

Find It Early Webinar Transcript

00:00:06 **Adele Costa**

Welcome and thank you all for joining us today for the Find It Early Webinar, a free educational event about recent changes to breast cancer screening recommendations and access policy, sponsored by the National Women's Health Network and DenseBreast-info.org. I'm Adele Costa, the Director of Communications for the Network, and I'll be your MC today.

00:00:25 **Adele Costa**

A couple of quick housekeeping things. We do have a staff person monitoring the chat, so that's where you can direct any technical assistance or topical questions. However, we will not be able to answer questions about breast cancer live on this call. We will be sending out a post event FAQ document to all attendees that address questions posed in the chat. And if you're listening to this recording, you can send any questions you have about breast cancer to alerts@nwhn.org. It is now my distinct pleasure to introduce our panelists. Congresswoman Rosa DeLauro is our keynote speaker today. DeLauro introduced the Find It Early act earlier this year. This is federal legislation that, if passed into law, would ensure all health insurance plans cover screening and diagnostic mammograms, breast ultrasounds and MRIs at no cost to the healthcare consumer. Joanne Pushkin is the executive director of Densebreast-info.org. Pushkin has written dozens of educational courses, articles, grants, and speeches

00:01:31 **Adele Costa**

on the topic of breast density and its relationship to breast cancer risk. She learned of her own breast density's masking effect on her mammogram after finding a palpable lump which went undetected by mammography several years in a row. Ms. Pushkin's advocacy has helped see many state and federal laws passed that have increased access to high quality breast cancer screening services, such as New York State's Breast Density Informed Bill and the FDA's Mammography Quality Standards Act. And last, but certainly not least, Denise Hyater-Lindenmuth is the executive director of the National Women's Health Network. Hyater-Lindenmuth is a public health expert and the former executive director of the American Cancer Society. She received a crash course in this issue when she was diagnosed with an aggressive form of breast cancer by chance in 2011. Although she'd been dutifully getting mammograms for years, it was self detection that brought her into the exam room after an unrelated Achilles tendon

00:02:29 **Adele Costa**

injury caused her to contort in a resting position that helped her feel a hard to find lump. A warm welcome to all of you. And now, without further ado, my first few questions are for Congresswoman DeLauro. Congresswoman, hello. It's an honor. So, my first question so for those of you who may not be familiar, the US. Preventive Services Task Force is an independent volunteer panel of national experts in disease prevention and evidence based medicine. Can you talk more about how this task force's recommendations have informed the cost of breast cancer screenings and how the Find It Early Act attempts to fix these issues?

00:03:10 [Congresswoman Rosa DeLauro](#)

Sure. First of all, let me just say good afternoon to everyone and want to say a thank you to you, Adele. As the director of communications. And I give a shout out to you, to the team that you are in charge of really helping to shape people's understanding of health policy, but also strategically shaping policy and being able to access accurate, unbiased information across the country. I also want to just say recognize JoAnn Pushkin of the densebreast-info.org critical, really. And I have to say thank you for help in drafting the Find It Early act and to make sure that we got all the details right in that effort. And Denise, to you as executive director of the Health Network. So I really am so delighted to be partners with all of you in this fight and just this personal point. I'm a 35 year cancer survivor, ovarian cancer, I might add. And I believe that it's early detection which has saved my life, but as well as the grace of God and the hardworking medical professionals in biomedical research.

00:04:36 [Congresswoman Rosa DeLauro](#)

And that's why we move forward with the piece of legislation. Now, let me get to your question. First of all, I was pleased when

00:04:53 [Congresswoman Rosa DeLauro](#)

the commission came out with the standards that the task force that recommended that women begin breast cancer screening at age 40. It was really complementary of that positive decision, again, detecting early, saving lives. But on that score, I am concerned about recommendation that only suggests biannual screenings. I think women should have screenings annually. Now then we get to the dense breast issue. 45% of women over the age of 40, they've not been in a position to be able to be we've not been able to be as effective in catching early stage breast cancer. We had two reasons here. One is that it was frustrating that the FDA didn't release the notification standards. This is the issue of notification and coverage. Those are the two pillars here. And letting women know that they have dense breasts, and I for one, have dense breasts. So this is critically important

to me. Now, those efforts will be addressed when the notification standards will go out effective September 10, 2024.

