

Yale CANCER
CENTER
answers

WNPR Connecticut Public Radio



Hosts

Anees Chagpar MD

Associate Professor of
Surgical Oncology

Francine Foss MD

Professor of Medical
Oncology

Ovarian Cancer Awareness

Guests:

**Heather Glazer and Rachel
Hayes**

Ovarian Cancer Survivors

Yale Cancer Center Answers

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Welcome to Yale Cancer Center Answers with doctors Francine Foss and Anees Chagpar. Dr. Foss is a Professor of Medical Oncology and Dermatology, specializing in the treatment of lymphomas. Dr. Chagpar is Associate Professor of Surgical Oncology and Director of the Breast Center at Smilow Cancer Hospital at Yale-New Haven. If you would like to join the conversation, you can contact the doctors directly. The address is canceranswers@yale.edu and the phone number is 1-888-234-4YCC. This week, doctor Chagpar is joined by Rachel Hayes and Heather Glazer for a conversation about ovarian cancer awareness. Here is Anees Chagpar.

Chagpar Why don't we start off Rachel with you telling us a little bit about yourself and how you got involved with this whole concept?

Hayes I am a 32-year-old school teacher. I work in Naugatuck, Connecticut as a special education teacher and I am a mom of three kids, two boys, and a stepdaughter who is in high school and last September 2012, I was diagnosed with a rare form of ovarian cancer. I have known Heather for over 10 years and we fell out of touch and through a strange series of accumulating events we ran back in touch with each other and she ended up being one of the founders of Connecticut Women of Hope. I was able to excitingly join the group, being a survivor now it is nice to be able to reach out and help other people and to spread awareness of ovarian cancer.

Chagpar Heather, tell us a little bit about your story?

Glazer I was diagnosed in November 2010. I had a routine physical and based on that the doctor suggested I have more testing done and at that time I was told I needed a hysterectomy, but I did not have to do it right away, and I ended up waiting about six months, got a second opinion and basically was told I need to have surgery right away because it could be cancerous and lucky for me, it was stage IB, so I had to go through six rounds of chemo and in the end I have been cancer free for a year and a half now and doing really well. It is our passion to spread the word about ovarian cancer because a lot of people do not know that there is no testing for ovarian cancer. Younger and younger women are getting ovarian cancer and if it is not caught in the early stages there is only a 30% survival rate right now and we are both extremely lucky, but we want to raise awareness so we can have more survivors.

Chagpar It is absolutely compelling and shocking I think to many of our audience to hear how both of you, very young women, were diagnosed with ovarian cancer. And ovarian cancer, as you say, is one of these diseases that tends to present late, that does not have a test like a mammogram that you can do?

Hayes Its nickname is the silent killer, you will see if referred to that way, as the silent killer.

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Chagpar Tell us a little bit about how it was found in each of you and what the early signs are that people should be looking for?

