

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. 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 directly at canceranswers@yale.edu or the phone number is 1-888-234-4YCC. This evening Dr. Ken Miller sits down for a talk with Lucinda Hogarty, Program Director for the Connecticut Cancer Partnership

Hogarty The Connecticut Cancer Partnership is a voluntary coalition, unincorporated, of people from around the State of Connecticut and organizations from around the State of Connecticut that are committed to reducing the burden of cancer. It is based on the principles of comprehensive cancer control, which means that if we work together we can accomplish more in a more efficient and effective way than agencies and organizations working separately without knowing what each other is doing.

Miller What brought you to this kind of work and to this position? What is your background?

Hogarty I have a Masters in Public Health from Yale and I have always had an interest in health promotion, broadly defined. I have worked in local community hospitals, I have worked in local health departments and I have worked in a coalition building specifically in the areas of elder care and public health, but the common thread was working with community partners to achieve a common goal. And the fact that such a high percentage of cancer is preventable really leads to the health promotion message, so I was very excited to be able to work on this coalition approach to comprehensive cancer control here in Connecticut.

Miller Obviously there are a lot of organizations in Connecticut that are interested in preventing cancer and better treatment for cancer, what are some of the advantages of having a coalition of these groups, and obviously it sounds like one of your skills and interests is putting people together, what is good about it?

Hogarty I think it comes down to the principle of synergy, which may sound a bit undefined, but I do believe that there are real advantages to working together in that. We learn from each others best practices. We learn what might need to be avoided as far as things that have not worked out as well as we might have hoped in the planning stages, and I think the most important part of what the Connecticut Cancer Partnership is doing right now is developing a statewide cancer control plan. This is to address the needs in the state over the next 5 years. We are wrapping up the first cancer plan which covered 2005 to 2008, so we are at a critical juncture right now looking at what we learned from the previous plan, what worked well in terms of our structure of organizations working together and how we might go forward differently.

3:32 into mp3 file http://www.yalecancercenter.org/podcast/Answers_Sept-28-08.mp3

Miller What are the main goals in the initiatives of the coalition as they exist now? Where do you think things may be going?

Hogarty The way the Cancer Partnership members are organized to achieve the goals of the partnership is divided into what we call continuum work groups across the cancer continuum. We have experts from the areas of prevention, early detection, treatment, survivorship, and end of life issues working as separate entities to identify activities that need to take place across this state. This might be zeroing in on a geographic area, on a population that has been underserved, and trying to address what their needs are. A lot of the comprehensive cancer control approach has been in trying to identify the best way to effectively deliver public health messages with regards to prevention of cancer, early detection, and getting quality treatment and addressing any barriers to care that people might experience with regards to disparities and access issues.

Miller Let me ask you a broader question. Let's talk about the United States in general and then we can focus a little bit on Connecticut, but if you were to give the United States a report card in terms of getting the message out for let us say prevention, cigarette smoking, diet, and exercise, what grade would you give in terms of the health care system?

Hogarty As a state?

Miller As a nation and then we'll do it as a state.

Hogarty I have seen a huge improvement over the past 20 years since I graduated and got my Masters in Public Health. The social marketing campaigns have been very effective and we know, for example, that in cigarette smoking in the past 40 years or so the percentage of Americans who smoke has been cut in half; that is a huge success story. There are more challenges right now in sun exposure and some environmental exposures. There is a much better understanding now about the importance of early detection, making sure that people find those messages acceptable and act on them is perhaps another issue. It is hard to give a grade, but I think that we have moved from probably average, C, not a very desirable grade, up to a B, B plus in some specific areas. There is certainly lots of room for improvement.

Miller How about as a state?

Hogarty As a state, I would say it is similar. There are some pockets in my position where I feel that I particularly have a challenge to reach out to areas of the state that might not receive the message. I came from the North Eastern corner of the state, which is good example of an area that I would like to reach out more to. Some of the smaller hospitals have not been as

6:56 into mp3 file http://www.yalecancercenter.org/podcast/Answers_Sept-28-08.mp3

involved as we would like to see them be in some of the statewide initiatives. There are grades in different categories that are commonly used measures of course, and I think in some of the end of life measures in pain control, palliation at the end of life, we have seen some improvement. We are also looking to make sure that the level of awareness and education among health professionals continues to increase so that the professionals are able to provide good guidance to cancer patients, but also to people in general before they are diagnosed with cancer.

