

Yale CANCER  
CENTER

answers

WNPR Connecticut Public Radio



*Hosts*

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The Connecticut Cancer Plan

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**Yale Cancer Center Answers**

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*Welcome to Yale Cancer Center Answers with Drs. Ed Chu and Francine Foss, I am Bruce Barber. Dr. Chu is Deputy Director and Chief of Medical Oncology at Yale Cancer Center and Dr. Foss is a Professor of Medical Oncology and Dermatology specializing in the treatment of lymphomas. If you would like to join the conversation, you can contact the doctors directly. The address is [canceranswers@yale.edu](mailto:canceranswers@yale.edu) and the phone number is 1888-234-4YCC. This evening Francine welcomes Lucinda Hogarty. Lucinda is the Executive Director of the Connecticut Cancer Partnership whose mission is to reduce the suffering and death due to cancer and improve the quality of life of cancer survivors throughout Connecticut.*

Foss Who belongs to the Partnership?

Hogarty We have about 150 organizations represented. They are represented by over 300 individual members who participate in committee work to develop and to implement cancer-fighting strategies within the context of their own organizations.

Foss How was this whole Partnership founded?

Hogarty It was founded by five original members. They were Yale Cancer Center, the UConn Health Center, the American Cancer Society's New England Division, the Connecticut State Medical Society, and the Connecticut Department of Public Health. Funding came originally from the Centers for Disease Control with some planning and then some implementation funds for the original organization for putting a comprehensive cancer control plan into place in the state of Connecticut. Since those original funding opportunities became available in 2002, we received some funding from the state of Connecticut.

Foss How long has this Partnership been in operation?

Hogarty It has been in operation since 2002, but it was only in 2008 that we received funding for staffing. As I said, we have been dependent on voluntary efforts and of course we continue to be, but we do have an infrastructure now that has helped with the development of the second State Cancer Plan. The voluntary organization created an earlier version of the Connecticut Cancer Plan, which covered the years 2005 to 2008, and we have just launched a new plan covering the years 2009 to 2013.

Foss You talk about the Connecticut Cancer Plan, can you tell us a little bit about that?

Hogarty Yes, the Connecticut Cancer Plan is designed to address priorities in reducing the burden of cancer in Connecticut. Its main goals for the Partnership, the members who were involved in creating this plan, are to reflect national goals such as Healthy People 2010, the American Cancer Society's 2015 goals, and the National Cancer Institute and the Institute of

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Medicines' blueprints regarding fight the fight against cancer. It has an overarching theme of addressing access and disparities issues. It also tries to incorporate the vision and the goals of its member organizations who work in the cancer fight everyday; we try to set priorities on an annual basis. Some other things that we are trying to address in the very preliminary period covered by this plan is to deal with prevention through the promotion of healthy lifestyles; including healthy eating and active living, which of course can prevent cancer as well as a number of other chronic diseases. We have divided our continuum of cancer control into prevention, which I just mentioned, the second committee area which is early detection, and we are looking to increase cancer screening particularly among underserved minority groups. In the area of cancer treatment, which is the third of our committees, one of our priorities this year is to support the creation of a state-wide clinical trials network to increase participation in clinical trials, and that's based here at Yale. The fourth committee covers the issue of survivorship and what we are hoping to do in that area is to increase the number of survivors, cancer survivors, who are able to use support services critical to their ongoing health as well as make sure that professionals involved in their ongoing care know about survivorship guidelines.

Foss We have talked with a number of other guests on this show about the whole issue of early detection and cancer treatment, but we haven't really focused on prevention alone. Is this a major area that you are looking at right now?

Hogarty Yes, it is, and it's a very important one. I think that one of the two advantages of the approach that the Connecticut Cancer Plan takes, and members within the Partnership, is to take a public health approach that it's better to prevent a disease than to treat it. We do have the opportunity to work in accord with other organizations that are also promoting healthy eating, active living, and smoking cessation to prevent disease before it occurs.