Hayes I have a history of kidney stones and back in early 2012 I had some lower flank pain, abdominal pain, and I went to the emergency room and they did a CAT scan and realized I was not passing any kidney stones, but incidentally I had two small teratomas in my right ovary and according to the doctor at the emergency room, teratomas are usually benign, less than 1% come back cancerous and he made me feel very okay about having the teratomas and sent me home to follow up with my gynecologist. Two weeks later I followed up with the gynecologist and again he said there is no reason to really look at these, when you look at the internet at what a teratoma is, they call it a monster tumor in Greek terms because it usually has teeth, hair and bone fragments in the tumor, so I said I want them out. My gynecologist said, "No there is no reason to worry about them." I went off of that and he said we will have an ultrasound in three months to see if they have grown. Three months came around, I had an ultrasound and they had not grown. However, from that time to August, from maybe May to August, I was having bloating, gas problems, I was going to the bathroom quite frequently to the point where it was interfering with work and sleeping and my gynecologist gave me a pill for urinary incontinence and again I was told not to worry about these things. I was very tired and fatigued, and I was having hormonal kind of, menstrual cycle symptoms, but not on a cycle just constantly and very-very tired and I was having a lot of inflammation and it was aggravating, kind of like a connective tissue disorder, and then about two weeks later I felt a mass right above my pelvic bone and it reminded me of, for women who know what I am talking about, a certain part of pregnancy where you start feeling the baby grow and it is right above your pelvic bone, but it was off to the right and I had taken a pregnancy test and I actually had two false negatives and so I went back to the gynecologist and upon internal exam he felt that there was a mass there, two days later I went for an ultrasound and it was the size of a softball, within three weeks, again they weren't worried about cancer, but they scheduled my cystectomy to remove it and a week later, actually September 21 was the day they removed my cancer. And by the time they removed it, so about four weeks from the August CAT scan, it was the size of a small melon and they ended up taking my right ovary and right fallopian tube, and again my doctor was quite certain it was not cancer because mature teratomas are less than 1% chance of being a cancer and a week later, the dates stick in my head, September 28, my doctor told me that it was an immature teratoma and it was cancer and that I was to go and see an oncologist and a week later I was at the oncologist and it was a grade 3 tumor, and I was never appropriately staged because when they did the surgery no one had the thought of it being cancer and so I was lucky that it was stage IA, the lowest stage possible, but my tumor came back at a grade 3 which needed three rounds of chemo just as a precaution in case there were any cancer cells hiding anywhere else in my body. But really it was intuition and when I reflect on the time, something was screaming at me, my inner intuition told me something was wrong even though the doctors kept saying there wasn't, and I am glad I listened to what my intuition was trying to tell me.

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- Chagpar Because the symptoms of ovarian cancer are so nonspecific that you really do need to advocate for yourself and to say, I realize that this seems like it may be nothing, but there is something that is wrong, I just know my body and this is not right.
- Hayes Yes, like I said my doctor gave me a pill for urinary incontinence, I am 32 years old, I should not have to go to the bathroom 20 times a day, that is not okay.
- Chagpar Heather what about you, what about your story?
- Glazer Once I had gone to my primary doctor and she had me do the ultrasound and I had gone to my gynecologist who said, you should have a hysterectomy, but it is not urgent and whenever you want to have it is fine, but somewhere down the line you should have a hysterectomy.
- Chagpar Just to be clear, were you having no symptoms, whatsoever?
- Glazer No, originally the doctor felt something on my ovary when she was doing a regular exam, my primary care doctor, so at that point I was not having any symptoms and when I went to the gynecologist, you know I am married, I have two kids, I would have to take 10 weeks off from work and have surgery, so if I do not really need it right now, I was going to put it off a little bit, and then I did some research and found that you can have it done laparoscopically in less time. At that point, I started to feel very tired, like if I had a day off from work, I would want to take a nap and I was just like, "I do not know why I am so tired" is it that I am working a lot, I am married, two kids, just regular life. So I made an appointment to see another doctor and when I went to see her, unbeknownst to me, she was a gynecologist/oncologist and she said to me, "Do you have cancer?" And I said, "I do not think so, why?" And she told me she was an oncologist and she sent me for another ultrasound of the same spot on the ovary as before, and she said if it is the same, it is up to me, I do not need to have a hysterectomy right now. However, if it has grown at all, she said we need to be concerned because it could be cancerous, so I made the appointment for a week later and went to get the ultrasound and I came home from the ultrasound and she called me and said that it had almost doubled in size and I was scheduled for surgery next week, that it needs to come out right away because she was concerned it might be cancerous. So the following week I had my surgery, I had a full hysterectomy and they took lymph nodes out. She said there was a spot that looked it might be endometriosis, but she felt like it could be cancerous, we would have to wait for the pathology. Pathology came back and it was cancerous, I was staged at IB. It was a pretty aggressive tumor, so she said a lot of doctors may only have me do three rounds of chemo, but she felt we needed to be a bit more aggressive, so we did six rounds of chemo, and I have been cancer free since.
- Chagpar Wow, so in both cases this was something where, Heather you were symptom free, were living your life aside from fatigue, and it was only because of your doctor, who happened to be an oncologist as well as a gynecologist said, we are going to check this out and we are going to

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be very vigilant about the fact that cancer can and does happen in young women. And in your case, Rachel, it was that you were very persistent about following up and saying, listen this needs some attention.

