

Yale CANCER
CENTER
answers

WNPR Connecticut Public Radio



Hosts

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The Impact of Patient Advocacy

**Guest Expert:
Deb Collyar**

*Patient Advocate and Director, Patient
Advocates in Research*

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 he is 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 at canceranswers@yale.edu or 1888-234-4YCC. This evening, guest host Dr. Lyndsay Harris, is joined by Deborah Collyar. Deb is the President of Patient Advocates in Research, otherwise known as PAIR.

Harris Deb, tell us what patient advocacy is and how you think the field has grown over the last few decades?

Collyar Patient advocacy includes many different things, so I usually try to explain the different categories of patient advocacy. Certainly, some more traditional approaches are direct patient support and services that are available to people who get cancer or other illnesses. There is also a type of advocacy that focuses on fund raising, and those are either private foundations or funding events that people take part in, like walks and things like that. Another type of patient advocacy deals with the political side, or lobbying advocacy, trying to make things better or push certain things through Congress and State Legislators. Another type is watch dog advocacy, which is more what people think about in the AIDS community, but that is where we bring issues that need to be addressed and put them on the table to shine a light on them and discuss and resolve them. The type of research patient advocacy that I focus on is research advocacy, working with the research community itself, both helping in grant development, and grant reviews, but also working with people after they get grants and they need to put them into operation and make progress toward cancer.

Harris You founded PAIR, which stands for Patient Advocates In Research, many years ago. Can you tell us what the mission of PAIR is and what changes have been made in the organization over the time that you have been involved with it?

Collyar PAIR was founded because a lot of people asked me to put a group together that focused on the research aspect of advocacy. We have so many wonderful organizations out there that focus on the other types of advocacy that I just mentioned, but the purpose of PAIR is that we can throw all the money in the world we want to at cancer research, but if we do not change the way the system works and the mindset of the researchers themselves, we are still not going to make progress and have the impact that we want to have on cancer. And that gets back to my personal background, which is in business, computers, and organizational development. But the real mission of PAIR is very simple; to get better answers to people more quickly. In order to do that, there are a lot of, shall we say, “opportunities” within the

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research system to do a better job of streamlining, and to create a more cohesive process from discovering new scientific areas to develop, and then actually developing those through the process and turn them into something that will work for people in the clinic; for people that have cancer and those that want to avoid it.

Harris Excellent! A very important area that has not been focused on in the past. Could you tell us what some of the challenges are that exist in the current structure of research for cancer, and how have patient advocates tried to meet some of those challenges and help us get over them?

Collyar The question would be where to start? There are a lot of areas that need improvement. One example would be a phrase we have used for years, tissue issues. Obviously researchers need tissue to work with so that they can discover what is happening in the cells of cancer patients, as well as normal people, so we can start to see what can be done, but for some reason researchers never seem to have the right kind of tissue that they need. One of the things that we have done is helped with not only sourcing new areas or new resources for tissue, but also how to explain the value of cancer research to people and why tissue, also called biospecimens, is needed, what people can do to donate it, and the risks involved in doing that so that they can make a good decision about whether it is something they would want to do. Consent issues are one of the things that we work on, and better ways to explain that to people.

Another issue is with the collection process itself. Sometimes, departments within an institution do not necessarily work well together and sometimes we can come in and help sit everybody down and say, okay why are we doing this in the first place? Let's figure out a better system so that it is a win-win for everyone, and make sure we get the tissue that we need. It also goes into areas of how is that tissue going to be used, and by whom? How can we make sure that it is used well, and that any research and discoveries that are made are then put forward so that they can be built upon? Another area is on the research side of clinical trials, which are research studies in people that have to be done before we get new standards of care and new treatments that we know will work. There are many ways that we help with that, including developing those clinical trials so that they are relevant to peoples' issues, as well as important scientific questions that are answered.

