

Yale CANCER
CENTER

answers

WNPR Connecticut Public Radio



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**Survivor Perspective: Lung
Cancer**

Guest:

David Gewirtz

Lung cancer survivor

Yale Cancer Center Answers

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Welcome to Yale Cancer Center Answers with Dr. Francine Foss and Dr. 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, Anees Chagpar welcomes lung cancer survivor David Gewirtz. Here is Dr. Chagpar.

Chagpar Let's start off by you telling us a little bit about yourself and how you were diagnosed with lung cancer?

Gewirtz I have been in New Haven for almost 30 years. I spent most of my career working at Yale in technology, working on information systems, and my wife was also a local attorney. I found that I had developed cancer in the way that most people find out about it, and that is that I had another complaint and then serendipitously I found out that I actually had lung cancer. I had bad pain down my leg, and I thought it was sciatica but it was extremely bad, worse than your typical case of sciatica so I went for an MRI and from there it was all down hill, they discovered that I had broken my spine in such a way that was indicative of having some kind of neoplastic disease in the lung and sure enough they took a CAT scan and they found that there was a tumor and from there it was rather shocking because six months prior to that my brother had died of lung cancer in a matter of nine months and it just seemed too incredible that six months later I also was diagnosed. So that is how I found out.

Chagpar I cannot imagine how that must have felt.

Gewirtz Well, it was shocking and it was surreal because the cancer took my brother so quickly and he was a scientist who developed novel therapies for hematological cancers using the immune system and knew a lot about genetic profiling of tumors and there was nothing in the world that could save him. He had access to the best medical care possible and he unfortunately had a poor quality of life in his nine months of life and then six months later bam, it happened to me and I did not know as much as he did as a scientist, but I have another brother who is a cardiologist and he said to me, lung cancer is merely a label, how your disease presents may be very different than Alan's and as it turns out, it really was. I had a very treatable lung cancer where Alan had a very untreatable lung cancer.

Chagpar Tell us a little bit about what happened then, you are handed this diagnosis and it is really surreal, what were the steps that you took that got you into this treatment process?

Gewirtz As I say we had a year of understanding what goes on from I guess a testing point of view of lung cancer through my brother who actually knew a lot about molecular biology and biomarkers and things like that, that was what his work was all about. So we had some knowledge of that and

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then when I was diagnosed I asked for the same kind of treatment. And as it turns out Dr. Lorenze who operated on my spine was able to get a section of the spinal tumor that was actually a lung tumor and they were able to look for genetic markers and they found a common one in nonsmokers, and that was the epidermal growth factor receptor, or EGFR, and my brother also had that, but unlike me, my brother had it in what was called the exon 20 and I had it in exon 19, which was particularly sensitive to erlotinib or Tarceva and if it was not for that drug I think I would be gone, I do not think I would be alive, and that drug has given me a year and half of high quality of life. It has actually been one of the best years of my life and I think it demonstrated how valuable personalized medicine actually is and that stems from our understanding of disease and not from a name or location point of view, but what is going on inside the tumor on a molecular basis.

Chagpar It sounds to me like you almost struck it lucky.

Gewirtz I did.

Chagpar That you were diagnosed, but that they were able to do this molecular profiling and that there was a drug that was targeted to the mutation that you had.

Gewirtz That is a good question, and we were living in New Haven and we always knew that Yale was a Center of excellence. At Yale that was standard protocol, we did not necessarily have to tell them that, but in many-many places if you read online some of the blogs, they do not do it and they blindly give out drugs like Tarceva and if it works well it works and if it does not work it does not work, but I think that you and I would agree that is a poor way of evaluating a treatment plan for a particular patient and does nothing to advance personalized medicine. I was very fortunate to have Yale in my backyard as well as Dana Farber, MGH, and Sloan Memorial Kettering, but I did not really have to do any of that because it was in my backyard. One thing that I did do was I went to Dana Farber, because my brother knew the top scientists there and we went there for a second opinion and they said, you are in very good hands at Yale, we would not do anything different, and that was quite comforting to know.

