Janet Brown, A Survivor's Prospective: Lung Cancer January 2, 2011Welcome to Yale Cancer Center Answers with Dr. Francine Foss and Dr. Lynn Wilson, I am Bruce Barber. Dr. Foss is a Professor of Medical Oncology and Dermatology specializing in the treatment of lymphomas. Dr. Wilson is a Professor of Therapeutic Radiology and an expert in the use of radiation to treat lung cancers and cutaneous lymphomas. If you would like to join the conversation, you can contact the doctors directly. The address is canceranswers@yale.edu andthe phone number is 1888-234-4YCC. This evening we continue our series of survivor stories with guest host Peter Lamothe who is a cancer survivor himself and Peter is joined this week by fellow survivor Janet Brown.Lamothe It is terrific to have you with us and I thought we could begin by first talking a little bit about who you are and about your background before we get into your cancer experience.Brown My name is Janet and I live in Old Saybrook. I was 48 when I was diagnosed and I am almost 52 now. I have three children in their early 20s and I have been married to my high school sweetheart for 28 years. Before my diagnosis I was a preschool teacher with a degree in special education, but I was teaching preschool in Old Saybrook.Lamothe Let's talk a little about the last four years beginning with your diagnosis.Brown I have stage IV non-small cell adenocarcinoma lung cancer. It started in my right lung and spread to 3 spots on my spine and to the pons area of my brain.Lamothe When was this exactly?Brown I was diagnosed on December 22, 2006.Lamothe What was your initial reaction when you got this news?Brown That is a hard thing to bring back to my memory, because it was such a horrible, horrible experience. I was all alone when I was told. It came totally out of the blue. I had always thought I might have cancer at some point in my life because my grandmother did, as did my mother and my aunt, but I never thought lung cancer at 48 years old. The whole world went black, I could not breathe, I could not talk. I just kept running to throw up. I just wanted to die right that second, I kept thinking I cannot do this to my children and a million emotions all flooded in.Lamothe Where were you when this happened, were you in the clinic with your doctor?Brown I was in an emergency room. What had happened was I had gone to my GP because I had back pain and she sent me in for an MRI and CT scan and then called me up a couple of hours later and3:13 into mp3 file http://yalecancercenter.org/podcast/jan0211-cancer-answers-brown.mp3 said I want you to go meet a neurological doctor and to meet him at the emergency room. She did not tell me why. I got to the emergency room and they started asking a million questions and they kept saying, do you smoke? Do you work in a toxic environment? And finally I said, why am I here? And the doctor just blurted out, "you have lung cancer" and so that's how I found out.Lamothe What did you do next with that information, you went home and told your husband?Brown Well it was pretty bad in my spine, the spots, and my spine was compromised. My husband was in the waiting room. They had not let him in. So the first thing I said was, "can you please go get my husband?" He came in and they wanted to admit me. So we talked to the doctor. He said "you need to be admitted, your spine is very compromised." Then I said, is this fast, is lung cancer fast, am I going to be gone in a few months? He said not a few months, maybe a year and I said to him, ”so you are telling me this will be my last Christmas?” And he said that was very likely so I said I am not spending it in the hospital. We checked ourselves out, went home and did not tell anybody, made it through Christmas and went back to the hospital the day after Christmas and spent the week.Lamothe Who did you meet with and what were some of the next steps that occurred because it was so aggressive?Brown I originally met with a neurological doctor. He was originally going to do surgery on my spine, take out the tumors and fuse my spine together. Then they found it in my brain, I had more CAT scans, more MRIs, more x-rays and they found that it has spread to my brain. So the plan changed. Instead, they just did a biopsy and scheduled me for radiation because they wanted to get the treatment as soon as possible, so I was there about a week.Lamothe Can you tell us about the type of treatments that you received over the course of the ensuing three months?Brown I started with radiation on January 2, 2007, I did not start at Yale, I started over at Saint Raphael's. Radiation lasted until February 15. I had radiation to my spine and to my brain. On February 15, I moved over to Yale and started on a drug call Tarceva, which is an oral chemotherapy drug. I have been on that since and then every three months now, it was every month, I have an infusion of Zometa, which is a calcium supplement.Lamothe Can you say little bit more about Tarceva, and why that particular drug was selected for you?Brown Tarceva was selected for me, thankfully, because I came to Yale. Yale was my second opinion,6:15 into mp3 file http://yalecancercenter.org/podcast/jan0211-cancer-answers-brown.mp3 Dr. Scott Gettinger was my second opinion and when I came to see him he asked if I had been tested for the EGFR mutation, and I hadn't. So he tested my biopsy and I have a mutation on my genes that the drug Tarceva works especially well with. So instead of going through the regular chemoinfusion, I went right to the Tarceva.Lamothe So after your diagnosis you were told that this was stage IV that you might not see a second Christmas, and that time was of the essence and yet you went and had a second opinion. What drove that decision?Brown I hate to sound curt but it seems like no-brainer. I was given a diagnosis that I had an incurable disease and it was going to kill me. I had