00:06:24 **Congresswoman Rosa DeLauro**

So now women will know something about this. So they will have the notification. And so what we need to do is to make sure once they have that notification, that to be able to do an MRI or ultrasound in order to really have the additional screenings they need, that, that needs to be free of charge, that needs to be covered by insurance. And that's the only way we were going to save lives. Now, what I took umbrances with the USPSTF, this task force is they did not make a recommendation on dense breasts. And I find that very, very troubling. And I so stated it with them. And they told me they needed more study. And I checked, I checked with the head of MD, anderson, et cetera, we do not need any more studies. That in fact, we have what we need to be able to proceed ahead to make sure that we get there because we require their stamp of approval in order for the insurance companies to be able to cover these costs. And I made it very plain to them that in fact, what they would be about here

00:07:53 **Congresswoman Rosa DeLauro**

is really risking women's lives. And we're all about you are your audience is all about saving women's lives. That's what this has been about. So I'm deeply, deeply concerned with what they did in this area. Now that is going to prevent us from dealing with screening, diagnostic, mammograms, breast ultrasounds, MRIs, because we know that if there isn't no cost sharing that you take a look at what the costs are. Women are not going to go and do that. This could cost more than \$1,000 to get done. So they're just going to not do it. And unfortunately, we put their lives at risk. And this task force, I'm going to say it plainly, has put women's lives at risk.

00:08:47 **Adele Costa**

Thank you, Representative, for that. Invaluable context, I think a lot of folks don't understand sometimes how these task force and these mini publics kind of interact with these big decisions that affect individuals. You also gave us a two-for answer there. You anticipated my second question, which was, without insurance coverage, right, women are being forced to pay out of pocket for these additional screenings. You kind of just touched on it. But can you talk more about the cost associated with these screenings and why these costs specifically worsen health inequities?

00:09:21 **Congresswoman Rosa DeLauro**

Well, look, as I said, it's our understanding let me just go back for 1 second on this. I think one of the strengths of the Affordable Care Act, really one of the real differences that the Affordable Care Act, there were many things, but the ability to get preventive care and treatment without any cost sharing, and particularly that is what the strength of the ACA was with regard to women. And for the first time, women's health was being treated in the same way as men's health was. And this is the same thing if you're going to look at out of pocket costs and they're forced to pay that.

00:10:10 [Congresswoman Rosa DeLauro](#)

And as I said, what we understand is it could be \$1,000, it could be more, and women should not have to pay more out of pocket than men to be able to get a clean bill of health. It's wrong. What do you get? You make a choice. Women are forced to make a choice, your health and maybe your life at risk because if you're not able to pay for the treatments that,

00:10:48 [Congresswoman Rosa DeLauro](#)

you know, that puts women's health on a lower scale. It doesn't really respect women's health. It doesn't

00:11:01 [Congresswoman Rosa DeLauro](#)

you know, the mammogram is not enough for women with dense breasts, punish them for something they cannot control.

00:11:15 [Congresswoman Rosa DeLauro](#)

If that was the case and they didn't need to do anything else. But we know, we know, we've seen all the screenings. We've seen that what happens with not being able to identify a tumor and which the other screenings are the way to do this and through no fault to their own, women are being punished.

00:11:39 [Adele Costa](#)

Yeah, thank you for that insight. You anticipate. JoAnn is going to show us a picture actually later of exactly what that masking does. I also wanted to raise that. Your comments about these prohibitive costs, this is not academic. We know that in this economy, most women can't afford a \$400 emergency expense, right? And we're talking about things in the thousands. So when you say we're making a choice, that point is well taken. It's an impossible choice today.

00:12:11 [Congresswoman Rosa DeLauro](#)

This is not just a sound bite. People are living paycheck to paycheck, are struggling to pay bills every month. You pointed out they're not able to deal with a \$400 emergency. But we lose sight that there is a continuous and it's right now, cost of living crisis in the United States that is the single biggest economic factor people's lives today.

00:12:38 **Adele Costa**

Yeah, we hear the same from our supporters, for sure. And in your answer, you expressed some frustration about how task force and other bodies seem to they want more science, they want more studies.

00:12:57 **Adele Costa, NWHN Director of Communications**

Right?

00:12:58 **Adele Costa**

But we know here at the network and you know, right, that women's health research is often overlooked, devalued, underfunded. Let's talk about that. What are some of the reasons for that? And how does this lack of research put women at risk for more adverse health outcomes?

00:13:14 **Congresswoman Rosa DeLauro**

Well, and I'll just say something which I said to the task force personnel. I asked them how long it took to deal with getting what they needed or thought they needed to get to go from age 49 to age 40. Years, years.

