

Paul Buchanan, A Survivor's Perspective: Melanoma December 26, 2010 Welcome to Yale Cancer Center Answers with doctors Francine Foss and 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 and the phone number is 1-888-234-4YCC. This evening, we continue our series of survivor stories with guest-host Peter Lamothe, a cancer survivor himself. Peter's guest this week is Paul Buchanan who was diagnosed twice with melanoma. Lamothe Let's get started by having you tell us a little bit about your cancer diagnosis? Buchanan My original diagnosis, and I have been diagnosed with melanoma twice, happened just over 15 years ago actually. I was just shy of 35 and I had what I thought was a mark on the back of my leg and I did not really think too much about it, I thought it was a wart actually. Finally, I ended up going to a dermatologist and had it taken off, did not really think anything about it, did not know anything about melanoma, had no concerns about it whatsoever, received a call a couple days later informing me that it was melanoma. I really did not have a clue as to what melanoma was at that point. I do not think it was as prevalent or as advertised then as it is today. It was a bit of a surprise. I called one of my brothers and said, is melanoma a bad thing? And he was like, are you kidding, it is definitely not a good thing. Lamothe And where were you living at that time? Buchanan I was living in White Plains, New York. Lamothe And you had family there? Buchanan Yes, that's where I grew up, my whole family was there. Lamothe What was your initial reaction when you got this news, besides calling your brother? Buchanan Lack of information was big. I really knew nothing about it. I had people calling me within days of my diagnosis telling me what they had read on the Internet and I went on and looked at some stuff and I found out pretty quickly that I did not want to look at the Internet to see what melanoma was all about, because being diagnosed with melanoma, the prognosis was not very good, and it was probably worse 15 years ago than it is today. Lamothe Right! Buchanan It was a shock. I had been married for about two years at this point and I still did not have any children, I still had a lot to live for and was not really appreciative of being diagnosed with it. 2:40 into mp3 file <http://yalecancercenter.org/podcast/dec2610-cancer-answers-buchanan.mp3> Lamothe When cancer patients are diagnosed, they often are surprised just like you were, but after learning a little bit about the disease, they learn that there are some signs that appear before diagnosis, was there anything that you were able to connect dots in the months leading up to and after the diagnosis? Buchanan No, it was the fact that underneath that wart, was a mole. It was something I should have had taken care of probably two years before. It had grown to the point where it had grown deeper into the skin and the chance that it had metastasized to my lymph nodes, was pretty high. Lamothe What were the next steps that you took after the diagnosis? Buchanan Besides the panic, I immediately, the next morning, called my doctor, my family doc-

tor that I had gone to for a number of years. He recommended a surgeon in White Plains. So I went to Dr. Gordon, a great man, he did the surgery and ended up finding out that the cancer had spread to a couple lymph nodes in my groin, and then he immediately recommended I go down and talk to folks at Sloan-Kettering and also at NYU, because they were both currently running experimental programs. I ended up going to Sloan-Kettering. The program was not currently running. They were going to start it up again in January, this was September now, and they were running their program starting it in January. He did not give me a very good prognosis either. I wanted to know what my chances of survival were and he was very blunt. He told me to get my affairs in order, and I probably did not have more than a year to live. I went down and visited Dr. Oratz down at NYU and they had a program running and I asked the same question, not that I had any other options at this point, but I answered the same question, and she felt that I had better than 50-50 chance of survival. Lamothe So you went from getting your affairs in order, 50-50 survival, to being here now, many years later, talking to us. What happened next, what type of treatments did you receive, what was the course? Buchanan It was an experimental program that they were running and I do not know what the protocol was called, but I had to go down about every three weeks, twice a week during that period, two successive days, one to get injected in four different locations on my body, just simple pricks under the skin with an injection of a vaccine that they were working on that they thought would help, and then I had to go down the next day to see what happened with the treatment. They did some measurements on the spot to see where it was. I went through that protocol for almost five years, four-and-a-half years actually, and at the four-and-a-half year mark, the FDA actually pulled the program. So I never really knew, and I was in the blind test, and so I did not know if I was getting the vaccine or if I was not getting the vaccine. After about a year or so, I called down there and actually spoke to the woman who always checked me every morning and she said, Paul you were definitely getting it, I can just tell, but I never heard officially from anybody but I was very fortunate. I never had another sign of the cancer after that. There had been no spread on any6:07 into mp3 file <http://yalecancercenter.org/podcast/dec2610-cancer-answers-buchanan.mp3> subsequent exams, scans, nothing for nine-and-a-half years. Lamothe So after the diagnosis, your treatments begin, last a considerable period of time, and at the same time you wanted to be living life as normally as you could, can you say a little bit about how you got on with your life? Buchanan In the beginning it was hard, being, as I said, relatively young I did not have any children, married for two years, trying to be strong for my wife, for my mother, my brothers, my family, I probably internalized a lot of stuff. I was a sales guy on the road a lot and I found that I did a lot of my thinking, and a lot of my crying about it, when I was by myself, but over the course of time, as the years went on, time went on, I never forgot about it, never could because it was part of my life, but I moved on. It was still there, I still went religiously every six months and then every year after five years for my scans and again never had a sign, never had an issue, never had a prob-