never met this man before, this first oncologist, why would I trust him with my life? It only seems sensible to go speak to somebody else. My sister happens to work at Yale, so she got me an appointment with Dr. Gettinger and I also went down to Sloan-Kettering and had an appointment with them and they agreed with Dr. Gettinger's plan of action. So I stayed here at Yale and I think you just know when you are not clicking with a doctor, and my first oncologist pretty much just said, this is the treatment plan I do with my patients. Dr. Gettinger said, this is the treatment plan I am going to do with you as an individual and I just really appreciated that.Lamothe With these targeted therapies, the Tarceva drug you are taking for the EGFR mutation, this is really treating your cancer and not just stage IV lung cancer.Brown It is treating my cancer with my mutation and there are more targeted therapies coming out. I have some friends online that are getting different targeted therapies that are treating their mutations. More things are being developed all the time.Lamothe Had you heard of targeted therapies before, or gene mutations?Brown I thought you got cancer, you did chemo.Lamothe Right.Brown That is what I thought happened.Lamothe I think the trends now are towards personalized cancer therapies so that you are not among only a group of lung cancer patents, but that your lung cancer is being treated in a personalized way that is specific to you.Brown And the success is just wonderful.9:07 into mp3 file http://yalecancercenter.org/podcast/jan0211-cancer-answers-brown.mp3Lamothe Can you say a little bit about the effects of Tarceva and what began happening over the ensuing weeks or months?Brown There is no sign of cancer progression and so it is pretty much stopped the growth. It has some lovely side effects that I have learned to live with. You think you are just taking a little pill and I look at it every night and I think, how can this little pill be stopping the cancer? But it seems to be. I lost my hair. It gives you a terrible rash that happened on my scalp and caused my hair to fall out. It gives you conjunctivitis like symptoms on your eyes, sores on your nail beds and pretty much constant diarrhea, so it is not an easy drug. I think it is much easier than traditional chemo, but it does have side effects. When people ask me how I am feeling, the cancer I could completely forget about, it is the side effect from the Tarceva that make you remember that you are sick.Lamothe This type of diagnosis and what you have gone through must be particularly difficult for you, but I imagine this is very difficult for your family and for your children.Brown I am not a father so I can't say, but I know the first thing that comes to a mother's mind is her children. I lost my mother when I was in my early 30s so the thought of my children losing their mother when they were in their early 20s was devastating. I just kept thinking, how can I do this to them I am ruining their lives and it has been very hard. They are very strong kids and we have decided to laugh about it and joke about it and some people are a little part put off by us, but it is the way we get through. They have been very strong and very supportive, but I still really worry. My oldest daughter is in Boston, she has got a career. I do not want her to have to stop that to come and take care of me as things get bad. My middle child just started medical school, I mean the last thing she needs is the stress of her mother, and my son is just about to graduate college, so it is very difficult. They are not at the point where I feel they are settled and they still need their mother, so I need to survive.Lamothe You do not ever stop being a mother. How have you individually, and perhaps with your husband and then your kids too, begun to maybe live your life a little bit differently since this diagnosis?Brown I think I live much differently. I did stop working. I taught 3 year olds and that is exhausting for any 50-year-old, for a 50-year-old on Tarceva it was really exhausting. So I did stop working. I wanted to be able to have the time and the energy to spend with my husband. He comes home for lunch everyday. I would like to be there. I wanted to be able to visit with my kids, so I did stop working. I have started volunteering so I am busy, but on my own terms. I am much more patient with people because I realize you never know what somebody is going through. If a cashier is grumpy at me, I do not grump at her, I just kind of let it go and I really live each day. I am not climbing mountains and I am not bungee jumping or traveling the world, but everyday, even if I do not leave my house, I live and I enjoy it and I enjoy all the little things and as a family we have13:09 into mp3 file http://yalecancercenter.org/podcast/jan0211-cancer-answers-brown.mp3 become much closer. It is odd to say, but it has really been a blessing and we have become a very close group of 5.Lamothe It sounds like you had always lived a very full life and have blessings in life and we know that a cancer diagnosis affects more than just the patient and their family, but also their friends and in many cases, the community. Can you say a little about how your friends and neighbors, people you have known for your entire life, took this news and how they responded?Brown Friends are amazing and immediately meals started coming in, people were cleaning my house, people were coming by with a glass of wine just to chat. My friends have really been behind me and supportive of me. My church has been behind me. The nursery school where I worked sent us on a cruise. I mean people been really kind. Some people have backed off and some people do not know how to deal with it and I totally understand that, sickness is hard, so you can understand that but they have been wonderful. Everybody has been truly wonderful.Lamothe We are going to take a short break now for a medical minute. Please stay tuned to hear more about Janet Brown's Story.Lamothe Welcome back to Yale Cancer Center Answers. I am Peter Lamothe and I am joined today by Janet Brown and we are discussing her story of cancer survivorship. Janet, before the break we were talking a little bit about how your close friends and family responded to your cancer and in the public at large, I think it is safe to say, that there is a certain stigma attached to a lung cancer diagnosis and I think there is a lot that we can say about that.16:20 into mp3 file http://yalecancercenter.org/podcast/jan0211-cancer-answers-brown.mp3Brown Lung cancer is a cancer where it is very hard to tell people what you have because the reaction is not usually hugs and warm fuzzies. 