

Yale CANCER CENTER *answers*

WNPR Connecticut Public Radio



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**CT Cancer Partnership: What's
New in 2014?**

Guest Expert:

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Welcome to Yale Cancer Center Answers with your hosts doctors Francine Foss, Anees Chagpar and Steven Gore. Dr. Foss is a Professor of Medicine in the Section of Medical Oncology at Yale Cancer Center, Dr. Chagpar is Associate Professor of Surgical Oncology and Director of the Breast Center at Smilow Cancer Hospital and Dr. Gore is Director of Hematological Malignancies at Smilow. Yale Cancer Center Answers features weekly conversations about the research, diagnosis and treatment of cancer and if you would like to join the conversation, you can submit questions and comments to canceranswers@yale.edu or you can leave a voicemail message at 888-234-4YCC. This week you will hear a conversation about the Connecticut Cancer Partnership with its Director, Lucinda Hogarty. Here is Francine Foss.

Foss Let's start by having you tell our audience what is the CT Cancer Partnership?

Hogarty The Connecticut Cancer Partnership is the entity in the state of Connecticut that formulates the cancer plan for the state and we just launched the plan to cover the years 2014 through 2017. The partnership itself is an unincorporated entity that is composed of about 450 members representing about 150 cancer control organizations in the state of Connecticut.

Foss What are these cancer control organizations? I do not think many of us are familiar with that.

Hogarty Many of our members are hospitals, hospital cancer programs. We also have a number of advocacy organizations who represent the interest of patients and survivors. As far as the professional affiliations of our members we have physicians from across the board, primary care doctors as well as oncologists, many nurses, patient navigators, social workers, advocates, people working in survivorship programs and a very important part of our work is with the public health community because we are not only interested in the cancer after it occurs, but in the prevention of cancer.

Gore Do you have a mandate from the government to make a cancer plan? How does that work?

Hogarty The way it works is the Centers for Disease Control back in the late 90s came up with a framework that they required that all the states have for cancer control, it is called Comprehensive Cancer Control and it took several years but in Connecticut by 2004, the Connecticut Cancer Partnership was formed, and the first plan came out at that time, where now as I mentioned we are launching our third plan, but we are required to follow basic cancer control elements that are stipulated by the Centers for Disease Control.

Gore What kinds of things does that include? What is in a cancer plan?

Hogarty A cancer plan requires that we collaborate with lots of partners. A new focus is looking at cancer as a chronic disease and not segregating our efforts from the efforts that would also be beneficial to people whose focus area is heart disease or diabetes, so again, we are looking at prevention and the

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adoption of healthy lifestyles. Comprehensive Cancer Control covers what we call the continuum of cancer control, so we are talking about prevention, early detection, treatment, palliation, survivorship and end-of-life.

Foss How do you get your hands around that whole problem? It sounds like a very big task to accomplish?

Gore Huge.

Hogarty Yes.

Foss Do you start with the epidemiology of cancer here in Connecticut? How do you get that information on how frequent these cancers are?

Hogarty What we do is in the development of a plan we have many different work groups that are addressing different components of the problem. As far as the background, the data, we have data in our surveillance committee. Our work is entirely divided up by committee so people are not covering the wide spectrum that I just talked about but have an interest in a particular area and are able to involve themselves in the work of the partnership which meshes hopefully very well with their day-to-day work. We rely very strongly on data that is collected by the Connecticut Tumor Registry in terms of the epidemiology, the incidence and mortality rates.

Gore And I understand that the Connecticut Tumor Registry is kind of unique, is that right?

Hogarty It's very interesting because it is the oldest in the country and it has been a preeminent leader, I think, in working with the hospitals and the cancer centers to ensure that we do have good data about trends in cancer over time and it just celebrated its 75th year of data collection last year.

Gore How does that work, do all cancers get reported to the registry?

Hogarty Yes, the cancers that are treated in hospitals do, so it is a question of recording that data so that it can be used for further research moving forward.

