

Yale CANCER
CENTER
answers

WNPR Connecticut Public Radio



Hosts

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Legislative Support for Cancer
Patients

Guest Expert:
Representative Rosa DeLauro

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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 an internationally recognized expert on colorectal cancer. Dr. Foss is a Professor of Medical Oncology and Dermatology and she is an expert in the treatment of lymphomas. If you would like to join the discussion, you can contact the doctors directly. The address is canceranswers@yale.edu and the phone number is 1-888-234-4YCC. This evening Ed Chu is joined by Congresswoman Rosa DeLauro. Rosa, a cancer survivor herself, is currently in her tenth term representing the Third District of Connecticut and has worked tirelessly throughout that time to advocate for cancer research and care.

Chu What got you interested in focusing on cancer research?

DeLauro Certainly most times there are efforts that you focus on in any legislative body, and for myself in the Congress, when I was first elected to the Congress, I went with an interest in looking at healthcare issues, women's health, because I am a survivor of ovarian cancer. It has now been 23 years that I am cancer free. I was treated at Yale-New Haven Hospital and did radiation therapy at Hunter radiation. When I had the opportunity to be able to serve in the House of Representatives, the whole issue of health, and health-related issues, was uppermost on my mind. I sit on the Appropriations Committee, and the Health Education and Human Services Subcommittee of Appropriations, and under that portfolio with health and human services, we have jurisdiction over the National Institutes of Health, and the Center for Disease Control, and in the other subcommittee that I now chair, the Agriculture and Food and Drug Administration, we have jurisdiction over the Food and Drug Administration. There is a confluence of areas that focus directly on health and on research and I have been excited about that these ten terms in Congress. My view is that the NIH, CDC, and the FDA are really the crown jewels of our health care system where we have the opportunity, particularly at the NIH, to do the kind of research that is ground breaking and look at not only cancer at the National Cancer Institute, but of a variety of illnesses. It's where we can look at biomedical research and how we can make progress in these efforts. I have been proud to serve at a time between 1998 and 2003, where we have doubled the funding for the National Institutes of Health. Unfortunately, we had some lean years after that where the programs were flat funded, but I am happy to tell you that we are getting ourselves back on track. In the economic recovery package, the stimulus program that was passed a few months ago, there is about 10.4 billion dollars in research efforts for cancer and for other illnesses. It's my direct experience and health issue that has brought me to this place.

Chu Can you tell us a little bit more about your efforts with the stimulus package, because obviously with this term in Congress, with President Obama coming on board and taking over as President at the end of January, and this huge stimulus bill, I didn't realize it was

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10.4 billion dollars for medical research, but what are some of the key goals for this stimulus package?

DeLauro The efforts here were to look at how we can create jobs, how we can look at economic growth for the future and how we can make sure that we are able to maintain services such as health care, education, energy related efforts, and the 10.4 billion dollars is for research and research-related activities; again, the research is around cutting edge illnesses such as Alzheimer's, cancer, Parkinson's, and heart disease. There is competitive effectiveness research on which treatments work best, and according to an organization called Research America, the investment could create 70,000 jobs.

Chu Fantastic.

DeLauro And it will help to stimulate the economy in a number of our states including the State of Connecticut. Every dollar that we put towards biomedical research, and I don't make up these numbers, you get 2 1/2 dollars pumped into the economy. Sometimes people don't understand the economics of the research and you have to deal with both the medical side of it as well as the economic side of it. We are on our way to distributing these funds. We have got about 8.2 billion dollars that is going towards research priorities, another 400 million for the comparative effectiveness research, and 1 billion dollars is going to fund the construction and capital improvements at research universities. Some of the funding is going toward what was already in the pipeline that we couldn't get funded, but that received very high scores in terms of research. We have got about 200 million dollars going towards challenge grants to address different kinds of scientific and health research challenges that will benefit from a jump start by these two year funds. Let me just say, which is very exciting for me, we have learned that Yale and other Connecticut Universities will receive over 3 million dollars in research funding for a number of topics including genetic research equipment, nicotine dependence research, and a whole variety of areas, and the funding is already coming through.

Chu That's just fantastic. Now do you see this funding continuing, because obviously there are concerns with all of the economic issues that you and President Obama are facing, that perhaps there may need to be greater prioritization to maybe get away from, to be diverted from, medical research. What are your thoughts on that?

