CT Cancer Partnership

Guest Experts:
Linda Mowad and Lucinda Hogarty
Director of the Partnership

Yale Cancer Center Answers is a weekly broadcast on
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Welcome to Yale Cancer Center Answers with doctors Francine Foss and Lynn Wilson. Dr. Foss is a Professor of Medical Oncology and Dermatology, specializing in the treatment of lymphomas. Dr. Wilson is a Professor of Therapeutic Radiology and an expert in the use of radiation to treat lung cancers and cutaneous lymphomas. If you would like to join the conversation, you can contact the doctors directly. The address is canceranswers@yale.edu and the phone number is 1888-234-4YCC. This week, we welcome Lucinda Hogarty and Linda Mowad for a conversation about the Connecticut Cancer Partnership. Lucinda is Director of the Partnership and Linda is Executive Director. Here is Lynn Wilson.

Wilson Let’s start off by having you tell us a little bit about the partnership and what that is? Can you explain for our listener some details about the partnership, how many members, things like that?

Mowad The Centers for Disease Control back in 1998 decided that there should be a rational approach to developing a statewide cancer plan and so each state was charged with doing that. The way the Connecticut Cancer Partnership came about is through 5 founding organizations, the Connecticut Department of Public Health, the New England Division of the American Cancer Society, Yale Cancer Center, UConn Health Center and the Connecticut State Medical Society formed a core group, a leadership group, that then developed the process that went forward to develop the first plan and to develop committees and a structure by which the organization would be formed.

Wilson Obviously these are different groups, but are there members from each one of these groups that regularly get together, is there a committee to represent the consortium? Can you tell us about that?

Mowad Yes, there is an executive committee which is made up of the 5 founding members plus the officers of the Connecticut Cancer Partnership. Each organization has membership, not only on the executive committee but also on the board and on the committees that we have cross cutting, such as early detection, prevention, treatment, surveillance epidemiology data, education, and communication, so every part of the five founding members is a representative on the board as well as the executive committee but also the overall organization as well.

Wilson Is this something that is fairly unique to a Connecticut, as opposed to other places in the United States?

Hogarty No, it is not. When the CDC started developing a frame work for comprehensive cancer control, a few states led the way. By now, all 50 states, the District of Columbia, tribal organizations, and some pacific island jurisdictions have a similar coalition, a comprehensive cancer coalition, and they are not all called partnerships, but they all do meet in a similar way, looking at cancer control across the continuum, and at this point I think they all have cancer plans that are identified as the priority list for cancer control activities within each jurisdiction.

Wilson And when you say cancer control, can you explain to our listeners exactly what that means?

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It is not just cancer care. One of the things that the CDC really has emphasized and has been increasing over the past 10, 12, 15 years, is that we are looking at prevention, so there is a great deal of attention being paid to things like tobacco cessation, healthy eating, active living, environmental causations of cancer, and as Linda mentioned, she is Chair of our early detection committee, which includes secondary prevention or screening, and early detection encompass a great deal of our activities particularly with breast, cervical and colorectal cancers. And then the treatment component is what we think of as cancer care after diagnosis, when patients are going through treatment. Survivorship is getting more and more attention now because of the increasing number of cancer survivors and we do have a component focused on palliation. Palliation is understood to begin at the very beginning of the continuum at diagnosis but it also includes hospice and end-of-life care.

Tell our listeners a little bit about what each of your roles is in the Partnership? How did you become involved and tell us about your backgrounds.

I was asked by the American Cancer Society near the end of 2001, as I am an American Cancer Society volunteer, to attend a meeting that was sponsored by the American Cancer Society and CDC talking about comprehensive cancer control. The CDC was then beginning to give money to states to prepare comprehensive cancer control plans and they were giving money as a startup to make plans. I sat with people from other New England states and we talked about how we could work together. The state health department was represented, the New England division of the American Cancer Society was there, Yale was there, but UConn was not there at that time, and they asked if we could form a committee, form a group to begin to write a plan, and we came back to Connecticut, the meeting was in Quincy, Massachusetts, and we all began to work together, talking to our bosses to see if we could continue to do this, which we did, and we have been very successful. I then said that I would be on the early detection committee which I then later chaired. I was asked to be the vice chair and now I am the chair of the board and still chairing the early detection committee, so that is how I started, years ago.

Were you involved in various oncology or cancer activities at Yale prior to that?

I was, I worked at the Yale Cancer Center actually and I was program director for a program that was funded by the National Cancer Institute to run the Cancer Information Service 1800 line. We did community outreach and in Connecticut we had the contract that covered the six New England States. So, we gave information via the telephone, we did clinical trial training, we did nutrition training, we did disparities work, but we worked mainly in the community. It was a wonderful run for us.