Foss And there was a national program called the SEER Program which collects information from different states, not all states but certain states in the country and Connecticut is one of those states that contributes to that?

Hogarty Yes, which has really helped us working with the tumor registry, and the data from the Department of Public Health, with prioritizing what our issues are. The Centers for Disease Control requires that we focus on certain things and one of the things that they focus on is high incidence cancers. We recognize it is such a huge problem, and we cannot address everything. So, there is a real

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focus on breast, lung, and colorectal cancer. Pancreatic cancer has a very high mortality rate, but a low incidence rate, so you keep the number of people effected in mind when you develop the priorities for plans like this for the state.

Gore It sounds like a very expensive endeavor, where does the funding come from?

Hogarty That is the biggest problem. There is some limited funding that does come from the Centers for Disease Control to the Department of Public Health for comprehensive cancer control, but that is a very minimal amount. All states struggle with this. Connecticut was fortunate in the earlier days, back in 2006 and 2007, to get a legislative appropriation that enabled us to have implementation projects for the period that went up through about 2009, and then an unusual occurrence happened which was we were the recipients of a court settlement negotiated by our Attorney General, Richard Blumenthal at the time, which allocated some funds for implementation. That took us through the period of 2011 to 2013, so as we embark on this new plan, we are looking to see what sources of funds may be available, maybe federal money through different allocation processes through the Affordable Care Act, maybe state funds, maybe legislatively allocated. But one of the things we are really focusing on that we want to emphasize, is that much of the work that we are advocating is in the area of policy systems and environment and it has to do more with making environmental changes than directing money to specific programs, that is the public health approach.

Gore Can you give us an example of that?

Hogarty One of the best examples, and one that is new, are smoking policies. That is obviously a policy legislative change that has a huge impact on public health in cancer and other chronic diseases as well. In public health in general, other sorts of examples of policy systems and environmental change are seat belt laws, shade structures in school yards for sun safety. Those are examples of what we are talking about in terms of policy systems and environment.

Foss A lot of the patients that I have seen ask the same question, which is, was I exposed to something at work, is this a chemically related cancer? I have heard this or that. Can you address, in the state of Connecticut, how big of a problem that is and is that something that you are addressing and looking at in the context of all these cancers?

Hogarty Yes, it is one of our goals in the area of our prevention committee, environmental exposures such as sun and tobacco smoke are fairly straight forward and we really understand the cause and effect relationship there. In some of the other areas such as occupational exposure to chemicals, that is

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a more difficult link to make and our approach is certainly to work with agencies and organizations that are delving into that but that is more of a general focus area under our overarching approach to cancer prevention.

- Gore I am a recent import to Connecticut from Maryland, and as my wife and I were getting ready to buy a property, we learned that, at least on the shore, radon seems to be a very common problem here?
- Hogarty Yes and that is an interesting one that certainly does fall under the purview of public health organizations. Radon is an issue, there is uranium along the shore too in some of the water, but these are low when you are talking about population effects, I think what we advocate is becoming informed, there is a radon test, and there is radon remediation. So, this is something you can do to protect yourself.
- Foss What about the issue of the high tension power lines, we hear about that all the time and again, there has not been any real direct association that I know of, but people are always asking those questions, should I buy a house near high tension power lines?
- Hogarty That is not something we have really had a great deal of emphasis on other than in general. The research that we want to make sure is supported as we move forward and the epidemiology develops.
- Gore As a new resident to the state, I see much more public smoking than I was used to in Baltimore and outside of my own office building. At Johns Hopkins, where I came from, you can't smoke within about a mile of that place and it is very difficult for me, I have to say, I am just not used to that.
- Hogarty It is amazing what the variation is, both within the state of Connecticut and even in smaller areas. Connecticut really does have a very good ranking in terms of smoking rates by comparison to other states, but it does vary, I know that we are trying to zero in on regional differences within the state and even though we do not have a very strong county system, you can take comparisons that are available by county and the highest rate of overall smoking in Connecticut is Windham County in the North-East corner and the lowest smoking rate is Fairfield County at 9.5%, so there has been a huge improvement, but there is obviously a lot of work that needs to be done. I think one other thing we want to focus on is helping people to stop smoking, both by providing cessation services and by making sure that policies nudge them in the direction of stopping smoking by prohibiting it in areas where it is still allowed.
- Gore Do you have any interaction or interest in e-cigarettes and the controversies on e-cigarettes.
- Hogarty Yes, actually we publish a monthly newsletter electronically and one of the articles is about e-

