

Welcome to Yale Cancer Center Answers with Dr. Ed Chu and Dr. Ken Miller. I am Bruce Barber. Dr. Chu is Deputy Director and Chief of Medical Oncology at Yale Cancer Center and Dr. Miller is a Medical Oncologist specializing in pain and palliative care, and he also serves as the Director of the Connecticut Challenge Survivorship Clinic. If you would like to join the discussion, you can contact the doctors at www.canceranswers@yale.edu and the phone number is 1-888-234-4YCC. This evening we are joined by Linda Mowad. Linda is the Director of the National Cancer Institute Cancer Information Service at Yale and she begins with an overview.

- Linda The Cancer Information Services, the National Cancer Institute, which is the Nation's lead agency for cancer research, established the cancer information service in 1975 to educate people about cancer prevention, risk factors, early detection, symptoms, diagnosis, treatment, and research, and the CIS is an essential part of the NCI's cancer prevention and control efforts.
- Chu When did the cancer information service effort begin here at Yale?
- Linda We took our first call in September 1976, so we have been here for a very long time.
- Miller Two-part question for you, when the public wants to call and get information about cancer, what number would they dial and then what happens?
- Linda They dial 1-800-4CANCER, or 1-800-422-6237. The phone is answered by a trained cancer information specialist who is trained to assess callers' questions. Most people call and do not really know what to ask for. They have just been diagnosed with cancer perhaps, or they have a family member who has been diagnosed with cancer and they really do not know what it is they need to know. The information specialists are trained to assess the callers, look at their questions, and are able to answer them.
- Chu As an example, the patient calls up and says that they have prostate cancer. How would the specialist help that person? What would they ask?
- Linda We first do our disclaimer that we are not physicians, but we can answer questions, and they talk about the information they use and their disclaimer. They might ask, for instance, when were you diagnosed? Where are you being treated? Where are you being seen? What have you talked to with you doctor about? What is it you would like for us to help you with today? Then after they ask their questions, another assessment is made. They say, well it sounds as though what you might be looking for is such and such. We also will give them resources that they probably have no idea exist, and we tell them what they are, and we are able to talk to them perhaps about a second opinion. We do not make second opinion referrals for sure. We do not do medical consultations, but we certainly can talk

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about a second opinion and the resources. We send them information and everything we do is free. There is absolutely no charge whatsoever. There is no charge for information that we send and we send information to over 80 percent of our callers. We just check in and keep telling them that they are welcome to call back the days we're open.

Chu Typically, on a monthly basis, how many calls does your office receive?

Linda I can tell you more easily how many calls we do yearly. The latest information I have is from 2007, and in that year we received 90,628 calls to the 1-800 number and we also have automated messages that are available 24/7, 365 days of the year. We have had 26,221 inquiries through that. We also have live help, which you can get on the internet, and a lot of people do that through either instant messaging, which is 15,232, or e-mail. People can get onto the web and there is an icon there and we are able to speak with them as well, 5,642. So for the year of 2007, we had 137,723 calls.

Chu So a very active service.

Linda Yes it is.

Chu What is remarkable is that it's free to the public.

Linda Absolutely, totally 100% free and tailored to the callers' needs.

Chu This is something where we really need to get that message out.

Linda Exactly.

Chu The services available should be taken advantage of.

Linda Absolutely, and they are from 9 to 4:30 everyday Monday through Friday through the phone service with TTY. We have TTY accessibility and the other services, as I said, are available 24/7 on the automated messages. Live Help is from 9 a.m. to 11 a.m. Eastern Time.

Chu Linda, if a patient or family member calls and their English isn't great, are there other language services that are available?

Linda English or Spanish, yes. We have bilingual information specialists for English or Spanish. We do not have other foreign languages. However, we do have some resources in other languages and we can refer them to other places where people can get information in other languages.