lem.Lamothe What did you tell your family and how do you think it affected them? You did a lot of thinking and crying on your own but what do you think their response was?Buchanan My mom was a nurse for 40 years and she knew what the disease was all about and I am sure she did not think I was going to make it through it. She always kept telling me, God only takes the good people Paul, you do not have to worry about it, and it is like, thanks mom! I think everybody just kind of waits and holds their breath. I did not have any other outward signs, nothing had ever happened again. It was not as if every few months they were taking stuff off of me and discovering things on scans. My life went on. It had to go on. I tend not to be the type of person that looks back. I like to look ahead to things that are going to come.Lamothe Then after this you began to have a family and get on with your career?Buchanan We actually put it off. After the initial diagnosis, we had been trying, but when I was diagnosed we decided we would just wait, and we waited a couple of years to make sure everything was okay, and then we moved forward.Lamothe And how old are your kids now?Buchanan My daughter is 10 and my son is 8.Lamothe That is terrific! I know that you are a member of the Melanoma Support Group at Yale and I want to talk a little bit about that, how did you get involved with that?Buchanan I am trying to think back to when it was. I think Dr. Sznol had mentioned it to me that they were looking at putting a group together, and whether or not I would be interested in getting involved, and I definitely was. I was one of the charter members and had gone to a number of the initial9:15 into mp3 file <http://yalecancercenter.org/podcast/dec2610-cancer-answers-buchanan.mp3> meetings. It is a group where survivors and spouses, or significant others, come together to sit and talk. Whether it is to openly discuss what issues you had, what problems you had, what you were going through, or to see what other people's experiences were, or even sit back and talk about other programs that are going on whether it is at Yale, the NIH, or the University of Pittsburgh.Lamothe Did your wife attend with you?Buchanan No. My kids are relatively young and this is something that they start at 6 o'clock, I believe it is, and runs until whenever it is really over. So that is time for my kids to get down to either doing homework or getting ready for bed. They have it on Thursday nights.Lamothe How do you feel that it benefitted you, personally?Buchanan I have never had any issues talking about my disease and what has happened in my life. I have always felt that the more I get it out, maybe if I can help one person, it would be worth it. I went there to help other people more than anything else. My wife thinks I am crazy, but this one I did not really internalize, this last time I was diagnosed for the second time. I just felt I needed to talk about it from the onset and I did not internalize it and I was very open and fair with my feelings and letting people know and see it.Lamothe I think that cancer survivors would agree that giving back, the obligation of the cure is something you hear sometimes, to those people who are going through cancer or who are having a difficult time in survivorship is important. What do you think that through this group you were able to bring to individuals that were having a difficult time or facing a somewhat uncertain future, trying to make sense of the trauma that had visited