Miller Keeping in mind that you want to incorporate people throughout the state, especially underserved areas or areas that have been less involved, how does the coalition try to incorporate people from underserved populations or more remote areas of the state?

Hogarty Right now our membership reflects representation from about 150 organizations and the numbers of individuals from each organization varies. Some of our bigger organizations may have 30 or 40 individual members but they may be representing very different programmatic areas within. For example, The Department of Public Health, Yale, the Uconn Health Center, and American Cancer Society, are all founding members of the Connecticut Cancer Partnership, and each one of those founding member organizations has many subdivisions and different organizations. Those are just examples, but what we really do is try to use our organizations ability to reach into their own communities, reach their own constituents to get the messages out. One of the things that we have been trying to do is identify the gaps, what organizations are not represented at this point, so we were reaching out to others, for example, minority health coalitions. With organizations at the grass root's level we know it is not our job to go out and talk to patients individually, but it is our job to make sure that those organizations that reach out to the individual have that synergy, or power of the collaborative approach behind them as far as getting the message delivered and learning about best practices that are working well, following examples, and being able to learn from each other's experience. That way we can identify gaps in service and avoid duplication.

Miller The Connecticut Cancer Partnership is going to produce a cancer control plan. What does that document look like? The sense is that it is probably a large document, but what is in there?

Hogarty The current document, the Connecticut Cancer Control Plan for 2005-2008, is a 150-page document. It was written with the input of experts from the different areas of the continuum. For each one of those continuum areas, there are identified goals and objectives and each one of those objectives has action steps or strategies that translate into action; that is the goal. The goal is to be able not just to have this document be a report, it certainly does use statistics and data to identify what the problems are and the magnitude of the problems in

11:03 into mp3 file http://www.yalecancercenter.org/podcast/Answers_Sept-28-08.mp3

each of the areas, but using that data to identify what needs to be done. We hope that moving forward for the 2009-2013 plan the document will reflect accomplishments, but also be able to, in very clear language, identify who needs to do what to promote a reduction in cancer in the state. That would lead, we would hope, to policy change, perhaps legislative change, sustainable funding, the allocation of resources, whether that would be identifying a particular clinic or a particular geographic area that might need additional funding or support, or advocating for an increase in the cigarette tax, for example.

Miller Which I have to say, I would be in favor of personally. Talking about the plan and then how to actually translate it, obviously one of the things is funding, who funds the partnership activities to keep it going?

Hogarty The way it has worked over the past several years is that each state in the United States was required by the Centers for Disease Control to have a comprehensive cancer control plan and some sort of coalition to implement that. There was planning funding available to the states through the Department of Public Health in each state to set up this planning stage. The CDC was able to convert the funding from planning to implementation. So, some of the funding did come from the Centers for Disease Control federal money to the State Department of Public Health. Subsequent to that, we have been able to use the work that was done in the planning with the identification of implementation strategies.

Miller We are going to take a break. We would like to remind you that you can e-mail your questions to www.canceranswers@yale.edu. Please stay tuned to learn more about the Connecticut Cancer Partnership with Lucinda Hogarty.

Medical Minute

Over 170,000 Americans will be diagnosed with lung cancer this year and more than 85% of these diagnoses are related to smoking. The important thing to understand is that quitting, even after decades of use, can significantly reduce your risk of developing lung cancer. Now, everyday patients with lung cancer are surviving thanks to increased access to advanced therapies and specialized care and new treatment options giving lung cancer survivors new hope. Clinical trials are currently underway at Federally Designated Comprehensive Cancer Centers like the one at Yale to test innovative new treatments for lung cancer and the patients enrolled in these trials are given access to medicines not yet 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 here with

14:22 into mp3 file http://www.yalecancercenter.org/podcast/Answers_Sept-28-08.mp3

Lucinda Hogarty, Program Director for the Connecticut Cancer Partnership. Lucinda, the Partnership was formed in 2002, what are some of the main accomplishments over the last 6 years?