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cigarettes. We are closely following it mostly through the prevention committee. The regulation from the perspective of the FDA and the recent Connecticut legislation is to ensure that this isn't an issue that encourages smoking by developing nicotine dependency among younger users.

Foss How do you interface with the other organizations? It sounds like you have a fairly complicated matrix of things you do, so how do you actually interface with the people in the department of public health and all the different communities in towns that have their policies, how do you pull that altogether?

Hogarty There are several different ways we do it. First of all, we have an annual meeting, which tends to bring all of our members together, and at that point, they can break down into special interest groups, which we can talk about later.

Gore 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 Dr. Lucinda Hogarty.

Medical
Minute

Breast cancer is the most common cancer in women and in Connecticut alone approximately 3,000 women will be diagnosed with breast cancer in 2014 and nearly 200,000 nationwide. But there is new hope. With earlier detection, noninvasive treatments, and novel therapies, there are more options for patients to fight breast cancer than ever before. Women should schedule a baseline mammogram beginning at age 40 or earlier if they have risk factors associated with the disease. With screening, early detection, and a healthy lifestyle breast cancer can be defeated. Clinical trials are currently underway at federally designated comprehensive cancer centers such as Yale Cancer Center and Smilow Cancer Hospital at Yale-New Haven to make innovative new treatments available to patients. Digital breast tomosynthesis or 3D mammography is transforming breast screening by significantly reducing unnecessary procedures, while picking up more cancers and eliminating some of the fear and anxiety many women experience. This has been a medical minute brought to you as a public service by Yale Cancer Center and Smilow Cancer Hospital at Yale-New Haven. More information is available at yalecancercenter.org.

Gore Welcome back to Yale Cancer Center Answers, this is Dr. Steven Gore and I am joined tonight by my co-host Dr. Francine Foss and our guest Dr. Lucinda Hogarty. We are discussing the Connecticut Cancer Partnership. Lucinda, before the break you were telling us about how your organization interfaces with other interest groups to try to break down this huge problem of cancer prevention, let's talk more about that.

Hogarty As I mentioned we have an annual meeting and this year it is going to be held on November 5, 2014 and it is going to have a focus on the area of survivorship care planning. Survivorship and treatment are just two of the areas that are special work groups within the structure of the Cancer Partnership. The way it works is we have separate committees addressing prevention, early

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detection, treatment, survivorship, and palliative and hospice, which is combined. We also have some-cross cutting committees, one provides an overarching focus and one has to do with disparities reduction, recognizing that while Connecticut is a well-to-do state and ranks well in many areas with regard to healthcare, there are disparities of the cancer burden among different populations. So even though we have the different committees, each one of those continuum committees, focuses in on disparities within Connecticut's population. For example, our hospice and palliative committee tends to be made up of many people who work in clinical settings, VNAs, hospice settings, which focus on end-of-life. Prevention is largely focused in public health settings, and then our treatment and survivorship, for example, and early detection, since those are all clinical approaches, tend to be people who work in the clinical setting. We have a wide variety of clinicians who work with us from early detection and we have a strong focus on clinical trials.

Gore I would like to hear more about survivorship, and as I recall, was not Connecticut one of the early adopters of the hospice approach?

Hogarty Yes.

Gore And was not Connecticut a leader in the hospice movement in the United States?

Hogarty Yes, the first inpatient hospice was in Branford which is now 30 or 40 years old.

