

# FIND YOUR MBC VOICE

## Science of MBC

### Episode Title: The Q's That Come Before the A's

**Guest: Hope S. Rugo, MD, Professor of Medicine, Director, Breast Oncology and Clinical Trials Education at UCSF Helen Diller Family Comprehensive Cancer Center**

**DR. COMEN:** Hi, I'm Dr. Elizabeth Comen, a medical oncologist specializing in treating breast cancer patients. When someone is diagnosed with metastatic breast cancer, they're often in a state of shock, especially when they find out it is the most advanced stage of disease. But we want to help you feel both informed and empowered. We are here to help you, find your MBC voice.

#### PATIENT

**SHANTE:** When I was initially diagnosed, it was it was devastating to hear because, when you think of stage four, it's almost like the boogey man of the breast cancer community. I thought I was going to die immediately. I was doom and gloom. I was hopeless and I kind of really just asked my physician, like, how long do I have? And what do I tell my daughter? So it took me a minute to figure out what questions to ask, outside of how long will I live?

**DR. COMEN:** Doctors know that a million thoughts and questions are running through a patient's mind when they are first diagnosed with metastatic breast cancer. Join me as we speak with Dr. Hope Rugo, professor of medicine at University of California, San Francisco, where she directs the Breast Oncology and Clinical Trials Education Program at the Helen Diller Family Comprehensive Cancer Center. In addition to her illustrious career, like so many of us who became breast cancer oncologists, it also hits close to home for Dr. Rugo as her mother battled the disease for 12 years. She's here to talk to us today about how to handle a diagnosis of metastatic breast cancer. This is Science of MBC. Hope, thank you so much for joining us today. We're honored to have you here.

**DR. RUGO:** Thank you for asking me to participate. It's an honor to participate in this great program.

**DR. COMEN:** Hope I know that you have both personal and professional experience with metastatic breast cancer. Can you talk a little bit about your relationship with the disease and what led you to this profession?

**DR. RUGO:** Yes, I mean, it's an individual conversation with every physician isn't it? Where, you know, what really led one to go into both medicine and then to focus on oncology, which, you know, certainly is not everyone's interest, I think, given the complexities of the disease and what we treat. But for me, it actually started a long time ago when I was a kid and decided I want to be a doctor. It was such a cool thing, and you could help people and learn how, you know, what was going on. And then the decision to focus on oncology actually was an interesting path for me because I started out thinking I would do global medicine and infectious disease and to actually spend time in third world countries working with community health workers. In the end, when I studied medicine, I really felt

# FIND YOUR MBC VOICE

like my focus wanted to be on the person as a whole, but I was interested in the science of oncology. So, you can be an all-encompassing physician where you take care of the whole person, but also focus on the science of a disease which is incredibly common and affects many people, next to heart disease, the most common illness that we have and we see in our patients. So that combination was something that I thought would be really interesting and it's turned out to be even more than that because, as we've evolved our treatment of cancer, and our understanding, what we now can do is not only take care of the whole person, because, that's part of oncology care, but you can actually apply scientific knowledge and scientific advances to the treatment of that patient, as well as all we've learned about trying to manage - the expectations and psychology of the disease and symptom management. So, to me, it's really the ideal field in medicine and it worked out very well for me in terms of combining all of those interests. And then, after I had already decided that I was going to go into medicine and was interested in some field in oncology, my mother was diagnosed with cancer. And actually, it was kind of an interesting story at the time because I didn't know much of anything about breast cancer at that time, and she just had a little cancer so everybody said, well, you're fine you know. They did mastectomies for a 1-centimeter tumor, which is what she had, and they looked for nodes but came up with no nodes on the X-ray dissection, and that was it. 12 years later, she had pain in her bones and, you know, by then I already was an oncologist and I was focusing on bone marrow transplants and sort of immunology and I said okay, you know, we have to look for breast cancer, I know breast cancer can recur late, and she turned out to have breast cancer and going through that whole course of her disease and treatment taught me a lot about the care of patients with cancer but, you know, patients go into the hospital for their treatment and the treatment is very intense. In breast cancer, you know, you're treating over a continuum and you're managing all of the aspects of going through treatment and having a diagnosis. So during that time of taking care of my mother and trying to navigate her care, I became very, very interested in breast cancer and had the tremendous opportunity midway through my career to change my focus to breast cancer, and that's been the best decision of my career.

