



MBC Perspectives Webinar: Scanxiety

ASHLEY:

Hello and welcome to our webinar.

My name is Ashley and I will be facilitating today's conversation sponsored by Pfizer.

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We are very happy to have two of our Ibrance Ambassadors here with us today to talk about their experiences.

Chris and Ruth know what it is like to face metastatic breast cancer or mBC and the associated treatments, tests and emotional burdens that go along with it are something they are very familiar with.

If you have questions for our Ambassadors during our presentation you can submit those using the Q&A box and we will do our best to address as many questions as possible following today's webinar via a follow-up email.

Please note that for any questions in particular about Ibrance or how Ibrance works you should speak with your doctor.

Thank you again for tuning in to today's webinar on battling scanxiety, how those in the mBC community describe their feelings of anxiety over their regular imaging scans and necessary medical tests.

There can be a lot of stress when facing these regular tests and waiting to hear the results.

Chris, Ruth, thank you so much for taking the time to share your journeys with us today.

We're really glad to have you here.

RUTH:

Thank you.

CHRIS:

Thank you.

ASHLEY:

So, let's start this discussion off with a brief introduction. Chris and Ruth, why don't you tell us a little bit about yourselves.

RUTH:

I'm a special education preschool teacher.

I'm a theatre and music lover.

I write.

And I'm the mother of two teenage boys.

I've been raising them alone for ten years.

My husband suddenly passed away.

And that was about three years after my initial breast cancer treatment had ended.

I was diagnosed with metastatic breast cancer and my mets are in my liver.

And it was a brutal diagnosis.

Um, my doctors recommended I take IBRANCE in combination with Letrozole in order to fight the disease.

My sons are in high school and college.

And I'm living each day hoping to see them both graduate.

ASHLEY:

Thank you.

CHRIS:

And my name is Chris and, outside of being a metastatic breast cancer patient, I'm also the wife to my husband Fred.

We've been married now twenty-three years this month and we have two boys.

My oldest will be starting college in fall of 2021 after getting back from spending a year in Thailand for his senior year of high school.

And then my younger son just started high school and is a freshman.

I was diagnosed de novo with metastatic breast cancer.

It has spread to my bones and I have retired from healthcare administration shortly after my diagnosis.

And I retired the same time that my husband was finishing treatments for follicular lymphoma.

So, our boys already have experience in the cancer world by seeing my husband, their dad, go through cancer and then my diagnosis of mBC.

And, really, one of the other reasons I retired was to spend time with the family and make everyday count.

And I also have more time now to help out.

I'm very active in our church and other community groups in town.

ASHLEY:

I'm so excited to welcome you both to this webinar.

Let's go ahead and get to the heart of the matter.

I think would you both mind sharing sort of what your initial experience getting scans was like?

Do you find that your doctors prepared you for the reality of facing these frequent tests?

RUTH:

I don't know that anyone can truly be prepared for the first round of scans.

The hard truth is that, going in, you already know that you have cancer and the scariest part is that the scans are looking for more sites and to get an exact idea of the tumor quantities and the sizes.

So, once you've been told you have cancer and you're not likely to have surgery, it's really hard to reconcile that there's no escape.

This is part of the deal now.

And you don't get a pass from cancer.

CHRIS:

My initial scans were around confirming my diagnosis of mBC.

When I met with my oncologist, they were ninety-eight percent sure of what I had, but the scans were going to follow up and confirm my diagnosis.

So, I want to say during those initial scans, that first month or two, I was in a complete haze, fog, just trying to absorb what having mBC looked like.

So, I did not know the difference between a CT, an MRI, or a PET scan until I actually went through them.

So, now, getting the scans, they don't bother me.

I know that when I go there, I know what to expect, given the type of scan that I'm scheduled for.

And I know that my subsequent scans are now looking to see that my cancer-- if it has progressed or if it has stayed the same.

So, like I said, it doesn't bother me to go into the machines, to drink the contrast.

What I have anxiety over the most is the results and waiting for those.

RUTH:

And, Chris, I think that's interesting that you feel more of your anxiety after the testing, because I definitely feel more anxiety leading up to the tests.

CHRIS:

Yeah.

And that just shows you that two people's journey with the same disease can be so different in how we handle the same topic of scan anxiety.

ASHLEY:

That is extremely interesting.

And, on that topic, who can the two of you talk to about your scanxiety?

Have you discussed it with your doctor, or do you have anyone else in your support system that stands out to you?

RUTH:

I actually don't think I'm good at talking about these things with people.

My best connections have been with women who also have mBC.

I'm not really great at sharing.

