

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, Dr. Chagpar welcomes Frank Terrazzano who wrote a book about his daughter Lauren's experience with lung cancer. Here is Anees Chagpar.

Chagpar Tell us a little bit about your daughter and the inspiration for this book.

Terrazzano Lauren was a journalist for 14 years in New York. She worked for Newsday and was just a terrific reporter. She was very altruistic in her writing. She wrote primarily about social problems, the abuse of children, the elderly, homeless, and so forth and had a genuine interest in trying to make things better for people who supposedly fell through the cracks in our society. In 2004 she was diagnosed with lung cancer, and for the last seven or eight months of her life she wrote a column entitled, 'Life with Cancer' and the column was very well received by the people in the New York area and on Long Island and she was also getting many, many cards and letters from well wishers from across the country because Newsday was syndicating the columns to other newspapers across the country and she even received cards from Scotland and England because people were reading her column online. As I said, she was a terrific reporter and she always wanted to write a book and obviously she never got the opportunity to do so, so this is my gift to her, so to speak, and hopefully I fulfilled her wish.

Chagpar It is certainly a great book. It is called "Life with Cancer: The Lauren Terrazzano Story." Tell us a little bit more about your daughter and when she was diagnosed and what that was like for her and also for your family?

Terrazzano To her mom and me, she was our only child, and it was devastating. Lauren was scared, as anybody would be with a diagnosis like that, and it hurt her deeply also, there is no question about it, but she always tried to keep up a good front, because she wanted to spare us from any hurt and so she faced the problem very courageously and had a very positive outlook. She would always say to me, we are going to get through this dad; we are going to get through this.

Chagpar How did it all start? How old was she and how did she end up

presenting with lung cancer?

Terrazzano She was 34 years old when she was diagnosed. There were no signs, other than the fact that she would come home and visit us on weekends and sometimes she said, dad, I feel tired and am just going to veg out, that was her famous line, she was going to veg out for the weekend. The last time she was at home to visit, my wife had noticed that her right arm had a bit of a swelling, and Lauren just prior to that had an annual visit with her doctor in New York, but my wife mentioned

3:53 into mp3 file <http://yalecancercenter.org/podcasts/2013%200106%20YCC%20Answers%20-%20Terrazzano%20copy.mp3> that Lauren should have it checked out, and she could not understand what was going. Well, she went back and we found out later that she was having shortness of breath in addition. When she went back to New York she did consult with the doctor and they did an MRI and that is when they determined that she had tumors on her right lung. The doctor that she met with was a thoracic surgeon at Sloan-Kettering and they immediately bonded. He was her age, he was an only child also, and they just hit it off. I think her original diagnosis was stage III B if I am not mistaken, and that isn't always the best diagnosis, I guess. He told her he would do whatever he could to try to get rid of the tumors and so they started a regimen of radiation and chemo for three months. This was in September that they first started, and then in December, just three days prior to Christmas, they made the decision that the radiation was not working as well as they thought it should as far as reducing the size of the tumors and so they decided to go in and remove her right lung, which they did and she made a remarkable recovery from that surgery. They took her lung out and she again was followed up with additional radiation and chemo, and she seemed to go into remission, or so we thought, but she was in remission for a period of time and with cancer one errant cell gets away and it starts all over again elsewhere in the body. So, she went through a number of surgeries. She had developed a tumor which was nonmalignant in her eye, they were able to remove that and then there was another tumor on her rib and again they had to remove part of the rib and they rebuilt the rib with what we were told plaster or something like that. Then it finally came back with a vengeance and she passed away in May, 2007.

Chagpar That is a tragic story. Did Lauren have any warning signs? I mean here she was, 34, she was an accomplished author, did she have any clue? Was she a chain smoker?

Terrazzano She smoked a bit in college, and that was about the extent of it. The doctors even considered her a nonsmoker, for length of time she did

try smoking. So other than that I remember her saying afterwards that she used to be tired all the time, but she worked very hard, she was a very devoted journalist. There were times when we tried to contact her, tried to reach her at home, and she was not there. We called the newspaper at 11 o'clock at night, and she would still be there working on a story. She was very devoted to her work, and maybe that was the onset of it, we really do not know for certain other than the fact that the swelling in her arm that her mother detected were blood vessels that were being restricted and that caused the swelling in the arm.

