

Just Talking Podcast with Alice Bast

September 6, 2016

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- Chris:** The views and opinions expressed in this podcast are mine alone, and do not necessarily reflect that of my employer. After all, we're just talking.
- Welcome back to another episode of Just Talking. This is episode 360. I'm Christopher. This is a podcast for September 6, 2016. I don't have anything pithy to say about September. Actually, by the time this comes out, it will be my dad's birthday, so happy birthday dad in case you're listening. On the other line, Alice Bast. Alice, how's it going?
- Alice:** Oh, it's going really well. Thanks for inviting me to the podcast, Chris.
- Chris:** I received a very thoroughly worded e-mail that intrigued me, and mentioned some things about Medicine X that we're going to get to by the end of this podcast, and I said, 'You know what? This sounds like a fun chat. I will follow up with this pitch.' And here we are today. My first question for you is, how often do people mispronounce your last name and say 'Best'?
- Alice:** You know what, they call me 'Blast'. B-l-a-s-t is what they say—Alice Blast, so I decided that I must be a blast. So I talk a lot about celiac disease, it might be boring to some people, but they do mispronounce my name every so often.
- Chris:** Yeah, I'm looking at my chicken scratch notes that I do for every podcast, and my handwriting is so horrible that your last name actually looks like 'Best'. This is how I write it, so I'm guessing that depending on people, if they're just looking at your name at a glance, or on a business card, they might accidentally say 'Best' instead of 'Bast', but maybe that's just a 'me' problem and not like the rest of the world. I don't know.
- Alice:** Well you know what, I'm okay with 'Best,' but no, it's 'Bast,' B-a-s-t like the cat goddess, right?
- Chris:** Yes, perfect. Alright, so I tend to sort of infamously do about ten minutes of research before my podcast, I'm not too prepared, so it's nothing too scripted, and in stalking you on LinkedIn I saw that you've basically had one job for the past thirteen years, and that's kind of incredible. I guess to sort of set the stage for this, how did you get involved in celiac awareness?
- Alice:** Well, my job is my passion, and I was for many years, eight years in total, I was undiagnosed with celiac disease. So I walked around from doctor to doctor, 23 in all, with lots of different symptoms, and lots of different diagnoses. I really

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started Beyond Celiac based on my personal story, so whatever the symptom was, was what the doctor would diagnose me with, some kind of medication to treat the symptom and not the cause of the illness. Not like diabetes many times has the same kind of chronic disease, it takes time to get the diagnosis, and in my case, before I was diagnosed, if you go from my head to my toes, my hair started to fall out, I actually had started getting a lot of cavities in my teeth, I had chronic diarrhea - nobody wants to talk about that - I had neurological problems, and then I had a full-term stillbirth, three miscarriages, and my youngest daughter was born at two pounds.

Chris: Wow.

Alice: And at the time you can imagine, because celiac disease is a genetic autoimmune disease triggered by consuming the protein called gluten, and we know about the gluten-free diet, which is found in wheat, rye, and barley - but when a person with celiac disease actually eats gluten, the protein interferes with the absorption and the nutrients from the food, which causes damage in the small intestine. So I was not absorbing my nutrients, and finally, the family veterinarian, when I was down to - I'm 5'9" and down to about 105 lbs. - said, 'You know, sometimes animals have trouble with eating grains. Ask your doctor to test you for a disease that's associated with gluten, and it's called celiac.' So I credit my diagnosis, after an eight-year journey, to the family veterinarian.

Chris: Wow. There's a lot to unpack there. I think just at the outset, I mean that eight years is a really long time to be told, not necessarily that it's all in your head, but also that your pain and your struggles are not necessarily as real as what they are. I mean I can just immediately draw comparisons between the diabetes community, between a lot of people that are experiencing chronic pain where they are just looking for validation that what they're experiencing is real. What did that ultimately, when you got that positive test back, what kind of emotions were you feeling at that point?