I always worry about the other person when I do that.

Because I'm widowed and an only child, and I don't have parents that are living, I have good friends, though.

But I wouldn't say I go deep and dark with my fears with many of them.

I think that's what I use my writing for.

It helps me a lot.

But I do tell my friends when I'm having a day of scans and I ask, you know, for good thoughts.

And they do send me jokes.

So, I just want to say I don't recommend not sharing or sharing.

It's just whatever you're comfortable with and it is definitely subject to fluctuation.

CHRIS:

Yeah, I think around that my doctor and I have had discussions around expectations.

I know his expectations around my treatment, and I think by now he knows my expectations with living with mBC.

And we work good together as a team.

And, as far as-- I do have a good family, a strong family and friend support team.

So, I've been fortunate not to go to an appointment or a lab draw or a scan without someone going with me.

And I know that my friends and my sister-- my family, they have sat me down and said they will support me one hundred and ten percent.

But there are going to be times where they can't fully understand what I'm going through, because they've never done it.

They haven't gone in for scans.

They don't know what it's like to live every four to six months trying to wait and maybe get different news.

They don't know what it's like to live that way.

So, even though everyone is very supportive and always tries to keep my mind busy and off any news that I would get, they know that sooner or later, we're going to run into times that they just can't comprehend everything that I'm going through on a day-to-day basis.

ASHLEY:

Thank you for sharing that, Chris.

So, what's the importance to both of you of having a good medical team who treats every part of mBC, both the physical and the mental aspects of it?

RUTH:

Um, I think I do more compartmentalizing of my physical care versus emotional care.

I have a therapist, who's amazing.

She saw me through grief counseling, and she's seen me through my diagnosis of mBC.

She has moved further away, and we have started talking about moving to remote sessions.

And that's where I am right now.

I feel like I'm transitioning to do-- get more back into the self-care.

And I also write and am writing about life with mBC.

CHRIS:

And I have-- you know, just like Ruth, I have a really good medical team and a relationship with my medical team.

It's not just my oncologist.

It's breast care navigator, it's his nursing staff.

But I, also, you know-- and we rely on each other.

You know, I think that my oncologist always tells me that the longer I live with it, the more I'll understand and get to know the world that I live in.

And to look to see how far I've come-- you know, initially, when he told me I had metastatic breast cancer, I must have cried six months of that first diagnosis.

And every time I walked in and saw him I cried.

And even understanding that breast cancer can move outside of the breast-- I mean, I remember him telling me I had cancer and it was in my bones.

So, I, for months, thought I had bone cancer, not realizing that breast cancer can move outside of the breast.

And the only thing I knew about breast cancer is that some people had lived with it a long time and some people did not.

I did not understand the difference.

So, when I look back at from when I was originally diagnosed to crying all the time, to look where I am today, I mean, I've met Ruth, I'm doing a webinar on scan anxiety, and I'm not crying about my diagnosis.

So, my physician has taught me a lot along the way.

And I joke with him now-- because when I first met him, I don't want to say it was like this wonderful love relationship with your oncologist.

Because he was very clinical-- came in, sat down, "This is what I think you have. This is the statistics," and I didn't like what he had to say.

And I walked away from that appointment not sure how I felt.

But now that we've been together for quite a while, he understands what I expect from him and, you know, vice versa.

It's taken a lot of growing on both of our parts.

I think now he knows that I'm not just a metastatic breast cancer patient.

I'm a patient that is interested in her treatment options and want to know what's out there and I understand how he practices.

And he is a lot more down-to-earth.

And we've both come a long way.

ASHLEY:

So, Chris, Ruth, clearly, it's important to stay up to date with tests, even with the accompanying scanxiety, anxiety. What helps you to stick to regularly scheduled scans and remember their importance in your lives?

RUTH:

I think that you can go in either extreme to scary medical news.

So, one extreme is to wish to go to the doctor all the time, have as many tests run as possible.

And then I think the other extreme is to avoid the doctor and to avoid getting your tests and to avoid bad news.

And, as much as I hate the scans, and as scary as they are, I actually want to go.

I know that there are changes in my diagnosis-- if there are changes in my diagnosis, the earlier detection can only be better than finding them out much later.

CHRIS:

I agree with Ruth when she says you get to that point is-- you know, should I get scanned or should I not get scanned, especially when you've had a change in how you're feeling.

Or I know, in my case, it's been sometimes I've had a side effect that may or may not be a result of my treatment.

And my boys are especially on top of me, that if I'm not feeling good, they want me to get scanned.

They want me to know right away what's wrong.