Chagpar Just as a heads up to people listening, cancer can start at any age and sometimes there are not any risk factors and it still happens, and you need to be vigilant so it was a good thing that your wife picked up on that.

Terrazzano The irony is that that her mom picked up on that and Lauren had gone back to New York and we did not find out that she had cancer. She was diagnosed in August and she just could not bring herself to tell us, and it wasn't until September that we found out, September 4, 2012. I will never forget that day. She decided to drive up and give us the news.

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Chagpar How did that make you feel?

Terrazzano Devastated. I mean, I was a smoker for 30 years, a heavy smoker, and I just could not understand how this could happen to my daughter; basically she was a health nut. She jogged in Central Park, and was always very active in that respect and went to a health club and so forth, and we could just not comprehend that would happen to her.

Chagpar A lot of times people struggle with how to tell family and friends about a diagnosis as devastating as cancer. In part, because it is devastating to them, but in part because they know how devastating it is going to be to their family.

Terrazzano Exactly.

Chagpar What advice would you give to people who are struggling with that?

Terrazzano We tried to give her as much positive support as possible. I will never forget an incident when she first was getting her treatment, and this was just before her surgery, her mother and I had gone to New York, we made frequent trips down there just to be with her, and cook for her while she was going through this, and on one evening, she had a small apartment at that time, and we were staying there and she could not sleep because she was vomiting from the effects of the chemo. I was sleeping on the couch in the living room and I told her to come out. I said just come out here and sit with me. I put a pillow on my lap and let her lie down. She said daddy, am I going to be okay? And I assured her, she was going to be okay, and to this day that statement haunts me because all the years that she was a child and when she was in college, moving from one apartment to another, we were always there for her, whatever she asked we were able to do and we doted on her, there is no question about it, but I could not help her with this, and that bothers me to this day.

Chagpar But you did do something for her. You were there for her and supported her.

Terrazzano Yes.

Chagpar It was a trying time for her and many patients need that reassurance that everything is going to be ok, and that is difficult. Oftentimes the responsibility for making things better rests in part on the care team, the doctors, the nurses, but in part on the families, how did you interact with her care team, or did you?

Terrazzano Oh yes, we did. Dr. Flores who is the surgeon at Sloan-Kettering, we all hit it off with him. He was very supportive, had a very positive outlook and we believed very highly in whatever he decided to do, and she did too. Lauren really respected him and as I said they became friends, which is something that normally does not happen.

11:26 into mp3 file <http://yalecancercenter.org/podcasts/2013%20106%20YCC%20Answers%20-%20Terrazzano%20copy.mp3> Chagpar It really is a team environment oftentimes. Not only do you have a team of doctors and nurses who are looking after you, you have your team of support people, your family, your friends and those teams all come together to really support you through that

diagnosis. Were there other resources that Lauren turned to, community support or faith-based organizations? How did you as her family, who clearly needed some support as you were going through this as well, and how did she kind of get through that whole experience that I am certain was very trying for you.

Terrazzano She maintained a notebook, and when I say notebook it was about 3 inches thick, and she documented everything she could possibly learn about lung cancer and about her treatments and I in turn being somewhat like her, did a lot of investigating myself. We convinced her to try to get some second opinions, we heard about proton beam therapy and that was available at MD Anderson in Texas, so I convinced her to fly down there with me to get another opinion, but that would have involved, her having to move down there temporarily and again there was no guarantee that this proton beam therapy was going to do the job, so she chose not to follow up and she wanted to take a chance up here in New York with the doctor and the hospital that she was dealing with.

Chagpar After the break, I would like to talk a little bit about other resources that she may have tried, and how you and your family got through this diagnosis of lung cancer and then talk a little bit more about the book. We are going to take a short break for medical minute, please stay tuned to learn more information about Frank and his daughter Lauren's experience with lung cancer.

