Gwen Orilio: How a High School Teacher Defied a Stage IV Diagnosis Transcript

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Introduction to Gwen Aurelio

This is the Doctors Making a Difference podcast, living with metastatic cancer, highlighting patients, doctors, and researchers who are fighting to win against cancer.

We're joined today by Gwen Aurelio. Gwen has an interesting story and maybe some of you like me saw her story in the Wall Street Journal. She was featured in that story as a very interesting person who has metastatic lung cancer.

And despite having it for over a decade, she has continued on working. In fact, it even highlighted Gwen, the idea that when you first got this diagnosis, you had said, maybe I'm not even going to worry about entering a retirement account because what's the point?

But now a decade later, you're saying, well, I think I'm going to live and let's just keep going. So it's this interesting, fascinating story. And I was so pleased to be able to contact Gwen.

But Gwen, would you mind introducing yourself to our audience and telling them a little bit of your story? Thank you so much for having me. I am a high school math teacher.

This is my 21st year teaching high-school math here in the schools in Clayton. and I live in Garner, North Carolina. near Syracuse, a small town named Casanovia.

I attended SUNY Geneseo, which is one of the state schools in New York. And I competed on the track team. That's actually where I met my husband. He was also a track runner.

We moved to North Carolina right after graduation. We bought a four bedroom house expecting to have a large family. And 18 months after my first daughter was born, I was diagnosed with stage four lung cancer.

So the cards showed that we would have one child instead of multiple. A lot of people listening to this are physicians. Some people are like you and me, folks who have to deal with cancer.

And so I think a lot people can maybe relate with that. Maybe just kind of walks through like, how was that? Because it's such a change in a course when you are a young person and suddenly you're told, oh, instead of this plan, you get this planet.

You have stage four cancer, or you hear those words and it is pretty hard. So I wanted to hear what your experience was with. Well, I was experiencing headaches, which is what brought me to the doctor.

Diagnosis Through an Eye Exam

And so I went and got MRIs. Everything was fine. Then I decided to maybe go to eye doctor, maybe I will work contacts and so maybe my prescriptions off and I need to get something fixed there.

That's actually where they found my cancer. There was a tumor on the back of my eye. So they told me that I needed to go see a specialist and many months and tests later, they discovered a tumor in my lung.

And at that point, I didn't know much about cancer, to be honest. I, didn' know that since it had already spread to my eye that it was stage four. and I.

Didn't even know there was actual stages of cancer. So I've learned a lot, but I don't think things just changed when they operated on my. Lung in January.

of 2015, they cut me open. The doctor came back while I was recovering and said, well, sorry to tell you this, but it is cancer. So I say, okay, what do we have to do?

What's our next step? Like, we're going to fight this thing. I don't know what I have do, tell me. And I do remember visiting my oncologist very early on and I said so what stage am I?

And she said well it's already spread to your eye so you are stage four. What's next? Oh, it's kind of wild. Especially, I mean, you were a young mother and starting your career and had all these opportunities in front of you.

And then it just stolen at that point. I'm just reflecting on my own experience. It's almost like you don't dare to plan for the next thing, or at least initially that was kind the first thought is like, well, let's just sort of finish the last few things and do everything we can and try to set my family in a good direction because I don't know if I'll be here.

It's such an overwhelming kind of crazy feeling. And I think anybody that has had a cancer diagnosis, especially if it's already spread outside the bounds of its primary tumor, it is a real heavy duty diagnosis.

So what did you do at that point? Obviously, you know, as a big deal and you discovered it through an eye exam, which is really interesting, unique way to discover it.

What did Well, I was given the option to freeze my eggs to maybe have more children. And I right away thought about the one child that I did have. I said, no, want to attack this right way.

It's already spreading. Let's get rid of it. So I opted to have chemo right a way before we even tested to see what kind of mutation was driving my cancer.

We started chemore right-a-way. My biopsy went out to test for the EGFR and ALK mutations, which are the largest, the most popular mutations in lung cancer.

And I was very fortunate to have an oncologist that was on top of all of the testing and stuff. She said, you're young and otherwise healthy. I know you have a mutation.

