Episode 71: Marleah Dean Kruzel

# KL: Katie Linder MK: Marleah Dean Kruzel

# KL: You’re listening to “Research in Action”: episode seventy-one.

# [intro music]

# Segment 1:

# KL: Welcome to “Research in Action,” a weekly podcast where you can hear about topics and issues related to research in higher education from experts across a range of disciplines. I’m your host, Dr. Katie Linder, director of research at Oregon State University Ecampus. Along with every episode, we post show notes with links to resources mentioned in the episode, full transcript, and an instructor guide for incorporating the episode into your courses. Check out the shows website at ecampus.oregonstate.edu/podcast to find all of these resources.

On this episode, I’m joined by Dr. Marleah Dean Kruzel, an Assistant Professor in Health Communication at the University of South Florida in Tampa. Dr. Dean Kruzel studies patient-provider health communication and is currently examining genetics and risk communication in hereditary cancer. Her research has been published in journals such as Social Science & Medicine, Health Communication, Academic Medicine, Patient Education & Counseling, Journal of Health and Mass Communication. A BRCA2-positive patient herself, Dr. Dean Kruzel is committed to translating her research into practice, which is why she volunteers for Facing Our Risk of Cancer Empowered (FORCE) and maintains a blog called “The Patient and The Professor.”

Thanks so much for joining me, Marleah.

**MK:** Thank you. I’m glad to be here.

**KL:** So Marleah, we connected online actually and you shared a little bit about your research with me and some of the things that you’ve been working on and one of the things that was fascinating to me was your personal connection to the research, so I thought we could start there and talk a little bit about that. Can you share a little bit about how you became interested in your research project?

**MK:** Yes. My mother was diagnosed with breast cancer at age 38 and I was 8 years old at the time. My younger brother was 4 years old. For a few years, it felt like we lived in hospitals and I watched my parents really navigate this cancer diagnosis and communicate with healthcare providers all while taking care of my brother at night, so my own experience really sparked my interest in healthcare communication, which is the use of communication strategies to understand patient and their family as well as healthcare provider experiences with health outcomes; that’s why I decided to get my PhD in health communication and ultimate become a professor. My specific research interest in hereditary breast and ovarian cancer came about a few years ago when I underwent genetic testing to determine whether I, along with my mother and her sister, who was also diagnosed with cancer at the age of 38 tested positive for BRCA too. It’s commonly referred to as the breast cancer gene. BRCA2 greatly increases your risk for developing lifetime hereditary cancers such as breast, ovarian, malignoma and a couple of other hereditary cancers. I was already interested in cancer communication research and then I tested positive for BRCA2 and started attending my own doctor’ appointments not for cancer diagnosis, but as a high risk patient. I realized that the doctors didn’t really know how to work with me because I didn’t have cancer yet, so that really moved my research in a different direction to look at individuals and their families who are at risk and how they communicate with their families and the healthcare providers in order to make informed health decisions.

**KL:** So I think that this is one of those areas of research that are kind of niche. People probably don’t even realize this is an area of research. We’ve had a lot of people come on this show and researching areas that, once you start talking about it, it makes complete sense that there would be research in that are, but it’s not something that many people would think about. I’m curious to talk a little bit more with you about who you are working with in this research capacity (maybe that’s a good place to start?). Who are the stakeholders in your research and what kind of questions are you asking for the things that you’re exploring?