**DR. COMEN:** And it's such a special and unique population that we work with.

**DR. RUGO:** Right.

**DR. COMEN:** In terms of how we address their needs, there are issues that come up about quality of life, about caring for family, whether they're caring for their parents or their own children, what they enjoy and how we incorporate that into the care of our patients, not just the biology of their disease, but the experience of it.

**DR. RUGO:** This is really an important part of it. So it's, we take care of patients who are of all ages, who have breast cancer, and the patient themselves, how they relate to everybody around them, and how their family relates to them, is something that I really recognized during that time, taking care of my mother, as a critical aspect that we really weren't addressing at all, at that time, during my career. We've really come around and in breast cancer I think I have really been able to focus on that in a much more effective way.

# FIND YOUR MBC VOICE

**DR. COMEN:** And your mother was so lucky to have you as her tremendous advocate through all of this, not just as her daughter, but as this extraordinary physician as well. And I think we all know from different perspectives, both as physicians, but also as caregivers and some of us, even patients, that there are so many stark reminders that there is so much more to be done in the work that we do. There's so many new and exciting discoveries that are upcoming. But with all of that, we have much more work to do. And do you think you can talk a little bit about when you tell a patient that they have metastatic breast cancer, and we all have different styles for how we do that, what are some of the initial questions that you hear that patients ask you? I find that once that emotional dust settles, even just a little bit, the first question is, "am I going to live?" I think that that's one of the most common questions I hear from patients but perhaps you can share some of your patient interactions or what you might find as that initial conversation that you have with patients?

**DR. RUGO:** Yeah, I think that this is one of the most challenging conversations we have, and the conversations we have over the course of metastatic disease. I think that in most patients where we're making a diagnosis of metastatic disease, we have a preexisting relationship with that patient. That relationship is very important because we have already established a sort of groundwork for talking about what's going on with the disease, the risk, what we're looking for in the future. When I have found that a patient has metastatic disease, I have often tried to prepare the patient as much as possible for the situation ahead of time. For example, a patient will have, you know, worsening back pain and come back to us with that symptom and, you know, we talk about how that could be a recurrent cancer so when we actually meet, when the diagnosis is made or when we're reviewing a scan or a biopsy, then I think the conversation shifts to here's the, "this is the diagnosis and what are the implications for you as a patient with this diagnosis, and how are we going to approach this? What are we going to know now and what will we know later?" So, the implications, I think first we start out with, what our goals of treatment are. And, to me, talking about the goals before I talk about what it means in terms of outcome is more important. So the goals of treatment are to live as long as possible with the best quality of life. So we want to try and target symptoms, want to help the symptoms be as well controlled as possible. We want to control the cancer. But we want to control the cancer in a way that interferes the least amount with your current quality of life and your ability to do the things in life that you most want to do. And then we talk about the different kinds of treatment options and what we can expect from them. Then after we've gone through those questions and that discussion and questions, I talk about what this means in terms of how we can assess what's going to happen. So, one thing is that breast cancer today is not curable. So, and you are, and most of our patients are, healthy, and you don't have any other life-threatening illness so it is likely that at some day, that you will die of this disease. But we don't know, we don't know that now, and you're not dying now. Most of our patients come in with great organ function, there's no life-threatening issue, they aren't dying right now and I really make sure that we've talked about that in detail. And then I talk about evaluating the response to treatment as a way to get a better idea of what the future will hold. And that's really important because that tells us a huge amount. So, we select what our treatment path will be, and then we know that the response, how well the cancer responds to that

# FIND YOUR MBC VOICE

treatment, how long the response to treatment works, will have an implication on what we can do next and how long you will live with that disease. I've also found that, in our first conversation, that it's hard to have too much information.

**DR. COMEN:** Yes.

**DR. RUGO:** People are so overwhelmed, and it doesn't matter if I'm talking to a PhD in biologic sciences or somebody who, you know, has no science background. It's overwhelming. All the voices are in your head all the time, and they're fighting with the things that we're saying, so I usually write down what our plan is and I plan to have a relatively close follow-up meeting where I can talk about results of any additional tests we've decided to do, and go over the treatment and the questions again. I just met with someone where I had this experience where, you know, you go through even on the second meeting, very, very smart woman I treated 19 years before who had a recurrence and how we're going to step through things was still very, very overwhelming. So writing things down, making sure... I make sure my patients, unless it's very late at night that I'm having my meeting and then we do it the next day, that they have a connection with my triage nurses, that they know that we're here to help them, that they can call or send in an electronic message through our electronic health record system whenever they want, about whatever question. And then the last part of our first meeting is setting up a visit with our symptom management program. And they actually provide a lot of support as well, both with symptoms and with expectations and family understanding. We also offer that the family can talk to us as well. For example, some people are on their own and their family is at another geographic area that they can call in, that we can communicate with them in any way that will be helpful. I'm trying to provide a sort of a supportive network, a basket to hold the people in with the soft lining where we're here to support the patients through their diagnosis, their understanding, their questions and their first foray into treatment.