Foss Does the Partnership itself actually reach out to people or do you do it through your affiliate organizations?

Hogarty We primarily do it through our affiliate organizations. For example, in the prevention area, some of the partners that would be involved in prevention activities might be local health departments in towns and in regional districts. What we have been able to do is offer them information, networking opportunities, to learn about best practices, lessons learned to establish programs that affect their citizens in their own locations. We feel strongly that it's the organizations themselves that know their communities, know the best ways to reach them, and know their patients.

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Foss In addition to working with the individual organizations, do you have a state-wide plan say for prevention that's implemented in a number of different settings?

Hogarty Yes, but the way that primarily takes place is through one of our other committees, which I haven't mentioned yet, which is our advocacy committee. We have four cross cutting committees in addition to the continuum ones that I mentioned. Advocacy is one, communications and education, which of course is very cross cutting, is another. We also have a committee that looks at data to make sure we can benchmark and track our progress. And then as I mentioned earlier, an over arching theme is issues relating to access, barriers to care, and to disparities. So, across the continuum committees, each one of those cross cutting committees is able to support the activity. So for example, in prevention, we may have a strong advocacy agenda to bring about policy changes, or in fact laws, which would support healthy lifestyles in communities.

Foss We have heard the word disparities on other shows as well, can you tell our audience a little bit about the disparities issue, and how much of a problem it is in Connecticut, and what the national agenda is to address disparities?

Hogarty That is one of the primary goals of the American Cancer Society as we look forward over the next five years. It is unacceptable that there are disparities in cancer burdens by population group, and the population group may be age, it may be race, it may be language spoken, or it may be geography. There are many ways to look at disparate groups, but what we are hoping to do is identify what those barriers are that may lead to different types of treatment, different access to treatment. For example, in the area of clinical trials it is very important to make sure that all elements of the population have access to clinical trials and that the findings of those clinical trials can reflect different populations needs.

Foss And one way to do that obviously is to make sure that the consent forms for those trials are translated into different languages and also that that information out in the public describing those trials is available in different languages.

Hogarty Yes, and even for English speakers, to make sure it is available in a way that people who may have low literacy understand. One of the things that the Cancer Partnership has been working on, has done in the past, and will continue to work on, is sharing resources, because we do find that there might be one area of the state or one small organization that has very effectively reached out to groups that may have been hard to reach in the past. And for us to be able to share their approach is very beneficial and helps save resources.

Foss What is the mechanism by which you interact with all these different communities? Do you

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have regular meetings of the organization, and how do you actually interface around the state?

Hogarty What we do is we have an annual meeting and it is an opportunity for people to really figure out how they want to be involved, that's not the only opportunity, but it is one. At that point, people usually are able to say, well I think the area I am most interested in, for example, is end of life care, palliation and hospice, which is one of our other committees, or they may say my skills are in communications or in data surveillance. Then they become a member of that committee. Those committee chair people hold meetings on a regular basis and we are trying, I think this is something we haven't done as well and going forward I would like to do, is move those meetings around to different parts of the state and ask some of our member organizations to host opportunities for us to have regional meetings.

Foss How are these regional meetings funded?

Hogarty Well, fortunately for us we have a lot of support from our member organizations, that's primarily in kind, though there are occasionally small grants that support some of the activities that we are doing, but because we are a membership organization and our goals and objectives align very closely with the goals and objectives of community hospitals, and local health districts, for us to go in and have an agenda that meets the needs of the local community, they are able to provide support or a location.

Foss For people out there who say aren't members of a Community Hospital Board or another one of the organizations and want to get involved in this, how can they do that?

Hogarty The best way is to go to our website, which is [ctcancerpartnership.org](http://ctcancerpartnership.org), but what would be helpful is for them to take a look at the new cancer plan, which is available on our website and figure out how they could fit in. I think that's what is very important. We want this new plan to be a document that is a call to action, not just a report. We would like them to say this is a goal, this is a strategy in a particular area, for example survivorship, where I see a need to get involved and what they would do is get in touch with us and say I would like to be involved in one of these activities.