00:13:35 **Congresswoman Rosa DeLauro**

So now you're going to tell me that we need more information, more science, and what we already have, which is going to be years more. And during that period of time, women will die. That's the essence of this. And look, women's research I have fought since the day I walked into the House of Representatives with regard to the issue on women's health research, what we found at the NIH all those years ago. But it's not that long time. It's 32 years ago. That's not a long time where women were not even part of the clinical trials at the National Institutes of Health. And in fact, they did that. And I am told that even the mice are not female, but that women the tests were done on men and data was extrapolated to women. Well, we worked at trying to address that. We did, and that's the case. We still have to be very vigilant to make sure that these studies are being done. And there is a tremendous way to go to make sure that we are appropriately funding women's health research. So I said we have

00:14:57 **Congresswoman Rosa DeLauro**

come a long way, but

00:15:04 **Congresswoman Rosa DeLauro**

there's still so much that needs to get done. I was very pleased with what we were able to do in the Appropriations Committee over the last two years. 47 and a half billion dollars for the NIH, two and a half billion above what we were able to do in 2022, and \$7.3 billion for the National Cancer Institute as well. And what we did with women's health and don't misunderstand, I don't mean to be self serving, but I got tired of women's health; The decision on how much money would move in that direction was for us to have our own budget line for women's health research. The office was funded at the discretion of the director. Now it has dedicated funds and it has grant making authority, but women are that lack of research puts women at a significant disadvantage. We've made some progress, but there's much more to go.

00:16:14 **Adele Costa**

Yeah, thanks for expanding on that. We thank you for your leadership on that.

00:16:25 **Congresswoman Rosa DeLauro**

You know, there and also at Health Resources and HRSA at the Health Resources and Services Administration. So we have to use the tools that are available to us. I'll just say this to you. We just received the copy of the 2024 Labor, Health, Human Services and Education Subcommittee bill. My friends, you need to go into full born advocacy here,

00:17:00 **Congresswoman Rosa DeLauro**

and the cut to the NIH is about \$2.8 billion.

00:17:04 **Adele Costa**

We were just talking about that. We thought it was astounding you were able to make time, considering today. We really appreciate it and we hear you for sure.

00:17:12 **Congresswoman Rosa DeLauro**

Advocacy, we need your advocacy.

00:17:16 **Adele Costa**

Well, speaking of advocacy and other things that you're leading and that we hope to support the Find It Early Act, let's talk about that. This legislation has received bipartisan support, which is

impressive. Let's talk about the path forward for this bill in Congress and how we, the people, can help support this bill.

00:17:37 **Congresswoman Rosa DeLauro**

Sure. No, and this is so much the action associated with this, and I appreciate you in this regard. I will tell you recently, you should know that Congressman Stephen Horsford, Brian Fitzpatrick, Republican, and I have introduced the bill, actually, Katie Couric, who has been wonderful and being on the stump on this, but just recently, Congressman Horsford and I secured a provision in the Defense Authorization Act got passed today. It would require briefings on the number of women's service members and their dependents covered by TRICARE, who require screening and diagnostic breast imaging, including mammograms, ultrasounds, breast ultrasounds, and MRIs.

00:18:28 **Congresswoman Rosa DeLauro**

And we're going to just see what the numbers are here. But what we have to do, I'll be very frank with you, we just have 21 co sponsors of Find It Early. In order to pass any bill in this institution, you have to have 218 votes. I need all of your efforts, all of your networks, to really get out there and get to their members of Congress and get them to sign on to the legislation again. Bipartisan.

00:18:59 **Adele Costa**

Right, Okay.

00:19:01 **Congresswoman Rosa DeLauro**

And it shouldn't be something that Democratic women. Republican women. That's ridiculous. This is about the saving lives of women. Right.

00:19:12 **Adele Costa**

Cancer doesn't discriminate, as I like to say.

00:19:14 **Congresswoman Rosa DeLauro**

Right.

00:19:15 **Congresswoman Rosa DeLauro**

Cancer does not discriminate.

00:19:18 **Adele Costa**

Right. All right, well, thank you for that. We know that your time is very valuable. Did you have anything else you would like to share with our audiences and the world before we let you go and save the world today?

00:19:32 [Congresswoman Rosa DeLauro](#)

Thank you for that. But I just think despite and again, I'll be frank, some of the political environment we are involved in, this is such a powerful issue, and we know, to be very honest with you, increased funding, increased efforts have been the result of the National Breast Cancer Coalition. When I look at what happens and how we've had increased research, how we've been able to go to the Department of Defense and get money there, that I think that the strength of this issue, and again, because it is bipartisan, that we need to be just shouting from the rooftops, not taking no for an answer. Advocacy groups ought to be going to district offices to their members and saying, you have to sign on to this legislation. That is not about politics. This is about saving women's lives. Yeah.