Foss Can you talk about the focus on survivorship? This is a new thing to focus on which is now a larger and larger group of cancer survivors out there.

Hogarty That is right and that is a very positive thing that there is this focus on survivorship and just in the state of Connecticut alone, recent estimates from the American Cancer Society indicate that we have probably about 172,000 Connecticut residents living in the state who are survivors of cancer. So the emphasis on survivorship is something that has been recognized by regulatory agencies with regard to accreditation, for example, the Commission on Cancer requires that hospitals begin to provide cancer patients on discharge, at the end of treatment, with treatment summaries and survivorship care plans. This is to ensure that as they move forward through their lives, they are equipped with the information they need to deal with late effects of treatment or the higher risk of other cancers and to ensure that they adopt healthy lifestyles or help them to prevent second cancers, for example.

Foss What is the plan actually doing to facilitate that? Are you going out to the individual practices? Are you trying to approach the patients directly about these survivorship issues? How do you actually get the message out there?

Hogarty We tend not to approach survivors or patients directly. The structure of our partnership is that we work with the organizations, about 150, who work directly with the patients. So our role is to

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really support the people who are working specifically in a focused area with the patients. What we do is we try to make sure that we support the efforts of those organizations to identify and disseminate best practices to make sure that as different best practice guidelines are being developed, we can help to provide training on that and that is why we have chosen survivorship as our focus for the November annual meeting.

- Gore Do some of these individual organizations look to you for guidance? If they are saying to you, we feel like we have not really been doing a great job with survivorship, should we go to your organization to get resources?
- Hogarty Yes, the best way to get resources is to share the resources. So what we have found from our members over the decade that we have been offering meetings on a regular basis, is that they find that those opportunities for networking are the most valuable and that was the concept behind comprehensive cancer control that the CDC envisioned in 1998, that there would be a way to avoid recreating the wheel and duplicating efforts, but at the same time identifying where there are gaps. Even in a small state like Connecticut, those things, unless it is a coordinated effort, there can be wasteful energy being spent that way.
- Foss That may also apply to the whole disparities issues that you brought up, there are communities that obviously have bigger disparity issues than other communities and I am wondering if there are now unified efforts on the part of some of these groups to get together to address that at a statewide level.
- Hogarty Yes, that is certainly true and what we have tried to do is have disparities reduction and health acuity as the overarching focus of everything that we do. What that might mean is making sure that there is a high level of cultural competence, appropriate language use, appropriate health literacy with any information that is being conveyed about cancer whether it is prevention, treatment or palliative/end-of-life and to take into account cultural sensitivities that might effect the way people respond to information, whether it is stopping smoking or whether it is being receptive to a referral to hospice at the end-of-life.
- Gore What about regional reactions? I would have to assume that the Connecticut cancer problem must share a lot in common with Rhode Island or Massachusetts, maybe even New York.
- Hogarty Within other states in New England my counterparts and I meet regularly, the New England Comprehensive Cancer Coalition, and Directors meet regularly and we are always sharing our ideas but as I mentioned earlier, within the State of Connecticut, the disparities are more marked than you would expect and we are really trying to go to those specific areas and say, we have a

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cancer plan, it is the big picture for the State of Connecticut, but to actually make a difference in your community, what we need is to hear from you, get your statistics, find out what populations you think are underserved and have specific needs.

