



How a Mother Turned Grief Into Advocacy: Realizing Jillian's Dream

Ros Miller

Lung Cancer Patient Advocate

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Andrew Schorr:

Hello and welcome to Patient Power. I'm Andrew Schorr. We're joined by my friend Ros Miller, who's in Tampa, Florida. I'm in Carlsbad, California, so we're covering the country. And I wanted to talk with Ros about being the parent of someone that we lost to cancer. In 2013, Ros, you lost your daughter Jillian at age 29 who was a nurse there, and then over the course of 10 months turned out to be stage IV lung cancer. What a tragic loss, but—must have taken a while to cope with that, but you've moved on in a very positive way. Tell us about that.

Ros Miller:

Well, you know, the diagnosis with Jill was very sudden, and it took us a couple of weeks until we actually knew that it was lung primary. And she moved back home, and we became her caregivers and her partners in her healthcare. And at the end and after 10 months, she did lose her battle with the disease.

Shortly thereafter both my husband, my sons, they ended up going back to work. But as I didn't work I was left at home, and not wanting to twiddle my thumbs I needed to put my energy into something, because I just couldn't sit around and just mope all day.

So I started with the help and support of my family Jillian's Dream a few months after she passed, because I thought the only way to make something positive out of all of this was to literally shout it from the rooftops that this is a terrible disease that anyone can get it. And we need to do more to educate, raise awareness and provide the funds for the research that is so critical to the 250,000 people in the U.S. alone who will hear the same words that Jill did.

Andrew Schorr:

Right. And so Jillian's Dream has been a wonderful foundation. You work very closely with one of the major cancer centers that's right there where you are, Moffitt Cancer Center, and I know you've been raising money to help the researchers there work on lung cancer, which is what Jillian passed on from.

Ros Miller:

She did.

Andrew Schorr:

I've also met you at conferences, and you do blogs on Patient Power. So have you felt like this has been not only cathartic for you, but you feel like you're making a difference? We have a long way to go in lung cancer, so many cancers, but you feel like you're doing something every day.

Ros Miller:

I do. When we first met at the IASLC, it was a fabulous opportunity for me, because I had internalized it, and it was very personal, and I thought that everyone needed to see Jillian as the poster child of lung cancer. Well, there I am thrust into a world conference to find out that there are 90 different countries, over 7,000 people attended, and this is an epidemic, worldwide, not just here in the U.S.

And the idea of being able to share my stories and my journey and meet other people who have someone they love going through this was very reassuring to me in a very strange way. I felt like I was no longer alone. I could talk to people about things and not feel that I was the elephant in the room.

Andrew Schorr:

Let's talk about that from the family perspective. So, unfortunately, too many of us lose a loved one to cancer despite news of breakthroughs. And doctors say it's exciting research and things like that, and often it is, but we still have a long way to go, both in the science and also, I think, increasingly as medicines are expensive and also access to medicines, and also I think along the way people not being afraid of clinical trials. And I know Jillian was in a clinical trial.

And what would you say to people about for their family member? Because often it's a family decision whether somebody is in a clinical trial, not just the patient about how we as families can help move research along.

Ros Miller:

What was very startling to me, after Jill's first doctor's appointment up at Moffitt, he strongly urged her because of her age and her overall general health that the clinical trial would be an excellent way to start to combat and fight what lung cancer was doing to her body. So we sat there with a clinical coordinator. We started going through some of the papers, halfway through it's like, okay, so where do I sign, and when do I start?

After she passed, I was at a gala with the people from Uniting Against Lung Cancer up in New York, and I happened to meet Dr. Eric from Moffitt, who was on their board at the time, and we sat down, and he told me that only 3 percent of lung cancer patients participate in a clinical trial, and I was devastated.

Andrew Schorr:

Definitely true across cancer.

Ros Miller:

It is. And I know that there's a lot of misconceptions. People think they're going to get a sugar pill, there's not going to be any beneficial treatment to them. But at the last conference I attended with LUNGevity, that is so far from the truth. And people have this preconceived notion that a clinical trial is not going to help them.

And Jill knew, however she knew, that that was the only way to advance the science. While it may help her short term, long term the analytics, the hypotheses, the drugs can be refined and reapplied in other patients. And she knew that that was the only way that we were going to end up with the survivor rate we know is out there is very possible and doable.