Alice: Oh, Chris, that's such a great question, because I was told it was all in my head. I was told I had postpartum depression. And my mom died of pancreatic cancer when I was twenty years old, so I was convinced I was dying of cancer. So when I got that initial diagnosis, and the doctor told me, I went in and had the blood test, and then they went in and they confirmed it with something called an endoscopy, and said, 'Well the good news is we've found out what's wrong with you, but the bad news is you can't eat gluten, and it's in everything,' I just remember that minute, I looked at them, and I said, 'I can't have gluten? I don't know what gluten is, but I'm not dying of cancer.' I felt relieved. I felt so relieved, I felt finally that someone had figured out what was wrong with me, and the best part about it was I wasn't dying.

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So I had to figure out what gluten was, and what I could eat, and what I couldn't eat, but at least I had a diagnosis. I had some kind of label.

Chris: So that crash course in understanding not just diet and nutrition, but also how to be on the lookout for potential opportunities for cross contamination, things like that, that's a really immediate learning process for you, especially because your health and your life is at stake, so you have to do whatever it takes to really get on board, and really understand what it's going to take that to lead a healthy life. What was that learning process like for you in the early months and years?

Alice: Well, I had a background. I've always been interested in health and wellness, and I've had a background in nutrition, and my husband was very cooperative, and so he said, 'Okay, well we can do this.' So there was a lot of elements there that really empowered me to take my health in my own hands, and really from going from doctor, to doctor, to doctor, and having been - again, as you're talking, it's in your head, or kind of putting that label on it, going through that journey empowered me to start to really take my health in my own hands, and look at how I could be as healthy as possible, and learn to speak up and advocate for myself so that I didn't take those risks. Because eating a one hundred percent gluten-free diet is not easy. It is not easy. Every time you put a bite of food in your mouth, you have to be concerned whether there's any kind of cross contact.

So you're constantly on call. And at the time, I had to learn to advocate for myself. I had to be a detective, and I had to make sure that I had access to gluten-free products, which was not easy. When I was diagnosed, which was twenty-three years ago, we actually had to order our food from Canada at support group meetings.

Chris: Wow.

Alice: Yeah, the world has come a long way, right?

Chris: Wow, okay,

Alice: Yeah, picture that world.

Chris: I was not ready for Canada to give you an assist on that one. So as you mentioned, when it comes to being aware of cross-contamination and specific ingredients like when you're going out to eat for example, there's that weird line of not wanting to be annoying, or overly aggressive with wait staff or anything like that, but also your health is at stake, so it's within your right to ask about how things are prepared. How did you go about navigating that fine line between the super annoying customer, and 'I have to ask these questions because my health depends on it'?

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Alice: It's changed. So it when I was initially diagnosed, nobody even knew what gluten was, so I would have to give an entire story. I would say, 'I have celiac disease. Do you know what that is?' I'm a very empowered person, and I may not be the norm, because I speak up, and I tell people that I have celiac disease, and I will tell them, 'If I have one particle of gluten, if you serve me a salad and you have croutons on it and you pull the croutons off that salad, the croutons will actually set off an autoimmune reaction.' I say it's like an allergy, which it's not really, but I want to make the point that it is a serious condition, and that that particle will set off a reaction, and I will be sick. So I started educating the wait staff in a very detailed process. Actually how I did that is I called in advance.

Because you don't want to be going out to dinner, especially I was working in a business environment, and all of a sudden you're the subject of the entire dinner table. Everybody is like, 'Oh, what? You have a disease? Tell me about it.' So typically I would call the restaurant in advance, and make sure that they could accommodate my diet, and if not, I would eat in advance, and I would eat a little bit of food. And I remember going to a wedding one day, and they couldn't accommodate the diet, so I brought my own food, and the gentleman sitting next to me said, 'Are you anorexic? You are the pickiest person I've ever seen.' So you do tend to get those labels, and people looking at you if you're acting differently.

Chris: So that's I think a perfect segue into the current dilemma that I perceive when it comes to living with celiac disease, and that's the other side of the equation when it comes to this food choice that some people can make as far as leading a gluten-free diet, where it's optional for them, they opt into it, and I think that there is sort of a stereotype and sort of like an internet meme of an uppity sort of hipster who's talking about how they have a gluten-free diet, and that's just like their new thing, and how they're so healthy and all these other things. But then on the same side, there are people that require a gluten-free diet that sort of suffer, because of the stereotypes of the people that opt into it, and because of the perceptions of those stereotypes, and everybody around suffers because of that perception. It's a really big topic to try to address, and also kind of leads into what you guys are doing with Beyond Celiac, how do you deal with that sort of broader stigma that comes with you requiring a gluten-free diet, whereas other people can opt into it?