Hayes I think Heather and I are both very lucky because most women do not find that they have ovarian cancer until stage III or IV and by then it is very aggressive and it has spread to other places in the body and it is a harder fight, where I felt my situation was scary, but a lot of my treatment was precautionary, and I was just very lucky.

Chagpar And both of you are fairly young, there may be people in the audience who are listening to our show tonight, who are thinking "My gosh, I always thought ovarian cancer happened in older women."

Glazer Absolutely, a lot of people think that it only happens in older women, I was 43 when I was diagnosed, I know somebody in Connecticut who was 8 years old when she was diagnosed and fortunately she is doing well now, but she had to go through chemo and everything else too. So there is no age limit in ovarian and we are trying to get the word out because I do not think that there is enough information out there about ovarian cancer and people sometimes just miss it or they are not educated. They think, I have a Pap smear that detects cervical cancer, but it does not detect ovarian cancer and I think people are confused by that.

Chagpar Are there any tests for ovarian cancer?

Hayes No screeners, I think if you are a young woman who is experiencing these symptoms, ask the doctor for an ultrasound, which would probably be the only way to really find out.

Chagpar We are going to learn a lot more about ovarian cancer right after we take a short break for a medical minute. Please stay tuned to learn more information about raising awareness of ovarian cancer with my guests Rachel Hayes and Heather Glazer.

*Medical
Minute*

This year over 200,000 Americans will be diagnosed with lung cancer and in Connecticut alone there will be over 2000 new cases. More than 85% of lung cancer diagnoses are related to smoking and quitting, even after decades of use, can significantly reduce your risk of developing lung cancer. Each day, patients with lung cancer are surviving thanks to increased access to advanced therapies and specialized care. New treatment options and surgical techniques are giving lung cancer survivors more hope than they have ever had before. Clinical trials are currently underway at federally designated comprehensive cancer centers like the one at Yale, to test innovative new treatments for lung cancer. An option for lung cancer patients in need of surgery is video-assisted thoracoscopic surgery also known as VATS procedure, which is a

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minimally invasive technique. This has been a Medial Minute. More information is available at yalecancercenter.org. You are listening to the WNPR Health Forum on the Connecticut Public Broadcasting Network.

- Chagpar Welcome back to Yale Cancer Center Answers. This is Dr. Anees Chagpar and I am joined today by my guests Rachel Hayes and Heather Glazer. We are talking about ovarian cancer and raising awareness of this disease with the 1st Annual Ann Miller 5K Walk. Heather, I want to start with you, tell us a little bit more about how this all started? Who is Ann Miller?
- Glazer Ann Miller, unfortunately, just recently passed away of ovarian cancer. She had ovarian cancer for 5 years, she was cancer free for a while and then she had reoccurrences of it and she was very vocal in the ovarian cancer community, trying to help survivors and people going through ovarian cancer. So Connecticut Women of Hope wanted to dedicate the first walk, and it is actually going to be a costume walk in her memory, and she was an animal lover, so there are going to be dogs there too. People can bring their dogs and walk. Ann was a remarkable person. After she graduated from college, she went into the military and she assisted in creating the first Rape Crisis Center in the military and then she did work in developmental health for the State of Connecticut. We want to honor her for all her work that she has done to help people with ovarian cancer and thought the walk would be a great way to do that.
- Chagpar That is fantastic. Tell me more Rachel about how this walk was organized? What is it raising money for and what does that do? I would imagine that it is certainly raising a lot of awareness about this disease.
- Hayes The primary goal is not to raise money as much as it is to raise awareness, and Heather might be able to answer this question a little better than I can as I just joined the group for my first meeting last week, and I am kind of coming in on the tail end of the preparation for the walk.
- Glazer We are trying to raise awareness definitely and any money that we raise stays in the State of Connecticut. It is going to be at Hammonasset Beach in Madison, Connecticut and again it is on the 21st, and we just really want to raise awareness for ovarian cancer. September is Ovarian Cancer Awareness Month so we feel that it is a great time to raise awareness, and teal is the color for ovarian cancer so a lot of people will be in costumes with teal representing that and the awareness is a big piece of the puzzle because a lot of people are not aware of ovarian cancer and that it is happening in younger and younger women and I think it is important to spread the word. The group is also there to help people, so if someone is going through ovarian cancer, we are a phone call away. We have a website where they can reach out to and someone from the group can speak to them and there are a lot of survivors throughout the State, and I think it helps sometimes if you are going through it that you have someone else to talk to and tell them your story because it