We just have to find which one it is. The first test came back that I didn't have those mutations. And she said, all right, well, we're just going to keep digging until we find what mutation, because I'm confident you have something that we'll be able to treat.

Then she encouraged me to not look at Google. She said those stats are not you. We're going, like every patient is different. So we are going find, what's driving this.

I ended up having the ROS1 mutation. Once we discovered the Ross one mutation, there was one at the time, but there is one medicine that I can just take a pill every day.

So I continued working through all of it through my chemo. I was still teaching math full time and I always coaching track at that time as well. It was out with the varsity track team coaching the jumpers.

with no hair. Yeah, traditional chemotherapy. I mean, I didn't have any hair to start with. But yeah, with the chemo, you didn' have the hair, but it sounds like you found a targetable mutation.

Finding the ROS1 Mutation and Starting Treatment

You found something that could be targeted by the medications that were available. at that time to slow the growth and progression of the tumor, which is great.

If we can have more of those targeted things, it certainly imparts a lot of benefits to a person. So have you maintained that type of medication for all these years or how has it gone over this time?

It's that tight, yes, but I'm on my fourth targeted therapy, the TKI. I was on the first one for about three years and the next one was about six years.

maybe it was the last five years. And then the next one for one, and then this one I've been on since August of 2022. I'm on my fourth one. So that's why I need science to just keep finding these mutations because as you most likely know, the cancer is smart and it figures out a way around the medicine and you develop a mutation to the mutation.

They've developed these new medicines that will target those new mutations. So this one's been working great. That's great, would you say that as time has gone on and you've started different therapies, those therapies are they being developed in real time?

Like when you first started, you said there was just one available and then these others become available. You have a mutation or you stop progressing or stop making response to the treatment.

So then they have to give you another one. And so the science really is kind of keeping pace with what you are doing. Do you like riding the front of this wave?

Yes. Yes, my doctor said that when I was diagnosed, she said, well, it was a good time to be diagnosed because all of these new treatments are being developed.

So I agree. It was good. The first medicine stopped working because I progressed into my brain. the medicine that I. Currently on my primary one after the chemo was not crossing the blood brain barrier.

So I had to switch to a new one. The doctors here in Raleigh said that after the scans, they said, well, I have more than a dozen. They stopped counting after 12, small lesions in my brain.

And they say that my option would be to just have whole brain radiation. But at that time I was what, 33, 34? And I had looked into the side effects of the whole brain radiation.

I was like, that could turn me into a vegetable at 34. My daughter was still only four years old, so I'm like no, there has to be something else. So that's when I started flying up to Boston.

And so, I guess it was only two years after, because I sort of flying to up Boston in 2017, where they had the Ross One Super Docs, they're called. People that specialized in the, the type of mutation I had.

So I started flying there and the first flights I was flying, I think once a month, had to fly up from Raleigh to Boston. I continued working. And I'm glad I have a supportive school.

Oh my goodness. Yeah. Not only is that time off and cost of flights, but it's also this huge inconvenience to go back and forth doing that again and again.

Do you still fly to boston or were you able to get some of that stuff a little bit more locally? They have been available locally, but each one I've done in Boston have be part of a clinical trial.

Even when they become commercially available, I'd still choose to stay connected with the doctors up there in boston, so I still participate. So the drug I'm on now I entered the phase one clinical trial.

It was one of the first patients. Well, as a testament to the fact that that's working, you're still going to work. You're raising your daughter. I'm sure it would have defied the odds had you asked any of those folks 10 years ago, will I still be working full time and coaching track and doing all these things and raising my daughter?

Brain Metastases and Clinical Trials in Boston

And nobody would have given you great odds, but here you are 10 years later and you've been willing to participate

in a clinical trial and pave the way for others.

It is really a unique story, Gwen, and pretty neat that you have been able to find the right treatment so that have a treatable mutation. it's just an amazing story.

And I love that. You can just go to work and do your normal job by day. and then you're like this superhero of the, in the cancer world when you not at work.