Alice: Chris, you hit the nail on the head. So when I founded the organization in 2003, we launched a national awareness campaign, it was a general awareness campaign, and we focused on access, availability, affordability of gluten-free products, and we did these events around the country called gluten-free cooking sprees where we partnered with doctors and chefs, and our goal was to make gluten-free food mainstream. That was it. We were going to get gluten-free food into grocery stores around the country, and make sure that our community had

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safe gluten-free products to eat. We didn't realize that the gluten-free diet would overshadow the seriousness of the disease. So ten years later, we took a step back in strategic planning, and said we need to be changing all of our messaging. We need to really listen to our community, and gauge our community, and understand how we could advance celiac disease as a research agenda, and establish it as a serious genetic autoimmune disease, and not one that is just, 'Oh, you're on a gluten-free diet.'

One example I like to talk about, and it includes diabetes, is if you go to the doctor, and the doctor thinks that you might have diabetes, they're not going to recommend you try a little bit of insulin to see if you feel better, and oftentimes, unfortunately for the celiac patient, when they go to the doctor, the doctor can recommend that they try a gluten-free diet to see if they feel better. So we have a lot of work ahead of us to really educate and empower the celiac disease patients to get properly tested, and actually work with the medical community as well, and to be publishing research so that celiac disease is seen as a serious genetic autoimmune disease, and our community is properly tested.

Chris: Do you feel - and this is kind of like a broader question for the entire celiac awareness and advocacy kind of groups - the larger you, do you feel like you sort of unknowingly created a monster in advocating for access to gluten-free foods and gluten-free products. and because there was a sort of outside kind of audience paying attention to that, that that sort of snowballed things out of your control, and changed the narrative of what you guys were actually trying to accomplish?

Alice: Well, that's a great question as well. We're really proud of what we accomplished, and we had to make sure that that there was access and availability to gluten-free products. So sometimes you solve a first generation problem, and it causes a second generation problem. I remember the pivot point in time when the message started to shift, and that was when I was working with Anheuser-Busch on launching the first gluten-free beer called Red Bridge, and we were really excited to be launching the first gluten-free beer mainstream in the United States. Now I'm a health care organization on that, I'm not advocating that people drink alcohol -

Chris: Drink responsibly.

Alice: Yes, drink responsibly, but you need access. People are going to cheat. What are they going to cheat on? They're going to cheat on beer, pizza, and things, so we have to make sure they have that availability. And what happened is, celebrities started to get on the bandwagon and talked about losing weight on a gluten-free diet. And I noticed in the media requests I was getting, people started asking me about losing weight on a gluten-free diet. So you're right, I was like, 'No, I gained weight on a gluten-free diet.' And that's when we had to take back

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our disease, and we had to really work on our communication planning, and listen, and empower our patients, talk to them on Facebook, talk to them on social media, gather the information, and then continue to advocate for their needs.

Chris: It's a really fascinating sort of timeline when you think about how celiac awareness and advocacy requires a push for a gluten-free diet, but then conversations about a gluten-free diet all of a sudden don't necessarily include mention of celiac disease, and it's like 'Wait, how did we lose track of this narrative?' It's a really interesting sort of thing. I imagine it must have been kind of frustrating to actually wake up to the fact that, 'Wait a second, we've sort of lost control of this, and now there's this other conversation happening alongside of us that might distort or overshadow our initial intent.

Alice: I'll never forget the day, Chris. It was our ten-year anniversary, and we had worked with all the mainstream grocery stores, and we were celebrating our success, and I had won something called the Philadelphia Award for working with Walmart to carry gluten-free foods affordably. And we were tracking all the messaging coming from the mainstream media, and you know when you're an advocate, and you're passionate, and you really want to solve a problem, you're going to go on to the next problem, and that problem was you know what? When I started this organization, I wanted to advance research for celiac disease, and when I had gone back to school at University of Pennsylvania in the evening to get my degree Nonprofit Executive Administration, now we had the access, availability, affordability - now we had to go back to our core messaging, and we had to go back to focus on early diagnosis, and how can we advocate for, and encourage the most at risk patients to get tested for celiac disease.

