



Updates from the CT Cancer Partnership

Hosted by: Anees Chagpar, MD

Guest: Maria Grove, Executive Director, CT
Cancer Partnership

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Welcome to Yale Cancer Answers with doctors Anees Chagpar and Steven Gore. I am Bruce Barber. Yale Cancer Answers features the latest information on cancer care by welcoming oncologists and specialists who are on the forefront of the battle to fight cancer. This week, it is a conversation about the Connecticut Cancer Partnership with its executive director, Maria Grove. Dr. Chagpar is a Professor of Surgery at Yale School of Medicine and the Assistant Director for Global Oncology at Yale Comprehensive Cancer Center.

Chagpar Maria, maybe we can start off by you telling us a little bit about what exactly the Connecticut Cancer Partnership is.

Grove The Partnership was founded a little over 12 years ago through a grant from the CDC. Every state has one -- an alliance, a coalition, a partnership per se. We are the Connecticut Cancer Partnership. Every state has to deal with the specific issues of cancer burden in their state and we offer state-wide contacts for cancer-related programming. We convene the groups to discuss and promote and to educate and to monitor anything cancer related in the state. The idea is that cancer is a bigger idea that one organization cannot handle at one time, so the more minds the better.

Chagpar That brings me to the question I was about to ask, which is, who exactly are the partners?

Grove We have a number of founding partners -- the hospitals in Connecticut, the Department of Public Health, the American Cancer Society. Those are the founding partners, and then we have grown to over 300 organizations -- they range anywhere from community health organizations and AHECs and smaller organizations. As I said the larger organizations -- Yale and Smilow, UConn, we are very, very blessed in that we have a lot of wonderful and influential partners in our group.

Chagpar So this is not any one particular hospital, it is really all of the cancer minds and all of the organizations touching cancer across Connecticut?

Grove Absolutely.

Chagpar Tell us some of the issues that this partnership addresses.

Grove We work with the CDC and their priorities, and right now, their priorities are HPV vaccination awareness and colorectal cancer. I will start with colorectal cancer.

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The idea is that we work with the National Colorectal Round Table and they are promoting 80% screening rates by 2018 and of course we are in 2018 now and we are almost there. Connecticut, I believe, is in the high 70s, which is very good. There is still more work to be done. Ideally, we would like to get 100% colorectal screening. And we just had a summit on that, which was very successful. We brought together a number of different organizations and we discussed what are the barriers to screening, how can we help patients get more screening, how can we help patients have a better process with screening. If you have ever had a colorectal screening, it is the prep, which is mythical, people just assume that the prep is so terrible that they do not want to do the screening. So, it is really about getting the education out there as well and also working with insurance companies to make sure that screening is a priority in terms of coverage. One of the ideas that we are promoting is to have companies give out screening days, free days of employment so that the employee can leave the office, go and get the necessary screenings and not be penalized for it.

- Chagpar Let's take a step back for a minute and talk about colorectal screening. I think it would be helpful for our listeners to really understand what the current guidelines are with regard to colorectal screening. I think that many of us think about colorectal screening as being a colonoscopy, but there are many other tests.
- Grove Absolutely. There is another test called the FIT test, which can be done in the privacy of your own home. The only drawback to that is that where a colonoscopy is good for every 10 years I believe, a FIT test has to be done every year. So, you have to be more proactive if you go the FIT test route, but a lot of different providers are offering the FIT test as a way to overcome as we were discussing earlier that fear of the prep for the colonoscopy, there are alternatives.
- Chagpar I think it would be helpful for our listeners really to think about colorectal screening in its context. When you talk about the FIT test or home-based testing for people who may not be aware, there are fecal occult blood tests where you take a stool sample and you put it on a little cardboard and it gets analyzed for blood. There are DNA tests where they look in your stool for DNA. Those are really the home-based tests that you can have done, and as you said, that needs to be done roughly once a year. The prep though is very important for the other kinds of tests that are also used for colorectal screening; things like contrast studies like barium enemas, flexible sigmoidoscopies, colonoscopies or even virtual colonoscopies which I think some of our listeners may have heard about where you swallow a camera and everybody has seen the commercials about the actor who says, 'I am so used to being in front of the camera but now I swallowed a camera', but the idea really being how important the prep is to see the wall of the colon.

Grove Absolutely. And what is really interesting is that there are a number of organizations in the state that are working with nurse navigators to make sure that patients do the correct prep. So, there are many steps to this. There is making the appointment, and keeping the appointment. So, when we talk about health disparities, we are talking about the ability to get to the appointment, the ability of follow through. So, nurse navigators are really helpful especially in this colorectal screening area because they can follow up with patients, make sure 24 hours beforehand that they are doing the prep, make sure that they are going to show up for the exam. We are working with a lot of nurse navigators at different organizations, community health organizations all around the state to make sure that that particular part of the screening is something that is active and working.