Chagpar Tell us about your experience, I am still kind of spinning at putting myself into your shoes, your brother just passed away of lung cancer, you thought that you had sciatica, and now you have bony metastasis from a lung cancer and you are seeing a spinal surgeon who is taking out a fragment of bone and sending it for molecular profiling. Tell me about your first experience when you actually sat down with the oncologist to talk about this genetic mutation and to talk about personalized medicine, what was that like?

Gewirtz Well, I still was in a state of shock and somewhat disbelief. It was all really unreal and we were waiting desperately to get the results on that. And when we sat down with Dr. Gettinger he

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actually said, you know that we are waiting on the results, but we think given your history of being “an experimental smoker as a teenager” that it is likely you have this particular gene and that it would have a mutation where a drug will be sensitive to. I of course just did not believe anything because my perspective was my brother’s perspective because it was so close in the family that no matter what I was going to die in nine months and that there was little hope for me. Dr. Gettinger kept on saying no, no, no, you are not your brother and that allayed some of my concerns, but not many, I thought I was just destined to go and as it turns out I wasn’t, and taking a pill just made it seem even more surreal. He said, well your treatment is simply going to be some palliative radiation to the spine and then you are going to take a pill every day and I said, what? And he said, yes that is it, you have a perfect match for a targeted therapy called Tarceva and you are very-very lucky because it’s rare that people like myself have that kind of mutation. I think only 5% or 10% of people get it, particularly in males. Women get it much more frequently so I somewhat hit the jackpot, not only did I have the right biomarker, but I had the right mutation and it was just so radically different from my brother. So, I started taking this drug and this drug produces terrible rashes. I never received a rash. It was like from the day I was diagnosed after I got adjusted to it, I have been living a life that has just been perfectly normal. It is amazing.

Chagpar So, your hair did not fall out?

Gewirtz No, it did not.

Chagpar And you felt fine, you did not get a rash, you were not having terrible vomiting or all of the terrible side effects we think about when we think about chemotherapy. Did you ever wonder, is this really working?

Gewirtz Yes, you do wonder. For the first couple of months I was praying that I would get a rash and I never did and then two months later I got my first scan and there was a radical change.

Chagpar For the better.

Gewirtz For the better, but still I did not trust it, I mean how could you after two months, but it was a dramatic response to the drug and I was saying, this keeps getting weirder by the moment and actually when I was diagnosed in June and then was operated on, the Closer to Free bike ride was happening in September and I felt good enough to ride.

Chagpar Did you really?

Gewirtz Yes, two months after having my spine reconstructed in a 12-hour operation by Dr. Lorenze, I rode 25 miles in the Closer to Free bike ride. They tell me I have lung cancer, but I’m just not acting like I have lung cancer.

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Chagpar And isn't that great?

Gewirtz Yeah, it is really great. It gives you a feeling of hope, a feeling that you can live a normal life for however long and you are not stuck with, well nothing can be done for me, which I think leads to somebody cascading into a deep depression and for me it was not, it just seemed unreal, that was all.

Chagpar Tell me about your motivation to ride in that bike ride. I mean here you are, you must have felt triumphant, right? You had lung cancer, you had this surgery, but you felt great and you were going to triumph.

Gewirtz I think that was a psychological way of me triumphing over this disease, that this disease was not going to be the end of me and I was going to resume something that I really loved, which was bicycle riding and road cycling and I just said, I am doing it, and it was a way of taking control of the disease because my belief really is that what happens biologically, I really do not have much control over, I have no control over lung cancer, I really was never a smoker, I kept in good shape, why did I develop lung cancer? I do not know. Why did my brother? I do not know, and so I think that riding in the race was just a way for me to say, you know what I am going to beat this thing and I can live a normal life with this disease.

Chagpar That is so fantastic. We are going to take a break for a medical minute. Please stay tuned for more information about David's experience with lung cancer as soon as we get back.