Chris: So if you're casually browsing the Internet, a lot of people feel strongly about a lot of things. What was it inside of you that decided to actually start this organization?

Alice: Well when I mentioned that my mother died when I was twenty, I wanted to go to medical school, and I had been accepted, and I didn't go, and I had a career in the medical field. And years later, when I looked at the organizations around the country that were working on celiac disease, there were patient support groups, but there was nobody actively raising awareness and advancing research in the field. Unfortunately, my dad died, and I decided you know what, what do I want to do with the rest of my life? I want to live my life to the fullest, and what difference can I make? And that's why I went back to school at Penn. And we did the environmental scan so that we wouldn't just start another organization, but wanted to make sure that there was a gap, and we did full strategic plan, a gap analysis to make sure that at the time, the National Foundation for Celiac Awareness, there was a need for such an organization.

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And now we've gone beyond awareness, and we've we rebranded the organization to beyondceliac.org.

Chris: I imagine that the press releases, whenever you made that transition from the National Foundation for Celiac Awareness to Beyond Celiac, were just kind of littered with the phrase 'beyond' to make sure you drove that point home, that you've got that first step of bringing people up to date on what's actually happening is there, but now you need to go beyond just that awareness component to all these things that we've been talking about, at least on this podcast.

Alice: Exactly. And we need to go beyond the awareness to advance research towards a cure, and to really understand the mechanisms behind celiac disease. In 2015, we actually held an international research summit where we pulled together patients, physicians, scientists, industry, and the government, to help us develop a patient-centered research agenda. So it's a very exciting time for us, and some of the physicians and the top researchers that we invited kind of questioned me. 'What are you doing? You're bringing us to a research summit, and there's patients involved?' And by the end of that two-day journey, they were telling us that it was one of the best scientific research meetings they've ever attended, and having that patient voice included was paramount to that.

Chris: That makes me really happy to hear not only that you included patients, but also you converted a lot of people to including the patient voice in these really essential conversations. Was a difficult sell internally before you started to approach other people and inviting them to this conference?

Alice: Oh, you know your business. Yes. There was one key, very open minded scientist, and I had an international planning committee, but that influential scientist and clinician, he understood that it was important to include the patients, and that our experience, somebody that if you're living in a little town in Iowa, versus if you're in Manhattan, or San Francisco or say, Philadelphia - you may have a very different experience, and we all have that journey, and it's important for us to capture the natural course of celiac disease, and really understand the personal and relevant family history. It's paramount to understand the psychosocial impacts, and we've already touched on that. Social isolation is rampant in our community. People feel very isolated. They feel that they can't just eat without fear, and then we also want to understand the disease management, and the best way to understand all of this is to be inclusive, and everyone's included.

And that's one of the principles of mutual respect and inclusive at Medicine X, is that everyone is included. And for us it was kind of being a patient run organization and a patient advocacy organization. We just went for it, and it worked out really well.

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- Chris:** Nice. So from my perspective coming out of the diabetes community, my association with celiac is often if you have type one diabetes, then chances are there's a decent shot of co-morbidity there, and you could also be living with celiac. As far as your angle is concerned, how you guys view the diabetes community? It's not necessarily a partner organization or partner kind of patient community, but there's a lot of overlap there if you're looking at a Venn diagram, right?
- Alice:** Oh yeah, there's huge overlap, and we do work with the diabetes community. And I'm part of the Digestive Disease National Coalition, and some of our scientists are working on studies that link celiac disease to type one diabetes, and type one diabetes to celiac disease – the TEDDY study. So there's research underway, and there's actually some research dollars coming from the NIH to study diabetes and celiac disease. So you're right, there is the co-morbidity, and it's important that we recognize that these diseases go hand in hand. And from your experience, you know if you have type one diabetes, the physician will most likely recommend that you're tested for celiac disease, but if somebody is coming in without diabetes, it may not be on the top of the mind of the physician - let's say they have neurologic problems - to say oh, let's test you for celiac disease.
- Chris:** That's a sort of like a weird order of operations depending on which thing is diagnosed first, to sort of determine where else you might go down the whole medical history thing instead. It's interesting.
- Alice:** And when I spoke at a conference with JDRF - this is not a study - I was speaking in front of a room of dual diagnosed family members' kids, and I asked them if they could choose one disease, which disease? Nobody wants to choose a disease, but which one would they choose? Nine out of ten chose diabetes over celiac disease. They said it was harder to be one hundred percent gluten-free, and I was shocked. I was shocked knowing the long-term health consequences of the diseases. So we knew that the psychosocial influences, and social isolation, and keeping a one hundred percent gluten-free diet, it's not easy, and we really need therapeutic alternatives, and we need to accelerate solutions for celiac disease.
- Chris:** That response that you received, while not a proper scientific study, is fascinating to me. I wonder if that's more a reflection on the tools and the access available to manage diabetes. While it does suck, I can speak from personal experience, I do have access to technology to make it a little less of a burden, whereas gluten-free food, and the access to it, and the worry about what you're going to eat is heightened when you're talking about celiac, as opposed to just knowing the carb count on my only type one diabetes side - having to know about the carb count, and also what is my food composed of. That additional kind of layer I