00:20:41 [Adele Costa](#)

You mentioned something that I was going to ask since you opened the door. I'm going to ask this follow up. You talk about how it's affected to go to district offices. Right. Can you talk a little bit more about what's the best chance for these folks to get the ears of people like you?

00:20:54 [Congresswoman Rosa DeLauro](#)

I think it is really obviously, being in Washington, I don't discourage any people from coming and do that. But going to a district office, doing an op ed, letters to the Editor, because I have run into so many groups, when I start to talk about dense breasts, a dozen hands go up and say, oh, my God, I've been diagnosed with dense breasts. But they don't know what's out there. And that's why we have to use this as a tool to educate the numbers. Yes. And I will tell you, if 15, 20 people show up in my district office and Jennifer, my director, calls and she says, rosa, there's all these people here on this issue. You pay attention. Pay attention. And people should talk about what it costs them, bring the bills with them and say, this is what it would cost me to get an MRI or an ultrasound. You got to get their attention there. And again, people can stand up locally and do press and do, as I said, op ed, get into local papers about this issue. So locally people understand what's happening.

00:22:12 [Adele Costa](#)

That is very helpful crash course in grassroots advocacy. I always think it helps to hear from representatives themselves on these issues. Congresswoman, I just want to thank you again for

making the time for us today. We deeply appreciate your leadership and your work as a women's Health Champion. You're welcome to stay on and listen, or I'm sure you have places to go.

00:22:35 **Congresswoman Rosa DeLauro**

I wish I could, because I want to hear from others, and I love what you're doing here today.

00:22:41 **Adele Costa**

We'll send you the recording, don't worry.

00:22:43 **Congresswoman Rosa DeLauro**

Recording. And please know how much I prize our relationship and our partnership with getting things done. And whatever you need from me, I'm there. Okay? Thank you. Thank you very, very much.

00:22:57 **Adele Costa**

Thank you. Congresswoman DeLauro everybody. Boy, that's pure serotonin, I have to say. My next few questions are for Ms. JoAnn Pushkin, again the executive director of Densebreast-info.org. We heard a little bit about dense breasts just now, and now we're going to do a deep dive on that. So welcome, Ms. Pushkin. Here's my first question. What are dense breasts, and why does it matter in this conversation about breast cancer?

00:23:26 **JoAnn Pushkin**

First of all, thank you for having me. We're delighted to partner on this educational effort, and what a delight to hear Representative DeLauro and her engaged passion. It is contagious, and she really has moved the bar forward on this. So thank you for making this forum available to discuss that. So what are dense breasts? Why are we all talking about them? So, dense breasts are normal and common, and actually, about 40% of women of mammography age have dense breasts. So what does it mean? Dense tissue refers to the tissue composition of your breasts. Your breasts are made of three kinds of tissues fat, glandular tissue, which is what makes the milk, and then fibrous tissue, which kind of holds it all together. So each woman's breasts are a distinct mix of tissues, and the more glandular tissue and fibrous tissue a woman has, the denser her breasts are. Okay, so if they're normal in common, why are we even talking about it? Dense breasts show up white on a mammogram, and why does that matter?

00:24:27 **JoAnn Pushkin**

Cancer shows up white on a mammogram. And Ringo, if you can pull up the first slide. So here we see on the left a mammogram of a not dense breast. And none of us have gone to medical school, or I certainly haven't. And yet there I can see that cancer from across the room, and on the right hand side is the mammogram of a dense breast. And even a large cancer is difficult to see. This would be completely obscured in the dense tissue, and that's what's so concerning. And in addition to hiding cancer, I've heard the analogy. It's like trying to find a snowball in a blizzard, and you can well appreciate that. But not only does it hide cancer, but dense tissue increases the risk of a woman's; increases her risk of developing breast cancer. So it's a double whammy. She's both more likely to get breast cancer and more likely for that cancer to be missed. And what's of concern is that for women like myself, who were going faithfully for mammograms and my own cancer did not show up an estimated five