Medical Minute

The American Cancer Society estimates that over 1000 patients will be diagnosed with melanoma in Connecticut each year. While melanoma accounts for only about 4% of skin cancer cases, it causes the most skin cancer deaths. Early detection is the key. When detected early melanoma is easily treated and highly curable and new treatment options and surgical techniques are giving melanoma survivors more hope than they have ever had before. Clinical trials are currently underway at Yale Cancer Center, Connecticut's federally designated comprehensive cancer center to test innovative new treatments for melanoma. The specialized programs of research excellence in skin cancer grant at Yale, also known as the SPORC grant will help establish national guidelines on modifying behavior and on prevention as well as identification of new drug targets. This has been a medial minute brought to you as a public service by Yale Cancer Center. 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 guest David Gewirtz. We are discussing his experience with lung cancer and just before the break David was telling us a wonderful story of how he was diagnosed with lung cancer,

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underwent a major operation on his spine and just a few months later cycled 25 miles in the Closer to Free bike ride. David, congratulations on that, it is just fantastic and I want to come back to what you were saying right before the break, which is that this was a way for you to control the disease. There are so many biologic things that you cannot control, but you can control how you respond to this disease.

Gewirtz I really believe that you can train your mind to respond to this disease in such a way that you can live a relatively normal life and not get terribly depressed over your situation and I think that takes practice and it is hard work, but it is worthwhile. It is something internal that you have to learn how to do and for example, today, yes I know I have lung cancer and it is a terrible disease, but I do not feel that, I feel happy and I really have to say that the last year and half were some of the happier days I have ever had and that just seems almost impossible, but it really is true.

Chagpar I find very much the same kinds of things with my patients who have this experience of cancer and it is transformative in their lives and I think to a certain degree they realize things about life that they had not realized before and the other part is that they understand that they can control this cancer and they are not going to let this cancer control them.

Gewirtz I think that is right. I got involved in advocacy work and that was very helpful because it is a way of fighting the disease. It is a way of giving back. I strongly believe that the Thoracic Oncology Teams take care of us, but as patients we have some kind of degree of obligation to help them and we can help them through advocacy. I got involved in the Lung Cancer Alliance in Washington. After I left Yale I worked a couple of years in Washington and so I knew my way around the town a little bit. So I got involved in the Lung Cancer Alliance and then I do not know who recommended me, but I was asked to serve on the External Advisory Board and wrote a patient's view of why this research is really important for people and also I think when you are involved in advocacy work, you are also fighting back and you are also honoring and recognizing people who simply did not make it, like my brother. So, for example, Tuesday, November 13, 2012, is National Lung Cancer Awareness month, or the beginning of that and there will be vigils all across the country honoring people who have passed away or succumbed to this disease and it also serves as a means to try to get Congress to finally pass the Lung Cancer Mortality Reduction Act which is really a frame work. It does not ask for money, it is a frame work that would lead to a 50% reduction of mortality of this disease by 2015 and I really believe that if the SPORE program is funded, which looks at lung cancer in a multidimensional collaborative way, and other institutions would also work on this disease, that it might not be so unreachable to reduce the mortality of lung cancer by 2015 through personalized medicine and understanding the biology of tumors. I am a living example of that, I would have been dead long ago had it not been for personalized medicine.

Chagpar There are so many things you touched on that I think are so important that I want to talk more about. You are quite right, I mean to think that it was one exon difference between you and your

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brother and that we have a targeted therapy for your particular mutation which was developed on the backs of so many patients who participated in clinical trials and so many researchers who did this great work. You mentioned being on the External Advisory Board in the SPORE, tell our audience a little bit about what the SPORE is and what the whole agenda of research into personalized medicine is about.