But it is very sad to see that most people, they are very afraid. And I think part of it is because they just aren't informed, and there aren't enough either nurse navigators, clinicians, coordinators out there to sit there once they hear the words, "You have cancer," there's so much bouncing around inside their head that they need time to process that. But they also need to be very proactive. And they need a team of people around them, whether it's caregivers, family, friends, doctors, nurses to help guide them through this.

Andrew Schorr:

Now, you've connected with other people in the lung cancer community worldwide. You found out you weren't alone as a family member. You weren't certainly alone as someone who lost someone to lung cancer, and you also met people, some had been in clinical trials, who fortunately now we're seeing a blip of more longer-term survivors based on medical progress. What would you say to people watching about the value of connecting with others, whether it's connected with

a family member, whether it's connecting maybe with a family that's been affected by cancer, whether it's a patient connecting with others that knowing you're not alone quality, if you will?

Ros Miller:

You're not. And it's funny, there are a lot of lung cancer organizations. There are many people affected by this disease and family members who are struggling day-to-day to figure out, you know, I need to talk to somebody, but my friends don't want to hear it anymore. They don't want that woe is me. They've heard it before, and it doesn't affect them past a day or days depending on the situation. So the fact that I was able to connect and reach out to a lot of people—I have friends I never thought I would. That adage of you find friends in the strangest of places, that is...

Andrew Schorr:

Well, you're my friend, Ros.

Ros Miller:

You're my friend, too, and I can't tell you how much support I feel and how much you've done for me in this journey of moving from that grieving parent to someone who can make a difference and maybe help somebody.

So the last conference I attended, I was there as a caregiver panelist. And we talked about that. How do you talk about it, how do you deal with it, how do you move on, and where do you find your friends? I think the people who I've met through the lung cancer community, they know the ups and downs. Some of them are looking for the answers I was looking for, and to be on the giving end of that is very rewarding.

I met a wonderful young woman who was the caregiver for her mother, and she has siblings, and they can't understand or handle it, and she's at a loss as to what she can do. And it's like you're doing what you're doing. And the gift you're giving your mother by being there and the gift that she's giving you of her time and the struggles you two will face are memories and feelings you will never be able to share with anybody else other than her.

And those of us in this community who see beyond what the disease is, and we're there to reach out, and we're there for the hugs and the laughter and the tears. And it's really bittersweet when someone you've gotten to know and they pass, and you see so many people putting it up on Facebook, and it becomes very social, becomes very personal. But it also becomes very focused in terms of you know you're not alone and that whatever you're going through someone is out there who can hold your hand and help you through this. And I found that to be so true from the survivors I met to the caregivers I've met to the advocates who have no relation to lung cancer other than they see this as a mission and a cause.

Andrew Schorr:

So, you do this every day. You've done blogs on Patient Power, you connect with people in social media, you're active in lung cancer organizations, and you're working closely with your local cancer center, Moffitt, in fundraising and helping the researchers. Is Jillian just clear and present in your mind every day as you do this?

Ros Miller:

Every day. I feel her in my heart. Sometimes I look through my glasses as though I'm seeing her eyes, or she's my eyes. And she helps me from within to do what I do. Because I know that if I—if I can be that friend, if I can be that voice to somebody who is so angry, to somebody who is so frustrated, who doesn't know which end is up, which way to turn, if I can be the ears or the voice and help them and give them a hug when they need it or just laugh with them, then I know that Jillian is living on through me in that regard. Because she was a no-nonsense girl, and she told it as it is. And I have to say I think I got my strength for doing this because she taught me how.

Andrew Schorr:

Wow. A gift your daughter gave you, and you give a gift to so many, Ros Miller. Although you lost Jillian way too soon, you're a tremendous support to all of us. I want to thank you for your activities on Patient Power and writing blogs and interviews you do with us and your work every day. And I think there's a—you're a wonderful mentor for other people, whether you're living with an illness or your loved one is or whether unfortunately you've lost someone that there's more to do, and we can do it together as a community.

Ros Miller:

Thank you. What you give is overwhelming.

Andrew Schorr:

Well, I want to wish you all the best down there in Tampa, and we'll get together in-person again, soon, Ros.

Ros Miller:

I hope too.

Andrew Schorr:

And I want one of your hugs, okay?

Ros Miller:

You got it, Andrew. Thank you so much.

Andrew Schorr:

Okay. Thank you. Well, Ros Miller joining you us and carrying on with Jillian's Dream. I'm Andrew Schorr from Patient Power. Remember, that knowledge and community can be the best medicine of all.

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