And, for me, my scans are scheduled every four to six months.

So, I really don't have to think about them. If something changes and I need to get a scan earlier, I talk to my oncologist.

But that's probably the hardest part is outside of my scheduled scans, when should I request one?

When is just a side effect a side effect and is it a cause of treatment or is it not?

And that's the discussion I have with my oncologist.

ASHLEY:

So, my next question to both of you is what helped or still does help you combat scanxiety when you have a scan scheduled?

What are some good resources for you that you'd care to talk about?

RUTH:

I have sometimes promised myself a drink after-- I don't know if you'd call that a resource-- at a cute bar by my hospital.

I always tell enough people that I'm going to my scans, so, it's okay for me to text here and there if I need to.

It can be test-related.

It can be scanxiety issues or I can notice something.

One day I got into an elevator and I spotted a celebrity, so I told everybody.

So, just things like that that kind of take me out of the anxiety of the moment, take me beyond the walls of the hospital.

And it reminds me that the scans will be over soon.

Mine are long and can go up to six hours just depending on how far apart they're spaced.

So, it starts to feel like I'm just never going to leave.

So, sending and getting texts has been very helpful.

And I think with things as terrifying as scans for cancer, there's-- for me, there's a disconnect between my emotions and my cognitive intelligence.

So, I tend to feel like if a nurse has trouble finding a good vein, maybe it can feel like the tests are going to go badly or feel like something's wrong.

And I try to tell myself, you know, "The hospital-- things run late. It's not a-- it doesn't mean anything. It's just things aren't going smoothly as you'd like them to."

And, so, I try to tell myself to listen to my brain more than how things feel, which isn't easy for me, because I'm a pretty emotional person.

But it's something I feel like I'm practicing as I go for more and more tests.

So, it's getting better with practice, that I don't let myself get emotionally overwhelmed for the testing.

CHRIS:

And, see, for me-- because Ruth pretty much has a whole day for scans and her tests, where mine are pretty much in and out.

I mean, if I'm there for an hour, two hours at the most-- so, my scans are pretty fast.

So, like I said before, I've been pretty fortunate to have people come with me to my appointments.

So, you know, they'll come with me.

They can't, obviously, go in the scan with me, but they're there for support.

And then we'll go out, do something.

Sometimes I just want to do things for myself, get a massage.

Most of the times, it's just come back home.

You know, everyday life still goes on, still have to get laundry done.

Still have to make dinner for the family.

So, I try to stay present, you know, even though it doesn't always combat my stress levels, it just keeps me where I need to be without sitting there holding my phone waiting for those results to come through.

ASHLEY:

Thank you for that.

What is it like when you receive results from your test that aren't what you expected? What do you experience?

RUTH:

On my third round, I when I kind of started to say, "No, I can-- I can do this." I was getting good results.

My third round of tests, I got back some truly terrifying results from a CT scan and it stated that I had more tumors had appeared and that the existing tumors had increased in size and I was at work when I found out and I just could barely function.

The hospital responded very quickly.

They got me in for an MRI the next day.

And, you know, it just turned out everything was good.

My CT scan had been misread.

One of the adjustments my team has made as a result is I don't get that CT scan for that part of my body but I go straight to an MRI each time.

And so, I'm really grateful for that.

For where my cancer is, the MRI is much more definitive and so I feel more confident with my tests now and I appreciate that.

CHRIS:

Well, unlike Ruth, I have not had bad results from a scan.

I'm happy to say that my scans have been good.

So-- but that doesn't mean that I don't fear progression.

I mean, it's always in the back of all of our minds and it doesn't mean that I don't keep up with what's in the mBC world, because I know sooner or later I'm going to have progression, but I try not to obsess about it every single time I go for a scan.

You know?

I know it's in the back of my mind.

I get the scan.

When my results are good, then I'm good to go for another four to six months.

But I always try and stay active in what's going on, because when that time comes, I have those questions to go over with my oncologist.

ASHLEY:

To reverse that, I'd like to talk about what it's like when your scan results are good.

I'm sure there's a bit of an emotional shift to go through sort of all that anxiety and then see that your treatment is going the way you expected and going well.

RUTH:

So, the relief when I get news that isn't bad, it's huge.

And I always cry.

I cry with relief and then I tell everybody who knew I was going in for the scan that things are good.

And I've asked people to let me tell them and to not ask.

CHRIS:

Yeah, that's a-- I just breathe a sigh of relief.

You know?

And I do text my core group of friends and family and let them know what my scan is like and then we just move on with life and I know I'll have another one scheduled in four to six months.