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imagine might be sort of lending it to it. I wonder if it's just the fact that these kids are holding on to their CGMs, and they're thinking about that versus having to stare at all the ingredients to make sure that things are properly cooked and prepared. I wonder how the overall technology access for diabetes management weighs into that decision.

Alice: That's an excellent question, and that's one, as we're looking at these communities and really understanding the perceived burden of the disease, and understanding how do you define health, how do you live life to the fullest? And some people will tell us, 'We're happy on our one hundred percent gluten-free diet.' Well that's great, you have a choice, and others will say, 'Sign me up for the first clinical trial, because I am not able to maintain a one hundred percent gluten-free diet. It's almost impossible.' And especially parents will tell us when they send their kids to school, especially college-age students, that they're putting their child's health into the hands of a food service professional. And that's why we wanted our great training program here to make sure that in colleges, and universities, and schools, that there's proper procedures and protocols in place, to properly train the food service professionals.

Because there's tricks to the trade. If they go, it's easy, but when you're in the back of the house, many times for example they recycle the water, so the water that you're using for pasta could be recycled for vegetables, or for gluten-free pasta, and it's not well understood that it's a particle, and you cannot recycle the water. So parents are very worried about their children, and it would be very interesting to better understand the psychosocial and the perceived burden of celiac disease, and type one diabetes, and really understanding from the patient's perspective why they're telling us that. It was just kind of a hand raised, but there is a study that did come out of Harvard Beth Israel on the perceived burden of the disease, and the perceived burden of celiac was higher than type one diabetes. It was actually second only to end stage renal failure. So yeah.

Chris: Wow. So you've mentioned a lot of high profile names over the course of this conversation. You mentioned Walmart, Anheuser-Busch, college campuses, grocery stores - there are a lot of big players here that have to be on board, and have to be willing to listen, let alone participate in actually providing a gluten-free option for people that need it. What was that process like for you early on, trying to get the attention of these large organizations and entities that control a lot of the food, buying, and selling, and making process?

Alice: Early on, I engaged a group of students from Drexel University, and it was a group of PR students, and culinary students. We decided we needed to create a signature event, and how were we going to make gluten-free food profitable? Because again, I came from a for profit background, so I looked at it as a business. How do I solve this business problem? We need people to have access

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to gluten-free food, and we have a number of challenges, so how can I marry all those challenges together? And we came up with this gluten-free cooking spree. We had done them a number of times in San Francisco, we did our last one on Treasure Island, and it was a great deal of fun. It was a very competitive experience, because we had all the doctors in the hospitals partner with the top chefs in the city to see who would cook the best gluten-free food, and the patients and the community had access to talk to the doctors and the chefs, and then we brought in the grocery stores.

And the grocery stores loved this engagement, they loved the event, we got a lot of attention, a lot of press, and our events grew to two thousand people attending. And we would have the physicians go through a CME continuing education program, we'd have the chefs go through a chef education program, and work with the grocery stores. So we started with Whole Foods and Wegmans, and then went larger and larger, and more mainstream and more mainstream, and that was really the strategy we used. Then we took a step back from that and said okay, and we started listening. That was the key. We had these events, and we started listening to the community saying 'Nobody's talking about celiac disease, it's all about gluten-free products.' And we really want to put a focus back on the diagnosis of celiac disease as a serious genetic autoimmune disease, and advance research. So that's the story of the access, the availability, and the affordability of safe gluten-free products, and how we created a model that was inclusive of all the players.