**MK:** Yeah, great question! You’re right – it is a little specific. Within the field of communication, I’m looking at the interactions between patients, their families and healthcare providers and the ways in which they communicate to each other about health-related messages. When it comes to genetic risk and health communication, I’m trying to understand how patients who test positive for BRCA2, like myself, how they make informed health decisions in order to prevent a future cancer diagnosis (that could be undergoing a preventative bilateral mastectomy like Angelina Jolie did a few years ago and said in a public health announcement in the New York Times). So, public health decisions and how they manage an uncertain future is another thing that I’m interested in – you haven’t been diagnosed with cancer, but you have such a high risk. For example: personally, I have about an 84% risk of developing breast cancer at some point in my life and a 27% risk of developing ovarian cancer at some point in my life in comparison to the general population, which has a much lower risk. For example: women in the general population who haven’t tested positive for BRCA have about a 13% risk of getting breast cancer at some point in their lives (about one in eight). The risk is definitely higher, but you don’t have cancer yet and you have to make these decisions in order to protect your health, make decisions that impact your family and those around you. Ultimately, I’m really interested in how patients communicate about their goals and interests to their families and their healthcare providers. I want to try to understand what the patients are experiencing, what their families are experiencing in order to encourage health outcomes because we know that the better communication is between healthcare providers, patients and their families, the likelier it is that you will have good health outcomes whether we are talking about patient satisfaction, treatment adherence, emotional wellbeing, quality of life, effective decision making, etc.

**KL:** Mmm hmmmm. One of things that occurs to me is that there could be some real benefits for your personal experience in relation to this research in terms of having a better understanding from your own perspective, but it could also have some challenges. Just the difficulty – I mean, this emotional baggage that you’re carrying. Can you talk a little bit about that? I’m curious: to what degree are you sharing this story with the people that you’re working with and how open are you with having the same connection with some of the research subjects that you might be working with?

**MK:** You know, you’re absolutely right. There are benefits and there are also some drawbacks. When I’m conducting research, whether that is sitting down and interviewing a patient or a family member or even talking to a healthcare provider (an oncologist, a plastic surgeon, etc), I usually do briefly share my personal story and I really do this for two reasons. One is that I believe that, since this person is going to open up and share with me, I want to be open and honest with them too. The second reason is that I believe that sharing my story demonstrates that I care about the research personally and not just professionally. My research isn’t just my job. Although I love my job as a researcher, I couldn’t imagine doing anything else. Because of my personal connection, because I’m BRCA positive, because I’m the daughter of a breast cancer survivor, I get the privilege of listening to all of these stories and I want to be upfront and honest with them.

**KL:** And, to speak a little bit about the challenges, what are some of the things that you’re finding more difficult and how are you dealing with that for other researchers that are maybe having the same thing? Maybe they have a personal connection to the research and maybe they’re struggling with it as well?

**MK:** Yeah, that’s a great question. So I do believe that sharing my story really establishes a connection with a patient, their family member, provider I’m working with, but there’s – the drawback really is that I’m never able to put my work down or put it away, right? So my professional and my personal lives are always intertwined. So when I tested positive for BRCA2, that was actually during my doctoral work at Texas A&M University, so I actually changed my dissertation topic to look at people who had tested positive for BRCA and how they were dealing with coping with uncertainty, making health decisions, etc. I was already going to do something about cancer communication, but it kind of took that different spin. And so that’s great – I think I do get to have a different understanding, perhaps that other researchers who might be studying the same topic might not have the same degree. But at the same time it can be exhausting, because when I’m talking to a patient and they’re describing how, you know, how their mother or their father was diagnosed with breast cancer. You know, it takes me back to when I was eight years old in that hospital, and I still feel the effects of those experiences today. So it’s a constant . . . I don’t want to say it’s a constant battle, but it’s a constant journey.

**KL:** Mmhmm, mmhmm. And one of the things I know in your research is you’re working with so many different stakeholder groups and audiences. We’re going to take a brief break and come back and talk to Marleah a bit more about translating her work to different audiences. Back in a moment.

# Segment 2:

[*intro music*]

**KL:** Marleah, as you were describing the personal connections you have to your research in our first segment, one of the things I was thinking about was, you know, part of your work with patients must be pretty emotionally charged. And I would imagine that as you’re working with patients they’re in a pretty emotional state, and some of them have maybe just found out about a diagnosis. For you and for them, it’s probably a very emotional conversation. Wondering if you could talk a little about that, and especially for our researchers who may be listening that are dealing with subject populations in their research that may have similar situations, that they’re dealing with highly sensitive topics or topics that are a little bit more emotionally charged. How has that looked for you, and are there things that you do to kind of help support the patients that you’re working with as research subjects?