Every November is Lung Cancer Awareness Month. So every November I make my students learn more and more about lung cancer. I give them a fact of the day, I have about 90 students every november.

so I'm trying to educate everyone about how lung cancers, not just a smokers disease, it deserves more funding. It does all cancer research. It's just interesting.

My cancer is called solitary fibrous tumor. So it's a rare type of sarcoma nobody's ever heard of. I think every type cancer just needs funding and it needs people with smart minds to continue to study it.

We need some of our high school students to become researchers. MD-PhDs and ones that go into this and look into it and find it because we're in an exciting time if you could call cancer exciting.

We're at an excited time of understanding things at that genetic level like you discovered. You found a mutation that was treatable and then they've found more treatments and as time has gone on, not only is that interesting from a cancer standpoint, it's life-changing, you know, and you're living it.

What has that been like as a mother? Like your daughter, she was just little when you had this, it's really all she's ever known is that mom has to fly to Boston every month and go get cancer treatment.

That's gotta be an interesting thing for you and for her and your whole family to deal with that. What does that have been? It is very interesting because she is locally part of a support group for kids whose parents have cancer.

And a lot of times they ask the kids to share what was it like when that your mom or your dad had cancer. My daughter doesn't remember, it was when she was 18 months old.

She just, okay, every year we go to this lung cancer walk and mommy has lung cancers. And she didn't even know what cancer was at that point. It has been very unique, I think.

Raising a child where all she's ever known is that I have lung cancers. Now that she is in middle school and actually understanding cancer. She used to be real open about talking about it with like her teachers, making sure her teacher's new.

Yeah, my mommy's got lung cancer, but now she's like, I don't know if I want to tell them. I have a 12 year old also, and it's challenging, you know, to go through that.

And I just turned 46. So my kids are a little bit older ones are in high school. My oldest is finished highschool and my youngest is 12. It is interesting to kind of talk to all them and just say like well, This is the reality, but we're still going to go on.

We're going live life and try to just make good choices because you can't know the future. My wife and I talk about that all the time. It's like, well, I can just not live.

we are just going on and let's not take on some crazy debt that's going be like a 40 year loan or something. But let's go ahead and just have the activities, go on the adventures, do whatever it is that presents in front of us, so we live fully with all the time that we have, because the amount of time we that have even before a cancer diagnosis is unknown, you can't know.

Somebody told me that time is the currency we spend without knowing the balance. And it's true. You don't know how much time you have left, but especially with a cancer diagnosis, a metastatic cancer, you say like, well, I will do the very best I can with what I've got, But I cant know the future and it'd be handy if we did.

But man, Gwen, when I see your story, it just inspires me. Like, okay, look, Gwenn's doing it. Gwen. I just think it pretty cool. like you figured out a way to just go on even with the uncertainties of cancer.

And I think it's pretty neat. Tell us a little bit about, you made this decision not to really put money into an investment or a retirement account early on because it seemed like it was a bit futile if you weren't going to be around long enough to use it.

And then I know in that Wall Street Journal article you mentioned, okay, now I've decided to go ahead and look forward to the future. So how did you go through that transition, that switch?

Well, it's still a decision that I'm not really sure if it was the right one, but it has beneficiaries on it. So if something does happen, the money is still going to be where it supposed to.

You know, since I am a teacher, I do have the state pension. I did decide to open a Roth account over the winter last year. I think it's smart. No, I, think is smart and I thinks that it reflects the idea that you're here and you plan to go on.

Like none of us can really know, but the, idea of it, even though the future is uncertain, you've been able to find a holding pattern and just hope that, it will keep on keeping on for a long time.

I was just going to say that in 2017, so two years after I surviving with cancer, my husband and I decided to buy a camper and go cross country with our four-year-old.

I don't recommend, because it was an eight-week trip and a camp with a four year old. And it just a travel trailer. So it wasn't even the fun time where you can play around while you're driving.

She had to sit in the car seat.

Living and Teaching Through Cancer

But we did go over and made memories for me and my We had talked about it a long time before my diagnosis about getting a camper, because my husband grew up camping with his family.