Foss Great, Lucinda I would like to talk a little bit more about this and compare it to what's available in other states when we come back after the break. We are going to take a short break now for a medical minute.

*Medical*

*Minute* Breast cancer is the second most common cancer in women. About 3000 women in

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*Connecticut will be diagnosed with breast cancer this year, but earlier detection, non-invasive treatments, and new therapies are providing more options for breast cancer patients and more women are able to live with breast cancer than ever before. Beginning at age 40, every woman should schedule an annual mammogram and you should start even sooner if you have a risk factor associated with breast cancer. Screening, early detection, and a healthy lifestyle are the most important factors in defeating breast cancer. Clinical trials are currently underway at federally designated comprehensive cancer center such as Yale Cancer Center to make new treatments not yet approved by the Food and Drug Administration available to patients. This has been a medical minute and you will find more information at [yalecancercenter.org](http://yalecancercenter.org). You are listening to the WNPR Health Forum from Connecticut Public Radio.*

Foss Welcome back to Yale Cancer Center Answers. This is Dr. Francine Foss and I am here with Lucinda Hogarty who is joining me today to discuss the Connecticut Cancer Plan. Lucinda, we talked a little bit about some of the details of the Connecticut Cancer Plan in the prior segment and I am wondering, do other states have a similar plan or is Connecticut unusual in this regard?

Hogarty All other states do have a plan similar to this. In the late 1990s, the Centers for Disease Control required that each of the states develop a comprehensive cancer control plan. So, around the country there are plans that are in various stages of development. Some, like Connecticut, are into their second 5 year plan, or second 3rd, 4th, or 5th year plan, and others are just beginning to implement plans, but this is something that you see around the country going across all elements of organizations that fight cancer.

Foss We talked about this being a comprehensive plan and we have a comprehensive cancer center here in Connecticut. Can you talk about the word comprehensive?

Hogarty Yes, what comprehensive cancer control is, is a concept that depends on an integrated and coordinated approach to reducing cancer. It does look at the continuum of cancer control, so we would prefer to prevent cancer rather than deal with it after it occurs; therefore, we start with prevention. We deal with early detection, which usually involves cancer screening and treatment, and that's a very large subject so in our cancer plan we usually focus on one or two priorities at a time in the cancer treatment area, survivorship, and palliation, dealing with pain and end of life issues.

Foss In the first five years, what did you accomplish and what are your plans for the next five years?

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Hogarty We have a lot of accomplishments as you can imagine. With the first cancer plan there were many strategies and objectives and we have spent the past year or so putting together a document that describes our accomplishments, and the progress we have made towards our earlier goals in a progress report, which is also on our website. But just to name a few, we were actively in support of smoking cessation programs around the state and that included additional funding for them. There was a great deal of involvement of our prevention committee in the school wellness programs looking at healthy eating and active living, in particular, cancer screening for the uninsured, education of professionals in palliative and hospice care as well as survivorship issues, and improved insurance coverage for hospice services, just to name a few.

Foss What about the clinical trials issue? This is something that a lot of patients obviously are concerned about and we talked a little about the disparities issue. You have been working now to try to set up a state-wide clinical trials network; can you give us some details on how that's going?

Hogarty I think it's going very well. The clinical trials network, which is being established here at Yale, is looking to coordinate the clinical trials that are going on around the state of Connecticut. There are a few issues to increase participation in the clinical trials. One would be making sure that the medical professionals know that it's something that they can, and should in many cases, offer to their patients. And another is making sure that the patients understand what's involved, and as we mentioned earlier, that may be ensuring that the information about the clinical trials is accessible to these patients. So, we are looking at consolidating a lot of the activities that otherwise could feel fairly scattered around the state into a centralized clearinghouse type of approach for the information to go out to patients.

Foss Will that be available say online for patients?