Medical

Minute The American Cancer Society estimates that the lifetime risk of developing colorectal cancer is about 1 in 20 and that risk is slightly lower in women than in men. Early detection is the key. When detected early, colorectal cancer is easily treated and highly curable and men and women over the age of 50 should have regular colonoscopies to screen for this disease. Each day more patients are surviving the disease due to increased access to advanced therapies and specialized care. New treatment options and surgical techniques are giving colorectal cancer survivors more hope than they 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 colorectal cancer. New options include Chinese Herbal Medicine being used in combination with chemotherapy to reduce side effects of treatment and help cancer drugs work more effectively. This has been a medial minute and 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 our guest Frank Terrazzano. We are

discussing Frank's daughter's experience with lung cancer. Frank's daughter, Lauren, was the inspiration for his new book "Life with Cancer." Frank, before the break we were talking a little bit about your journey with your daughter to look

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for new therapies as you were faced with this unsuspected diagnosis of lung cancer. Tell us a little bit about what other modalities you looked at; did you consider experimental therapies, alternative therapies, clinical trials? Tell us about what you did?

Terrazzano There were many alternatives that I thought of, that I would have like to have pursued but Lauren felt very comfortable with her doctors in New York. I indicated earlier about the trip to MD Anderson, and she was reluctant to go there but I convinced her that we had to do something to see what else is available and we did go down, but apparently it was not something that she was ready to go along with, and one of the other things I remember is there was research being done at the University of Alberta up in Canada and they had come up with, I cannot think of the name, but it was a compound that is in everyday use and they claimed that it had very good results in the treatment of cancer cells and killing cancer cells without harming the existing cells, the healthy cells, and I looked into that, but again it was in the experimental stages and they had not even started clinical trials on it, so there were a number of things like that, but just didn't pan out.

Chagpar At the break we were talking a little bit about your daughter's column, 'Life with Cancer.' Tell us about her philosophy about the difference between living her life and allowing cancer to live it for her?

Terrazzano Lauren was very strong about that, that is the one thing that gave us hope because she had that positive attitude that she was going to beat this and she always said that we were going to beat this together, and she titled her column 'Life with Cancer' again because life meant more to her than the cancer she was fighting. It was an important part of her life, but she vowed that she was going to live her life, however long it was going to be and that cancer was going to be a secondary part in her life.

Chagpar And how did she do that? I mean one of the things that is evident is that even while she was being treated for her cancer, she continued to

maintain her column. Tell us about how she kept in control of her life, because for so many patients when they are diagnosed with cancer, they feel like their life is going to spin out of control and it sounds like your daughter really took the reins on this and said, "I am going to live my life, it is my life, it is not cancer's."

Terrazzano Absolutely, she wrote those columns with a passion. The research she did, the statistics, I was just amazed at some of the statistics she came up with that I myself did not know about lung cancer. The fact that lung cancer kills more women than breast, uterine, and vaginal cancers, I did not realize that the numbers were that high and the fact that the disease did not get much recognition. Lately it is starting to get some recognition and the research dollars are being spent on it, and the public is getting to see that lung cancer is a very serious problem and also the stigma of smoking is not necessarily the cause of lung cancer, so she did a lot to enlighten the public about lung cancer and she attacked those columns, no different than when she was out doing a story. She was a

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stickler for detail and would not just accept the status quo, she went after things and really made sure that she had all the information and presented that information in whatever she wrote.

Chagpar It is so important to have people who have a voice and give that voice to causes that they believe in and I think that your daughter, although her story is tragic, really did lend a voice to the cause of the fact that lung cancer is the leading malignancy, the leading cause of cancer related death both for men and women, and that for many, it is not entirely related to smoking and it can hit at any age, things that many people do not know, and to push researchers to find a cure for these diseases.

Terrazzano Absolutely.

Chagpar Tell us a little bit more about your endeavor, about your book, was this your first book and what gave you the inspiration, aside from memorializing Lauren's story?