But it's just that wave of relief that washes over me and then I don't even think about it until the next one is scheduled.

ASHLEY:

Ruth and Chris, what advice would you give to others facing scanxiety?

What do you experience that you think you can share that might benefit others?

RUTH:

I think for people who don't go through the process of scans that are literally to see how the rest of your life is going to be, at least till the next set of scans, it feels like the scans are contributing to possibly making you sick or to outing your cancer and further messing up your lives.

I mean, it feels like the scans are actually enlarging the problem.

Of course, it's not.

But the whole process of scanning just sucks.

So, it's supported in the process that that's what it feels like.

So, like, I go to four different locations within a building.

Sometimes a few buildings, depending on where my scans are.

I'm in tunnels.

I'm on tables.

I'm injected with dyes.

And, you know, it just goes on and on and on.

And, so, even if the stakes weren't so high, it would be a yucky day.

It would-- you know, it's just not a fun day anyway.

But I just try to remember that even if I do get difficult results, better earlier than later.

Sooner rather than later. And I think, as far as the day goes, everybody has to decide how to handle it.

I've taken a friend before and it was great.

But, after that, I've kind of decided it's just easier to go alone.

I don't have to talk.

I can read a book.

I can check my email.

I've even had gaps that were long enough that I could find a spot, watch something on my phone maybe.

I can go where I want for lunch.

So, I usually just prefer to do it solo, because I don't then feel like I'm having to kind of help somebody else with the day.

It's just easier.

And I get why we say, "scanxiety," but, to me, the stakes are so high it's actually beyond anxiety.

It just-- the stakes can't be higher.

It's about your life and surviving.

So, I think, you know, allow yourself your feelings.

And I've actually learned to tell the medical people if I'm, for some reason that day, you know, not handling it, I'll tell whoever.

It could be a nurse, somebody I've never met before.

And they've been able to, like, you know, talk me down and tweak me together to get me ready.

So, I just am very open about it.

My big advice-- and I'm a hypocrite and I've learned the hard way-- is to not decide on the day of your scans that you might have skills as a radiation oncologist.

And I have been guilty of that.

I've tried to peak over shoulders.

I try to read their faces.

I try to figure out what those images mean.

And it'll make you crazy.

I think one thing that's always disconcerting is when you think you're finished and somebody says, "We need a few more images." And just tell yourself it doesn't mean that you have worsening circumstances.

It can mean that they goofed up.

It might have been that you didn't breathe like they wanted you to.

It could have been a slight movement.

You just don't know.

Or something in your body's covering where they want to see.

So, don't try to guess what your outcomes are on the day of the exams.

And if the results are delayed, that doesn't mean bad news either.

So, it's always trying to figure things out and it's something Chris talked about that she's not in control of it.

What's really hard is there's a surrender that you have to-- you just have to give it up.

It's not yours to manage that day.

You're trusting a world of professionals and medical people to help you.

And it's your dynamic and whatever helped you during one set of scans might change next time.

So, I just always acknowledge that it sucks, but then, you know, try to dig deep and find that gratitude that you're being looked at and that the whole spirit of this is to keep you as healthy and living the best life that you can.

CHRIS:

Yeah, and that's exactly what-- Ruth hit the nail right on the head, that getting-- I don't know if getting scans gets easier or harder, but all I know is that it's part of my life.

You know, just like getting up, making the beds, doing-- making dinner.

I get scans.

And I will continue to have scans.

And there's nothing that I can do about it.

And I know that it is there to watch my cancer.

I've had good scans, you know, to-date.

So, that's something that I'm very grateful for and then just know that the scans that I continue to get are just to be proactive and watch where I am now and watch where my cancer is going to go.

I know a lot of people have advice for everyone going through it.

I've even heard people say, "I don't know how you do it," and "I could never do that." Well, you could.

You know, when you get a diagnosis like we have, you learn to live with it.

You have to live with it.

It is your new normal.

So, it's exactly what you have to do.

There's nothing you can do to change it.

It's always about how you react.

And you learn exactly how to live with it.

And if you have questions around your scans or if you have concerns or anxiety, that's when you talk to the people going through it.

I've always found it helpful to surround myself not just with my network of support, but, also, surround myself with women going through the same thing that I am.

You know?

So, if I know that I have a scan coming up that I'm worried about, connect with someone else that either you've met in a social media group or maybe a support group, because everyone goes through the same thing and we all have to be there to support one another.

So, know that-- and it's all cancers.

You know?

I can even talk to my husband about it.

My husband had scans.

He knows what it's like.

So, he knows how I feel.