Harris That is very helpful to have you explain those issues to us, and clinical trials are a critical part of what Yale Cancer Center is trying to develop in order to improve treatments for cancer patients. But there are many barriers to patient involvement in clinical trials, can you tell us a little bit about some of those barriers and how patient advocates can help dispel them?

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Collyar Well certainly one barrier is the image. Some people have never even heard about clinical trials, and unfortunately, when someone is diagnosed with a life-threatening illness like a cancer or cancers, because there are many different diseases within cancer, that is not a good time to have this thing thrown in front of you so you have to make a really quick decision. There are some ways that we can talk about clinical trials in general so that people understand more about what that means. For example, one thing that people need to understand is that the treatments that exist today for cancer, which have improved quite a bit in the last 20 years or so, exist because clinical trials were done. People who were willing to volunteer to participate in those clinical trials so that tomorrow's patients will benefit from clinical trials that are done today and we can find out which drugs or which treatments work better for people than what we already knew about.

Harris That is really an important point. It is perhaps a lack of understanding of the fact that what we use today as standard of care was in a clinical trial yesterday, the day before, a year ago, and it may not be apparent to people who are just being introduced to the idea that they may have cancer, that clinical trials are really a part of the standard treatment of patients. You also mentioned to us earlier today when you gave a talk to our group, that clinical trials can also benefit the individual patient, could you elaborate a little bit more on that?

Collyar I think one of the things that people sometimes have a misunderstanding about is that there are no choices that someone has in a clinical trial, but there are choices that they have. In cancer, there are usually different treatment options for clinical trials that are called arms or groups of that study, so it is not like they are not going to get any kind of treatment at all. The other thing that I think is important is that the ethics committee a lot of times will talk about clinical trials and research as being totally experimental and that it is not treatment, but in fact, for a cancer patient, that is their treatment, and so we have to think about clinical trials and research studies as a part of treatment options that people can consider. They are not right for everyone, but it is important for people to know that they are out there and that they are a possibility as they are starting to make decisions about what they are going to do about their situation, and that includes not only people who have cancer, but people who do not have cancer as well. A lot of studies are done in people that are maybe at higher risk, such as ways to prevent cancer, ways to screen for it, diagnose it, as well as early stage cancers. You do not have to be in a dire situation to consider something like that.

Harris Deb, I think it is important for the audience to realize that you have personal experience with cancer, both with yourself and in your family. You have mentioned to us that you do not know a person who is not in some way touched by cancer. Can you tell us a little bit more about your personal journey, and how that has impacted what you do now?

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Collyar Well, if I had not had cancer myself I would not be doing what I am doing now, which is working with researchers all across the country to try to make their work more timely and effective for people. I had my first breast cancer at age 32, and I was an executive in a computer company at that time and my boss actually put it in the company newsletter, so it became a very public thing very quickly, which was okay on my part, but through that experience I became involved with an organization when cancer patient advocacy was just getting started back in the early 90s. As my husband says the volunteer role can be a giant sucking sound where your professional life takes a backseat to some of the passion and involvement that was important to let takeover. That is a very normal experience by the way, with the patient advocates that get involved in research or really any of the areas that I mentioned before. People have a personal experience with cancer, either directly themselves or with loved ones, and want to do something to try to help make it better for the next generation, because our kids should not have to face the same issues that we have had to face, that is not the way it is supposed to work.

Harris Your personal experience, you said, is not unique, and yet you have made it your mission and have dedicated your life going forward to trying to help people understand the way that they can change cancers and research strategies, and what individuals, the patients themselves can bring to the table to form the way that cancer researchers and cancer doctors impact on the disease, and that is something that is incredibly important. Your dedication has led to your role at the level of the National Cancer Institute on the SPORE program, to your role in the cooperative group, clinical trials organizations, and has blazed the way for other patients and patient advocates, family members, and all those touched by cancer, to become involved. Can you tell us a little bit about how the individual patient or their loved one can contribute to try and make a difference in cancer? I am sure it seems very intimidating to a person who is diagnosed with cancer or whose loved one is.

