight back to the patient and/or their doctors.

Chitra Ragavan:

Vanessa, what do you see as the future, having actually, from a patient perspective, having been through all this?

Vanessa Slavich:

I think a big part of it is the mindset leading into it, moving from, "I go to this doctor, or I go to this hospital." I've learned a lot of things like the bigger the hospital brand, the more risk-averse they're going to be because they're protecting that brand. And so the best cancer centers might not actually be the best treatment. And so a big part of it is that you're the one living the reality and so as the patient, and so you have to advocate for yourself at the end of the day.

Vanessa Slavich:

And it's overwhelming when you are the one getting treatment and managing all this stuff. You need a team around you. That's literally the only way to do it. And I'm so grateful to Pete and the rest of our team for kind of jumping in. Pete's educated me so much on gene sequencing. I would watch the docu-series. I read the book. I'm learning so much about this process, and he's definitely helped educate and advocate for me.

Vanessa Slavich:

And in that process, I've been owning more and more of my journey and my kind of own medical care. And I think this is the future that the reality is it takes a lot of time and energy. And so, again, the team is an essential component of that.

Vanessa Slavich:

But if we can get real data and this is where the startup and data-driven decision making, right? Data's not the answer. Data's not everything, right? It's art and science, but right now in the last 10 years, it's only been art in a way. It's like, "Well, we could try this. We could try that," and there's been no data to kind of justify any decision for my care ever.

Vanessa Slavich:

And so I can be on some chemo for a year and not know if it's going to work. Even the way we measure it, the MRIs are kind of a broken system too. And so this kind of patient-centered care where it's literally about my case and not about some standard norm. Clinically proven doesn't matter when you have a rare disease because it's rare. The stats don't matter, and so what are my stats?

Vanessa Slavich:

And so I think the future is really driving your own kind of data discovery and bringing a team around and then tapping into the care that you need. And I hope that more people have access to this because it's really... I predict it's going to be a huge game-changer in my care.

Chitra Ragavan:

I was very struck by one of your thoughts in your piece. You say, "As this journey continues with no end in sight, I have slowly transitioned towards a mindset of acceptance and love. I attempt to speak positively to Ursula, to check in and see what she needs. I've slowly let go of my suffering and moved to a place where I can mentally and emotionally help others and surround myself internally and externally with joy."

Chitra Ragavan:

And I was just so struck by this idea of being able to speak positively to this incredibly aggressive tumor that's haunting you, and this huge step that you've taken from when you had major surgery and you were dealing with all of the consequences of that.

Chitra Ragavan:

What advice would you give others who are dealing with these situations of how they can get to the place where you are of being able to speak positively to a tumor that's endangering them?

Vanessa Slavich:

Are you familiar with the word equanimity? It's that still point between effort and ease and so acceptance... some people are like, "You can't just be accepting and passive," right? And so there's this... that's kind of one end of the spectrum, but you also... my initial approach was like, "Let's get... this is going down." And so it was probably the other side of that spectrum. And so I've personally found this state of equanimity by going through the range of acceptance to full kind of aggression. And I think it is an evolution.

Vanessa Slavich:

There's something called the grief cycle. And when I get new information that the tumor's growing, I definitely go through my own grief cycle of denial, et cetera, but then eventually, I get to acceptance, and I have a bunch of tools. I play the harmonium, I hike, I bike, I have a community, I cook. There's all these things that help bring me and ground me.

Vanessa Slavich:

And then once I can process the reality of this kind of situation or whatever's going on, I move into planning and in December, when I reached out to Pete, that's where I was. I was like, "I need a plan."

Vanessa Slavich:

And so I think part of it is just recognizing as a patient or as someone who's dealing with something kind of heavy and overwhelming. It's like, "Where am I on? Where am I on this grief cycle" because it's overwhelming. And again, right after surgery, I wasn't ready for a plan.

Vanessa Slavich:

And so part of what's helped me is recognizing where I'm at, acknowledging it, moving myself through the cycle. And then once I'm ready to plan, finding the right people or resources to help me kind of put together what I need to do and kind of move on.

Vanessa Slavich:

But the reality is if you got some cancer diagnosis today, you're probably not going to be ready to engage with Research to the People tomorrow. It is definitely a journey. So just being kind to yourself and knowing that you might just be in the cycle and you might be in this process and finding whatever tools help you lift out of that cycle so that then you can find the people who can really make a difference for you.

Chitra Ragavan:

That's amazing. And you even managed to run a half marathon last March in the middle of all of this. I don't know how you pull that off.

Vanessa Slavich:

That was amazing. It was actually March 1st, so it was right before they shut down. And so I'm so grateful I did it. I was on chemo at the time, and I ran 8:30 pace which I was pretty proud of. And it was my first big run post-surgery, and it felt like a huge accomplishment just getting back out there and training with my good friend, Arielle, waking up every day and just seeing what the body is capable of.

Chitra Ragavan:

Physical and symbolic.

Vanessa Slavich:

Exactly.

Chitra Ragavan:

Wonderful. Pete, do you have any closing thoughts on this journey that patients like Vanessa are going through and on your efforts to try to help them?

Pete Kane:

The program that we've put together is really possible because of the huge biotech influence in the Bay Area and the universities here. And none of what we would have done, none of what we've built, and how we've worked with the patients would be possible without an incredible number of industry and academic partners and just the all the scientists willing to dedicate their time to a patient case. So I think I like to default to their accomplishments and the patients versus our program. I really just feel like a connector in between the two spaces.

Chitra Ragavan:

And you have some really important strategic partnerships, both completed and underway, as well with some of these major healthcare institutions and academic institutions as well.

Pete Kane:

We're excited to make some announcements soon.

Chitra Ragavan:

That's great. Well, Vanessa and Pete, thank you so much for joining me today and for this great conversation.

Vanessa Slavich:

Thank you, Chitra.

Pete Kane:

Thank you so much.

Chitra Ragavan:

Vanessa Slavich is head of community for Celo, an open source platform making financial tools accessible to anyone with a mobile phone. Slavich is taking an innovative and strategic approach to combat her rare and aggressive tumor. You can read about her efforts in her fascinating new post in Substack called *The Startup Body: Managing My Health Like a Boss*. And don't miss Vanessa's original story about her battle with the tumor, which she's nicknamed Ursula, also in Substack, entitled *Ursula: The Tumor Origin Story*.

Chitra Ragavan:

You can follow Vanessa on Substack under Vanessa Slavich.

Chitra Ragavan:

Pete Kane is Founder and Executive Director at Research to the People, a nonprofit biomedical research initiative based in San Francisco. Research to the People helps patients co-lead and direct new research and treatment options for their conditions. The group is creating a bold new model for patient-centric treatment and giving voice to patients who are grappling with rare and complex diseases.

Chitra Ragavan:

This is Tectopia. I'm Chitra Ragavan.

Chitra Ragavan:

Techtopia is a podcast from Goodstory, an advisory firm helping technology startups with brand strategy, positioning, and narrative. Our producer is Jeremy Corr, founder and CEO of Executive Podcasting Solutions with production assistance from Kate Cruse. Our creative advisor is Adi Wineland, and our research and logistics lead is Sarah Möller.

Chitra Ragavan:

Don't forget to subscribe to the show on Apple Podcasts or your preferred podcast platform. And if you liked the show, please rate it five stars, leave a review, and do recommend it to your friends, family, and colleagues. For questions, comments, and transcripts, please visit our website at [goodstory dot io](http://goodstory.io) or send us an email at [podcast at goodstory dot io](mailto:podcast@goodstory.io).

Chitra Ragavan:

Join us next week for another episode of Techtopia. I'll see you then.