Terrazzano I started this in December of 2010 and not having any training in writing, this was my first attempt at writing and not having any training whatsoever, I just wanted to learn. And I will go back even further, when she first started her career in journalism; she said that some day she was going to win a Pulitzer. Well, she did not actually win one herself, I mean she got there, she shared a Pulitzer prize for the flight TWA disaster that happened in Long Island, but she also used to say that some day she going to write a book. She never got the opportunity to do that, so I decided that I was going to do it for her and this book is my attempt to write a book about her and for her and to let people know just what type of person she really was, a warm and caring individual. She used to refer to us as Mr. and Ms. Helicopter, because for 39 years of her life we hovered over and there is no question about it. She was our only child and we always hovered over her and she did the same for us. I mean she was the same exact way, she would worry about her mother, if I sneezed or coughed the wrong way, right way she was panicked, and I do not know what it is, maybe it is our Italian heritage or whatever the case may be, but that was the way it was and this book was primarily not only to show her courage in fighting this disease, but also about the work that she did on behalf of the problems in society. She wrote about these problems and brought them to the politicians and higher ups in society so that they could see them and would go and make changes to benefit the people involved. That was my biggest thing as I said, to let people know she was a social journalist and that she really cared deeply about society's problems, for the homeless, for the elderly and for the abused children, as so on.

Chagpar And she certainly did a lot for many of those causes, and so as a helicopter dad, it must have felt so much like the TWA crash when the helicopter could not hover anymore?

Terrazzano Exactly.

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Chagpar That it spun out of control. Tell us about that and tell us about how you regained some of that control.

Terrazzano I do not think I have ever regained that control, I will be honest with you. She is missed daily and there isn't a day or night that I do not think about her. I can be looking at her picture and I just think of good things that

happened and I get emotional. I cannot put it into words what this kid meant to us, she was our whole life. She was a princess of our Kingdom.

Chagpar And certainly the book is a tribute to her and to your family and to the many great things that she had done and it is certainly abundantly clear how close your family was, but what do you think you can now do to pay this forward even further? I think that the book is a great tribute to Lauren but it seems to me that there is a bigger fight here. There is a bigger fight against lung cancer. Do you have plans to take that mission forward, and if so how?

Terrazzano The one thing my wife and I have made a pledge to do as indicated in the book, when Lauren passed away, she got her Master's Degree at Columbia School of Journalism, we established a scholarship in her name at Columbia in 2007, and we try to support as best we can each year and also the support of her many friends and colleagues that she worked with, the fund has grown overtime and they have been able to grant scholarships to deserving journalism students for the last four years, not very much, \$1000, \$1500, but at least it is something that journalism students can use to help defray the cost of education for them, and secondly, whatever is raised from this book, and I will share because I do have a co-writer who is here by the way, and his name is Paul Leonardo and he co-wrote this book with me and helped me because I did not have any experience, and Paul kind of brought everything together for me and helped give some structure and helped me to put this thing together so that we actually had it in book form because I had pages of scribbblings', but to get back to what I was saying, what we hope to do is whatever proceeds we raise from our share, we have committed ourselves to two organizations, primarily the Lung Cancer Alliance and Joan's Legacy: Uniting Against Lung Cancer. It is an organization in New York that also specifically works for the benefit of lung cancer patients. So we are giving back something and by doing so I think Lauren still continue to help others and her name will remain proprietary long after my wife and I have left this earth.

Chagpar And it is such important work.

Terrazzano It is, absolutely.

Chagpar It is a tragedy that Lauren died so young, but it is a celebration that from that tragedy can come new research advances, new philanthropics, and we can try to make a difference in this disease that can help other Lauren's down the line so that we can start to make a difference in this disease. Tell us

a little bit about support frameworks, it sounds like your family was so close knit and you were

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each other's rock, but sometimes that structure shatters when things like this happen. Were there other people, other organizations that came to your rescue?

Terrazzano Absolutely, our friends, my wife's and I, were very-very supportive during Lauren's ordeal, but there were also five girls, five of Lauren's friends, colleagues in New York that I refer to as de facto siblings because whenever we were not able to be there in New York these girls were there for her. They would do whatever they could, they would accompany her to chemotherapy or radiation treatment, just the support that she got from those girls, there were others also, but these five girls were just incredible and as I say, I look upon them today as her sisters. There is no question about that in my mind.

Frank Terrazzano is the author of "Living with Cancer: the Lauren Terrazzano Story," the story of his daughter Lauren's experience with lung cancer. 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.