It was just something that I worked with the college students on, and we were very excited. Because there was a lot of walks and runs, we wanted to do something very different.

Chris: Yeah, that's definitely out of the ordinary there. I imagine after the first few major organizations, or groups, or businesses came on board, once those first few dominoes fell, it was a little bit easier to approach newer and larger businesses and organizations to follow through with this, right?

Alice: Yes. And at the time, you have to think about it, you have to envision a world where you didn't have gluten-free aisles. Gluten-free products were not mainstream, and it was a very exciting time for us. We also were extremely fortunate, because we had a spokeswoman. Her name was Heidi Collins, and she at the time was on CNN, and she had celiac disease. And in the morning on her television show, she would talk about how she couldn't have gluten, so we got some national news, and she could say, 'Oh no, I can't have that, I have celiac disease so I can't eat whatever that product is,' which was really pretty incredible. And she came to all of our events, and we were very fortunate to have her as our spokesperson.

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Chris: That's fantastic. So the one thing that I've been thinking about throughout this entire conversation, the past thirty-five minutes that I've had this red button on recording our chat, how do you manage burnout? Because I worked for the American Diabetes Association for about four and a half years, and whenever your life is diabetes because you have it, and also your job is diabetes, at least for me it was really easy for me to get burned out on one or the other, either my job, because I would occasionally take things more personally because I could see there is a potential negative impact downstream for the diabetes community based on certain things that were inevitable, or that were a cost of doing business, and that's fine, but also my diabetes management might suffer because during my day job, I'm thinking about diabetes and how to reach the diabetes community through my actual paid work. So trying to balance those two was really difficult for me at times.

For you, you're running this organization where celiac awareness is your life.

Alice: You have such astute questions, and it's because you have type one diabetes and you really know what it's like to walk in the shoes of somebody with a chronic disease.

Chris: Thank you. So ultimately, how do you balance those two? Because it's important to build that awareness for other people out there that might not necessarily have the platform that you've built up, but also you have to live this stuff whenever you punch out of the end of the day.

Alice: I manage the potential for burnout with balance and good luck. It is my passion, it is my life - one of the things that I did this summer was, I got a full scholarship to Harvard Business School, and it was a one-week program for nonprofit CEOs, and that really re-energized me, because it gave me tools to take the field to the next level. So I think managing burnout, because it is my passion all day every day, it's important that I take time aside to continue to educate myself, and also make sure that I'm as healthy as I can be. There were times where I was sleep deprived, you know those situations, I was just on a plane all the time, and I had to slow down a little bit. I have to admit I had to slow down. I couldn't be traveling day in and day out, because it was taking a toll on my body.

Chris: Well I guess to that end of education, you will be among the many people educating onlookers, and people viewing the live stream, and people in attendance at Stanford Medicine X a few days from now, which I need to figure out how to pack for that thing. I don't know what I'm going to wear. But you're going to be at Medicine X, right?

Alice: Yeah, I'm going to be on Medicine X, and we're really excited to be on Medicine X.

