

Advocacy

Richard Michaelson, MD

Tape 1

THE CAUCUS EDUCATIONAL CORPORATION

SLATE: His name is Richard Michaelson, M-I-C-H-A-E-L-S-O-N, MD, Chief Medical Officer for Oncology at the Saint Barbus Cancer Center.

Q: At what point in the process do you actually see patients, as in what do you do?

RM: It depends, Paul. We see patients at various stages of their illness. The most common situation is that we see people after a cancer has been found, biopsied, and often surgically removed. Occasionally we see people who do not yet have a diagnosis of cancer or people where a diagnosis has been made and the question of what the first treatment should be.

Q: Talking about what the first treatment should be when a woman is diagnosed, what should her next step be? Let me just back up one second. The whole story we're doing is on personal advocacy, trying to help yourself, and what are the things that women can do to best help themselves -- so in the context of that.

(Background Conversation)

Q: So when a woman is diagnosed what should her first step be?

RM: I think when a woman is diagnosed with breast cancer the first thing she should do is take a deep breath and realize that there is no urgency to make a decision that, there, the next day,

what to do. She has time to gather information and make an intelligent on what to do with the next step.

(Background Conversation)

RM: I think when a woman receives a diagnosis of a breast cancer the first thing she should do is take a deep breath and understand that there's no immediate urgency to move forward. She has time to gather information and make sure that she's comfortable with what she's going to do next and who she's going to see next. I think there are several things that need to be done at the beginning. One is to find from her physician, whether it's her gynecologist or her primary care physician, the name of the next physician that ... he or she thinks that the patient should see.

(Background Conversation)

RM: So I think the first thing when someone is diagnosed with breast cancer is to take a deep breath and realize that there's no urgency to have to act immediately, that there is time to gather information. Probably the first step is to go and see an expert in the field and probably the first person would be a physician who's recommended by either the gynecologist or the person's primary care physician. In breast cancer treatment that's often a breast surgeon.

So a first step typically is to go and see a breast surgeon, to gather information from that surgeon in terms of the type of treatment that he or she recommends. Simultaneously, a woman who is diagnosed with breast cancer can also begin to gather information for herself. She can go online and look in some reliable websites trying to understand what she's dealing with and what her treatment options are. So that when she sees the surgeon she can have some understanding what the surgeon is saying, she's not

hearing this information for the first time, she can put it into context with what she's already learned.

Q: But isn't that ... it all sounds well and good but isn't that a little difficult when somebody is like diagnosed with breast cancer? One woman said ... actually Valerie Tremley(?) said to me the first thing she did was go home and get her things in order and make a lesson plan for the next month for her kids because she wasn't sure she was going to survive. I think people are so emotionally distraught, how can you be logical? What are the things that can help you keep yourself on track and just make sure you are doing the right thing and not just panicking?

RM: Sure. Well, I think one thing is to share your feelings with the doctor who's giving you the news. Whether it's your primary care physician or your gynecologist, you want to sit down with the person, you want to have an understanding of exactly what you're dealing with. If a biopsy was done, what did the biopsy show? What did the mammogram, the ultrasound, if those were done, show? What does your primary care physician or gynecologist feel he might hear when you go and speak to the next physician? And then go and get the name of the physician to go and gather information.

Q: That still sounds very, very logical, but should people be writing it down? Should they bring a friend with them? Should they tape it? What would you recommend?

RM: Sure. I think because people are in the state of shock when this diagnosis is made I think it's important that you have other people around you to help you decipher the information and record it. I think it's very important to bring somebody with you at each of the visits when you're gathering information, a relative, a

friend. If there's no one available, certainly bring a pad and paper, take notes yourself. If not ask the person who accompanies you to take the notes. But I think that's very, very important, is to have somebody else there, another set of ears who can help you understand the information and remember it.

Q: What about things like second opinions? Because let's say a lump is found, then you have the option maybe of a lumpectomy, a mastectomy, how do you make those decisions? What do you base them on?

RM: Well, again, I think the more informed you are, the better it is to make it. So I think the first thing you want to do is you want to speak to some physician, I mean, this case would be a surgeon. Have a surgeon make his or her recommendations and ask questions at that time if they come to mind to better understand why that decision is being made. If you have the ... ability to gather some information prior to the consultation, if you can go online and get a little bit of information, maybe talk to some friends who have been through this, so you have some idea of what you may hear when you go to see a physician, that makes it a little bit easier to go with a list of questions that you can ask. So I think you certainly want to ask the first physician who you see those kinds of questions.

A second opinion is always a helpful thing to do. I don't think that it's always an essential thing. There are lots of different physicians and health care professionals who a woman diagnosed with breast cancer is going to see. She may also see a surgeon, a radiation oncologist, a medical oncologist, she may see some psycho-social counselors, perhaps a genetic counselor. And I don't think at each step a person actually needs to get a second opinion. So how do you decide when to get a second opinion?