00:25:32 [JoAnn Pushkin](#)

years in a row on that mammogram. Is that the letter we were getting after our mammograms? Every one of those years simply said, normal. So you don't know what you don't know. Sometimes I didn't know to worry about it. Ringo, if you can pull up the next slide. So what women don't realize is that a normal mammogram in a dense breast does not reliably mean that cancer is not present. And I don't know if you can see this. When you have your mammogram, your breast density is rated into four categories. Fatty breasts are the least dense at the bottom. Then they're scattered, heterogeneously dense, and extremely dense. So the top two categories heterogeneously dense and extremely dense. If your breast density is rated into one of those two categories, you are considered to have dense breasts. So look at the percent of cancers that will not show on a mammogram for women, that extremely dense breasts. And I had extremely dense breasts. That's the low end 40%. That's almost half. We're talking a

00:26:36 [JoAnn Pushkin](#)

coin to us here. And so it's so important for these women to have additional screening after their mammogram because look at all the cancers we're leaving on the table here, literally.

00:26:47 [Adele Costa](#)

Wow, that is an education. I'm so glad that you gave us those visuals, because, yeah, wow, you really can't see that cancer. You talked a little bit about how mammograms are not the be all, end all, especially if you have dense breasts. Let's talk about what other breast screening tests can be done after a mammogram or in addition to and when and how should a patient ask for additional tests.

00:27:13 JoAnn Pushkin

So the first thing to know, and I want to make this clear, is while mammograms are the first step in screening for all women, for women with dense breasts, they should not be the last. So the type of additional screening recommended should be based on your density and other risk factors and whether you are determined to be at high risk. So high risk women are people with a genetic mutation like the BRCA gene, prior chest radiation, or other certain combinations of other risk factors like breast density, family history, and prior biopsies. So if you have dense breasts and are not considered high risk, it's recommended that in addition to your annual mammogram exam, you consider an annual ultrasound or MRI, because it will find cancers that are hidden on the mammogram. And this is a conversation to have with your referring provider, either your OBGYN or your family practitioner when you meet with that person before, when you get your script for your mammogram. So I'm going for my mammogram.

00:28:16 JoAnn Pushkin

Is it enough? Is the question, did I have dense breast last year? They will know. They can look at the report last year and let's discuss my other risk factors. And is it enough if you're high risk, if you're determined to be at high risk, whether or not you're dense, the recommendation is an annual screening mammo and a yearly screening MRI. And Ringo, if you can pull up. And if you're a breast cancer survivor and have not had a double mastectomy, the recommendation is an annual mammogram and an annual MRI if you had dense breasts or if you would diagnose before the age of 50, whether you're dense or not. So here we see the cancer detection of other screening tests after a mammogram. So if 1000 women are screened with dense breasts and have just a 2D mammogram alone, the number of women found to have cancer will be five out of 1000. If they do a 3D mammogram, it'll be six. 3d mammograms do not drastically increase cancer detection in dense breasts because it's still an X ray technology.

00:29:23 JoAnn Pushkin

And X ray technology is very affected by dense tissue. But after the mammogram, if we add an ultrasound, we see we find eight cancers per thousand women screened. And look at the contrast enhanced MRI 21 cancers. Some new technologies you might be hearing about, not as popular as ultrasound or MRI, but you'll be hearing about them, is molecular breast imaging. And that finds 13 cancers per thousand women screened. And then contrast enhanced mammo finds 15 cancers per thousand women screened. The newest guidelines recommend that all women be given a breast cancer risk assessment with possible genetic testing by age 25. And again, this woman needs to speak to her OBGYN or primary care. So for women who are determined to be at higher risk, the

recommendation may be that they start mammogram screening before 40. Or if they're determined to be at high risk, the recommendation could be that they start MRI at 25. But of course, what we need coupled with that is once she's told that she needs to

00:30:30 **JoAnn Pushkin**

be able to access and afford these screenings right?

00:30:34 **Adele Costa**

It's not just about the education. It's about the access.

00:30:37 **JoAnn Pushkin**

We'll do it right.

00:30:40 **Adele Costa**

I will say, first of all, you're a comms person's dream, because this takes very scientific information and makes it very understandable. I want to let everybody know all these resources are going to be available, are already available, I believe, on the web page. And at Densebreast-info.org before I open the floor.

00:31:01 **Adele Costa**

Talk to me about are providers aware of these new recommendations? What work needs to be done in the provider space about educating? And why is self advocacy sometimes necessary for this issue?

00:31:13 **JoAnn Pushkin**

And this is where the pedal meets the medal on this, and it's falling apart. Women need guidance. They need to be told that they're at higher risk. But if she doesn't know to ask, should the onus be on me as a patient to know, to tell you that, shouldn't my provider be educated and ready to do risk assessment, to have a discussion about that and understand what supplemental screening I need? So we need patients educated and their providers educated. When she turns to that referring provider to have a conversation.