**MK:** Yeah, so oftentimes when I’m interviewing a patient I will ask a question and it will cause them to reflect back to a memory they might have had with a family member who was diagnosed with cancer. Or perhaps – a couple months ago I was talking to a young male who had recently test positive for BRCA within two weeks of getting his genetic test results. And with both of those cases I came into the interview expecting to talk about some sensitive subjects. I expect that what we talk about might bring up some emotions for them as they reflect, but also for me, right? Because I understand oftentimes where they’re coming from. At the same time, I try not to understand too much or assume anything just because I have some commonality with them, but I try to come prepared emotionally. I also try to teach what I teach my health care providers, which is to be an active listener, be a good communicator, be empathetic. I also thank my participants for sharing difficult topics or experiences. And then personally I – another strategy I find helpful when you’re dealing with emotionally sensitive topics as a researcher is to find a colleague who can kind of be your debrief. So after an interview that might have been particularly difficult, perhaps it made me think of my own mother or when I received my genetic test results, would be to turn to a colleague, give her a call and say hey, I just had a really difficult interview, can I debrief it with you? And doing those different types of strategies, it really helps me, but I hope also helps the patients in sharing their experiences with me.

**KL:** Mmhmm. So, I know your research goes beyond just interviewing patients. Can you share a little about the other kinds of groups you’re working with? Because I think you are translating both kind of your research as you’re collecting data, but also the results to a range of populations. So who are some of the different groups you’re working with as you’re going through the whole trajectory of your research process?

**MK:** Right. So since I am personally interested in my work, and because I believe that research should be communicated with research participants in the studied population, I really work hard to translate my research to a variety of different audiences. So, of course as a professor, one of those is an academic audience. So publishing in journals, professional conferences, things like that, but not just within my own field of communication. I also try to target medicine, because that’s where my work can be most visible and most useful to the medical profession. And then I also try to, when I have funding, try to publish open access articles, and so then that way the general public can get access to my findings. But in addition to that, I also work heavily with the Hereditary Breast and Ovarian Cancer Community, and one of my key partners is an organization called FORCE, it stands for Facing Our Risk of Cancer Empowered, and I’m a volunteer with them and I serve on a couple of their committees. And so I’m able to use my experiences as a patient but also as a researcher to help them help other patients and their families. And then I also seek to translate my research online. I keep a blog called The Patient and the Professor. I try to stay active on Twitter with different types of health advocates, providers, so that I can be learning from them and I can be sharing my work with them as well. And more recently I was able to share my research as well as my personal story with the very broad general audience in the CDC’s Bring Your Brave campaign. So I was pretty excited about that, but it was also a little nerve-racking to share your story with such a large population.

**KL:** [*laughs*] I can imagine. Well it sounds like you’re juggling a lot of audiences with this, and it’s exciting because you can get the word out about the things that you’re learning and what you’re learning through your research with lots of people, but I imagine that there are a lot of challenges that go along with that. Even just thinking about the rhetoric, you know, the stories you’re trying to tell and the outcomes you’re trying to share. Can you talk with us a little bit about the challenges you’ve encountered, and are there strategies you’re using with these different audiences in a really kind of intentional way to try to combat some of those challenges?

**MK:** Yes, so I love what I do, but I think probably one of the most practical challenges when you’re translating your research findings is simply that it takes additional work that I don’t really get credit for as a professor. So I think that could be difficult to balance getting my work done as a professor and what counts, but also translating my research findings to actual patients and their families. And since I’m personally connected to my research, I can’t imagine not doing either one, but it just kind of adds another level of complexity to the work that I do. And the other challenge is that I wasn’t trained as an academic to translate my research findings to a general audience, and so I’m making it up as I go. And I’m turning to different resources, trying to learn as much as I can. Sometimes I feel like I’m back in graduate school, but I think that’s a good thing because life is learning and I can’t imagine doing anything else. So hopefully I will continue to learn what is most effective as I try things and things work well and I can repeat those, or I try things and they don’t work so well and I can revise it.