## **PATIENT & CAREGIVER:**

**LINDSEY:** Definitely write down questions as you have them for your doctors. It's really important when you go in there to ask those questions. And I know a lot of times I'm just worried about what my side effects are going to be and how I'm feeling and Jeremy stops and says, wait a second, let's, you know, let's talk about some of these other things. And I will leave and be like, oh, did you ask about this? So make sure you write down any questions that come up and take those with you to your appointments, because that's really important when you're going through everything.

**JEREMY:** You have to accompany them to doctor's visits because sometimes they just get overwhelmed as to some of the information that's coming in, and you just really need to advocate for your patient with your care team.

**DR. COMEN:** I think, you know, we often talk about a team to take care of patients, but I really liked your metaphor of the softly lined basket, because what we know is that we can do a lot when we're talking with our patients but that there, at times, there really does need

# FIND YOUR MBC VOICE

to be a larger support network, a psychosocial support network, a supportive care network, pain management, all of those things that become so critical to how we care best for our patients and not as a treating island. And one of the things we also know is that the treatment landscape, and I'm sure you can speak to this, has really changed in terms of not only the treatments available, but expectations from patients. I think probably 15 years ago we didn't have a patient bill of rights in our hospital but now we do, and there's a lot of movement towards shared decision making, informed consent, informed decisions. And increasingly, it's so important that patients feel that they can best be informed and their own best advocate, along with communications that they have with their doctor and treating team. What advice do you give patients for, in the sea of information that's out there, of how they can be best informed and sort of ground the knowledge that's coming to them?

**DR. RUGO:** So maybe if I start with the second part, which is grounding the knowledge, I think that it's very important for us all, in all aspects of life, to understand what our goals are. And you know, that may be very difficult because you have goals in all different parts of your life, but understanding the goals of treatment for a patient is really important and balancing out the different aspects. So, do you want your treatment to be close versus far from where you live, and the side effect profile? And these are really important. I think younger patients balance things quite differently. Whether you have a young family, an older family, are older, have other medical illnesses, may play a role as well. So having your goals first helps to ground the information to some degree. So then I say to patients that there are several things, you get information from your greater circle, right? Your family, your friends, the people you know. Be very careful about that information source. And in many situations where people want to give you information, it may be better for you to very nicely say, "that information for me is not right now so I would like not to hear about your relative who died of a cancer and went here or there," because people sometimes, you know, your friends and the people who love you don't understand the impact of what they're telling you. And also a lot of people will get information from their friends or family about diet or about things they may have done to make the cancer worse, which we know.

**DR. COMEN:** Or they've read on the Internet.

**DR. RUGO:** We don't have that information scientifically now, I tell people really take that information with a big grain of salt and try and avoid information that maybe actually put you in a bad frame of mind or not be helpful. Sort of delay information. Then what do you do about getting more information about your treatment options? Because, well, there actually are resources to just learn a little bit more. There are patient focused resources from the American Cancer Society, from the Breast Cancer Research Foundation, from Komen and then the National Comprehensive Cancer Networks, NCCN, actually have patient focused, disease focused information that gives you actually a path of what you would do if you had this kind of cancer with this kind of situation. So then the next thing is, you know, how about looking at different trials? Well, there's actually really nice resources now. Breast Cancer Trials dot org has information with different trials around the United States, and actually can coordinate them with the kind of disease you have. But I encourage



# FIND YOUR MBC VOICE

patients, this is what you want from your oncologist, you want to be able to look at these sites, find trials that seem to fit or information, and be able to send it back to your care team and say, “does this fit for me?” And, “how does this relate?” So I think those are very good information sources for patients. But it's really important in this information to be able to have your care team to bounce those ideas off of. You have to be able to have an open communication where you can question the recommendation without feeling bad. And if you feel badly because you're asking questions or questioning a recommendation, that's not the right place for you to be. And it can be difficult, because I find a lot of patients who want to get second opinions, they don't want their doctor to know, because they're afraid the doctor might be offended. So, you know, when patients come in and talk about their diagnosis, they need to also be able to interview the doctor and make sure that they can ask questions, that they can get a second opinion and they won't offend that doctor, and the doctor will be a willing and able participant in a team that can include external advisers.