00:31:46 **JoAnn Pushkin**

Is he ready?

00:31:47 **JoAnn Pushkin**

Is she ready?

00:31:48 **Adele Costa**

Right.

00:31:49 **Adele Costa**

Thank you for highlighting that. Okay, so I am going to open the floor now to all of our panelists for the rest of these questions. Speaking of providers, what can providers do to ensure patients are well informed about their risk for breast cancer, especially if they have dense breasts?

00:32:10 **Denise Hyater-Lindenmuth**

I'll take this one. You know, I think Joanne already mentioned that providers need to be able to have this level of conversation, but also, we need to be able to, as women, be able to go into the office and ask, what are my risks? I don't know about your experiences, but it seems like when I would go into my OBGYN or my primary and they would do the breast exam, it was done in silence. Or they may ask me if I had vacation plans, or they may ask me how are the kids? You know, I think somewhere between residency and clinics or know, doctors, PAs are trained. They need to have the conversation around breasts. But also, as JoAnn said, at the same time, we need to be able to be proactive about that too. What are dense breasts? Go in with the question, what are dense breasts?

00:33:03 **Adele Costa**

Well, and just know, follow up on that. You wrote a really incredible op ed about your personal experience. And if I remember correctly, were you aware that you had dense breasts?

00:33:12 **Denise Hyater-Lindenmuth**

Had no idea. It had never been mentioned to me that I had dense breasts. And I would, of course, go in regularly for my mammogram. Even had a situation where the radiologist thought she saw something, but then they did a sonogram later, and they said, no, it's nothing to worry about. Well, it was something to worry about, but they never said, you have dense breasts. Let's keep an eye on it at all.

00:33:41 **Adele Costa**

That's scary. And we'll be sure. Again, her op ed for the whole experience is linked on the page. Joanne, do you have anything to add to that?

00:33:50 **JoAnn Pushkin**

My own experience was similar. Of course. I found out I had breast cancer. I found out it was missed because of dense tissue, and I found out I had dense tissue all within ten minutes of each other. Just to clarify, dense breasts have nothing to do with the way your breasts look or feel. It's determined on your mammogram. And that's why it's so important. Of all the risk factors, we're going to talk about my family history, my personal history, my lifestyle, of all of those, the only one that someone needs to tell me is my breast density. That's the one I'm relying on. I can't see inside my breast, so I need someone to tell me that. And that's why notification is so important in this sense. And we really need these referring providers. As Representative DeLauro said, the national reporting standard is coming. It's already in 38 states. Already 90% of women receive some level of notification. Some of them are way better than others. But certainly referring providers need to have a protocol

00:34:48 **JoAnn Pushkin**

for patient risk assessment. They need to get ready and get their game face on for that.

00:34:55 **Adele Costa**

Yes. So speaking of, so you find out, oh, no, you get this bad news, right? You have dense breasts, and maybe you have cancer, or maybe you don't find out, right, because the costs of additional screenings are so dissuasive from seeking preventative care. So what are some tips with dealing with the sticker shock and that cost of when you're having to make those choices?

00:35:24 **Adele Costa**

Let's talk about that.

00:35:27 **Denise Hyater-Lindenmuth**

Well, since I'm here for the lived experience yeah. I got online and started to look for clinical trials, right.

00:35:40 **Adele Costa**

And we're going to talk about talk about why you did that, because that is something not everybody would do, I feel like.

00:35:46 **Denise Hyater-Lindenmuth**

Well, because I'm that type of person, but also, just having had experience with the American Cancer Society, understanding that there are opportunities out there to really address some of those health issues head on, and I wanted to make sure that I had the best information out there.

00:36:10 **Adele Costa**

Well, and it's also true that it's customary, right, that if you are accepted into a clinical trial, it's no cost to you. Is that right?

00:36:18 **Denise Hyater-Lindenmuth**

It is no cost to you.

00:36:20 **Congresswoman Rosa DeLauro**

Yeah.

00:36:21 **Adele Costa**

And that was your experience, right?

00:36:22 **Denise Hyater-Lindenmuth**

That was my experience with my clinical trial, and I was diagnosed with triple negative breast cancer. So it's very aggressive. It moves very quickly, particularly if you have dense breasts and it is not diagnosed. It quickly moves into the lymph node. It's fast moving

00:36:41 **Denise Hyater-Lindenmuth**

and having that shock of hearing the news, one, you have cancer. Two, it was undiagnosed because you had dense breast and it wasn't seen. And three, it's triple negative. I was in a stupor for, like, I don't know, a day before I could really gather my thoughts and say, okay, this is what I need to know. I called every particular doctor I could know that I knew. I called a couple of clinical trials just to see if I could get in. But because I was fortunate enough to be here in DC. And to be here at Georgetown, it was easy to get into the clinical trial that they had.