DeLauro My own thoughts are that we can't be diverted from that. The President's budget for 2010 didn't have as much money as I would have liked to have seen, it's only about 442 million dollars, and I think we need to increase those dollars for research. Clearly the recent 10.4

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billion dollars will sustain us for a while, but I think what we can't do is to have this research drop off a cliff, and what we need to do is to deal with the funds and the resources that will allow us to sustain these efforts. The fact of the matter with research, and you know this as well as I do, is that you don't see the outcome overnight.

Chu That's right.

DeLauro And from our investments 10, 15, 20 years ago, we are seeing the benefits of that now in terms of new discoveries, and new areas of treatment for some of these illness that have plagued us for a while, and if we do not continue to make that investment then we will not be making the kinds of medical breakthroughs that we have been able to make because we will not have done the proper, if you will, seeding of the field here, in order to create a new opportunity for people to survive. Federal government deals with a lot of different areas, there are road, bridges, parks, defense, etc, but this is about life and being able to look at research that gives people a second chance in life.

Chu And I think cancer research highlights what you have just talked about because the investment that Congress and the President made in cancer research over 20-25 years has paid huge dividends. We have a better understanding of what causes cancer, there are an amazing number of new treatments and what we call new targeted therapies.

DeLauro That's right.

Chu We can cure cancer, and if we can't cure cancer we certainly are prolonging lives and we now have these extraordinary methods to detect cancer at a much earlier stage. You really do have to make that investment up front.

DeLauro You are absolutely right. I was diagnosed with ovarian cancer 23 years ago. Today, when you think about the kinds of drugs, the kind of research, that has been done to address the issue, they were not available 23 years ago. Those are the strides that we have to make and one thing that is important for people to know is that the members of Congress, and the administration, we are not determining where the money goes, we are not scientists, but we have the opportunity, and I believe I am blessed with the opportunity, one to be in Congress, and two to be on this subcommittee so that we can say we are going to provide you with these resources, you and the scientific community will make the best determination of where it needs to go. Otherwise, we are just pinpointing a specific illness and that sometimes can happen with other things and that gets to be a potentially political process.

Chu Yes.

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DeLauro That's not our job. We are not scientists, but we want to make sure that there are resources available to carry out this research.

Chu As you mentioned, you are a cancer survivor, you had ovarian cancer, and you played a key role in passing legislation to support ovarian cancer research in a particular Johanna's Law. Can you tell us a little bit about what that legislation involves?

DeLauro I will be delighted to because that is a bipartisan effort. Myself, a Democrat from Connecticut, Sandy Levin who is from Michigan, another Democrat that we have is Dan Burton who is from California, a Republican Darrell Issa who is from Florida are all involved in that. Sometimes you think that people can't get along and work across the aisle, but we have worked across the aisle on this and we introduced the law. It's an education campaign lead by the Centers for Disease Control and Prevention. It's about increasing awareness and knowledge of health providers. For women with respect to gynecological cancers, often times we don't have providers who are trained in these areas or have the educational background to be able to do the kinds of diagnosis that is necessary for one to be able to treat these illnesses early, and we know that early detection, early treatment, is critical to survival. The program has been funded for the past two years and the CDC is beginning a national awareness campaign about the signs and symptoms of gynecological cancers. Again, along with my colleagues, we are going to be introducing the bill again and we will be doing that next week.

Chu Great. You are listening to Yale Cancer Center Answers and I am here this evening with Congresswoman Rosa DeLauro discussing cancer research and her key support for cancer research and cancer patients.

Medical Minute

The American Cancer Society estimates that in 2009 there will be over 62,000 new cases of melanoma in this country and about 2400 patients will be diagnosed here in Connecticut alone. While melanoma accounts for only about 4% of skin cancer cases, it causes the most skin cancer deaths, but when detected early, melanoma is easily treated and highly curable. Clinical trials are underway at federally designated comprehensive cancer centers such as Yale Cancer Center to test innovative new treatments for melanoma. The patients enrolled in these trails are given access to newly available medicines, which have not yet been approved by the Food and Drug Administration. This has been a medical minute and you will find more information at [yalecancercenter.org](http://www.yalecancercenter.org). You are listening to the WNPR Health Forum from Connecticut Public Radio.