95% of the people who I have told I have lung cancer, the first words out of their mouth are, do you smoke? And that is a really harsh question for a couple of reasons. First of all, what does it matter? And if I said yes, what would your answer be, what would your response be? I did not smoke, but even people who do smoke do not deserve lung cancer. Nobody deserves that and because it has got this negative stigma and people seem to feel that you brought it on yourself it does not get the funding that it deserves. It is the biggest cancer killer that kills more people every year than breast, prostate, colon, and pancreatic cancer combined, and yet it gets a really small fraction of the funding. The money that it raises usually gets put towards smoking cessation programs instead of research. Tarceva was discovered with research dollars and we need more research dollars to find more targeted therapies so the negative stigma is very hard and it is hard to have a cancer that people have no sympathy for.Lamothe Why do you think that stigma exists?Brown In one way I think it's the media and you know cigarettes are bad, and in another way it makes people feel safe to think it's cigarettes.Lamothe Smoking cessation is important, but it's the research into the disease after it affects people, you are saying, is so critical and is being short changed.Brown Maybe 65% of the people who are newly diagnosed with a lung cancer never smoked at all, or quit smoking decades ago, so even though it is important to stop smoking from many reasons, not just cancer but for your heart, for your general health, stopping smoking is not going to stop lung cancer, it is happening whether you are a smoker or not.Lamothe There are many-many environmental factors, genetic factors as you have said with the EGFR mutation, that can effect this. During the course of this journey that you have been on, have you reached out to or joined support groups, have you come into contact with other cancer patients whether they be lung or another cancer, and if you have, how has that helped?Brown When I was first sent home with the radiation and everything I got on the computer and I joined an online support group through a group called LUNGevity and it is a kind of support group where you can send questions and everybody who has experience would answer that and there is also just the chat room where we just chat and I have met some very good friends through that. It got very difficult for me because I also lost some very good friends through that. And then on Facebook I have become friends with cancer survivors and caregivers that I found through Facebook or groups. When I first started at Yale, Irene Scanlon who runs the Lung Cancer Support Group at Yale, came up to me after every appointment and said, I just want to let you know that we have a20:13 into mp3 file http://yalecancercenter.org/podcast/jan0211-cancer-answers-brown.mp3 support group, she always said it very gently and I always very politely said no thank you. I did not think that that would be for me, face to face talking with people, I thought it would be too awkward, but after losing quite a few friends on the online group and with all the worries going through my head about my children and the guilt about leaving work and not helping out with the family finances and feeling very, very alone, I finally joined at the beginning of the summer.Lamothe What has that experience been like for you?Brown It is wonderful. It is a wonderful group of people. It is not at all what I expected. There are probably 20 of us, survivors and caregivers, and everybody is there to help each other. We laugh a lot, we cry some, it is wonderful to have somebody verify what you have been thinking. You will think that you are the only one that thinks that way and somebody will come out and say it at support group, and it is just a good feeling. With the side effects from the Tarceva, there are other people there that are on the same drug. We help each other out. We give each other names of doctors and drugs that we have tried. We just were interviewed by a journalist from the New Haven Register and she was shocked when she came in. I think she expected to see a group of sad faced people and she walked in and we were all just laughing and having a nice time with each other.Lamothe Now that you have lived with this disease for a few years, it sounds to me that you have moved through or beyond just dealing with and focusing on it, to reaching out to other people for help and now it sounds like you are giving help. Have you got into any advocacy or fundraising or things like that in lung cancer?Brown No, I really have not. My daughter and I walked in the Boston Lung Cancer Walk in November and that is the first thing I have done. Most of it has been just helping people on the support lines and being in a support group, but I really have not got into any of that yet.Lamothe In your support group, have you found yourself giving advice and comforting other people?Brown Certainly, when new people come into the support group or on the