Lucinda, how about yourself?

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Hogarty  I was the first full time staff member hired, everything had been volunteer as Linda was just
discussing, and by 2008 there had been money allocated by the legislature to some of the
implementation activities that were laid out in the first preliminary plan, the Connecticut State
Cancer Plan, which was 2005 to 2008, and one of those initiatives was to hire an executive
director. My background is in public health. I had worked for state, local, nonprofit organizations,
and I had done a lot of coalition work in the past, and I think the main objective is to get
organizations, whose mission is to reduce the burden of cancer in their population, together. It is a
matter of organizing a group of people who have either a mission in accordance or sometimes are
in competition. So it is a little bit like herding cats.

Wilson  Getting to some of the details, do you look at health disparities?

Mowad  Yes, we do. We do a lot with health disparities. Actually, it is one of our cross cutting
committees, meaning that the disparities committee, which is now a disparities resource committee
chaired by Betty Murray who does an enormous amount of work, there is representation from
disparities resources on each cross cutting committee. Lucinda can speak more to the issue of
working with Betty, because she is housed with Lucinda in Rocky Hill.

Hogarty  Yes, I am housed at the American Cancer Society, the position of disparities coordinators are a
wonderful example of how we are sharing the resources. There was actually MCI American
reinvestment recovery act funding that went to Hartford Hospital to address an initiative
identified in the state cancer plan because as Linda said, disparities reduction was the overarching
theme of the plan that we are operating under now, which is 2009 to 2013. We chose to use that
funding to hire a person who could keep track of that issue, and her primary role is to work with
each of the committees as they roll out their own implementation activities, make sure that we
always keep that lens focused on disparities reduction, and that may mean cultural sensitivity
training, or it may mean just tracking the data that will show us whether there is a difference in
incidence, morbidity, mortality, or cultural differences in terms of perceptions about clinical trials.
So that is something that Betty has done across all of our committees and she also has been
instrumental in developing new liaisons for the cancer partnership to involve representatives from
under representative populations. I think that has been a great success over the past 18 to 20
months and it is something that we plan on doing going forward, as we get ready to write the next
version of our plan, which is 2014 through 2017.

Wilson  You mentioned clinical trials, give our listeners a bit more information about how that is
something where perception may exist in the community.

Mowad  Clinical trials was one of the priority objectives in the 2009-2013 plan in the chapter that was
headed by the treatment committee. There is an understanding that people do not enroll in clinical
as much as we would like to benefit research moving forward, but that is even a greater problem in
minority populations. The number or percentages of cancer patient's who enroll in

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clinical trials is much lower among certain populations, and there is a long history, a cultural
history, of mistrust, for example, from both the Holocaust era and from the Tuskegee era where
there has been legitimate reasons for mistrust and fear about people perceiving that they are guinea
pigs. So, there is a huge initiative to put the idea forward that there need to be clinical trials to
ensure we have the best treatment options going forward in populations representing all ages, races
and types of cancer.

Wilson Tell us about the cancer plan.

Mowad Our first cancer plan was 2002-2005, our second plan was 2005-2008, our present plan is 2008-
2013 and we will begin writing our next plan. This summer we will begin gathering information
and people to begin to write. What we do is we write a plan each, and it is all done by committee.
The committees get together, and I can speak to my own committee, which is early detection, and
the committee gets together, we have meetings, we have phone calls, conferences, and we look at
what our objectives are, and everything we do is based on data from the state and we use those
numbers to decide what it is we want to do, where are we, for instance with breast screening in the
state, and where do we want to be? We put those together as goals, and we then look at our
objectives and strategies to meet our objectives. We have been overly zealous, but we are figuring
out now how we are going to do something that is not so large and work on something that is
manageable.

Wilson And how often do you renew the plan or device a new plan, you had mentioned some dates, but is
there a regular interval by which you try to do that?

Moward It has been two or five years, so we are hoping this next one will be five years as well.

Wilson We are going to take a short break for a medical minute. Please stay tuned to learn more
information about the Connecticut Cancer Partnership with Lucinda Hogarty and Linda Mowad.

Medical Minute

This year over 200,000 Americans will be diagnosed with lung cancer and in Connecticut alone
there will be over 2000 new cases. More than 85% of lung cancer diagnoses are related to
smoking and quitting even after decades of use can significantly reduce your risk of developing
lung cancer. Each day, patients with lung cancer are surviving, thanks to increased access to
advanced therapies and specialized care. New treatment options and surgical techniques are
giving lung cancer survivors more hope than they have ever had before. Clinical trials are
currently underway at federally designated comprehensive cancer centers like the one at Yale, to
test the innovative new treatments for lung cancer. An option for lung cancer patients in need of
surgery at Yale Cancer Center is video-assisted thoracoscopic surgery also known as VATS
procedure, which is a minimally invasive technique. This has been a medical minute. More

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Welcome back to Yale Cancer Center Answers. This is Dr. Lynn Wilson and I am joined by my guests, Lucinda Hogarty and Linda Mowad, and we are discussing the Connecticut Cancer Partnership. What sorts of things are actually discussed at the annual meeting? We have talked about some things, but go ahead and explain that to our listeners.