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Chu Welcome back to Yale Cancer Center Answers. This is Dr. Ed Chu from Yale Cancer Center and I am here in the studio this evening with our Congresswoman Rosa DeLauro discussing cancer research and all of her great efforts on behalf of cancer patients. Congresswoman DeLauro, you were talking before the break about Johanna's Law, which is focused on ovarian cancer, but you have also been a tremendous advocate for woman with breast cancer. Can you tell us a little bit about what that involves?

DeLauro Sure, I thank you for the opportunity to be here to talk about some of these issues. It must be about 12 years ago, a surgeon from Connecticut, Dr. Kristen Zarfos, came to see me in my office and what she was experiencing as a surgeon was that women who were having surgery for mastectomy or for lumpectomy were being sent home within sometimes less than 24 hours of care in the hospital. Those decisions were based on insurance coverage and she asked me if there is anything that we can do about this, because in essence it's kind of like a drive-thru mastectomy and often time's people need more care in the hospital to avoid critical circumstances afterwards. What we did was we worked and put something together called the Breast Cancer Patient Protection Bill. It simply says that a doctor and patient will make the decision on length of stay, but we are only asking for at the maximum 48 hours of insurance coverage for the hospital stay. If it is possible to be less than the 48 hours, then the doctor and patient together will make that decision. If there are no difficulties, and you can go home, then you go home. As you know, when you do leave the hospital after breast cancer surgery, you usually have tubes that are tied to you and the tubes with the fluid have to be drained and from my own experience with that, when I went home from the hospital my husband, step kids, and my mother were all very caring and solicitous, but they are not trained professionals. And if something goes wrong, they can't make a diagnosis. We are not asking for two weeks, a month, or six weeks, we are asking for two days, for 48 hours of insurance coverage. I will tell you, that when I introduced that legislation 12 years ago, over past eight years we were unable to get a hearing on it. We were finally able to get a hearing last year and it passed and the subcommittee, the full committee, it went to the House of Representatives and it passed by a vote of 421 to 2.

Chu Wow.

DeLauro That tells you that there was tremendous support again in a bipartisan way and it hasn't yet come up in the United State Senate. We are going to introduce the bill again, but what's unfortunate is that insurance companies are still forcing women to leave the hospital too early in my view, and that can have serious consequences. As I say, I am not a trained physician, if a doctor and a patient make that determination, then go home.

Chu Right.

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DeLauro People want to go home from the hospital. One patient from North Carolina testified before the Congress that she had to delay her chemotherapy for six weeks due to an infection she developed after being sent home too early. I don't make this up, last month alone, we have a Lifetime TV petition that supports this legislation, and it garnered 725,000 signatures. Since this effort started the petition has been signed 24 million times. That tells us something about the need that is out there.

Chu That is critically important and I think it's unfortunate that these financial issues take over what should be appropriate medical care and what's in the best interest of the patient.

DeLauro Well insurance company shouldn't make the decisions; physicians and patients should be making these decisions.

Chu You have also been very actively involved in the screening and early detection efforts for cervical cancer.

DeLauro Right.

Chu And you are in fact a founding member of the partnership to end cervical cancer. What's the main focus for this organization?

DeLauro Being on this subcommittee has been such a learning experience with regard to health issues and I can recall when folks from the National Institutes of Health came up to testify before our committee, and 4000 women die every year from cervical cancer, but they were clear when they said to us that in fact we could eradicate cervical cancer, that's staggering to me. And where I work, we have it within our capacity to provide the kinds of resources that can be utilized in this way and that means saving, or potentially saving, 4000 women a year. Think about this, on 9/11 we lost close to 4000 people at the World Trade Center. Those people went to work and they didn't go back home again. We went to war, as we should have I believe, and I voted to go to war in Afghanistan because of what happened there that day and the loss of 4000 lives. We are losing 4000 women every single year to cervical cancer, and we couldn't predict what happened on September 11th, it happened, but we know what's happening here; we can do something about it. I said to myself at that time, my God! And we have an obligation to go to war against cervical cancer to eradicate it and that is what I believe we can do. What we are able to do here with this effort is about vaccination and we have an opportunity to be able to do that. We need to make the information known to people and this is what we can do with the resources, we have the partnership and what we want to do is to include vaccination to prevent cervical cancer, along with screening, routine preventive health care for all women in the United States. We are focused in on four barriers

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that impede access to cervical cancer vaccination. We want to deal with minimizing the health disparities that exist in the United States and that has to do with minorities.