00:37:21 **Adele Costa**

So you, Denise, your experience was that you got into this clinical trial. JoAnn, what about folks who maybe are ineligible for those trials? Do you have any additional tips on controlling cost or at least exploring cost options for treatment?

00:37:34 **JoAnn Pushkin**

So, as you all know, I'm executive director of the educational website DenseBreast-info.org, and by far, 99% of the emails that come into us to our "Contact Us" page are from women who are trying to navigate the cost of additional screening. So it's extremely frustrating to them if their doctor says,

yes, you need this, and the insurance company denies it, which is their right, or it's covered but the copay and deductible are too high. And we hear from women just heard from actually, she was a reporter. The copay and deductible with good insurance for her MRI was \$1,400. That's with insurance or frustration. About 22 states, I think it is now, have expanded insurance laws for additional screening after your mammogram. Not all of them are without copay and deductible, but some of them are. But there are so many plans that are exempt from state insurance laws. So, for instance, in New York, we passed the first very progressive law that all screening and diagnostic imaging both were to be covered

00:38:44 **JoAnn Pushkin**

at no cost to the patient. And we thought this was fabulous, and we're done. And then, of course, my phone begins to ring. So self funded plans are exempt from state laws. And the only way a woman can know is to ask the administrator of her policy, is it a self funded plan? It's not like an HMO where the number is different or the card is different. You have to ask.

00:39:04 **Adele Costa**

Well, who would know to ask?

00:39:06 **JoAnn Pushkin**

Who would know to ask? Who would even know to ask that question? Absolutely. Out of state plans are exempt. So if you're in New York and you're thinking, oh, this is going to be covered, but you work for a company that's based in Kentucky, it'll be that state's law that determines your coverage no matter where you're having that testing. And of course, federal plans like Medicare are exempt from state laws.

00:39:29 **Adele Costa**

Wow, there's a lot of loopholes.

00:39:31 **Adele Costa**

That's a rodeo of loopholes.

00:39:33 **Adele Costa**

That's right.

00:39:34 **JoAnn Pushkin**

To the great credit, Rosa DeLauro, Representative DeLauro and Fitzpatrick, and we work very hard with them. The bill is extremely comprehensive and will close these loopholes. This is this bill is important. Find It Early, Correct. Even in states where there are insurance laws, this will expand coverage in those states. And I'll pass on this tip, too, for anybody who is in that situation right now. I do hear from women who, even though they have insurance, will call the Imaging center and say, what's the cash price? In other words, if I had no insurance, what would you charge me for this screening for the ultrasound or the MRI? And believe it or not, sometimes it's cheaper than their copay and deductible.

00:40:18 [JoAnn Pushkin](#)

If you're really stuck and you should have that screening if it's recommended, sometimes it's worth a call to the Imaging Center to find out if there are any considerations can be given if you have a very high deductible plan and really need that screening.

00:40:31 [Adele Costa](#)

Wow.

00:40:31 [Adele Costa](#)

Yeah. These are steps that I think not everybody realizes, like the on the ground labor of negotiation with insurance companies is currently passed on to the consumer. Right. And a lot of people don't know that. So thank you for your work on the Find It Early act. This is one of those bills that was written by an expert in the field. Right. So that's always good. Um, so we talked about the cost barrier, right? But there are other barriers that exist to getting good cancer care. And I was know Denise could speak to that a little bit.

00:41:08 [Denise Hyater-Lindenmuth](#)

I think if you look at the barriers of racial inequity and representation and clinical trials, you'll see that a lot of clinical trials do not include people of color, do not include African Americans, or have not routinely done that just to see or to value the efficacy of that particular trial. So that's that side and then there's, of course, the side of trusting the medical community of whether or not this is really going to help me or is this going to hurt me, do the risk outweigh the benefits for that? And a lot of people of color and African American community are going to be thinking about that when looking at clinical trials because of the history of the medical community's practices on black bodies.

00:41:55 [Adele Costa](#)

Right.

00:41:56 **Adele Costa**

And that's a long and horrifying history. Can you talk about, then, some of the green flags? I like to say the opposite of red flags that maybe these communities can look for if they are seeking out clinical trials or something like that.