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is comforting to know that someone has gotten through this. I can get through this. And someone maybe has gone through the same type of chemo that you have. If someone can just be there to listen, so we are there to do that also.

- Chagpar Rachel, you had mentioned that you reconnected with Heather years later. What was it like going through your first experience with ovarian cancer at 31 to 32 years old? For most people, they are thinking, at 31 to 32 I was starting my first real job, starting to raise a family, ovarian cancer certainly must have thrown you for a bit of a loop?
- Hayes It was devastating. I have two young children. At that time they were 8 and 4, and it was very difficult for them, I think more than for me. I took my role as a mother before my role as a patient. So I was able to really say, there is no option in this, I still have my role as a mother to fulfill and I had a very supportive family. My mother was my Guardian Angel. She was there for me every moment that I could not be, for my family and losing my hair and having my kids watch that was difficult, but I felt the process really taught me a lot about myself as an individual person. Yes, I was sick and I had to go through the chemo and I lost all my hair and our family was emotionally and financially burdened, but in the end, I think I came out of it stronger and more spiritual and more tenacious in life. So in the end it was good.
- Chagpar It is remarkable to hear cancer survivors say it was good, but I find that is a common thing that people can and do get through this disease and they end up on the other side stronger?
- Hayes I do not think people realize how strong they are until they are tested. You do not know how strong you are mentally until you face chemo every day with a positive attitude. I never thought I could do that, but all I heard the whole three months of treatment was I cannot believe how positive you are. It was uplifting to other people.
- Glazer I agree and I think having a positive attitude is what got me through. My children were also young when I was going through it, they were 6 and 8 and it was difficult on them so I tried to do whatever I could to make it easier on them, my family with a huge help also for me, my daughter was a little bit older, so she understood more than my son did, but just taking it one day at a time and saying, I can do this, I can do this, and definitely you do not realize how strong you are until you have to go through chemo and you just say, I have to do this and I am going to do this and I am going to get well, and definitely a positive attitude will make it much easier.
- Chagpar And I can imagine that the Connecticut Women of Hope, that organization where women can hear the positive stories of other women must be incredibly empowering.