And at one point I was like, let's go ahead and do it. Let's just buy the camper. Things like that. We do take trips. My husband's also an educator. He's a middle school science teacher.

So we have the same schedule. we both have our summers off. so we do try and take summer trips And spring break trips, we went to Universal this last year.

We're going on a cruise over Christmas. And I think even if people don't have cancer, you should just live your life to the fullest. I don' think people should go into tremendous debt to have wild experiences.

But if you just save as you go along, man, go have the trips. Go have these experiences, do stuff because you don''t know. Like I said, time is one of those things.

You don's know how much we have left. you're leaving a legacy for your daughter and also for students. Like you say, over the course of a decade and hopefully decades to come, you will have had a direct influence on many hundreds, if not thousands of students and then that goes on to that ripple effect of influences them and their families and so many people.

And I think everybody, me included, we can think back to people who, teachers we had in high school that had

tremendous impact on how we interact with things and see things.

And you've done this as a coach for Track and Field. Those who are on the YouTube video aspect of this can see Gwen Strong on your t-shirt. Tell us about that.

So every year locally here in Raleigh, the Lung Cancer Initiative puts on a 5K for lung cancer survivors. It's a fundraiser for them. They support lung-cancer researchers and are actually a patient support group.

but we put together a team of people to do a 5K. The past few years I've walked it, but at the very beginning, I actually used to run the 5k. I can remember some of them that I was the first female survivor to finish the five K.

It's been crazy. That whole experience to think about other survivors that have to carry around the oxygen tank or people that had been there the year before that are no longer there because they have passed away.

And it's just crazy to be actually running during that event and knowing that I'm well enough to do that. Your team is called Gwen Strong. Are those primarily made up of people in your family or do you have some of your students or your high school athletes running it or who participates in Gwen strong?

It's usually a lot of my family and close friends, a lotta my coworkers will come out and run with me. But since my school's over in Clayton, and this is an event held in Raleigh, I don't get very many of students to join.

Well, it's a really cool thing you do. I appreciate you sharing this. One of the questions I wanted to ask you is, you know, so you've lived this experience for a decade.

You've tried to impart this knowledge to students and others in your sphere of influence. inspirational I read that and when you have these moments of uncertainty and doubt you say well I'm not the only one look what Gwen is doing look at these other people who have figured out a way to live with cancer what advice would you give to others who are facing a similar diagnosis themselves or to their family members well every person's different every cancer is different like my doctor told me don't look try and keep a positive mindset and be a self advocate.

Sometimes you need to speak up for things that you are feeling or things you know that are right for you and your family and just be there for each other.

One of the reasons I kept working was because I knew that if I was at home by myself, all I would think about was the cancer diagnosis and only my mind would take me to bad places.

So I knew I had to stay active and keep with my routine and try and carry on like I didn't have cancer. Carry on, like everything else was normal. It worked for me.

I tried to give that advice to my uncle who was diagnosed in December of last year and he's not having the same experience. really depends on the case, I guess.

Yeah. I like the idea that you just try to live the best you can with what you've got and don't give in to despair, but say I will do everything I can to keep a positive mental attitude.

And then another thing that I think is interesting in your case Gwen is a lot of people would say, well, the only things that are available to me are things in my own little media area, You were willing to travel.

Family, Travel, and Making Memories

You've been able to go see whatever needed to be done and try to find wherever the most cutting edge research was, not just for yourself, but for your family and others who count on you.

And that's an interesting part of the story too, to to able find a way to, travel to Boston every single month for years and years. That's a tremendous expense.

Like you mentioned before we hit record, think about all the trips you might've gone on if all of the funds weren't going toward traveling to and staying in Boston every month.

But you've gotten to know Boston really well. Yes, to the point where I'm like, I have to go to Boston again. I was fortunate enough, they found the tumor in the back of my eye in September of 2014. As you may be aware, open enrollment for healthcare and the extra little benefits like the cancer policies and stuff.

You can sign up for those in October. So I was like, well, let me just go ahead and signup for that cancer one, just in case that thing in my eye is a tumor.