**KL:** Have you found that exploring partnerships with particular health provider communities, or – this seems like a relatively niche group, even though the broader population might not be aware of some of these issues. But particularly for people who have been diagnosed or who have family members who have been diagnosed, is it relatively easy to communicate with those groups, or is that still something you’re working on thinking about?

**MK:** I’m still working on how to really connect with health care providers and health care systems. As a researcher, if I’m able to give them something in return, usually those conversations go better, but I usually have to try and get my foot in the door somehow. So that often looks like, you know, one of my colleagues knows someone at a new institution and I reach out to them to see if they’re interested in collaborating. So that’s one of the partnerships I’ve made is with genetic counselors in a different state, so I couldn’t have done that without one of my colleagues at Northwestern University. So it’s kind of, again, go with the flow. [*laughs*]

**KL:** Mmhmm, I would imagine constantly looking around to see what the opportunities are. I’m curious if you have any interesting examples of particularly effective mediums that have been helpful for you, especially for non-academic audiences. Is there something that you, maybe social media or something you’ve tried that you feel works really well?

**MK:** So I think that Facebook has been probably the most effective medium for communicating with patients who are at risk for developing cancer or who have been diagnosed with cancer. There are so many amazing people who connect online to give each other emotional support, social support, informational support, etc. So when I published a study or perhaps when I present at a conference I will tweet that or, you know, have a Facebook message saying that this is what I am doing, and that’s a nice way to connect with people. And then sometimes that just creates some contact late who emails me and says hey, I saw you were presenting at this conference, I’d love to talk to you more about your research. And then with my research participants I think actually one of the most effective mediums for translating my research to patients and the general population has been email. Emailing my research participants who have been involved in the project, of course with their express permission. When I email them, I’ll provide them with an update on how their interview or their survey response was used, whether that was a journal publication, a conference presentation, or perhaps a community outreach project. So I really think it’s important as researchers, especially those that work with human subjects, is to show our research participants how we are using their information, how we are using their data, because most people want to help others, right? Just like I do as a researcher, I want to help other BRCA positive patients like me, and so I want to keep them informed on how their stories are impacting other people with those stories that they have shared with me.

**KL:** Mmhmm. Well I know that a big part of this has been some of your with the CDC’s Bring Your Brave campaign, so we’re going to take another brief break and when we come back we’ll hear from Marleah a little bit more about that.

# Segment 3:

[*intro music*]

**KL:** Marleah, one of the things you sent me to help me prepare for this interview was a video of you as part of the CDC Bring Your Brave campaign, and it was fascinating to hear more about your work and also your personal story. We will definitely link to this in the show notes so that listeners can take a look at it, but I’m wondering if you could share a little more about what that campaign is and how you came to be involved with it.

**MK:** Yes, so that was a great experience. The purpose of the campaign was to communicate information about breast cancer, including topics such as cancer risks, prevention strategies, family health history, and survivorship. And the campaigns intended audience was women between the ages of 18 and 44 years old, because many young women really don’t know if they’re at risk for breast cancer, or the ways in which to manage their cancer. And we’re not just talking about individuals who are genetically predisposed to developing hereditary breast and ovarian cancer, just young women in the general population as well. Much of the rhetoric that goes on talks about older women, you know, fifties, sixties, who have been diagnosed with cancer. So the goal was to connect with younger women to talk about their risks for breast cancer and the ways in which they can manage their risk. So the idea was that through sharing real patient stories, other women would not only learn about breast cancer, that breast cancer can affect younger generations, but also inspire young women to seek additional information regarding their breast cancer risk.

**KL:** Ok, so you found out about this opportunity somehow, email, Facebook, social media. It probably came across your plate. What was the next step?

**MK:** Yeah, so after I saw the post, and I can’t even remember where it was, but as a researcher and patient I actively monitored different types of sites. So I contacted the CDC and I said hey, I saw your call for young women about this campaign that you’re doing for young women and breast cancer risk. Here’s a little bit about me and here’s my story, and then they contacted me from there. I completed an interview, and then I was one of, I believe, seven or eight women who were chosen to share their story. And of the seven or eight women, I think there where three of us who actually did video footage, which I think you said will be posted in the show notes.

