

InVisible InCourage

Thursday, May 28, 2020

Transcription provided by Stacie Valle for Virtual VRI

Kellie Pokrifka: Hello everyone! Welcome back to Invisible Incourage. I'm Kellie and am excited to have Beth McNoughton here from Inspire.

Beth McNaughton: Inspire is a social network for health. We have over 200 different medical communities ranging from oncology to rare diseases to chronic diseases. We are a place where you can go and meet someone who has the same diagnosis or as a care giver, someone similar to you to get and give tips and share experiences.

Kellie Pokrifka: How does someone join?

Beth McNaughton: By going to Inspire.com and searching for the condition you are interested in. You can give us any email you want and be anonymous if you want to do it that way. It is different compared to other social networks requiring you to use real names and private information. With Inspire you can really be anonymous. You can talk about whatever you need to and not have a profile associated with their real life.

Kellie Pokrifka: What is the value of an online support group?

Beth McNaughton: I think the value lies in meeting someone who has "been there." People come to us from a google search often. You get a diagnosis you haven't heard of, and you type it into a search engine and look into it. When you come to an Inspire community you can maybe meet someone further along the path than you. There are fears of the unknown and it is a place you can come and others are there that say "I get it, I was there." People like the camaraderie.

It isn't medical advice, you don't want to take that from the internet, but it is invaluable to talk to someone with more experience and that is further along in that journey.

We have conversations like "I wish I had known this ..." when I was first diagnosed. And members are so generous with their advice and time. If you are newly diagnosed and scared, or a scared caregiver, that experience from others is incredible to see.

Kellie Pokrifka: Feeling like you are the only one on the journey is scary so meeting others is huge.

Beth McNaughton: And we have many who can't travel and are homebound and we see some of those people sharing their lifehacks of how to set up a home office or how to be isolated at home. It is interesting to see those people reaching out and saying "let me help you, this isn't new to me" because there are many that are immunocompromised and they wear a mask and have protocols that they must follow.

Kellie Pokrifka: Is there a list of communities or do you have to state what you are looking for?

Beth McNaughton: There is an alphabetical list at [inspire.com/groups](https://www.inspire.com/groups). We cover everything from chronic to oncology to rare. Things that most people might not even know are a thing. Like, if you get diagnosed with sarcoidosis and you have never heard of it or knew it existed, you can come here and meet others with it too.

We know too that most don't have just one health challenge they are facing. Maybe you have headaches, are caring for an elderly parent, and a child with ADHD. You can join a community for all of those things and then each space gives you that area to discuss that specific

thing. Each community faces different challenges with different treatments and ways to cope. Being able to have those specific conversations in those spaces is nice. There is just one log in and you can use the site.

Kellie Pokrifka: Is there any sort of monitoring to keep people from giving out medical advice?

Beth McNaughton: Yes. Moderation is important. My team is responsible for monitoring the held desk and questions about how to log in, or how to post. But we also watch to make sure things are simple and that no one is giving medical advice or false cures. We have been very lucky and our communities are strongly self policed. They want the quality to remain high. We have been lucky in that people that try to come in and sell or promote or do a research study - we make sure it goes through us if they are selling or taking advantage. The last thing we want is a vulnerable population to be taken advantage of. We have a moderation team on basically 24x7. If you have a question or challenge, you can email and people will get back to you.

And if you really need we can chat on the phone. We'll call you up and talk you through it. It is a differentiator for us. We don't make you wait a week to have a question answered. We have a strong moderation team and ways on Inspire that if you see something that doesn't seem quite right, you can report it. The moderators will look into it.

We also make sure no one is using the site in nefarious ways or spamming people. There is a lot of protections in place that way. We make sure photographs are appropriate. If they are sensitive we can mark them that way. So if you scroll by there might be a photo that is reasonable to be posted, but it can be surprising if you aren't expecting it.

Kellie Pokrifka: Speaking of rapid response, what about mental health crises?

Beth McNaughton: In those, usually someone will post and ask us to reach out to a person. We have several different crisis hotlines to recommend. We will look to see what country you are in and try to recommend something relevant to where you are. It really depends on what kind of trauma you are dealing with. We have an extensive list of resources. One of our partners is Mental Health America and they have a strong community too. It can be very quick and we keep an eye on it. We aren't trained crisis counselors but we want you in touch with someone that is as quickly as possible.

Kellie Pokrifka: How did you get involved with Inspire?

Beth McNaughton: Almost from the beginning. I went to college with the founder and they did some ground work through non-profits. At that time twitter didn't exist and Facebook required a .edu email address. We signed our first partner in 2006 and they needed someone to do the launching of the community and the partner management so I came on board. It was just me at the beginning but we have expanded our reach. We have over 100 non profit partners. The lung association, the sarcoidosis foundation, TMJ, etc. The roster is incredible and I hope they agree on the value we provide to their members. And of course IDA.

The biggest thing I have learned is that you never know someone's story until you sit and listen to them. It is interesting how things present themselves. If it is anger, tears, a smile or nervous laughter. If you aren't trying to figure out their story, you aren't understanding them. I have a tattoo that says "everyone's story matters" and I really believe that. With all the invisible challenges people face - I

myself have anxiety but mostly people wouldn't know that. So I can seem off putting or very grumpy but its just my protection. I think we are so quick to judge based on appearance and it is really important to hear everyone's perspective and understand what is causing them to act and react the way they are.