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- Chris:** So I guess without necessarily spoiling, because as a member of the executive board, I have to remind people to sign up for the free live stream, medicinex.stanford.edu, can you give everybody a preview of what you're going to be talking about?
- Alice:** Yeah, we're going to be using an in-depth patient engagement model to help advocate for celiac disease diagnosis rates. So we're really encouraging those most at risk to be tested, and that's the biological relatives, and we developed a methodology so that our community could impact their relatives, and talk to their relatives. So we're really excited to share this methodology, and I think Chris, you would be excited as well, because we learned that social media is not really the best place to impact our relatives.
- Chris:** Well I imagine that might be the case. I'm a big fan of social media, but I think it depends on the audience and the type of message. I've been learning and trying to reach other patient communities, and simply being on Twitter and using their hashtag definitely is not enough in trying to find the right way to reach people, and trying to find the right messenger as well is important in trying to get people to actually act upon whatever your call to action ultimately is.
- Alice:** Yeah, you're right about that, and we really needed to understand the high risk population, and when we were in 2012, we partnered with Beth Israel and Emerson College to conduct a patient centered research to better understand poor screening participation for genetically at risk relatives for celiac disease, and really, using behavior change methodologies, we had to figure out what do we do. That's where we did use social media and did our market research and our interviewing process. We found that there was not success with patients talking to their relatives to get them properly diagnosed, and we took our behavior change methodology, and we created the Seriously, Celiac campaign. So it's the nation's first family testing initiative for autoimmune disease, and we're excited to talk about it at Stanford Med X.
- Chris:** That sounds like a lot of fun. I might check out the schedule and find out when you guys will be presenting that, and at the very least if I can't attend your session specifically, I will definitely be finding you after the fact, and give you a fist bump and a high five. How about that?
- Alice:** That would be great. I would love that fist bump and high five, and I know that we would be really excited to have you in our session to learn all about our health communication theories and constructs, and really how we learned about our community's emotion, and the psychological impact and considerations that need to be taken when you're going to talk to your family members about getting tested for celiac disease.

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Chris: So I guess sort of the round out on this methodology, and again wouldn't necessarily spot too much about what about you're going to be presenting, but do you find that there's an opportunity for expanding the general theory behind your approach to getting family members to test themselves, not just for celiac, but for other conditions that might necessarily have the same social stigma, that might be a little bit easier to talk about?

Alice: We're actually using the data, we're repurposing the data, we'd like to be able to take it to other diseases, and we're creating a dynamic learning system based on the data that we have collected, and we partnered with several different universities to do different screening studies, and to test our approach to see if it can be more widely used in other chronic illness as well. But one of the things that I found very interesting with the data that we collected as we analyzed the Seriously, Celiac Disease market research to better understand the burden of the disease and how it falls on the patient, we started working with the university of Massachusetts in Boston - they were looking at how physicians should be talking to chronically ill patients, and they were also studying how the community manages their disease outside the doctor's offices, and to understand as I said, the burden of the diagnosis on the family and the patient numbers.

So we could apply some of the learning from the Seriously, Celiac campaign to working with collaborators so that we can take that data and extend it further so that not only our community learns, but anybody in the chronic illness community can learn from the data.

Chris: I'm a big fan of cross disease learning. Any opportunity to make something like that happen, I am wholeheartedly in favor of, so best of luck with that one. So if anything, I look forward to a future PR pitch saying, 'Hey, guess who we partnered with this time? We definitely want this to come back on the podcast,' and I will happily bring you back on once that happens.

Alice: Oh sure, and since you brought up all in your head, we're going to be doing a study on brain fog as well, and understanding the burden of cognitive diagnosis on society. So I'm very excited to be able to come back on your podcast. You are an incredible host.

Chris: Thank you. So beyondceliac.org is the main website to go to for more information about celiac, about what you guys are doing, about research and all these other fantastic things, there are a bunch of social media links in the header very well placed for people that want to engage outside of just the main website. Anything else you want to plug before we get out of here?

Alice: I want to plug that if anybody wants to, please come to Stanford Med X if you can to hear our presentation, and if you think you might have celiac disease, go to our symptom checklist. If you're diagnosed with celiac disease and want to

www.BeyondCeliac.org



donate to the cause, we are accepting donations all day, every day, to advance research and accelerate solutions to a cure.

Chris: And again, that website is beyondceliac.org. I'll include a link there in the show notes. For me, feedback@justtalkingpodcast.com is my e-mail address. Again, justtalkingpodcast.com is the blog URL. If you want to stop by for links as mentioned, beyondceliac.org, there's an iTunes link, there's a Google Play link in case you're one of those crazy Android folks that like to listen to podcasts. I'm actually one of them.

Alice: I am too.

Chris: Awesome. Team Android. There you go. That's a great note to end this podcast. Thanks again for coming on the podcast. Congratulations thus far on the success of building and spreading celiac awareness. I know this is a very serious thing, I wish you the best of luck in continuing to combat all the hipsters out there that are really doing you guys a disservice.

Alice: Thank you, Chris. Thank you for such a great podcast interview.

Chris: Thanks, and on that note, that's episode 360 of Just Talking on the books. I'm Christian. We'll see everybody in a week.

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