Our annual meeting usually covers a variety of topics under one unifying theme. We had a meeting on communications and cancer control and how to utilize communications and how to work better with communications, the effects of the affordable care act, what is that going to do to cancer control and care for cancer patients and how we will look at that differently perhaps. Disparity again is another issue we have in cancer control and statewide planning for cancer control. So, we have kind of run the gamut and we are always looking for new information. We are grouped together to see what we would like to focus on that year, and we are getting ready to do that again actually.

We talked about participation in other states; these is really a national initiative as we mentioned in the beginning of the show, but could we talk a little of bit more about more specific expectations of the Centers for Disease Control, for example, in these programs.

When the Centers for Disease Control first came up with this concept they were looking to make sure that state resources were wisely used. The found that there were lots of gaps in areas that were not being covered, but there were also areas of duplication because there was not any sort of convenient mechanism for the states to figure out who was doing what most effectively. So they came up with the basic overlying concept to reduce the burden of cancer in the population, and the idea was to come up with a plan using the kind of input that Linda was talking about with regards to the history of our own cancer partnership and getting participants whose organizational missions all have to do with cancer control together to say well, in our particular state we want to focus on this area. We cannot do everything every year, but we can dedicate whatever resources we have available to us and those vary considerably from year to year to tackle one issue and then it is kind of an organic process in that each year there is revisiting of what the priorities are. The CDC does provide us with guidelines and some tools and Linda and other members of the partnership have attended national meetings in Atlanta and elsewhere around the country to meet with our colleagues and learn from their best practices and what they do. We are moving into an era now where there is more focus on common risk factors for other chronic diseases. So, the chronic disease approach is something we are going to be moving toward as we get ready to develop our next cancer plan.

Is there any interaction between two states or several states on particular projects?
Mowad Yes, in New England, in particular, we have had opportunities to attend meetings in Massachusetts and New Hampshire and we work closely with colleagues in Vermont, and occasionally Rhode Island. It depends, and what we try to do is put out feelers. Since they were doing this, we do not want to reinvent the wheel and what has worked for them, and occasionally, especially in the area of survivorship, we will share resources.

Wilson That is terrific. Do you have relationships with community organizations?

Hogarty We certainly do. And just to be clear, the community organizations and the organizations that serve the needs of the patient, we do not directly work with the populations of patients and survivors, but we enhance the ability of that organization to do that and because we are able to do that we have members on our committees that are from community organizations. We have a monthly newsletter that we send to all our members and we ask them if there is somebody we have missed, would they please send it to, or if there was somebody they thought should know something please send it on. So, we are always communicating with the organizations and helping them in anyway that we can, giving them information, sending them information, helping them out. This past weekend we had an African American disparities group meet and we worked with them to make sure that they had what they needed.

Wilson Do the meetings tend to be in one central location, or it is possible with all the meetings you have that they could be at a variety of locations?

Mowad We meet every other month as a board and we meet in Rocky Hill because we are able to use the American Cancer Society office space in Rocky Hill. It is not so much in the middle of the state, but it is what we have and is available to us and does not cost as anything. We do meet by conference call, and we do regional meetings that we have had in the past so we get all areas of the State, and we have members from all over the State that either meet with the committee by phone if they cannot make it, but we do cover most all of the State.

Hogarty And our annual meetings, which are open to our entire membership, but that is not a pre-requisite for attendance, are held in different locations. We have held it several time here in the New Haven area, but that is not always where they are. We are also really trying to maximize the use of the materials that we post online to have things available whether it is the presentations that are made at the annual meetings or as Linda said through our phone in conference options so that people who do not want to travel from the North East or the North West corner of the State can participate, and it really is working, I think we have actually improved our geographic representation considerably over the past couple of years.

Wilson That is terrific, let’s talk about some of the accomplishments that have been achieved so far starting with the first plan that you had.

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Mowad One of the wonderful things is we received 7.15 million dollars in state funds in 2006 to implement our comprehensive cancer control plan, that is the 2005 and 2008, and that supported numerous projects along the continuum of cancer care including the publication of the Connecticut Comprehensive Cancer Control Plan, press releases and awareness campaigns, creation of a statewide smoking cessation program, targeting Medicaid recipients, pilot testing of evidence based nutrition curriculum in the Connecticut schools, enhancement of the states breast and cervical cancer early detection program, development and implementation of a program promoting colorectal cancer screenings for state residents, development and implementation of a statewide clinical trials network, as we talked about previously, identification and provision of services for cancer survivors, identification and provision of services to organizations that offer educational programs on palliative and hospice care and evaluation of the Connecticut Cancer Partnership. So, we think we have done a lot but we are continuing to do even more.