- Gore I guess one of the advantages of being in a small state is that one can get very granular about individual communities without having to interface with the county level government and all of that.
- Hogarty That is true and we are getting better at it. It has not always been easy to get that granular data but what we are finding is that more and more hospitals are doing community needs assessments. They are working with their local health departments and there is a focus on really pinning down what the specific needs are so that that can be a focused effort.
- Foss I am wondering how of all this interfaces with the Affordable HealthCare Act and the availability of healthcare resources and insurance coverage which is decreasing for a number of folks. Can you talk about how you actually interface with that part of the problem?
- Hogarty We have a chapter in our new plan called ‘The Evolving Landscape’ and we decided since we are writing the plan in 2013 and the roll out of the Affordable Care Act is going to be taking place during the lifetime of our plan, 2014-2017, for the most part, we decided we just had to acknowledge that things are going to be changing and we do not really know where things are going. So we are setting ourselves up so that we will be able to reanalyze and reprioritize on an annual basis during this period of the plan. We are going to have a period of time where we gather information and then at the beginning of each year we will say, okay this is what has happened. These are new problems that have cropped up because of the Affordable Care Act roll out, or these are new areas that have been ameliorated and we do not need to focus on that anymore. So it is going to be something where we are constantly checking to see what the statistics show us.
- Gore And I guess we should all be sort of relieved and proud that the roll out of the Affordable Care Act and the exchanges, Connecticut had I think one of the most successful roll outs throughout the country. I think that is really wonderful.
- Hogarty Yes, that has been very hopeful and I really do hope that it will lead to some great analysis so that, for example, in the area of early detection where access has been a barrier without insurance and we think that that is going to be much improved now, we still will be able to identify who, for example, who is covered for a colonoscopy or a mammography but is not taking advantage of it and why not.

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Gore What an incredible opportunity.

Hogarty Yes, it is.

Foss I heard that the new plan was recently presented at a press conference with Governor Malloy where he spoke. Can you talk about that experience and rolling the plan out and what did the Governor say?

Hogarty It was a wonderful opportunity. Governor Malloy came to our press conference that was held at the Capital in April to promote the fact that cancer is a problem in Connecticut. He definitely understood and identified that it is comprehensive cancer control prevention through end-of-life and that it was a very important area for us to work collaboratively and cooperatively and as I mentioned, what we are really focusing on is policy systems and environment and that lends itself to a governmental approach and a focus on the chronic disease, common risk factors that will not only improve the population's health with regard to cancer experience, but other serious chronic diseases such as heart disease, stroke and respiratory disease. So it was very helpful and we had members of our board, such as Dr. Salner, Linda Mowad, and Pat Checko present treatment prevention and it was an opportunity for us to get the word out that there is a cancer plan and there are ways for Connecticut citizens to be involved in this effort.

Gore We are in an election year, and to what extent is your organization, in your efforts, susceptible to parties and politics, are you insulated from all of that?

Hogarty I think what we want to do is make sure that we identify particular policies that are in the public interest in terms of public health. There is an Advocacy Committee of our group that identifies particular state legislative actions, something like the e-cigarette legislation, things that have to do with smoking policy, those are things that we educate our members about so that they can take a stand with their own legislators to promote efforts that will help access to services, for example, and there is a new legislatively mandated counsel on palliative care now. So we have a relationship where the policy systems environment, advocacy linkage is made quite clearly.

Gore And do you feel like you have gotten a lot of support in the legislature over time?

Hogarty Yes, I think that the problem has always been in the state budget, it has been for the past several years.

Gore Everyone wants to be healthy as long as it does not cost anything, right.

Hogarty Exactly, so we will have an ongoing effort of course to have recognition in a way where there is money allocated to support some of our efforts.

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Foss Lucinda, I am wondering if the average listener in the audience can actually access what your plan is, is it outlined somewhere, is there a website?

Hogarty Yes, we have a website, it is ctcancerpartnership.org and we encourage people to read our plan online, identify areas where they can begin to play a role and that may very well be on a local basis as well as adopting healthy lifestyles.

Lucinda Hogarty is the Director of the Connecticut Cancer Partnership. We invite you to share your questions and comments. You can send them to cancer answers at canceranswers@yale.edu or you can leave a voice mail message at 888-234-4YCC. As an additional resource, archived programs are available in both audio and written format at yalecancercenter.org. I am Bruce Barber hoping you will join us again next Sunday evening at 6:00 for another edition of Yale Cancer Center Answers here on WNPR Connecticut's Public Media Source for news and ideas.