their lives. Buchanan When people look at melanoma and they read everything about it on the Internet, the prognosis usually is not very good and whether it is me or some of the other folks that are in the group, being survivors not just a year or two years, but long-term survivors, I think helps them look at us and say, okay, I have hope. That is the big thing. Lamothe Dr. Mario Sznol is the Co-Director of the Melanoma Program at Yale. So he sees patients and also conducts research in the disease. How did you get hooked in with him? Buchanan By luck. I was actually going to see a Dr. Tansino at Mid-State, and he had recommended Dr. Sznol the second time that I had been diagnosed but for some reason, whether it was my insurance, there was something going on, but he just could not get the appointment with him for me, and then lo and behold when I became deathly ill, we were able to get the appointment with him and came down and saw him. Lamothe And when was that? 12:16 into mp3 file <http://yalecancercenter.org/podcast/dec2610-cancer-answers-buchanan.mp3> Buchanan That was in September of 2005. Lamothe How much time had elapsed between the first diagnosis and the second? Buchanan It was right at 10 years. Lamothe What did you think when you were told the second time? Buchanan When I was initially told I had a tumor that developed in leg, I went through my scans, nothing popped up, I did not really think it was much of anything, had the lump taken out in the same leg that I had the original one, and it came back full-blown melanoma. I never really went into a panic thing, I just said, you know what, my immune system has been good over the last 10 years; I will beat this, I am confident I am going to beat it. I will see what I need to go through, what kind of protocols they are going to put me through, but it rocked me. I was at a sales meeting one week giving a presentation and that following Monday I could barely get out of bed, and the following Tuesday I was down at Yale, almost two weeks after that sales meeting, I was down at Yale barely able to walk or talk. Lamothe What did you tell your kids? By this point you had two children? Buchanan They were young, three and six actually, and my son's birthday was coming up. They did not really know what was going on. The original sign that there was a problem was I had some real pain in my back, serious pain in my back, so I went through chiropractic care and physical therapy, and they just thought it was my back. Lamothe So they just thought dad was in some pain, he was not very, very sick. Buchanan Yeah, we were not going to spring that on them, and it was not until a couple of years ago at Relay for Life which I have been involved in with since my last diagnosis, and I was wearing the purple shirt and my daughter kind of looks at me and goes, "Why are you wearing a purple shirt daddy?" I said, "Well, I have been diagnosed with cancer twice," and she just was dumbfounded. She was shocked, and my son was there and he said, "Really?" And I was like "Yeah." So we talked a little bit about it, what the realities of it were. Lamothe Wow! That is very powerful. Let us come back to that after we take a break. We are going to take a short break now for a medical minute. Please, stay tuned to hear more about Paul Buchanan's story of survivorship. Lamothe Welcome back to Yale Cancer Center Answers. This is Peter Lamothe and I am joined today by Paul Buchanan and we are discussing his story of survivorship. Paul, before

the break we got into the beginning of your second diagnosis, and how you came to know Dr. Mario Sznol at Yale. Can you say a little bit more about what the next steps were after this second diagnosis and what happened? Buchanan I became sick very quickly. It was pretty dramatic. Over a two-week span I went from being at a sales meeting, giving a presentation, to being at a point where two weeks later I was at Yale seeing Dr. Sznol, and he put me in the hospital that day. I had become so sick. I could barely talk. When I walked I shuffled my feet, and that was the best I could do, I could not really lift my feet, and he saw me and just kind of looked at me at one point and said, we are putting you in today because I want to treat you, but you are not strong enough to be treated. We need to get you stronger. They put me into Yale for, I think that was Tuesday and they let me out on Saturday and their whole thing was to see if they could get me strong enough to go through with the Interleukin-2 treatment. I do not think Dr. Sznol thought I was going to be strong enough to do it. I think my guardian angel at that point was Dr. Kluger. She came in, she had young children, and she had seen my children and she looks at me and says, we are going to treat you, I have made the decision and we are going to treat you, I just have to go up and tell Dr. Sznol, and it was really because of her that I went through the IL-2 treatment. As I found out later from Dr. Sznol, their choices were not too many for me. It was either IL-2 or put me into a hospice and because they did not think that I would be strong enough for the IL-2, he was leaning toward hospice. Lamothe What was done to get you stronger so you could have the IL-2? Buchanan Just get fluids into me, get fluids into me more than anything. I had become so dehydrated. I really was not eating anything. They kept checking just to make sure I was strong in my feet, my arms, it was kind of surreal. Lamothe So you had a team of people here at Yale working with you? Buchanan Yeah, they were awesome. 18:00 into mp3 file <http://yalecancercenter.org/podcast/dec2610-cancer-answers-buchanan.mp3> Lamothe So you went on IL-2 and what happened? Buchanan It was pretty amazing. I felt like it was working almost right away. Lamothe How did you know that? Buchanan The lump that they had taken out of my thigh a couple of months earlier had come back. It had grown pretty significantly again and I was in bed, it was probably after my first or second treatment of IL-2, and I just kind of reached down to my thigh and it felt like it had gotten smaller. I had some swelling, things that happen because of the treatment, but it just felt like it was smaller. I will never forget, Dr. Tansino is the doctor from up at Mid-State, and he came into my room on rounds one morning and he just had a sad look on his face when he looked at me. I have seen him for about five years and I said, doc, I think it is working, and you could just see the doubt in his mind and I said, I am telling you, this lump is getting smaller, I think it is working. Nobody believed me, nobody could. They were still going through scans, still doing some stuff and they saw the cancer was in my bone marrow. There was cancer on the spine, I was basically a mess, and then I got stronger over the course of time, and I guess it was after my next round of treatments which was probably late November, and I looked at Dr. Sznol and said, I want to go through some physical therapy and he kind of looked at