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- Chu Great.
- Miller There is another group of callers, I would imagine, who have done their reading and have learned a lot and they want real specific information, such as what protocol is available or what kind of studies they can participate in. What can you do for that?
- Linda The callers to our service are educated. We do demographics on 50% of our callers and they are highly educated. A lot of college graduates and postgraduate work as well, so they have already, as you said, done their research. They have talked to their doctor, they have their questions and they want very specific information. Our information specialists are very well trained and can provide that sort of service. For instance, somebody calls up and wants to know about a specific clinical trial, for instance, where it is, what is happening, and if we can tell them a little about it? We certainly can do that. We have access to the clinical trials from the National Cancer Institute that are in the National Cancer Institute database. We can also refer them to other NCI designated cancer centers across the country. We can help them look for second opinions if that is indeed something that they need, but we can tailor the information by the way the information specialists are trained to assess the callers' needs, we can actually give them whatever it is they need, and if we do not have the answer to a question, we certainly have no problem saying, I do not know the answer to that but I will get back to you. Almost 100% of the callers' questions are answered at the time of the call. We very rarely have to call back.
- Miller That is interesting; you mentioned that you generally refer patients to the NCI designated cancer centers for clinical trials. I am just curious why is that the case?
- Linda Our policy says that we cannot make second opinion referrals to specific physicians. So if someone calls, for instance, and they want a second opinion, and we talk about a second opinion and during the conversation they say they would like a second opinion, what we tell them is to certainly go back to their doctor. We never, ever interfere with the doctor-patient relationship, so we refer them back to their doctor. We then talk about the NCI designated comprehensive cancer centers in the area within which they live, and if they are calling from Connecticut, the only NCI designated cancer center is the Yale Cancer Center. So we could make a referral to the number there, not to a specific physician but to a number that we have been given by the cancer center to use. After that, we refer them to the American College of Surgeon Cancer Program Approved Hospitals in the state within which they live, or if they'd like, we can give referrals all across the country. That is never a problem because we have those kinds of resources, and in this day and age of the internet, it is very easy to do so.

Chu Maybe the other rationale for referring people to NCI designated cancer centers is that, as you said, Yale is one of 39 designated comprehensive cancer centers. That means they have state-of-the-art, cutting edge, innovative new therapies either for direct treatment, prevention screening, supportive care or survivorship, which is obviously a huge interest of Dr. Miller's. All of the groundbreaking work is being done at NCI designated cancer centers.

Linda Absolutely, and being funded by the National Cancer Institute, we have all of the information quickly at our fingertips. If we need anything we certainly can call them and get more information, and if we have people calling wanting to know about something that is not in our database, there are ways that can be included. We have physicians call and ask how their trials can be included, and we can give them that information as well.

Miller I would imagine that when patients call, or their loved ones, they are scared.

Linda Oh, yes they are.

Miller The people that answer the call, what are they hearing from the callers and what do they do with that?

Linda Well especially somebody that's a younger person, for instance, they are terrified that they have heard the word cancer. The other thing is that when they call they really do not know what to ask. They have not heard, perhaps, what the doctor has said so they are looking for information. A young woman just diagnosed with breast cancer may have no idea what to think and has talked to her doctor but really does not know what the doctor is saying. The information specialists have been trained really well; it is a very intense training that they go through. They are not social workers and they are not counselors. We have many nurses, but they cannot give medical information as they would if they were working in the hospital or in a clinic. They are able to assess and try to help calm the fears of the person by giving them the information. They will go step by step through the information, what to do the next time they go and what they need to bring. They recommend that they bring someone with them and write everything down. You can ask if you can record it and it is okay to ask questions and it is even okay to expect an answer to your question. These are things we tell them to do. We can reinforce that with the information that we send them. They talk about what they should do when they are talking to their doctor, and what their options are. And we tell them that they should keep a journal. They should write down the date they talk to someone, who exactly they talk to, what was said, and they should call us back so we can help them through the whole process of how to talk to the doctor. When you are assessing a caller's needs, even though we have a plethora of information, we clearly do not send all that. We do not want to overwhelm our callers. Some people want everything you can give them, so we try to decide

what the caller needs at this point in time, not to overwhelm them. For instance, they may have chemotherapy, they may have radiation, and you would want to send the right information. You also want to send information about support groups and resources because they are going to need that. How they use that information certainly is up to them.

Chu Is there a mechanism for if an individual caller is calling for the first time, and they develop a rapport with someone on the other end, if they call back can they get that same individual in order to maintain that conversation?

Linda It is discouraged that they make a link with the person they are speaking to, because they do make a link from the moment they talk to that person and become comfortable with that person, they only want to talk to that person. However, everyone has trained the same way and everyone can do the same thing. The information specialists are taught in their assessment that they can make that decision if they want to, if they think that it would be more beneficial to speak to them, but they do tell them that anyone they speak to can talk to them the same way they have.

Miller I have a personal question. What is your background and how did you get into this part of cancer care?

Linda I am a nurse and I worked for many years in an operating room and then decided I wanted to do something different with my life, so I looked into public health and cancer control. I worked at a mobile health van screening patients and talking to patients, and I learned a lot there. I then came to Yale and I worked and I did some research studies. I worked with a friend who was getting her PhD, so I did some studies with her and then a job opening came up at the cancer center and I have been at the cancer center since 1984. I have been here a long time.