I had no idea that it was lung cancer. Everything was fine. Like I could breathe fine, I've never smoked a day in life. It can't be lung Blunt cancer was the last thing I thought the tumor in my eye was.

But I was like, let me just get this cancer insurance. So the policy I have actually refunds me for my travel and they'll pay for companion. I always bring a friend or I just brought my brother last time, went to a Red Sox Yankees game up at Fenway.

That was an experience of a lifetime for sure. I try and make the best of it. But when I was first thinking about going to Boston, I said I would do anything to stay around for my daughter.

I think that was a huge motivator, was to make sure I here for her. Yeah. Well, thank you for sharing that. In that same vein, what advice would you give to others who have children?

Like I told you, you have a 12-year-old, and it's kind of hard to say, like, well, i've got metastatic cancer. Because then there are immediate questions, where are you going And you think, well, I'm sure going to try, but you can't know, like nobody can.

What advice or what experiences would you share with others, people who are dealing with that? They've still got kids at home and there's so much uncertainty with cancer.

You have any advice for other parents who were dealing a similar situation? I would just advise you to make memories with the kids. That's the only thing I can think of because I was saying earlier, my daughter hasn't known anything different.

My story's a little bit different. I was diagnosed when she was so young, but just make memories. My daughter has made other friends with kids who have lost parents due to cancer.

And I think her friends remember the fun trips they had. Doesn't even have to be a trip. Go to the park all the time or Saturday morning donuts. Yeah, make the memories, have the experiences.

Gwen, you're like this silent hero. You know, You have done this stuff. you are not a person to just be full of rage or frustration. And yet your story is heroic.

challenging, uncertain time. You're still coaching and teaching and leaving this impact and this legacy. And you've taught us the importance of having financial preparation.

Get financial tools like insurance in place early on. Have the experiences while you can. Don't lose hope and just don't despair. Keep going even when times are challenging.

don t be afraid to share your story because probably somebody else out there is having something similar. And then to just bravely, quietly go on, even with a challenging disease, like it may not seem like much when you're living it day by day, but for others who watch that, I'm certain of this in your own circle.

And those who have come across your story through a news article, and I am certain others will listen to this, will derive the same sort of inspiration.

This is a person who just quietly goes on and lives life. And I also think if you're entering in phase one trials with your folks in Boston, I mean, you going to be one of their superstars, like someone that shows up and fights the fight.

That's why they go to work. Why they do it is because of someone like Gwen O'Reilly that still goes on and their research and work has this long lasting impact that goes out and extrapolates across a lot of different people.

So thank you for what you are doing. It's pretty remarkable actually. Well, thank you. That was all very nice. I just have complete trust in my doctors.

So if they tell me that, hey, this drug looks very promising, I say, okay, let me try it out. Yeah. trying to find blood samples. They were testing something in my blood.

I don't even know what that was. It was like, sure, sign me up. The podcast is called Doctors Making a Difference.

Advice for Patients and Parents

Most of our episodes are about doctors who are doing just that. And as I've talked to physicians all over the place, the thing that really drives physicians, that thing, really motivates all of us to keep doing what we're doing is the patients.

It's the stories of individuals who got this huge benefit from something you did. Because everybody starts off in middle school or high school saying I want to be a doctor, I wanna help people.

And then maybe you get a little bit lost along the way because it gets so chaotic and busy and you're so frustrated with the insurance systems and all the different complexities.

But when it really boils down to what kind of impact am I having, It's individuals who benefit from that. So you're one of those, you know, You've been able to do it.

One of your students in your school that you've taught, you make them study cancer every November, one of them is going to go on and say, hey, we're going keep changing this.

We're gonna change the trajectory for cancer patients. So that metastatic cancer is not always a death sentence, but is instead something you can live with more like a chronic disease rather than something that's going take your life.

What happens to Gwen Aurelio next? What comes next for you? Like you've had all these really impactful, amazing life. You've a decade of uncertainty, but you're still gone on.

What do you see coming next. Just keep doing the same. I'm hoping to retire in 10 years. All right, I'll have 30 years in. Actually need nine and a half more.