Chagpar And the other thing is, I think it is helpful for our listeners to know who should get screened.

Grove Everyone, although I am not a scientist.

Chagpar Absolutely right. Everyone over the age of 50 should get screened for colorectal cancer and certainly as you mentioned Maria, the interval at which you should repeat the screening really depends on which test you chose, whether you had a colonoscopy which is every 10 years or whether you have for example a fecal occult test, which may be every year. It is really important for people to talk to their doctor about what test might be right for them knowing the frequency with which they will need to have that test repeated. The other disadvantage for the home-based test like fecal occult bloods and stool DNA tests of course is that if it finds something, well now you need a colonoscopy because you need to have an evaluation of the colon. Similarly, for people who opt for contrast-based study like a barium enema or a virtual colonoscopy, the one where you swallow the camera, if something is found, you need a colonoscopy because with a colonoscopy, that is the only way that the gastroenterologist or the surgeon can actually look inside the colon, see something and at the same time as they see it, they can get a biopsy and potentially for small cancers, that may even treat the small lesion if it is small enough. So, there are a lot of different options and I think one thing that is important for our listeners to know is that there are these myriad of options out there and you should really talk to your doctor about which option is right for you.

Grove Absolutely.

Chagpar I think the other point though, I was at a health fair earlier this weekend actually in Richmond, Virginia. We were talking about cancer prevention and awareness and screening and so on, and one of the misnomers I think or misperceptions about

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colorectal screening, particularly because we say everybody over the age of 50 should undergo colorectal screening is whether colorectal cancer only occurs in people over the age of 50.

Grove Actually, there has been a huge upswing in the cancer burden in the younger generation. Younger people are getting colorectal cancer at a much higher rate and we are not exactly sure why that is. So, there are a lot of efforts in Connecticut and around the country to get colorectal screening in much younger patients.

Chagpar And while screening guidelines still recommend for people over the age of 50, I think one thing that is important for our younger listeners to remember is that if you have any of the common symptoms that may be warning signs for colorectal cancer, you should go and get yourself checked. So, things like blood in your stool, change in bowel habits, change in the caliber of your stool, feeling of bloating, abdominal discomfort, unexpected weight loss, these are all signs potentially of colon cancer and you should remember that no matter what age you are, you should really get these things checked out. Maria, one of the things that you mentioned was the efforts that the partnership has had in working with insurance companies to make sure that screening is covered, I was under the impression that with the affordable care act, many of these preventative services were covered, screening, tests and so on. How has that changed or has that changed, are insurance companies mandated to cover screenings, all screenings, only some screenings or is this really an issue?

Grove Well in particular with the colorectal screening, with the colonoscopy, it is considered a screening during the colonoscopy, but if a biopsy as you mentioned is taken, then it is considered treatment and a patient could wake up and have had a completely different procedure than they were expecting and that the insurance company might or might not cover at that time. So, we have been working with insurance companies to make sure that the whole scope and the range of treatment from screening to treatment is covered. At least in making sure that patients understand the right and the responsibilities when it comes to what is covered and what is not.

Chagpar And I guess the other question is, there are patients in our state and in all states who do not have insurance, and now there is no individual mandate, they are not obligated to have insurance to cover these screening tests. For those patients, what are the options?

Grove There are a number of community organizations, community healthcare organizations all around the state who have relationships with providers who will give screenings pro bono and they are also covered by various grants and awards through the CDC or

private organizations to cover these screenings. We do understand how important these screenings are and so that is an option for people. They can go and they can find a location like that.

Chagpar How do people find out about that? I know that there are community health clinics where many of these people go, is that where they start or do they call the partnership or the American Cancer Society?

Grove Yes, you can contact the partnership absolutely and we have a list of organizations that offer free screenings and we definitely will be able to point you in the right direction. If I do not know off the top of my head, I can definitely find out with our network of partners throughout the state, there is probably someone who is going to be able to help you.

Chagpar I think what is really important is we think about even if you get a pro bono screening as you mentioned, there is all of the cost associated with treatment downstream, which really raises the issue of making sure that people have good insurance coverage for all of their healthcare needs. We need to take a short break for a medical minute, but please stay tuned to learn more about the Connecticut Cancer Partnership with their executive director, Maria Grove.

Support of Yale Cancer Answers comes from AstraZeneca. The Beyond Pink Campaign aims to empower metastatic breast cancer patients and their loved ones to learn more about their diagnosis and make informed decisions. Learn more at LifeBeyondPink.com.

This is a medical minute about head and neck cancers. Although the percentage of oral and head and neck cancer patients in the United States is only about 5% of all diagnosed cancers, there are challenging side effects associated with these types of cancer and their treatment. Clinical trials are currently underway to test innovative new treatments for head and neck cancers, and in many cases, less radical surgeries are able to preserve nerves, arteries and muscles in the neck, enabling patients to move, speak, breathe and eat normally after surgery. More information is available at YaleCancerCenter.org. You are listening to Connecticut Public Radio.