Kellie Pokrifka: That is a huge point. The coping mechanisms can seem off putting but it is protection and we miss so many opportunities to help if we miss understanding that.

Beth McNaughton: And being more comfortable with who you are. For years I never would tell anyone about my anxiety because there was a stigma attached to it. So now I speak out about it and how I cope with it. I have really had to make sure I am tending to my own mental health while helping others tend to theirs. Online communities are more important now than ever, you can't go to in person support right now. And I think one of the things I love the most about what I do is that I am always so moved and encouraged by the people that are willing to share their stories and are open to newcomers.

We have the idea of expert by experience. I have lived through this and I am an expert in my disease. And it is really invaluable to talk to someone and say "that's exactly how I feel" and "I wonder if I try yoga, will that work for me?" It is nice to see people with their own challenges still have the emotional energy to help others.

Kellie Pokrifka: It is so nice to hear these suggestions knowing they come from a place of this helped me, maybe it can help you. Vs. being from a know-it-all that knows nothing about your condition.

Beth McNaughton: Right! You hear people say "stop eating gluten, you'll feel better!" and that has nothing to do with your diagnoses. The well meaning people are there, and we want to see where they are

coming from, but it can be very frustrating. The rare and chronic needs more than just "drink some orange juice." Just taking an aspirin isn't going to fix everyone. Some are incapable of getting out of bed. Vitamin D won't be their cure.

It really helps to have someone say "yeah, me too, I get it." And caregivers can have fatigue but also guilt. There are days when the person you care for drives you nuts. You don't want to say that, but you need an outlet and this is real. Logging in to talk to other caregivers and hearing them say they had those days too, and what some of their coping mechanisms are, can really validate your feelings. It happens to all of us, we're human. It is nice to find someone to validate how you are feeling. And you don't have to deal with the guilt.

Kellie Pokrifka: And it can build up inside and you feel you can't talk about someone. Like people will think something is wrong with you.

Beth McNaughton: Right. So being authentic with likeminded people can ease some of that stress. Realizing you aren't terrible, just normal and stressed. Or maybe you need some extra help and need some resources for myself. And it is important for them to realize they need to take care of themselves. You need your own support system and everyone needs that. If you are under stress and stuck at home, there are so many more stressors and irritants from the outside that taking care of yourself is really important. It is hard.

Kellie Pokrifka: There is something so powerful. I myself am a positive person but sometimes you just need to vent to people that understand it. That therapeutic relief is huge.

Beth McNaughton: You will see people make comments like "I feel like I have found my community." "I'm being heard for the first

time." People will come to a rare disease community and say they are meeting someone for the first time ever with their same diagnosis. They can get questions answered and find out from real people dealing with this how to then deal with it. I think that is also very powerful.

Kellie Pokrifka: Definitely. Do you have any messages you want to get out to the disability community?

Beth McNaughton: I think one of the most important things is to use your voice and advocate for yourself as much as possible. We want to give members the opportunity to participate in research if they want to. If you are interested in that, we want to share those opportunities. It is important to bring the patient voice into the treatment and protocol and development. It helps with outcomes at all levels. Use your voice any way you are comfortable. If that means being totally anonymous, but you help one person, that is incredible and wonderful. That has a lot of value.

And there are people that live their disease in the public and they advocate for research and medications. Everyone has a story that matters. One voice can make a difference and if you are using your voice and advocating for yourself, it is really really important and is great.

Kellie Pokrifka: Absolutely. Any specific accommodations the Inspire website offers for people with disabilities? Like voice to text?

Beth McNaughton: Yes, we have voice to text. And there was another I was going to mention and it has left my head. But we try to keep in mind all populations when we do something. Videos are always captioned for the hard of hearing. There is always more that could be done and I would love to start more in the coming year.

Team@inspire.com is an email anyone can send a suggestion to. We talk as a team about where things are going and what we want to see.

Kellie Pokrifka: I know I like the ability to set the background as dark as I read.

Beth McNaughton: We have that.

Kellie Pokrifka: During your tough hours what gives you the courage to get through one more day?

Beth McNaughton: Seeing other people being courageous. I have really seen things and learned so much from our members. Their generosity to help strangers gives me a reason to get out of bed daily. I want to support them supporting others. I want the website to help them so they can continue to share the knowledge I don't have. My expertise is online website moderation. I want to provide that space so the experts in their areas can be there. I want them to trust our website and that is where I share my expertise.

Kellie Pokrifka: Incredible. Letting someone else take the microphone when they're the expert. That's huge.

Beth McNaughton: It is really important in all aspects, not just health.

Kellie Pokrifka: Anything else you want to say before we sign off?

Beth McNaughton: I don't think so. I appreciate you contacting me for the interview. I am beth@inspire.com if anyone wants to talk to me.

Kellie Pokrifka: We are so grateful for safe spaces like this. Thank you for joining us today and we will see everyone Tuesday. Thanks for tuning in!

[End of show]