Hogarty We are in the process of evaluating those accomplishments over the last several years so that we can learn from them and use them as a springboard for the formation of our new plan. What we have been able to do is identify accomplishments by the continuum elements that I have talked about. So, for example, starting with prevention, when we talk about our accomplishments we are taking credit, I should say, for many of the accomplishments that are done by our partners. We are, as I mentioned, an unincorporated voluntary coalition. We are not out there delivering services to individuals, but through cross-cutting themes, cross-cutting activities, such as advocacy, we are able to accomplish something with the force of our membership behind us. Many of the accomplishments have come about in that way. For example, we have been able to devote over 2 million dollars to smoking cessation programs in the State of Connecticut through legislative appropriations. There has been additional funding for breast and cervical cancer early detection programs through an existing program at the Department of Public Health, but additional funding has been able to go to that. Quitline, which is one of the smoking cessation tools that has been used in the state, was in jeopardy of losing funding, and through some good advocacy and support from the Connecticut Cancer Partnership, we were able to infuse some funds into sustaining that. These are for example, accomplishments in the prevention arena. Early detection of course would include some of the work that we have been doing both in breast and cervical cancer detection programming, but also in the area of colorectal cancer. We have been able to grant funds to community health centers to provide colonoscopies to people who otherwise would not be able to receive those. That is one of our achievements that we are very pleased about. The clinical trials network which was established very recently here at Yale is something that will address treatment and we can look at best practices, what successful options are and evaluate the differences between different types of new treatments for cancer. That is an area that the coalition has been supporting in the area of treatment.

Miller Recently, I believe that the CT and the Partnership funded two initiatives to make a list, or compendium, of services available in end of life care and also in cancer survivorship. Can you tell us about those initiatives?

Hogarty The survivorship component of the Connecticut Cancer Partnerships work has gone from recognizing that there are many more cancer survivors now than ever before and that they do have very special needs. With the survivorship work, one of the big things is, as I mentioned earlier, getting the information out. There are lots of survivorship programs, but

18:16 into mp3 file http://www.yalecancercenter.org/podcast/Answers_Sept-28-08.mp3

survivors may not know about them, or their medical providers may not know how to direct the patients to them. So, one of the things that is currently ongoing is the development of an inventory of resources and services for survivors that will be made available to clinical providers and to the patients through many of our existing partners.

Miller The partnership very recently held its annual meeting, what were some of the main areas of focus?

Hogarty One of the things that we were trying to do for the annual meeting is making sure that we get the input, the expertise from our members in this development of the new plan. The new plan should be completed by early 2009. This past 5 or 6 months the focus has really been to make sure that we are listening to our experts and our member organizations. With the focus on disparities and access to care, equality and inequality, we looked at all of the continuum issues and what we were able to do is evaluate our previous goals and accomplishments and prioritize some of those action steps that I was referring to with the input of 150 people representing more than 100 organizations. In terms of funding, we are saying, these are the most important things to do and these are most important things to do in this order, so that the plan does not just look like a report, but more like marching orders.

Miller I have to say, hearing about it I feel like a soldier myself as I am treating patients with cancer, but it is very exciting because there is a flavor that there is whole group of people in the state looking at the continuum, of which treatment is really just a part.

Hogarty That is right, yes, and that is a very interesting perspective when you do look at comprehensive cancer control. That is one of the things that is very exciting about the partnership. We would prefer to prevent cancer and we would prefer to detect it early and once you are diagnosed, once you are a cancer patient, those other 3 components of the continuum kick in to one extent or another, and we want to make sure that the services represent that continuum.

Miller As Director of the program, what are some of your goals, and more broadly, the goals that you see for the organization coming up?

Hogarty What we are learning as we develop this new plan is that it is very important to get the most diverse representation that we possibly can to ensure that the plan is representative of all elements of our population, and our population is always changing, so we need to be aware of that. When I did an analysis of our membership I identified particularly that we would like to reach out more geographically. Connecticut is a small state, but there are still underrepresented geographic areas that I would like to reach out to and perhaps one way to

22:05 into mp3 file http://www.valecancercenter.org/podcast/Answers_Sept-28-08.mp3

do that is to have meetings and forums where we can draw input from people who are located in the Hartford/New Haven area. I would like to draw on the expertise and the connections that local health departments have. The State Department of Public Health is a partner in this and we have ways to reach out to local public health, and local public health is charged with health promotion so it seems like a natural connection to develop. Community Health Center is another that we need to develop a relationship with where they recognize us as a resource, and the smaller hospitals as I mentioned. We would like to get into having stronger relationships with survivor groups, with home care agencies and there may be organizations that are community based that we do not even know about yet.