Chagpar This is Dr. Anees Chagpar and I am joined tonight by my guest Dr. Maria Grove. We are talking about the role of the Connecticut Cancer Partnership in the state of Connecticut and their current initiatives. We talked a little bit at the top of the show about the partnership which is really a conglomeration of all of the different associations, hospitals and providers who are interested and active in the area of cancer to really keep our state and the population cancer free as much as we can. Before the break,

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we talked about one of their big initiatives, which was with regards to colorectal screening, but Maria you had mentioned that the other big initiative was with regards to HPV and cancer awareness. Tell us more about that.

Grove We have a vaccine for HPV now that will prevent 6 different types of cancers. It is recommended for boys and girls, ages 11 through 12, but you can get it as late as 45, which is a new FDA ruling. The idea is that when you get it at 11 or 12, it is before any exposure to HPV has occurred, it benefits as I said boys and girls to get this and it is 2 shots, so you cannot just have the one at the appointment. We are recommending it at the same time as measles, mumps and rubella. So, you have to ask your pediatrician. Hopefully, your pediatrician will bring it up, but you do have to ask your pediatrician for this particular vaccine. One of the efforts that the partnership is working on is provider awareness, having those tough conversations with parents to add another vaccine to the list. At the moment, it is not required for school-aged children in the state of Connecticut. There are other states – in New England and around the country who have required it for school, but HPV vaccine is not required in Connecticut. I hope personally someday that will change, but at the moment we are relying on informed parents and informed providers.

Chagpar And so, tell us a little bit more about HPV vaccine and the 6 different kinds of cancers that it prevents. Many of us may know about cervical cancer, but what are the other forms of cancer that HPV is associated with?

Grove Oh! You got me. Alright, let's see. It is anal, head and neck – that is a big one; head and neck is interesting. That is a growing cancer burden in young men and that is not something that people are aware of. As you said, cervical cancer is the thing that people assume it is, and then they assume that boys do not need to get the vaccine, but head and neck cancer and a variety of others.

Chagpar Head and neck cancer kind of sums up a lot of cancers. And there are all kinds of non-cancer related things that HPV is associated with, everything from genital warts and so on. And the reason I bring it up is because you mentioned that both girls and boys should get vaccinated and a lot of people think, well why should my boy be vaccinated, I mean he does not have a cervix. But the whole concept of head and neck cancers, esophageal cancers, anal cancers, these are ubiquitous and so really vaccinating people against HPV can reduce your risk in many of these cancers. How are the efforts with regards to screening going in our state? Are most kids getting screened, most people getting vaccinated these days or is this really something where we need to put a lot more attention?

- Grove We are doing very well. We are high in our New England neighbors in terms of vaccination rates. The problem is there is no central location for vaccines and that is all about to change. The Department of Public Health is launching something called CT Whizz, which will chart vaccinations from birth to 18 and will have a much better sense of what is going on in the population and then we will be able to also work with providers in terms of catch up vaccines. I can just say from my own personal experience, I am very involved in this area. My daughter received her first shot at 12 and then because of life and circumstances, she is now almost 14 and has not gotten the second shot. So, I am in that area that needs to do the catch up vaccine. She is getting it next month when she goes for her appointment, but it was not something that the pediatrician called me to follow up on to make the appointment, you have to be so proactive and so that is what CT Whizz is going to be able to give us, a much better idea in terms of data and surveillance of what population, what ages and what groups need the catch up vaccine. We have a very good initial vaccination rate, but then there is the catch up.
- Chagpar Tell us more about this CT Whizz, is this going to be a public facing platform where parents for example will be able to get a reminder that oh! My gosh, the second dose is due or will this be more of a provider facing platform where providers will get a best practice advisory pop-up on their computer saying this patient requires a catch up vaccine, how does it work exactly?
- Grove My understanding is that it is going to be both, both provider and public facing. The idea is that it will give providers a better opportunity to make sure that the vaccines are on track and that also parents will be able to see what has and has not been received, and then we can use that information to just have better vaccination rates.
- Chagpar One of the questions I often have when we think about HPV vaccine, especially when you consider that the vast majority, not all, but the vast majority of cervical cancer is caused by 3 main types of HPV and we have very good vaccines against these stereotypes. So, again, it does not eliminate cervical cancer but pretty much, I think the rate is somewhere north of 90% - 98% of all cervical cancers are HPV related. So, why is it that there is some trepidation in vaccinating kids against HPV? I mean, you said that these were difficult conversations. Why is it difficult?
- Grove It is difficult because HPV is a sexually transmitted disease and the idea is that the HPV vaccine prevents 6 different types of cancers and not all of them are sexually transmitted, it is a complicated issue, most parents when they are in the pediatrician's office with their 11-year-old cannot even imagine that their child will be having sexual relations in the next few years, but the idea is that this vaccine prevents 6 different