**KL:** Mmhmm, yeah, we’ll let people take a look at the video. So, this is something we’ve talked to a couple researchers about recently who’ve had television opportunities or opportunities with video. What was that like to prepare for that? It’s always different to have a kind of interview recorded, and especially one when you’re on camera. Were their things you did to kind of prepare yourself?

**MK:** It was very fascinating, but it was a great experience. I really enjoyed it, and felt lucky to do so. A team came down to Tampa, Florida, to interview and record me. It was a two-day process. The first day we recorded different types of B footage, walking my dog on the beach, rock climbing, kayaking with my husband in downtown Tampa, and then the second day we did more of the interview, so we sat down and I told my story as a patient but also a researcher; how those different things connected. So, in preparation for the interview, I kind of went over what I hoped to share, but much of it was prompted by the directors and the producers by what they wanted to hear from me as it related to the purpose of their campaign.

**KL:** I imagine that’s kind of nice, to be directed in that way and kind of know what the messaging is. Was that something that was helpful to you? You mentioned you were able to say what you wanted to say, but was it useful to have that kind of direction as well?

**MK:** Yes! It was very helpful, I had a great experience with the whole team. I had a makeup artist, and it was quite an experience, and at the end I felt really good about sharing my story because I hadn’t shared my story in such a large scale before. You know, I often talk about it in academic conferences, or even online, but to see myself on video, to see my husband, who’s been so supportive of me and my research and my work, that was really cool.

**KL:** So I know kind of speaking in front of larger audiences, you’re currently working on a TEDx talk, and I think this is something that researchers are interested in with larger audiences and how they can share their story and some of the work they’re doing. Can you talk a little bit about how that came to be? How did you come sign on to do a TEDx talk? And also I’d love to hear a little more about how you’re preparing for it.

**MK:** Yes. Perhaps this is an academic thing, I’m not sure, but I am obsessed with TED. I think they’re great, it’s a great organization. I often show many TED talks in my classes. They are a good opportunity for good discussions, but there’s a TEDx at my university, the University of South Florida, coming up, so I submitted an application and I’m one of six speakers. There are three professors and then three undergraduate students, and we are talking about, or our theme is limitless, and my specific talk is going to be a combination of my own personal stories as a patient who has tested positive for BRCA2, but also the research I’ve conducted in regards to genetic risk and hereditary cancer. So my talk is called “How to Make Decisions in the Wake of Uncertainty,” and one of the things I love about my work is that even though it’s a very niche subject, as you kind of mentioned earlier in our interview, everyone deals with uncertainty, right? So whether that’s everyday decisions like what to wear to finding your lifelong partner or your dream job, whatever it may be we all have to make decisions in the wake uncertainty. So this talk is going to look at how we can do that.

**KL:** So, I know from other people who have done TED like events it can be kind of nerve-racking to think about just the timing of it. For people who may not know, we’ll link to some examples in the show notes, and it may be that yours is available at that point to, so we’ll link some information about that if it’s available online. But these are relatively short talks, typically, and people can feel some pressure to make sure they’re really hitting the timing right, and I’m just wondering, you know, what are you doing to prepare for this? As it’s coming up, what is helping you to feel like you’re going to hit a home run?

**MK:** Well, I certainly hope that I hit a home run. I love public speaking in general, so I’m very excited about it. Basically, I have been practicing a lot and getting lots of feedback from a variety of different audiences. My mother, who is an English and communications professor, has taught public speaking for several years, so she’s given me lots of guidance and direction on it. My husband, my dad, my friends, my colleagues, so just trying to practice as much and really being comfortable with the material. And much of it is what I already do and talk about on a daily basis as a patient and a researcher, but it’s just kind of putting it all together in 12 minutes. [*laughs*]

**KL:** Well we wish you the best of luck, and I will also remind our listeners that if you haven’t seen it yet, we have an episode on best practices for scientific and research presentations with Michael Alley. We’ll put that in the show notes in case anyone wants to take a look. But Marleah this has been so fun getting to hear more about your work, especially your personal connections to your research. Thanks so much for taking the time to come on the show and tell us a little more about the work you’re doing with this communication work.