Wilson And who is the funding agency that provided the many millions of dollars?

Mowad The State of Connecticut.

Hogarty And that was funding to fund initiatives from our first plan and now we are sort of in the second wave and we have about 16 different projects going on with a new round of funding that actually came through a settlement at the attorney general’s office worked out, so as opposed to depending on legislatively allocated funding, which is difficult in this economy, we were able to access another source of funds for the period that will bring us right to the end of the current cancer plan.

Wilson You listed some absolutely terrific programs. Could we get a little more specific information and go ahead and choose several that you are most comfortable with discussing. Give us a little bit more information about some of them.

Mowad I can talk to you about the breast and cervical early detection program and with that, the colorectal cancer program. We have used money from the early detection committee and the money that is allocated is by committee and we talk about what we want to do and what are the dollars we can allocate, so for instance, in early detection, because there is always underfunding of breast and cervical, we give a lot of money to breast and cervical, and as a matter of fact, we are hoping for another 50,000 dollars to come because they are still underfunded, but we are hoping that we are going to get another 50,000 dollars this year to help them. A part of that will be used for breast and cervical early detection for mammograms and the treatment piece of that as well. ‘Wise Women’ is another program for early detection breast and cervical cancer and colorectal cancer screening. I think we have used the money judiciously and that is voted upon by the early detection committee to use the money for that.

Wilson These funds will actually be directly utilized to help fund these screenings, provide these opportunities for patients who might not be able to get these services?

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Hogarty Yes, we work very closely with the federally qualified health centers and with the department of public health. So it is a process which is very inclusive but it is also very targeted to the patients that need this kind of opportunity to get screening, they are under insured or uninsured in many cases.

Wilson Tell me a bit more about the ‘Wise Women’ program?

Mowad I really do not know all that much about it at this point in time because it has changed over time, but it helps women that are underinsured or uninsured to be able to have a screening mammogram. If anything is found, if there is a biopsy needed, we also have the funds to have these women treated.

Hogarty As I mentioned, there is a focus on common risk factors for other diseases. So, there is a component that has to do with healthy eating and active living, reduction of risk factors for heart disease or diabetes. So, it is the design of it, and we try to be as cost effective as possible since many of the risk factors, if those issues are corrected, it is a benefit across the board.

Wilson We talked a little bit about the geographic location of committee meetings, and so on, but how do you reach out to the different parts of the state where they may not have access to certain things necessarily?

Hogarty We have primarily been working with our organizational partners. The federally qualified health centers through the community health center network of Connecticut is one way that we ensure widespread geographic distribution supporting their efforts. We also work very closely with all of the hospital cancer centers, so they are geographically distributed around the state and we may provide them with resource material or educational opportunities for their staff for development initiatives and it is usually a direct connection with the organizations that are serving the patients, but the ones that are geographically distributed.

Wilson Talk a little about some of the big challenges that you face because there certainly must be plenty of them.

Mowad There are actually, and as you may know firsthand, funding and resources are big one for us. Also having everyone understand who we are, who we serve, what we do, the time constraints of partners and conflicting priorities because remember all of our committees are made up of volunteers. So, it is a juggling piece between your job and your volunteer work and the uncertainty about the effects of health care reform as we know what is going on in the world today, but really a biggie is the resources, but we try to work around them and we try to get as much we can and do as much as we can for as little as we can.

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Wilson  How are the resources in Connecticut, for example, in terms of funding amounts compared to other states, pretty typical or are there some states that really dominate?

Mowad  We are unusual because there is a statute in the State of Connecticut that does direct pharmaceutical court settlement funds to comprehensive cancer control. I do not know of another state that has that source of funding. We know that over a number of years tobacco settlement funds were to be directed to comprehensive cancer control or tobacco cessation activities and it did not happen in Connecticut, and it did not happen in most of the other states either. Some states tried things like direction of specific income tax amounts or raisings bond issues, but over time those things tended to fall away with the downturn in the economy. So, we are unusual, each state has its own story and right now we are in good shape, but there are challenges moving forward one to two to three years out.

*Lucinda Hogarty is director of the Connecticut Cancer Partnership and Linda Mowad is Executive Director. If you have questions or would like add your comments, visit [yalecancercenter.org](http://yalecancercenter.org), where you can also get the podcast and find written transcripts of past programs. You are listening to the WNPR Health Forum on the Connecticut Public Broadcasting Network.*