types of cancers. It is not a green light to go and have sex, it is not a green light to be promiscuous, this is a cancer-fighting vaccine and the country of Australia has all but eliminated HPV-related cancer because of their efforts for HPV vaccination and I think that we can take that as a wonderful marker for Connecticut. It is a great opportunity for us, but I do know as a parent, I am actually a cervical cancer survivor myself, there is a lot of discussion about the vaccine and if it is safe, the vaccine itself is 20 years old. I would not have been able to receive it, I was younger than that, so I missed the opportunity to get the vaccine myself, but I know being a cervical cancer survivor now that what if I had had that vaccine? And so, I take it as a responsibility to give my daughters that and if I had sons, it would be the same way. I can understand as I said, it is a very complicated subject. It comes into vaccination concerns and also the sexuality concerns, but really at the end of the day, it prevents 6 different types of cancers and we have a responsibility to our children to prevent that if we can and we do have this tool, why not use it.

- Chagpar Right. And I think the other thing is aside from parents do not ever think that their children will have sex, the news flash is, they will, and the other big concern is with regard to vaccines in general, and I think that there are a plethora of data to suggest that vaccines and the HPV vaccine is no different, is very safe. And so, when you talk about patient and provider education, do you provide both patients and providers with data on the fact that HPV vaccinations will not lead to autism for example and so on.
- Grove Absolutely. One of the efforts of the Connecticut Cancer Partnership is in making sure that more providers receive the You Are The Key Training, which is from the Centers for Disease Control. We have a wonderful partner in the southern part of the state who is giving these workshops and we have all gone through it, the members of the partnership have gone through it as well, and it is an opportunity for providers to learn how to have the difficult conversation and how to address any issues that might come up during a patient visit and so the next step for that, You Are The Key Training is to provide it to more dental providers. I spoke with my dentist and I said do you ever recommend the HPV vaccine, and he said oh! You know I don't, I should, I don't think about it that often, but to get that message from different locations, so if I were to bring in my say 10-year-old to the dentist and he or she brings up the HPV vaccine and talks about the 6 different types of cancers that it can prevent, and then when I go to the pediatrician the next year for the 11-year appointment, I hear it again. It is coming from different and trusted sources. It is a wonderful opportunity.
- Chagpar Right, and I think that is so critical. The other piece of education, however, and I hope that you will address this is, if you have HPV vaccines, do you still need to be screened for cancer? So, for example, do you still need a Pap smear even if you have had an HPV vaccine?

- Grove Yes, yes you do. It is just considered surveillance and it is good practice. As I said, I am a cervical cancer survivor, I still have a Pap smear regularly because the cancer might come back, the HPV might still be there, so there are different tests that are important for screening even if you get the vaccine.
- Chagpar Yes. So, importantly, remember cervical cancer, a good proportion, over 90% I think it is close to 98% are caused by HPV and we can all but eradicate these with the vaccine, but there is still that 2% and so, people still need to get that screening, which then brings us back to a conversation that we started to have before the break, which was how do you get the screening, is it covered, what if it is not covered, how do you have this conversation with your insurance company?
- Grove That is a good question. I do not know if you have the conversation with your insurance company, but you have it with your provider and you can talk about options and you can talk about different locations, where it might be possible to get this screening, similar to the colorectal screenings, there are many community clinics around the state who offer free screenings. It is very important. So, there are options out there for people.
- Chagpar And then finally, and you kind of touched a little bit on this before the break as well, tell us about the efforts that the partnership is having in terms of getting healthcare covered, not just the community resources with regard to screening but the thing about screening is that every so often you are going to find a cancer, and the great news about that is, if you have got screened, you are going to catch it early, yeah! when it is most treatable, double yeah! But that is only of benefit if you can get treatment, and so, what is the partnership doing about increasing access and affordability to cancer care throughout the state for people who cannot afford it?
- Grove Absolutely. The level of insurance coverage is directly correlated with the access to healthcare. So, we at the partnership are very interested in health disparities, making sure that various populations have access to the education about screening and what is needed and also actual access to the screening themselves. We want to make sure that we are promoting and advocating for the recommended screenings and we are doing it in the right languages, we are doing it in the right communities and then we are making sure those resources are available.

Dr. Maria Grove is the Executive Director of the Connecticut Cancer Partnership. If you have questions, the address is canceranswers@yale.edu and past editions of the program are available in audio and written form at YaleCancerCenter.org. I am Bruce Barber reminding you to tune in each week to learn more about the fight against cancer here on Connecticut Public Radio.