Hogarty Yes it will. There is going to be a website that will be launched I think within the next month or so based out of Yale Cancer Center, but there will be a link to it on the [ctcancerpartnership.org](http://ctcancerpartnership.org) website as well.

Foss Will there be an opportunity for patients to get new kinds of treatments in the community setting or will this still be based on referring patients to the academic centers?

Hogarty I believe that it's going to be available in both situations.

Foss So that would require developing an infrastructure among all the different medical practices within the state to try to get those treatments out to the community?

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Hogarty There is going to be a lot of that and I think as we move forward with the Cancer Plan for 2009 and 2013, we really do hope to build on some of the accomplishments. The first year of the clinical trials network has just wrapped up, and we are hoping that the work that has been accomplished under that first year will be built upon and the cancer plan, the Cancer Partnership, will be able to take that next step out to the communities to develop that infrastructure.

Foss What about the whole survivorship issue? This is a new area that we are now focusing on in cancer and we have talked to some survivors on prior shows about these issues. There are a number of medical issues as well as psychosocial issues that patients face. How are you going to bring that together around the state?

Hogarty An interesting accomplishment under our prior plan was to conduct a state-wide survey both of survivors, and of medical providers, to determine what survivors needs are. That's going to provide us with information going forward to see what programs, or what materials, need to be developed going forward, and I think one of the things that is being developed, for example at Yale, is a survivorship program that looks at the person as a whole person and takes all that complicated information from their cancer treatment period in their lives to see what their risk factors going forward are, and whether there are additional cancer risks or whether there are other kinds of health risks as they get older.

Foss I know from talking to some of my own patients that are survivors that one problem is trying to address that care with their primary care doctor and other physicians that are non-cancer physicians taking care of them. I am wondering how the survivorship effort will extend beyond the cancer providers?

Hogarty One of the goals that the survivorship committee is looking to develop is survivorship guidelines that would basically be documentation that the survivor can carry with them to other medical settings. So, when they are not seeing an oncologist anymore, they can go to their own primary care provider and say this is my cancer history, this is what you need to work with going forward to ensure that I get the best care, and the best screening. But I think it's also a matter of educating the patient. Unfortunately, some statistics have shown that cancer survivor's don't embrace healthy lifestyle habits as well as we would hope. So, part of this is educating the survivor and educating the provider as well.

Foss On the flip side of it is the palliative care issue, and you mentioned that that's one of your major initiatives, to try to educate the community and health care providers about addressing palliative care and hospice care and also improving access to that around the state?

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- Hogarty Yes, and this is building on some very successful work that's been done over the past few years under our hospice palliative care committee. One of the things that they have done is some education programs for a number of different types of professionals. They are also trying to extend the number of facilities, or the number of settings, that offer hospice care. They are trying to extend hospice care, or awareness that hospice care might be needed, in pediatric settings, veteran settings, prison settings, as well as community settings.
- Foss What about the issue of advocacy? This is something that you have talked about, you have alluded to, a number of times in the discussion, and it seems like that's really a major part of this whole effort?
- Hogarty It is, it's a way that we bring together issues across the continuum of care because we find that education and advocacy in fact do that. What we find is if there is an issue, for example with regards to barriers to care, that's going to be a barrier for preventive services, early detection services, prevention, etc., going across the continuum. So, if a problem can be addressed by an improvement in policy or a change in law, that's something that the Connecticut Cancer Partnership with its 150 organizational members can voice a very strong advocacy position for.
- Foss Do you have patients who are also members at this point?
- Hogarty Usually they are survivors, yes, and we have survivors who are either representing themselves as patients, or survivors, or representing survivor groups. Usually our individual members do see themselves bringing the approach through the Connecticut Cancer Partnership back to some organization where they can leverage that kind of information in a wider venue. For example, we may have breast cancer support group representatives who will go back and bring information to their members.
- Foss What about reaching out to the other two areas that are involved in health care, namely government, the people that are making our laws, and also the insurance industry in Connecticut? Are you interfacing with them, are they part of this whole Partnership?
- Hogarty Yes, we do have representatives from the insurance industry, in particular, here in Connecticut who are members of the Partnership and we're very involved with our governmental representatives. Through our advocacy committee we develop a legislative agenda, and one of our roles is to provide information to our law makers about advocacy issues that are important in fighting cancer.