So, it's good to know people that are going through the same thing as yourself, because you sort of lean on each other.

And there are strength in numbers.

And the more people you surround yourself with and-- the more support you get.

And your oncology team is another good resource to have.

ASHLEY:

Chris and Ruth, thank you so much.

Thank you so much for all of your insights and for speaking so openly about a really, truly difficult topic.

We appreciate you.

As I mentioned at the beginning of our webinar, if you have more questions for our Ambassadors, you can submit those using the Q&A box at the bottom of your screen.

And we will do our best to address as many as possible after this webinar.

If there are any questions that we don't answer, we will do our best to follow up via email.

Now, please note, that for specific questions about IBRANCE and how it works, you should speak with your doctor.

ASHLEY:

Thank you all for taking the time to join us for our webinar today.

And a special thanks to our guest speakers, Chris and Ruth.

CHRIS:

Thank you very much.

RUTH:

Thank you.

ASHLEY:

This concludes the webinar.

Please stay tuned to fill out a brief survey about our session today.

We greatly appreciate your feedback.

And for more information about IBRANCE and the Ambassadors, you can visit Ibrance.com or find us on Facebook.

Now, we'll be sharing some important safety information about IBRANCE. Thanks again!

VO

IMPORTANT SAFETY INFORMATION &

INDICATIONS

IBRANCE may cause serious side effects, including:

Low white blood cell counts (neutropenia). Low white blood cell counts are very common when taking IBRANCE and may cause serious infections that can lead to death. Your healthcare provider should check your white blood cell counts before and during treatment.

If you develop low white blood cell counts during treatment with IBRANCE, your healthcare provider may stop your treatment, decrease your dose, or may tell you to wait to begin your treatment cycle. Tell your healthcare provider right away if you have signs and symptoms of low white blood cell counts or infections such as fever and chills.

Lung problems (pneumonitis). IBRANCE may cause severe inflammation of the lungs during treatment that can lead to death. Tell your healthcare provider right away if you have any new or worsening symptoms, including:

- chest pain
- cough with or without mucus
- trouble breathing or shortness of breath

Your healthcare provider may interrupt or stop treatment with IBRANCE completely if your symptoms are severe.

What should I tell my healthcare provider before taking IBRANCE?

Before taking IBRANCE, tell your healthcare provider about all of your medical conditions, including if you:

- have fever, chills, or any other signs or symptoms of infection.
- have liver or kidney problems.
- are pregnant or plan to become pregnant; IBRANCE can harm your unborn baby.
 - **Females** who are able to become pregnant should use effective birth control during treatment and for at least 3 weeks after the last dose of IBRANCE. Your healthcare provider may ask you to take a pregnancy test before you start treatment with IBRANCE.
 - **Males** with female partners who can become pregnant should use effective birth control during treatment with IBRANCE for at least 3 months after the last dose of IBRANCE.
- are breastfeeding or plan to breastfeed. It is not known if IBRANCE passes into your breast milk. Do not breastfeed during treatment with IBRANCE and for 3 weeks after the last dose.

The most common side effects of IBRANCE include:

- Low red blood cell counts and low platelet counts. Call your healthcare provider right away if you develop any of these symptoms during treatment:
 - dizziness
 - shortness of breath
 - weakness
 - bleeding or bruising more easily
 - nosebleeds

Other most common side effects include:

- infections
- tiredness
- nausea
- sore mouth
- abnormalities in liver blood tests
- diarrhea
- hair thinning or hair loss
- vomiting
- rash
- loss of appetite

IBRANCE may cause fertility problems in males. This may affect your ability to father a child. Talk to your healthcare provider about family planning options before starting IBRANCE if this is a concern for you.

Tell your healthcare provider if you have any side effect that bothers you or that does not go away.

These are not all of the possible side effects of IBRANCE. Call your doctor for medical advice about side effects.

Tell your healthcare provider about all of the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements. IBRANCE and other medicines may affect each other, causing side effects.

Know the medicines you take. Keep a list of them to show your healthcare provider or pharmacist when you get a new medicine.

Do not drink grapefruit juice or eat grapefruit products while taking IBRANCE as they may increase the amount of IBRANCE in your blood.

Tell your healthcare provider if you start a new medicine. Take IBRANCE exactly as your healthcare provider tells you.

If you take too much IBRANCE, call your healthcare provider right away or go to the nearest hospital emergency room.

Please see Full Prescribing Information and Patient Information.

This video is for U.S. residents only and is intended to be viewed as it was originally produced by Pfizer. The information provided is for educational purposes only and is not intended to replace discussions with a healthcare provider.