me like, you want what? I said, I have lost all my muscle, there is nothing left of me, I had lost 50 pounds, so I ended up doing it for a month, then had to go back in for treatment again. Lamothe So were you a physically fit, physically active guy before these two episodes? Buchanan I was when I was younger, more so, but it was just something I knew I had to do for myself. It was a choice, go home and lie in bed, or get out of bed and go do something. Lamothe I think that many cancer patients and survivors who are listening to us are probably nodding their head saying, you know, I could tell when it was working too, and it is hard for doctors, I think they are of the mindset that they should be cautious and that is great, it is good for us, but you know your body and you can tell when something is working. How long was it before the doctors knew that it was working and that you were going to come out of this? Buchanan It was not until the end of January, that following year. I was feeling pretty good, and I went in to see Dr. Sznol. They gave me between six and seven, maybe even an eight-week break in between treatments with the IL-2 so you could get your body back going and because it impacted so much, your liver, your kidneys etc. Lamothe Say a little bit about that Paul, what is the impact after you have your treatment, what are you feeling like, what are you doing? Buchanan I was warned, Dr. Sznol obviously gives a warning, it is almost like watching those commercials21:06 into mp3 file <http://yalecancercenter.org/podcast/dec2610-cancer-answers-buchanan.mp3> about prescription drugs where it is going to basically impact everything and even give you psoriasis, and he told me there could be a chance that I could be put into the ICU if it impacted my liver, or kidneys. They were basically drawing blood or taking blood about every 15 minutes when I was in the hospital, just to make sure everything was okay. Lamothe What were the lengths of your hospital stays when you were being treated with IL-2? Buchanan There were four separate weeks that I was doing the treatment, and I was in as long as my body could tolerate it. For some, I was in for five days, and I made about every treatment they wanted to give me the second time. I was in maybe for four days, and then as I went for the third treatment and fourth treatment, my body just could not deal with it, I do not think I was in for more than two-and-a-half days. He was hoping to get more out of it, to pump more into me, but it just did not work out that way. I went back in after that break, I went back in to see Dr. Sznol and he kind of looked at me, and he said, we had a vote on whether or not we were going to put you through another round of treatments and he was not sure another round was going to be helpful or not, but he said they were going to put me through another round. I said, oh please, please do not. I was kind of begging him. Here I was feeling good, I knew it was working, I knew it had worked, and I was begging them not to put me through it again, because IL-2, when they give it to you, as you start to feel a little better, going in for the IL-2 treatment just tore you down. It tore me up pretty bad to the point that after being in there, it would be about a week before I would actually be moving and doing the things I needed to do. He said well, we went to vote on it and we are going to put you through another round, and he said he voted not to, and I said, well that is good enough for me, and he kind of laughed. He said, tell you what, you

go through your scans again and we'll do another bone marrow biopsy, and if you are clean, we won't do another round of treatments. I asked him what the odds were of that, and he said, not very good. So I did my stuff, went down to see Dr. Sznol, sat waiting for him, and he came in and said, I cannot believe it, there is no sign of cancer in your body at all. With my first bone marrow biopsy, the lab first diagnosed me with myeloma, and Dr. Sznol said no way, we know it is melanoma. The lab came back and said, you are right and he does not have any bone marrow left, it is 100% tumor. So I went basically from, my bone marrow being 100% tumor to not having anything in me five months later.