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Foss Do you at this point have funding to fund individual groups around the states who may have an initiative related to cancer?

Hogarty Right now, because of the state funding crisis, budget crisis, we do not have funding going forward. We are hoping that that will be resolved, and there are opportunities for us to either receive some funding through state legislative allocations or through a state law that some court settlements, negotiated by the Attorney General, do provide funding to the State Department of Public Health for the purpose of comprehensive cancer control. In that case, there may be opportunities going forward, but we are facing the same challenges that all grant funded and government funded agencies are facing with this budget crisis.

Foss I believe last year there were some opportunities for funding through that mechanism, through the Attorney General's fund, to get some of these say breast cancer groups together and some other advocacy groups together as part of this Partnership.

Hogarty Yes, there was a settlement made between the Attorney General and a pharmaceutical company that did allocate some funds for this purpose. Because of the hold up with the state budget, we haven't seen that money flow down to the level where we would like to see it.

Foss That's unfortunate.

Hogarty Yes it is, and that's one of the things where we feel that the more support we get from our members to let their legislators know that that money needs to be released to the purposes that it was intended for, the greater voice we can have.

Foss So that's certainly one way people out there can help?

Hogarty Absolutely yes, and that's something where we will share information with people from around the state, because I think it's very important for people to contact their own legislators, their own state representatives, and say in our own corner of the state this would have an effect on people like me who are fighting cancer, who want this for our own local community.

Foss What are your goals for the Partnership moving forward?

Hogarty We have a very ambitious agenda. This 5 year cancer plan is filled with specific strategies, many of which don't require funding fortunately, some of which do, but I think immediately what we would like to do is bring together people and organizations who will benefit from the synergy of sharing their approaches with each other and really bringing forward and

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bringing to fruition some of the strategies that will decrease the burden of cancer in Connecticut.

Foss Are you looking throughout the state now, are you looking at an increased incidence of cancer or has it leveled off?

Hogarty Our data always lags, and this is one of the problems that we have. We are looking at breaking things down to an issue where we can really measure. In many cases things have leveled off, but one of the problems that we have not seen progress with is these disparities and access groups. We can't feel that our job is done when cancer numbers begin to stabilize. What we really need to do is dig deeper and say, that's great for overall, but we as an organization want to be able to focus on areas where much progress is still needed.

Foss Certainly in the area of early detection when you have interventions for early detection it takes years before you start seeing the benefits.

Hogarty Exactly, and again that's true with prevention as well.

Foss If people are interested in participating in the Partnership, how can they learn more? Could you just tell us little bit about the website?

Hogarty The website does have a number of links to documents that are important; our progress reports, which talk about the progress that's been made under the previous cancer plan as well as the new cancer plan, 2009 to 2013, and again that's at [ctcancerpartnership.org](http://ctcancerpartnership.org).

Foss Something for everybody out there to remember. Many of us have been touched in our lives by cancer in one way or another.

Hogarty Yes, that's true and we feel that there is a place for many people who have some interest at whatever level in cancer. There is a place for them to be active in the Connecticut Cancer Partnership.

Foss Lucinda, I would like to thank you very much for joining me tonight on Yale Cancer Center Answers. We are grateful for the work of the Connecticut Cancer Partnership and we look forward to hearing more about the progress of the State Cancer Plan. Until next week, this is Dr. Francine Foss from Yale Cancer Center wishing you a safe and healthy week.

*If you have any questions or would like to share your comments, you can go to [yalecancercenter.org](http://yalecancercenter.org) where you can also subscribe to our podcast and find written transcripts of past programs. I am Bruce Barber and you are listening to the WNPR Health Forum from Connecticut Public Radio.*