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- Hayes How I wished I knew about them when I was going through treatment, and wasn't until after that I was able to connect with the Connecticut Women of Hope. It would have been something I would have loved to have been able to reach out to.
- Chagpar Something else that strikes me, and we mentioned it a bit before the break, is how ovarian cancer is this silent killer and yet both of you are so vivacious and because you caught it early and because of your own persistence or your doctor's persistence in getting things checked out, the smallest symptoms, it was caught very early, tell us what your doctors told you about your prognosis?
- Hayes My cancer is graded in two ways, you have your stage and you have your grade. Being stage IA, my prognosis is excellent because of its early stage it was just located in the ovary and did not spread anywhere else but the prognosis is a little different with having a grade 3, grade 1 is not cancerous, grade 2 has both non cancerous and cancerous cells and a grade 3 tumor is mostly cancerous which would be a more aggressive tumor. The likelihood of a recurrence is a bit higher but since it was an immature teratoma, those are very responsive to chemo so if I did have a recurrence there is still an excellent chance of the chemotherapy being able to do what it needs to do and the tumor is going to react to it. So my prognosis is good.
- Chagpar Excellent. And Heather?
- Glazer My prognosis is very good and the doctor said to me even after my first round of chemo, that the surgery, the chemo wiped out the cancer and I was going to go through six rounds of chemo, and then come and see her every three months for two years. Now I go every six months and she says after three years she is going to release me to a regular gynecologist. She does not see any issues, any sign of recurrence. Luckily having ovarian cancer was the first time I had any surgery in my life, and the first time I was ever in the hospital. I recovered from the surgery very quickly and my doctor said I was very healthy, other than the cancer which was a kind of funny, but I had never been sick in my life before so I bounced back relatively quickly and she said my prognosis is excellent so I am excited about that.
- Hayes I also went a step further after my chemo and did a hysterectomy. Just as piece of mind of not having another ovary or uterus, it was what I needed to do. I already had my children, I was done having a family so we went a step further and did a full hysterectomy.
- Glazer I did the BRCA test 1 and 2 because I do have breast cancer in my family on both sides so that was something that my doctor wanted me to do because breast cancer and ovarian cancer are closely linked, so we wanted to rule that out and luckily I did not carry the gene.
- Chagpar Terrific.

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- Hayes Since I had an immature teratoma which is more of a rare type of ovarian cancer, I did not need to be tested for the BRCA.
- Chagpar That is fantastic. The themes that I am hearing here are that ovarian cancer can occur in anybody, it does not have an age limit and so if you are young you still need to be concerned about it. And also that if you catch it early, the prognosis is really good, it is not a death sentence and you can bounce back and live your life after a diagnosis of ovarian cancer. What has that been like for you? Now that you are on the other side getting back to living your life, has that been difficult?
- Hayes The most difficult part for me was that I am a school teacher, I am a special education teacher in Naugatuck and being out of work for six months, leaving my students, leaving my school, which is like another family, was hard and when I returned to school, I wasn't one to go with the wigs, I was more comfortable with the little bit of hair I had, but everywhere I went I just seemed like forever that everyone was going, how are you feeling? People constantly reacting to it. It seemed like forever before I had enough hair where I did not look like a cancer patient anymore, or I looked well enough that people just talked to me about regular life and that was the hardest part for me, going back into that role I was in before, now being such a changed person. Even though it was all for the positive, it was still hard, and every day I thought about it. I mean I am only 8 months cancer free so it is still a very new concept for me and when I go back to that third or fourth month, it was all I thought about all day, cancer, cancer, is this pain cancer, a sense of worry always that it is going to recur. Now that I am eight months it is a little better but it never really goes away, you are always somewhat changed by that, it is like a mourning process. I relate it to my husband who lost his father, you go through these series of grief and mourning, and time does heal things and makes it easier. You do not forget, but the time makes it easier. Every day I do not forget that I had to go through that and that cancer was such a life changer, but time is making it easier, I am not so worried.
- Chagpar Heather, you are further out from your diagnosis, but one of the questions that I think comes up, and to your point Rachel, when people have gone through cancer and they have lost their hair and they are getting back into society and people want to show empathy so they say, how are you? Is that helpful or is that just another reminder of, I do not look like my old self yet, how do cancer survivors feel about that? I think that your friends and family and audience members who are listening to our show want to know, how do you show empathy, is it better to integrate you back as though nothing ever happened, back to old life, or whether they should talk about that it?
- Glazer I think it is good to a point, I think you want to talk about something other than cancer all the time but for me I stayed out of work for 10 weeks, I went through my chemo while I was working so I

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had chemo, took a couple of days off and would go back to work. The routine really helped me and I think my kids, so when people would talk to me about having cancer, and say you are so stronger whatever, it was nice to hear to a point, but it was like there is more to my life than cancer.

That was Rachel Hayes with Heather Glazer. If you have questions or would like to add your comments, visit yalecancercenter.org where you can also get the podcast and find written transcripts of past programs. You are listening to the WNPR Health Forum on the Connecticut Public Broadcasting Network.