Chu Right.

DeLauro And minority communities. We want to make sure that there is health insurance coverage that is adequate to take care of the course of treatment and we want to ensure that physicians embrace vaccination as a way to eliminate cervical cancer. And we want to provide the tools that are necessary for women and girls to understand about cervical cancer. Again, when you think about illnesses that can be eradicate, my God! Why aren't we doing it? And my view is that we have an obligation to do it.

Chu I applaud you for all of your strong efforts in that regard. One issue that I thought we could touch upon that has received a great deal of publicity is the whole notion of nationalized health insurance. You have been such as a staunch advocate for health issues and for providing for affordable high quality health care to individuals, not only in the State of Connecticut, but really throughout the United States. Where do you see things heading with respect to providing universal health insurance?

DeLauro I think what we need to do in terms of health care reform, and we attempted to deal with health care reform in 1993 and failed for a variety of reasons, but the issue that is at the uppermost with regards to health care reform is cost. The affordability of health care is what we have to address and we have to look at making it affordable and accessible to everyone. We also want to be able to try to preserve choice and that is what we are looking at in terms of health care reform, a system that says, 'if you like what you have now, if it is providing you with health care coverage and the benefits that you need in your life and your families life, then let us make sure that you can keep that choice.' We are not saying that everyone is going to change their health care system and go into one system that is going to be a government run system, that is not what we are talking about.

Chu And unfortunately, I think that's a misperception.

DeLauro It is a misperception, but by those who don't want to see healthcare move forward in the way that we need it to, because we have to deal with cost and we have to deal with accessibility. 44 million people in this country today do not have any health insurance, and most of them are working in small businesses, and it isn't that the small business doesn't want to provide health care; they cannot afford to do it. So maintain your choice, let's look at what your out of pocket costs are, try to bring some sense to that, maybe capping the cost on an annual basis, look at subsidies to businesses, to be able to provide health care, look at giving

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people what we call a public option so that they can choose between a private health insurance and some sort of a public program that they pay for; it's not free. It is a program that they pay for which meets criteria that would be established at the federal level for benefits, but that would be based on other benefit packages so that they would have a comprehensive benefit package that they might avail themselves of if that is something that meets their needs, because today individuals on their own can't get health insurance. We would eliminate this whole issue of pre-existing conditions so that you can't decide not to insure someone because they have a pre-existing condition. There would be no lifetime or annual benefits or limits on benefits for a participant or for a beneficiary. We have to try to take a look at how we deal with the issues of cost and affordability and make sure that our system allows for everyone to be able to have coverage and for businesses to have the opportunity to offer it. The notion that insurance companies will be making all of the decisions in this effort, in my view, has to be turned around, insurance is about shared responsibility and risk, and people don't decide to get sick. They get sick, and when they have those challenges in their lives, they need to be able to get affordable healthcare and they need to be able to have access to that healthcare. My family could take care of my needs as someone who was diagnosed with ovarian cancer; it shouldn't be that someone else can't get the access to the treatment that's necessary in order to be able to survive. We also need to look at health technology and get the best advice as to how that may happen, we need to take a look at prescription drugs and bringing the cost of those prescription drugs down, how do you decrease the cost in the system today? That's going to be the goal, it's going to be a tough couple of months to pull all that together. But what I am most optimistic about is that it is front and center, it is at the top of the national agenda and the President has said that we cannot tackle economic recovery in this nation unless we tackle health care and its cost.

Chu Congresswoman DeLauro, it's amazing how quickly the time has gone. We thank you for being on the show. I particularly want to thank you and applaud you for all of your efforts on behalf of the State of Connecticut and also Yale-New Haven Hospital and Yale Cancer Center for all that you have done with respect to health care, health care reform, and cancer research. We look forward to having you on a future show to hear about the success that you and the President have with respect to this whole health care reform issue.

DeLauro Thank you very much and thanks for your good work, I appreciate it.

Chu You have been listening to Yale Cancer Center Answers and I would like to thank our special guest this evening, Congresswoman Rosa DeLauro, for her time. Until next time, I am Ed Chu from Yale Cancer Center wishing you a safe and healthy week.

If you have questions or would like to share your comments, go to 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.