Gewirtz It stands for specialized program of research excellence and I think Yale has always been known for excellence and each SPORE has a package so to speak and in the Yale lung SPORE there are actually four projects; one will look at why people develop resistance to EGFR drugs, and why don't they work after a while? Because if the body did not have resistance then I could be maintained on this drug for life and I would have a chronic disease not a terminal disease. The other project that the SPORE is going to investigate is using different kinds of techniques to get people to stop smoking who already smoke and the other part is what my brother often thought was probably the best and that was to use the immune system as a means of having cancer cells seen as foreign bodies and having the immune system do what it does best to kill them, and finally, for people who have very difficult cancers to treat, to say that scientists really do not understand the signaling that causes a cancer cell to divide, they are going to develop something with something called micro RNAs, and I am not really an expert on that. I know what it stands for but that would have been something that my brother Alan who did not respond to anything might try and so it is those four areas which cut across the spectrum of lung cancer that they will be looking at. And for me, obviously understanding why people develop resistance to the EFGR mutation is really important to me, very important to me.

Chagpar It sounds like it is such a fascinating portfolio of research and you can really see how this makes a difference to you and to a lot of people who either have lung cancer or will develop lung cancer and how finding those answers could affect mortality.

Gewirtz It definitely would reduce mortality and I think one of the things that has been debated for a long time, but there seems to be some evidence now, is that in high-risk people, CT scans, low dose CT scans according to the New England Journal of Medicine, actually do save lives and so if you can find the cohort and screen them, not only will you be saving lives, but the cost of treatment would be significantly less because although I do not pay for my drug, my drug actually costs about 30,000 dollars a month which is unaffordable to most people, unless they have insurance. I am lucky in that way and with screening, the ironic thing is that I wouldn't be a candidate for screening. I was not a smoker. I was in relatively good health. My mother actually died of lung cancer but at 90 after smoking for 70 years.

Chagpar I guess it goes to the whole concept that lung cancer is such a multifactorial disease and that it

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really is not always just about smoking, although smoking certainly plays a role for many people, but for some people they can be nonsmokers and they can have mutations and this is why this personalized medicine approach is so important.

Gewirtz And I think that the SPORE, what they learn through the SPORE will inform other types of cancers. For example, the EGFR gene and mutations in that gene are not only helpful with lung cancer, they are also used with pancreatic cancer. So my thought is that over time personalized medicine, or medicine that relies on biomarkers, will kind of change the focus whether or not you have lung cancer, or some other cancer, that location will play less and less of an importance and it is all going to be all about the molecular biology of the tumor and I have to believe, and it is just an assumption, that there are going to be similarities there and that we will be able to build off of those similarities so that better drugs can be developed to treat multiple kinds of cancer at different organ sites.

Chagpar I think you are right. You know, one of the things that I think is fascinating is how proactive you were, I mean, you got involved in an External Advisory Board, you were in Washington doing advocacy. How did you get involved with all of that? I can imagine that there are lung cancer survivors and other kinds of cancer survivors or families or friends who want to do something but just do not know how to start, or where to go.

Gewirtz I think the best thing to do, and it's how I went through all of this is I joined the support group at Yale run by Irene Scanlon and Linda David, and it was through going to that support group that I learned about these organizations and how people advocated in the past and I made a personal decision really, I did not have to work so I felt that it would be meaningful to my life to get involved in doing advocacy work because I felt strongly that research dollars for lung cancer are not balanced and the squeaky wheel gets oiled, and so the more we make people aware of lung cancer in our community and the nation, the more likely the government would be to fund more SPORE programs and it became a passion for me, and hopefully for other people because that is what is really needed, particularly in a tight market where the economy is making it very difficult for scientists to pursue their work. So they need all the help they can get and I would like to see a group like Komen is for breast cancer, for lung cancer, that raises enormous amounts of money. I would like to see that done for lung cancer.

Chagpar And Komen was started with one patient and her sister who said, let's do something about breast cancer and let's make a promise that we are going to move it forward. During the break you were telling me that was one of the things that you talked about in your section for the External Advisory Board.

Gewirtz Yeah, I think that is really necessary. It is needed. It is a real obligation on our part to raise as much money as we can for the science. I actually called it a pledge, that we would pledge

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to be advocates for our oncology team and I think that is a motivator and there are a lot of people who actually do that and I am pleased about that.

David Gewirtz is a lung cancer survivor. 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.