Lamothe Two-time cancer survivor, two pretty harrowing experiences with a period of time between each of them where you had children and moved on with your career and your life, but coming out of cancer the second time, how is it different and how are you living your life differently now as a result of these two profound cancer experiences?

Buchanan People go through it in different ways. You read a lot of stuff about people having that epiphany where they saw something and they went on to do things. For me, I had a young family, I had to get back to work, I was back working a month later, traveling, and doing the things I needed to do to support my family. It is going to be a part of my life, it will be a part of me forever, it will be a part of my children forever too because now we have to watch and make sure they do not go through the same thing I went through. I am not sure that a change for me has been as profound.

Lamothe 24:55 into mp3 file <http://yalecancercenter.org/podcast/dec2610-cancer-answers-buchanan.mp3> maybe as it has been for other people. I just want to live everyday and make it through and do what I need to do.

Lamothe What do you say then Paul to other people who have gone through this experience, people you talk to in the Support Group or people who are listening now at home, driving their car, what do you say to them?

Buchanan I wish I had known more about melanoma the first time around, and I would not have had to have gone through the experiences I had gone through. If there is a strange mole, even if you do not think it is a strange mole, go have it checked, go see a doctor just to have something looked at is not a big deal, and it could save your life. Not only can it save your life, it could save you a lot of heartache, a lot of trouble, a lot of issues going forward, and listen to the doctors. There is a lot of stuff out on the Internet, different treatments, different places, and I just put my faith in the doctors, put my faith in God, that I was going to get through it and that is what I did. That is what I needed to do, especially the second time around.

Lamothe It sounds like you also had a close-knit supportive group of people around you who helped you with your cancer, but also just helped you with who you were. I am sure you did not talk about cancer all the time when you got together with your buddies or your family and we know how profoundly the cancer impacts the patient, but it also has an impact on their family, their friends, their coworkers, their neighbors, and many people believe that they need certain levels and types of support too. Say a little bit about your own personal experience with your family and friends.

Buchanan I think it is harder on the family than it is on the patient. After my first round of treatments I had been told pretty bluntly that if the melanoma ever came back,

I probably would not survive it, and when it came back so fiercely I got to a point where I kind of figured I was going to die, and I was okay with it. I did not want to die, but I was okay with it, but you know I had a 79-year-old mother who came up to help us; one of my brothers came up and lived with us. I had my two children, I did not want to die, but you could see the impact that it had on the people that knew what was going on around you. No parent wants to see a child die before them, ever, nor does a brother, or a wife, friends, or anybody else. We had only lived in our neighborhood just over three years. It was a new neighborhood. It was a new development, and people really came together, it was unbelievable. There was stuff that needed to be done, whether it was mowing the lawn, cutting the bushes or hedges and I had friends that came over and did everything that they could. They supported my wife, helped with kids, cause their life had to go on, just because I was sick did not mean that they were not going to swimming practice or they were not going to go to the YMCA for their programs there. They needed to stay focused and stay level with their life, and I always felt it was harder for them than it was for me, to watch me go from where I was a very healthy 45-year-old man to having lost 50 pounds and was not even an image of my former self. Lamothe Paul, we have just about a minute left, and this is kind of a difficult question to answer, because 28:36 into mp3 file <http://yalecancercenter.org/podcast/dec2610-cancer-answers-buchanan.mp3> this could be answered in so many different ways, but if you could say something to cancer, what would you say? Buchanan From my own experience, I kind of look at it and say, if it is going to come again, just bring it on, I will deal with it. I think we all need to deal with it. It is never going to be easy. The diagnosis is not going to be easy. The treatment more than likely is not going to be easy, and as you move forward, it is going to be difficult for everybody. I would like it to just go away, go away, and leave us alone. Paul Buchanan and Peter Lamothe are cancer survivors. If you have questions or would like to share your comments, visit 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.