Chu As I understand, last year you were Chair, or President, of the local American Cancer Society.

Linda Yes, I am the immediate past chair of the American Cancer Society, New England Division. I was for 2 years. I now have been nominated to the National Board of the American Cancer Society and that will happen in November of this year.

Chu Terrific, congratulations.

Linda Thank you, thank you very much. It is a wonderful ride for me.

Miller You are listening to Yale Cancer Center Answers. We are learning about the Cancer Information Service with Linda Mowad, Director of the Cancer Information Service at Yale Cancer Center.

Medical Minute

The American Cancer Society estimates that in 2008, there will be over 62,000 new cases of melanoma in this country and about 2400 patients are diagnosed annually here in Connecticut alone. While melanoma accounts for only about 4% of skin cancer cases, it causes the most skin cancer deaths, but when detected early, melanoma is easily treated and highly curable. Clinical trials are currently underway at Federally Designated Comprehensive Cancer Centers such as the one at Yale to test innovative new treatments for melanoma. The patients enrolled in these trials are given access to newly available medicines which have not yet been approved by the Food and Drug Administration. This has been a medical minute and you will find more information at www.yalecancercenter.org. You are listening to the WNPR Health Forum from Connecticut Public Radio.

Miller Welcome back to Yale Cancer Center Answers, this is Dr. Ken Miller and I am joined by my co-host, Dr. Ed Chu and also Linda Mowad, Director of the Cancer Information Service at Yale Cancer Center. We are talking about the resources that are available through the Cancer Information Service. Linda, the CIS, Cancer Information Service, provides information to the public and professionals. What are some of the other goals and projects?

Linda We have a 3-pronged approach at the Cancer Information Service. As we just talked about, we answer telephone calls through the Cancer Information Service with the information specialists. That is how we work reactively. We work proactively through our partnership program which goes into the community, community outreach you might say. We have worked proactively to collaborate with organizations with the shared goal of working together to identify, address, and reduce cancer health disparities experienced by medically underserved audiences. Medically underserved audiences, I do not have to tell the two of you, are those audiences or population groups that traditionally have had less access to the health care system than the general population, or face linguistic, cultural, or socioeconomic barriers accessing cancer-related services. The CIS has established partnerships with nonprofit, private, and other government organizations at the national, regional, and state levels. Through the partnership program, or outreach program, the CIS reaches people throughout the United States and the territories. We work with partners that have an established presence in the region, are trusted within their communities, and are dedicated to serving minority and medically underserved populations. We help these partners develop and evaluate programs on breast cancer, cervical cancer screening, breast cancer screening, clinical trials, tobacco control, and cancer awareness especially for the medically underserved. The CIS also helps partners develop coalitions, conduct training on cancer related topics, and use NCI resources. I mentioned we are a 3-pronged entity. We also have CIS research. In our research, we

participate in cancer control and health communications research that supports NCI's programs and priorities. Our research helps identify new and better ways to communicate health information to a variety of audiences. Today, we have collaborated on more than 50 studies through the Cancer Information Service that have helped researchers learn better ways to communicate with people about healthy lifestyles, risk, how to prevent disease, diagnose, and treat cancer. We also have 140 peer-reviewed articles about this, so we have been doing research for quite some time and I think we do a good job. We actually collaborate with people here at Yale.

Chu You do a great job Linda.

Linda Thank you.

Chu It is really remarkable the breadth of the services that you provide.

Miller Let's go back to the community outreach piece.

Linda Sure.

Chu There is no question that I think the National Cancer Institute is mandated, the NCI designated cancer centers, to reach out to the community and try to identify barriers that exist, especially for minority and underserved populations as you have mentioned. That really is an important goal because a lot of the minority and underserved populations do not have the same level of access to care, and as you mentioned, screening and early detection are a huge part of it. Can you tell us a little about some of the projects that have taken place here at Yale and the State of Connecticut?

Linda We partner with Yale Cancer Center on clinical trial education and awareness programs using the NCI's cancer clinical trials education series. We continue at this point to provide resources to support programs at Yale, such as the Yale Cancer Center lecture series, the Cancer Center Symposium, and other events. Did you want me to talk about other state agencies that we interact with?

Chu Maybe just more specific programs in terms of trying to enhance breast cancer screening, or as you mentioned, cervical cancer screening efforts.

Linda Working with Yale and the community we work with federally qualified health centers through breast and cervical early detection programs that have been funded by the CDC. We work and interact with them, and Yale, because some of the federally qualified health clinics go to Yale for followup for breast and cervical cancer. We also do the clinical trials education series, as I mentioned a moment ago, and we are working with Dr. Kevin Kelly on a treatment committee.