Miller A lot has become digital, how will you get this information, for example the resource guide for the cancer survivors, or resource information for end of life care, out there to the public?

Hogarty We do have a website and the website is quite good, but we see expanding it with these additional resources and with lots of linkages to other very good websites that currently exist. There are so many sources of cancer information. The Cancer Information Service and the American Cancer Society are just two large examples of ways of getting information out through the web, but we do want to use every meeting that we can think of. We have a very active communications committee as well as an advocacy committee that identifies ways to get the message out in a way that is going to work. One point I would really like to make is that once the plan is developed, we hope that our member organizations can use that plan as a framework for their own strategic plans or operational plans moving forward so that they can peg what they do locally to what we have identified as statewide priorities. What we are doing statewide is also tied into national cancer goals.

Miller It sounds like the plan will be a 3- or a 4-year plan, during that time, how will you evaluate if you are meeting your goals?

Hogarty What we have is a Data Surveillance and Evaluation Committee and we use the expertise of many people at Yale, many people at the Uconn Health Center and some expert evaluators. They are looking simultaneously at this point right now, because we are bridging our old plan and our new plan. They are looking at the evidence-based findings on what has been done in the past and trying to apply that to our goals looking forward, while simultaneously developing an evaluation plan so data can be collected on an ongoing basis, not just retrospectively, to see what is working and what is not working. We feel very strongly that it is important for us to advocate evidence-based strategies and interventions and make those a part of our plan and also to get the word out to our

25:49 into mp3 file http://www.yalecancercenter.org/podcast/Answers_Sept-28-08.mp3

community-based member organizations, what they should do, if it is pegged to a larger picture, needs to be evidence based and based on good evaluation.

Miller What do you see as roadblocks in implementing your cancer plan?

Hogarty There are always the financial issues. We are operating in a period of scarce resources and the state is facing some real fiscal challenges, so that is certainly one. We need to work smarter and I think the whole idea of synergy and collaboration does allow us to use scarce resources in a more efficient way.

Miller Are there internal politics between organizations, and if so, do you see the coalition helping to pull people together?

Hogarty I see the coalition helping to bring people together, in fact, when we have done evaluations the primary benefit that people cite to being a member of the organization is the opportunity to network and to meet their counterparts at other institutions. Inevitably there is going to be some jockeying for position, but I think that the very nature of comprehensive cancer control overrides that competition to a certain extent and if it does not, that is one of our goals that we would certainly try to address.

Miller As a personal observation, as I am listening to you, I sit one on one with patients making decisions about treatment, but what I am hearing is a much broader view of cancer. Looking in your background, is that related to your own training in public health. Is that how people in public health look more broadly?

Hogarty Yeah, I think that is one of the differences between public health and medicine and it is very interesting to see those two perspectives come together within the Connecticut Cancer Partnership and within comprehensive cancer control. That is one of the very exciting things that this approach does bring. I agree, cancer patients are not looking at the continuum, they are looking at where they are right now and most medical providers have to focus on the moment. This takes a step back and says, yes we are on a continuum and the best way to leverage all of our resources is to look at the big picture.

Miller What are the working groups, again, because I think it does reflect that whole continuum.

Hogarty The working groups are across the continuum and so we start with prevention, we have early detection and then treatment, of course, and treatment focuses in on issues that relate

28:56 into mp3 file http://www.valecancercenter.org/podcast/Answers_Sept-28-08.mp3

to quality treatment, that would involve clinical trials and access and barrier, then survivorship which is a growing area, and End of Life Palliation Pain Control group. We also have cross-cutting work groups that address communications, data surveillance evaluation, and advocacy.

Miller It is very exciting hearing about all that and about your work. Lucinda, I want to thank you for joining me on Yale Cancer Answers.

Hogarty Thank you for having me.

Miller Until next week, this is Dr. Ken Miller from the Yale Cancer Center, wishing you a safe and healthy week.

If you have question 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 written transcripts of past programs. Next week Ken Miller speaks with Dr. Susan Higgins about radiation oncology for gynecological cancers, I am Bruce Barber, and you are listening to the WNPR Health Forum from Connecticut Public Radio.