That's another thing. Like I really excited about trying to get to retirement, Am I still gonna be around? Like every now and then, like when I'm real dark.

I don't know, should I just quit teaching now? I got nine and a half more years, I can do it. Yeah, well, thank you for what you're doing, Gwen. Like I said, it's tremendously impactful to a lot of people.

I appreciate you sharing your story. And I encourage folks who want to read about Gwen in the Wall Street Journal to do so. If you search up Gwen Aurelio on WallStreetJournal, you'll find it!

I'm the only Gwen Arrelio here, and I think I am the one in this world. So just Google my name. There you go. It will pop up. No, that's inspiring, Well, and I appreciate you sharing any final words or things that you would want to share with our audience as we wrap up here.

The questions you had listed for me, you have asked about a horror story. So I'm just going to, my current worry right now is that the insurance that I am provided by my employer, the state of North Carolina, It's trying to drop the coverage from the hospital that I've been going to for 10 years.

I'm worried about what that's going look like if they actually do drop that and they will become out of network. It will cost me like $18,000 every time I have to go get a scan.

That is my big major worry right now. Gwen, you've hit on something. That's a podcast in and of itself. Why do they have to be so mean is a good question.

And I think sometimes on the physician side of it, it can be frustrating. You know, a person needs X, Y or Z or they found a specialist that really is helping with what they've got going and then suddenly somebody in some place that's far away makes a decision that has a tremendously negative impact.

It seems like they hear the stories but don't really respond and it seems we're in a changing insurance landscape where we are a little bit more focused on investors and financial incentives rather than patient outcomes.

And I think as a nationwide push, we all need to push back against that and say, look, insurance is supposed to be about patients. and make sure that we continue to offer patients this excellent healthcare system that We've developed, but we don't want to leave people out just because their insurance system decides to make an arbitrary decision that really has a negative impact.

It's a challenge. What have you found to be successful when you've had insurance challenges like that? Luckily, I haven't had any challenges. We'll see.

At the end of October, i'm going to find out if I need to find a new place to get scanned, which I really don't want to do. Like, I just scheduled scans this morning.

That's what I did. I was on my to-do list before this call. Since I am a teacher and we have today off from students, it was actually able to hit my personal to to list.

Insurance Concerns and Closing Reflections

And one of those was to schedule my scans. All I had to was call the hospital that I've been going to for 10 and a half years. My one guy, he's like, I'll take care of you instead of having to call the call center and I get three scans done at the same time.

I want them all scheduled between this time and this and they're like oh, well we can't do that. But the guy that I've been going to for 10 and a half years, He gets it done.

And I wanna stay with this guy. Wanna stay the people that know me that have been on this journey with me. I appreciate that call out. We need to make sure we raise awareness of these issues because insurance companies, I mean, always tell my patients it's the golden rule.

Whoever has the gold makes the rules. And unfortunately, you know, in our healthcare system, a lot of those decision makers are not clinicians and not patients.

There's a third party middleman, which is insurance and we need insurance, and there's a lot of benefits to having medical insurance. But if insurance companies become so profit driven that they forget to take care of patients, then it's easy to lose sight of what that is actually all about.

So I appreciate you sharing that. Any other insights that you thought of, Gwen, that would you want to share with our audience? I would say if you know anyone that's got cancer, reach out to them.

They like to be remembered. Yeah, remember, exactly. Make memories with them. Yeah. Don't forget. Maybe the

other big point as I've listened to your story, Gwen, is when somebody gets a metastatic cancer diagnosis, don't immediately have your next thought like, oh, well, they're going to die because that's not always the case.

Keep going with life because life is precious. Every single breath is pressure. You want to live it to the fullest and it sounds like that is what You have done it.

I really appreciate you taking the time to share with us, Gwen. It's been inspiring. And I just hope that things go really well for you and your little family.

Appreciate you being willing to the share kind of on a little bit larger scale, the work that you're doing, and I wish you the very best. Well, thank you for the invite.

Have had a great time. Keep in touch, Gwyn. Thank you very much. Thanks for tuning in to the Doctors Making a Difference podcast. And thank you for what you do to help your patients and your community.

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