online group, they are so lost, and you remember that. You remember how scared you were and so it is important to tell them that it gets better and it is hard for them to believe that and we give them advice, what to do when they go to a doctor's appointment, what to ask, and just to let them know that here I am, it is four years later, it can happen.Lamothe In my definition of survivorship, it is from the moment of diagnosis, and also includes those people who are closest to them. With my own case of Hodgkin's disease almost five years ago, I think my wife and son and many of my family members survived that cancer too, so thinking 24:07 into mp3 file http://yalecancercenter.org/podcast/jan0211-cancer-answers-brown.mp3 across the cancer disease spectrum, what would you say to that cancer survivorship community based on your own experience? What types of tips or suggestions for dealing, or not dealing because sometimes it is better to shut it down if you have to in the cancer experience, would you give?Brown For the patient, I think I would say you are not used to doing it, but you have to put yourself first, stick up for yourself, do not give up hope. Do everything you can and research, bring people with you to the doctor's appointments, that is so important because the doctor is throwing terms at you and numbers and to have somebody there with a pen and pencil writing it all down is great. When people offer help, take the help. It felt really funny at first, but someone reminded me that that is a gift to them, they do not know what else to do and you are helping them out by accepting it, accept the help, take care of yourself. When you need a nap, take your nap, when you do not feel up to going to a party or doing what is supposed to be done that day, do not do it, put yourself first. For the family, it is hard, but they have to take care of themselves too and they cannot live their life around your disease. I know that it is very hard for them but they have to remember to take care of themselves and not let themselves get worn down worrying and to live their lives.Lamothe For patients, talking about their cancer when they are able to is very therapeutic, and you sound like you have always been, if not at least talking about it, it has not been something that you have been unable to talk about, but what always strikes me as interesting is what other peoples say to you about your cancer, or cancer in general, and I will not bore you with some of the things that I heard, but I think what was most meaningful to me was what people closest to me had to say. My son was not old enough when I was diagnosed first to have a conversation about it, but we have in the intervening years, and my wife and my family as well, I am just curious to say a little bit about what you have heard from your children and what it may have taught you about them or how you raised them.Brown My children all have reacted very differently, and when I have first diagnosed my son could not even get out of bed, and now I find out that he talks with his friends. His friends write to me now to offer support or something they have read. He calls them with the good news if I had a good report, so that just makes me feel so good. My oldest daughter has always been the one who needed me the most, and when I was first diagnosed that got even stronger where she could not leave my side, and that was frightening to me, but she has grown so much and I know she can do this now and she still has a hard time talking about it. She does not like to talk about it, but she will, and then my middle daughter, and people who know her will be surprised because she seems very fun loving and easy going, is the sensible child and she has started medical school and we talk about it all the time and I actually call her up and ask her to tell me exactly what the Tarceva is doing and she will explain it to me and I think it is wonderful that she is doing this because I think28:35 into mp3 file http://yalecancercenter.org/podcast/jan0211-cancer-answers-brown.mp3 she will be a huge comfort to her brother and sister if things get bad. She will be able to explain things to them and it will be good.Lamothe We talked a little bit about changing perspective in your life and your are living with the disease now, but my question is, you seem to me a person who has boundless energy and optimism and it would not strike me, even though we have only known each other for a little while, as unusual that you have a long term plan for life, and I am just curious as to how you look at the rest of your life in front of you and what you want to accomplish and whether cancer will always be a part of your life.Brown I have strong faith, and when I got cancer I said to God, I need to see my children settled. And what I meant by that is I want to see them married, I want to see grandchildren, but I am not going to ask for all that because I know not to ask for too much. I wanted to see my son graduate high school, and he graduates college in May, and I tell everybody I am going to be the loudest mother at that ceremony, but I want to see my children settled and then as little things happen in life, the recession and the breakups with long-term boyfriends, I say okay this is good, things are a little unsettled, it will keep me alive longer, so I don't plan on going any place soon. I am having too much fun and I have things to do and I have always wanted to be a grandmother and my children have no intention of making that happen anytime soon, so I am sticking around.Janet Brown and Peter Lamothe are cancer survivors. If you have questions or would like to share your comments, visit to yalecancercenter.org where you can also subscribe to our podcast and find written transcripts of past programs. I am Bruce Barber and you are listening to the WNPR Health Forum on the Connecticut Public Broadcasting Network.