Collyar It can be intimidating. It is certainly not something where you have to become a scientist and know everything, but you do have to educate yourself and keep up on what the new concepts in cancer are. One of the key areas that we talk about is just asking why are things done the way that they are done? Is there a better way? Who else could we be bringing in to the conversation? How could we move this forward, and what are the barriers that you face? Sometimes there are ways that we can work together to eliminate them, or certainly resolve some of the issues so that we get better answers to people more quickly.

Harris Deb, if people want to contact you either on the web or by email, what number should they use? Is there an email that they can use?

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Collyar Right now I am between websites, so I do not have one I can give immediately, but my email is my last name collyar@att.net.

Harris Thank you Deb. We are going to break for a medical minute. You are listening to Yale Cancer Center Answers, and we are here discussing patient advocacy with Deborah Collyar, President of PAIR.

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. 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. You are listening to the WNPR Health Forum from Connecticut Public Radio.

Harris Welcome back to Yale Cancer Center Answers. This is Dr. Lyndsay Harris and I am joined by Deborah Collyar to discuss the importance of patient advocacy in research. Can you tell us a little bit about the program that you started under a national grant, called PART, what the goal of that NCI funded program was, and what are you doing with that program now?

Collyar PART stands for Patient Advocate Research Team program. The idea was how to, in an organized way, bring patient advocates that were interested in the research aspect of things together with the research teams that are actually doing the work, so that their discoveries and their research could be informed by the patient experience? So make that become a part of the dialogue, but also learn what barriers were thwarting the research from being translated into results, and what we can do to help with that.

Harris That is great. Can you tell us about what sort of initiatives led to it and where are you taking that program now?

Collyar The program is moving forward. I talk a lot with different cancer centers and different kinds of cancer programs within institutions and a lot of people are very excited about it. There are certain projects and activities that people can get involved in without having to know a lot about science. An example of that is a workshop that we set up called, Clinical Trials and People, which is meant to bring a good discussion and start a dialogue within different

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communities with researchers, so that we can talk honestly and directly about what clinical trials are about, what research is about, what researchers need to know about various communities, and by that it could be ethnic communities, racial, or older citizens; all the different groups that may or may not have good representation in clinical trials, or within the medical system even. But the idea there is to not only talk about it and to explain a little bit more about research, but also for researchers to hear about what community needs are and what patient needs are. At the end of this workshop the thing that is really exciting is that people are able to talk about an informed consent together, which explains the research, and the community members can also talk about how that explanation and how that research can be done in better ways that meet the needs of their community. It immediately sets up a relationship and a way to continue the discussion.

Harris That is a great example Deb, and as Director of the Office of Eliminating Cancer Disparities at Yale Cancer Center, I have had a number of conversations with community leaders about how we can reduce cancer disparities. We know that some groups in this country, and in the world, do not fair as well after a diagnosis of cancer, and we are starting to understand what some of those reasons are. They appear to range from the nature of the tumors that develop in different populations of people, to access to good medical care, and cultural barriers. Maybe you could give us an example of a way that you have tried to breakdown some of those barriers using the PART program.

Collyar To begin with it is important to discuss issues and past atrocities, especially to certain populations, in a very frank, open, and direct way. The fact is that none of us like that some of those things have been done, and there are more protections in place today and it is important for people to know what that is about as well, but also to know that they can have a voice in the way research is done. Getting there sometimes is the issue, which is another part of what the PART program tries to do. We give training, resources, and have a communication network for people interested in getting together with researchers. What I find when we talk honestly about research, issues, and problems, as well as the potential for it, people are very receptive. If they feel that they can play a part in that and have input into the process, it solves a lot of the problems.

Harris In your experience with the Indian tribes in Arizona, for example, could you tell us how that meeting led to some significant changes in the way research was being done at that cancer center? It's an example of how these sorts of initiatives can really make a big difference and change the future.