Well, first of all, the more educated you are, the more you can determine if what you're hearing from the physician that you're speaking with, or the health care professional, isn't keeping with your understanding. Secondly, I think for the major decisions, you're going to go for surgery or if someone's recommending chemotherapy it's always helpful to get another opinion from a professional to see if you're hearing the same, the same thing as you heard from the first physician.

But I think there are situations where people cannot get a second opinion: their insurance may prove somewhat obstructionist in this regard. Some people just emotionally have a very difficult time seeing more physician than they need to see. And I think a person who is educated, understands the options and chooses an option that feels comfortable, that I don't think it's essential that she get another opinion.

Q: Let me go back to the insurance issue now that you've brought it up. How much of a hinderance is insurance in a woman being her best advocate in something like this?

RM: I think in general, at least in my experience, insurances have not been tremendous obstacle. The biggest obstacle that I've seen is in terms of women choosing who they would like to see for a second opinion. Excuse me. There are certain insurances that only cover certain physicians during(?) institutions, so there may be some limitation in who a woman can see for a second opinion. Everything that we have not found, in our practice at least, that insurance has been a major obstacle in terms of patient care.

Q: Let me go back to something you said before, and that was people looking on the Internet. What sites specifically

would you recommend? Because obviously you don't want to go to a chat room and this and that. What would you recommend?

RM: All right. I think(?) in terms of the Internet I think people have to be very careful. I'm certainly not recommending that we censor people and surely people are welcome to look at any website that they're comfortable looking at. But there are some websites that do have a bias or approaches that may not in fact reflect accurately what's known medically. So my recommendation is to go to sites that I think are objective. And there's several websites that we recommend.

One is the National Cancer Institute website. The National Cancer Institute is a part of the government that gives out cancer research dollars and regulates cancer research, or directs cancer research in the country. Their website is [www.nci.nih.com](http://www.nci.nih.gov) ... I'm sorry, dot gov.

(Background Conversation)

Q: And ... another good website is actually our professional society, the ... American Society of Clinical Oncology has a website, which is www.asco.com. and they have within that website a section called "People Living with Cancer," and that also gives information about options for therapies. Those are the two websites I'd direct people to.

RM: Okay, and I think those are the ones that Wendy actually mentioned that we'll see them at her home. In terms of finding a doctor that you click with, I mean, I'm not sure how much you have to click with a surgeon because you don't see them for that long, but in terms of somebody like yourself where there's ongoing treatment, how important is it to click with the doctor and how

important is the communication between that woman(?) patient and

...

Q: I think it's essential that people have good communication ... with their physician. I think when people are searching for a physician obviously you want to find a physician who's knowledgeable and who you feel comfortable with in terms of their breadth of knowledge and their experience. But I think almost equally important is to find a doctor who you have a comfort level with. You need to have confidence in what your doctor is telling you, you need to feel comfortable that the doctor is being honest with you, is giving you options for therapy, not just his or her prejudices, and someone who you're comfortable sitting down asking questions to and who you is going to give you a full and honest answer.

I think it is very, very important that you feel that kind of confidence with the physician who is treating you. And I believe that your physician really should be your advocate. This is an illness that's affecting every aspect of a person's life, and it's obviously potentially a life-threatening illness, and there are multiple options for therapy. So you need someone you feel is your advocate who's going to give you the information you need and be there to answer the questions and give you and your family the support when you need it.

Q: I want to just go quickly to Wendy a little bit. How diligent was she and how much of an advocate for herself did you find her to be? When Wendy came in here what?

RM: Wendy came in here with her husband Steve. Wendy had taken the opportunity to investigate on Web and all the news various aspects of her disease. She understood what her pathology report meant, what the implications were, what the stage

of her disease was, and she had a general idea of some of the options for therapy that she might be hearing about in the office. So when we sat down and I reviewed her pathology report and then I made my recommendations to her after reviewing treatment options she was able to put those into context. It was not the first time that she was hearing some of those options, it was not the first time she was hearing the name of the drugs, so she had specific questions to ask me in terms of why this regimen, what side effects might I experience, and why not some other regimen that she may have read about.

Q: Did she have a choice after she had her lumpectomy to get chemo or not, or were there other options?

RM: Oh, I think there's always a choice of what a treatment you get in a situation like Wendy's. Wendy was in the situation where the cancer was removed and as far as we knew there was no residual cancer. In a situation like Wendy's we looked for certain that there was some chance that a cell could have escaped from the cancer before it was removed. We didn't know for certain that there were any remaining cells in her system.

So in that situation people really do have several options. There are some people who may choose to get no further therapy recognizing that we can reduce the risk of the cancer occurring, but some people choose not to take that path. If people are interested in reducing the risk of the cancer recurring in their system there are various options for therapy, and each person has to weigh for himself or for herself what is the potential benefit of the therapy versus what are the side effects. So that's a long-winded to say, yes, Wendy did have choices. She elected to take a relatively aggressive approach in trying to maximize the benefit of therapy and

"The Typettes, Fingers That Dance!" (212-505-6518)

1-9

was willing to go through the side effects of treatment to reduce the chance of the cancer coming back.

(Background Conversation)

(END OF TAPE)