**DR. COMEN:** I couldn't agree with you more. I think that I always encourage, if my patients feel like they want to have a second opinion or someone's coming to me for a second opinion. If you have a doctor whose ego is such that they're threatened by either, you know, they... you want a second opinion or your doctor doesn't think you should have one, something's definitely not right because we all work together as a team and I would be delighted if my patients saw you and I'm sure vice versa. And that's the way that it should be, that the focus is on what's best for the patient and not the ego of any other person on the care team certainly.

**DR. RUGO:** And then it doesn't mean that you have to agree with the second opinion and you want to be able to take those opinions and bring them back home and say, “what does this mean for me?”

**DR. COMEN:** So Hope, we know that especially when someone's first diagnosed with metastatic breast cancer and that they've had, let's say, no treatment prior for metastatic breast cancer, it's so important what treatment they have as that first line of therapy as we know that it can influence the next line of therapy options that they have, whether it be standard of care or even clinical trial options. Can you speak to how critical those first decisions are in a treatment's course?

**DR. RUGO:** It's important to understand your alternatives, and to be able to ask your care team what your alternatives are and to look at the NCCN patient guidelines to know that this is tracking with what you have been recommended. So if you have the ability to just take one half step back and take a minute to think about it, ask the questions and make sure that that is really the optimal choice of therapy that makes a really big difference. So, I think that, feeling empowered in the overwhelming time of being diagnosed with metastatic disease is important and the one thing that can help with that is bringing somebody with you, who is your scribe, so you can ask to record, if you don't have somebody come with you, or you can bring a friend, a family member with you and have them take notes. Have

# FIND YOUR MBC VOICE

them record, if the physician or caretaker agrees, have them take notes. This is going to start you on the right path.

**DR. COMEN:** So for patients to feel that they've truly made their own informed decision based on all the opinions that they've heard. So with that in mind and with all your experience, is there anything else you'd really want our audience to know about either how you treat metastatic breast cancer patients or what's really important for them moving forward in tackling their diagnosis?

**DR. RUGO:** I think it's important for patients to understand the heterogeneity of breast cancer because, you know, now most people know somebody who has had breast cancer before, and if they don't know them, they can hear about them from their friends or family or extended circle. It's really important to know that there are subsets of breast cancer. What subset your breast cancer is, is one of the first pieces of education that a patient needs to know so they really can understand where they fit within the continuum of breast cancer as a diagnosis, in terms of their treatment options and in terms of their expected outcome. It's really important. What we understand is all based on that. And then I think it's really very important when patients have a diagnosis of metastatic disease to be able to talk to their family, honestly. What is frightening and what isn't? What kind of support do you need now or later? It's really important when, to have that, because sometimes it's just, you know, people feel like they're all by themselves. They don't want to talk to their family. It's too upsetting for their family, or they don't want to reveal to their family that something is wrong. So many patients tell us that they haven't talked to their kids about their diagnosis. How you talk to your kids, use your care team to help you learn that. There are child life support at most institutions and, if not, you can find it through symptom management programs, through psychologists. It's really important to have that support so I think that that's one thing. It's a team, it's a balance. There's a lot of decisions to make as you go along and you want to be able to prepare yourself, be able to ask your care team and understand what kinds of things you can still question. What are the right scans? Should I have genomic testing? Have I had the right testing? Are the different places that do testing the same or different? All of these things come up, all the time. Do I want to do a clinical trial? What clinical trials? How will that help me? Will this treatment hurt me? What are the side effects I should expect?

**DR. COMEN:** Those are so many excellent points, Hope, and I'm so grateful that you were able to share them with all of us today. I think one of the key things in the thread that I hear in what you're saying, about informed decision making and having patients speak up, is that, that sense of unwanted aloneness is so completely overwhelming and the key is that patients are not alone. They're not alone with their doctors. They're not alone with this broader basket that you described, that we really try to envelop patients with not only compassion and empathy, but lots of options in ways to help them make informed decisions with their doctor and with their care team. Thank you so much Hope, for your time today and for sharing your thoughtful discussion. And thanks to Pfizer for sponsoring this conversation. As Dr. Rugo shared today, a diagnosis of metastatic breast cancer can understandably be very hard to speak up about and talk about. But it's so important to

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Speak up so you can have an informed role in making decision treatments with your health care team. Visit Find Your MBC Voice dot com for an interactive discussion guide to help you have an informed conversation with your doctor.

**END**