We go to the Yale Cancer Center lecture series and we bring NCI materials and are there to answer questions and help in any way we can. Through networking and working with other people, we have also been able to identify other partners that we can work with across the state. It is a win-win situation for us, the Cancer Center and other entities in the state a well.

Miller I want to go back to the other components of your research. Can you give us one example of a project your group has worked on recently?

Linda NCI funds a lot of research, well, I should not say a lot perhaps at this point in time, but they are still funding research. We have an RO1 here at Yale where we are looking at using the 1-800-4CANCER line. We have just finished two studies looking at our callers with regards to physical activity and fruit and vegetable consumption. We have just done our final accrual and we came out of the field about 2-1/2 weeks ago. We are now working with the federally qualified health centers to work with their populations of African American, Spanish speaking, Hispanic, and Latinos in New Haven doing, again, fruit and vegetable consumption and physical activities. We are just now getting through the focus groups, and talking to key staff as to how they think things should be done. We will do four projects there, and we will do two more in 2010 using the 1-800-4CANCER line. So, that is an RO1 we are working on. We are also working with Mashantucket people at tribal nation, here at Yale, and that finishes at the end of this month. We looked at making recommendations to the NCI about the materials that we have and how they can be adapted for Native American audiences. We are also looking at a survey that we have done with health care providers and how they talk with and treat the Native American population here in the State.

Chu Is there much difference in the needs of the Native Americans as opposed to Caucasian Americans?

Linda I think there is, and I think it is how they view information and how information is written and at what level it is written. When we talk about doing a focus group, or a support group, the Native American community does not look at that; they talk about 'talking circles'. It is very enlightening and it is really a wonderful experience for my staff and me to be able to work with them because they are so eager to work with us. They are really terrific collaborators and partners. We are helping a population that is not easy to get to through some collaboration that we have had through Yale Cancer Center. We have been able to identify that population and work with them, and it has been very-very rewarding.

Miller Along those lines, your program has been in Connecticut for essentially 30 years at this point, and it is one of the first, in your career, what are some of the changes

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that you have seen in terms of the ability of the National Cancer Institute, at Yale for example, to get the message out. Are we doing a better job?

Linda I think we are. The technology for one makes it so much easier. I mean think back to before the internet, how were we ever able to do what we do? Just getting funding, for instance, so that we could stay alive has changed a lot, but I think we have become much more knowledgeable about the needs of our callers and the needs of the general public. Things have changed. Again, the internet, that explosion has changed the way people get information and there is a lot of information on the internet about cancer for instance, as you know, but it is not all as it should be. Our callers will call, and they have gotten all this information from the internet. They look at the unproven methods and have to sift through that. We are able to help them identify what is correct, and what is not correct, what they should think about perhaps, and what they should perhaps do, or what the next steps may be. Our research has changed a lot too. We have worked with people that we have known, that I have met at breast cancer committee meetings for one, one of our researchers that I work with, and a grant came up and I picked up the phone and called them and said, can I meet with you, and we did, and we have done several RO1s. We have done a Donahue. We have done digital divide projects, so we have done a lot and the relationships that we have helped immensely.

Chu Linda, for those who are just joining the program, can you repeat the number that people can access to get on to the Cancer Information Service.

Linda For any information that you would like, please call 1-800-4CANCER and that would be 1-800-422-6237. We are available from 9 a.m. to 4:30 p.m. local time. We have information specialists in English and in Spanish, and we would love to have you call us and hope that we can help you.

Miller On the internet, how do people access information?

Linda www.cancer.gov and look for the icon that is a live help, then you will be able to get to us through the internet, again at www.cancer.gov

Chu Linda, it is great as always to have you with us. It is amazing how quickly the time goes, but we look forward to having you back on a future show and give us an update on where things stand with respect to the Cancer Information Service.

Linda Great, thanks so much for having me. It has been a pleasure.

Chu You have been listening to Yale Cancer Center Answers and we would like to thank our guest Linda Mowad for joining us this evening. Until next time, this is Dr. Ed Chu from Yale Cancer Center wishing you a safe and healthy week.

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If you have questions for the doctors, or would like to share your comments, go to www.yalecancercenter.org where you can also subscribe to our podcast and find transcripts of past programs. Next weekend, Ed and Ken will discuss the latest information on clinical trials for breast cancer. I am Bruce Barber and you are listening to the WNPR Health Forum from Connecticut Public Radio.