**MK:** Thank you so much for the invitation, it’s been a pleasure talking to you and I look forward to listening to more podcasts.

**KL:** Thank you!

And thank you to our listeners for joining us for this week’s episode of Research in Action. I’m Katie Linder, and we’ll be back next week with another episode.

[*outro music*]

# Show notes with links to resources mentioned in the episode, a full transcript, and an instructor’s guide for incorporating the episode into your courses, can be found at the show’s website at [ecampus.oregonstate.edu/podcast](http://www.ecampus.oregonstate.edu/podcast).

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# “Research in Action” transcripts are sometimes created on a rush deadline and accuracy may vary. Please be aware that the authoritative record of the “Research in Action” podcast is the audio.

# Bonus Clip:

[*intro music*]

**KL:** In this bonus clip for Episode 71 of the “Research in Action” podcast, Dr. Marlean Dean Kruzel

shares about how she mixes the personal and professional on her blog The Patient and the Professor – take a listen.

Marleah, you have this blog, “The Patient and the Professor,” and I wanted to make sure that we talked about it because there’s a couple other people we’ve had on the show – I’ll link to them in the show notes – who talked about academic blogging, but that blogging was more purely professional, and this is a blog where you’re doing a little mix of personal and professional. So I was hoping you could share a little bit more about how you decide what goes on this blog and how you’re kind of putting in a mix of the things that are more from your personal life with your researcher life.

**MK:** So the very nature of the title, “The Patient and the Professor,” really communicates, or I hope it communicates, what I’m trying to accomplish with this blog, which is to share information that is relevant to new patients who have been diagnosed with cancer or who perhaps are at risk for cancer. It’s some very practical strategies, advice, as well as my own personal stories and the things I’m going through as a patient who is BRCA2 positive, but also communicating and translating my research findings about that professor side with the general public. So it’s personal and it’s professional, but often times any post actually has a little bit of both, it just might be focused more on one or the other. So my blog, my blog posts could look at one week, it could be a summary of an article I had recently published, so I think January’s was about an article I had published in the *Journal of Genetic Counseling*. So I did a layman’s terms essentially of what the article found and tried to use that as a way to help other patients who have tested positive for BRCA2 who are making family health decisions, family planning health decisions. But then there are also stories on there about me as well as my mother, my experiences growing up, resources that have been helpful for me as a patient. So, I have one blog on practical books and movies, and actually other blogs that I’ve found to be helpful both on the information side as well as the emotional side. And then I also have a few blog posts on there about teaching. So that’s something we haven’t talked about, but another side of being a professor is teaching, so I have a couple on there where I talk about maybe things that my students are teaching me, or that I’m trying to teach them, and how I’m trying to encourage them to be empowered patients in their own medical encounters.

**KL:** As you’re working with this mix of personal and professional, I’m wondering do you have firm boundaries. Like where do you draw the line, and you say nope, that’s not going on the blog? And even when you’re telling your story in research contexts, you know, how are you making those decisions?

**MK:** That’s a great question, and I think that’s one of the things that anybody who shares online in a speech, in public, really has to deal with. We were talking about earlier one of the great things about my work is that it is intertwined as a patient and a professor, as a researcher and a teacher, but also that can be a drawback too at some point. So what are my boundaries? I try to think about what is representing my community well, so my patient community, my university well, my family well, but also just trying to be honest about what I’m going through in ways that are professional and appropriate.

**KL:** Alright, thank you for sharing about some of your experiences blogging both personally and professionally.

[*outro music*]

**KL:** You’ve just heard a bonus clip from episode 71 of the “Research in Action” podcast with Dr. Marleah Dean Kruzel sharing about how she mixes the personal and professional on her blog The Patient and the Professor – thanks for listening!