Collyar With the University of Arizona, and what they called their GI SPORE, which is the gastrointestinal, primarily the colon cancer group, they were interested in conducting this

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workshop. We invited nine different American Indian tribes. It was a team effort to put the workshop together with the University, with my program, and with the American-Indian Oncology Program, which has worked with tribes. In doing so, we had these sessions both on research and what research studies were about, but we also had presentations from the community on what researchers needed to know about them. It was a dialogue, and the result of that workshop was that we were able to interest one person to become a patient advocate with that research team, which was our goal, and so she now attends research meetings, gives input into the process, finds out what kind of problems are going on, and gives a good perspective from the people that she represents. Another result from that was a member of a different tribe who helped bring in the University's cancer information service, to start a whole cancer education program that was, again, a two-way dialogue, so that there was learning on both sides of the fence.

Harris That is a wonderful example of how just sitting at the table together with the invested parties can accomplish so much in the long run, that eventually, increased understanding of what the researchers are doing and what the patient's needs are, can only serve to improve the ultimate outcome for both; the people doing the research need to understand what the value is of what they are doing, and the individuals receiving the results of that research want to see that they apply to their own population. It is another unfortunate gap that exists not only between different socioeconomic groups, and different racial groups in this country, but also between patients and researchers. There is a large gap that we need to address, and the term that is coined is translational research, which attempts to translate results from the bench to the bedside and the reverse. How do you think that the patient advocates and representatives play a role in bridging that gap?

Collyar Of course translational research is bench to bedside, which is a term that is used a lot, but what that really means is taking basic science discoveries and figuring out how to apply those to people in ways that can be tested well and carefully, so that we can have new treatments and answers, risk profiles, and stuff like that for people. Part of what we have to discuss here in this particular area is that there are research cultures within institutions that are not necessarily set up to help foster translational research. Sometimes, as a patient advocate, we get involved not only with the researcher, but also with some of the systems that have evolved within an institution that are not helping us get results, because a lot of institutions and academic universities are set up to build knowledge, but not necessarily set up to get results. It is changing some of the culture within those institutions and we do that through a variety of ways, sometimes it is talks like the one I gave this morning, sometimes it is getting involved in a specific program, sometimes it is talking with the institutional review boards that look at research and review it for human risk, and sometimes we go a little bit overboard

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in trying to protect people, but do not allow the research to take place to get the answers that we all would like to have. I do not know if that answered your question or not.

Harris Absolutely, and it is really important that patients and families understand that we look forward to and appreciate their input. For those individuals or groups who would like to become more involved in the research that is going on here at Yale, either in cancer disparities or any other specific type of cancer, feel free to call us at 1888-234-4YCC or ask to speak to myself or leave a message for our groups. If you would like to email questions, we would be more than happy to address them. It is critical that patients and consumers of medical care become more involved in the outcomes of the research and influence what happens at the level of the cancer center.

Collyar I agree with that Lyndsay, and just as one last point, it is incredibly important that patient advocates play a role in helping to tie excellent research institutions such as Yale together with community practices and community clinics where people are being treated regularly. Again, cultural differences sometimes can get in the way of cooperation and coordination and the type of research that needs to be done has to be done in a collaborative way. There is no one group or one person or institution, or even company, which can get the answers that we need as we move toward personalized medicine.

Harris That is a great point Deb. I would like to thank you so much for joining us on today's program. The information you have given us is incredibly helpful, and again, just to emphasize for anyone who wants to contact Deb, Deb can you remind us of your email?

Collyar Collyar@att.net and thank you very much for asking me to participate in this, I am very honored to be here.

Harris It was a great pleasure, and do feel free to contact me, Lyndsay Harris, Head of the Office of Eliminating Cancer Disparities, and the Breast Program at Yale Cancer Center, at 1888-234-4YCC if you want to become involved.

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 program. I am Bruce Barber and you are listening to the WNPR Health Forum from Connecticut Public Radio.