00:42:11 **Denise Hyater-Lindenmuth**

If you have the opportunity to talk to maybe the investigators on the clinical trial. The medical staff involved with the clinical trial. Interview them as they are interviewing you because they're going to always ask for interviews to see if you're going to be a candidate for their trial, if you're going to be a good candidate, but also see if they're going to be a good candidate and a resource for you in case you have questions. One of the things I experienced is that the medical group with my clinical trial, they were available to me 24/7. That was a huge green flag to me. If I had any kind of twitch, pain, question, worry, they returned my call. They were there for me. That's always a good thing to look for. Also look for a clinical trial that provides all your resources so you don't have to worry about any kind of out of pocket expenses. Or if there are out of pocket expenses, they can connect you to other resources that can help supplement those other expenses. So some of those clinical

00:43:15 **Denise Hyater-Lindenmuth**

trials will also do that. Other people may be more interested in what is there monetary value in doing this clinical trial? Will I get paid?

00:43:24 **Denise Hyater-Lindenmuth**

Some will.

00:43:25 **Denise Hyater-Lindenmuth**

Some may pay you. For me personally, that was not an issue for me. I went into my clinical trial knowing that I could have a list of 500 potential side effects because of the drug. But I was willing to take that risk if it meant saving my life.

00:43:45 **Adele Costa**

I'm glad you brought that up because one thing that shines clear in your op ed is before any trial was started, they really made sure that you had informed consent. Can you speak a little bit to that process.

00:43:59 **Denise Hyater-Lindenmuth**

Wow.

00:43:59 **Denise Hyater-Lindenmuth**

So that process, it was intense. And I'll say, because I had to really, again, weigh the risk of this, what could I potentially be walking away with? What is the worst of the risk? What are the least? And I could just only pray that I would walk away with the least. But it was also on me to ask questions of my surgeon, made sure they coordinated care with my primary care, made sure I coordinated care with my reconstructive surgeon.

00:44:33 **Congresswoman Rosa DeLauro**

Okay.

00:44:34 **Denise Hyater-Lindenmuth**

Because I wanted to do everything at once. That was my decision. But, yeah, it was really having a committee meeting with all of the doctors and medical staff involved to make sure that I had my care taken care of.

00:44:56 **Adele Costa**

Right. JoAnn, any additional thoughts on other barriers besides cost to getting good breast cancer care?

00:45:03 **JoAnn Pushkin**

Not related to clinical trials, but certainly for screening. I mean, clearly there are disparities in outcomes in black and Hispanic women, and there's been a call for more research on the issue across minorities. And because these women are more often diagnosed at a much earlier age, sometimes in their 20s, these women in particular may benefit from risk assessment by the age of 25. We had mentioned that before, but it's particularly important in these communities. And again, if they're determined to be at increased risk and to need insurance coverage for that screening, it should be covered. And certainly on the individual patient level, certainly language is a barrier and a concern. If the patient doesn't understand the information being given or shared to her, what good is it to her? For instance, Spanish speakers are the fastest growing segment of the US. Population, and there is a need for patient materials in Spanish but translated by medical professionals. You just don't go to a

00:46:09 **JoAnn Pushkin**

Google Docs Translate. We need it by medical professionals. And if anyone is interested in that, on the DenseBreast-info.org website, we have an entire suite of content in Spanish, things you can print and videos, FAQs, and we also have a patient fact sheet about dense breast in over 30 languages that can be downloaded. So part of access is comprehension. I need to know the information is only as good as I can perceive it, understand it, and act on it.

00:46:40 **Adele Costa**

Amen. Absolutely. And thank you for creating all those resources. Those are also linked on the event page. All right, well, does anyone have any final remarks? And this is your chance to plug anything. This is the speak now moment of the webinar.

00:47:00 **JoAnn Pushkin**

Well, if I could pipe up, I'd like to please everyone with dense breast, both patients and health providers, please visit DenseBreast-info.org. It's the world's leading resource on the topic. It is meticulously, medically sourced and specific to the Find It Early Act. And you heard Representative DeLauro say we need feet on the ground about this. We'll be, our organization will be making a tremendous push on this next month. But in the meantime, if you need to know, I don't, never called my congressperson. Who is he? Who is she? What do I do? Please go to FindItEarlyact.org. Its on our page, on our website, there's a Lobbying 101 section about how do I ask my congressperson for support? It tells you what to ask, how to make the appointment, what to bring, how to follow up. It walks everyone through it so no one has an excuse not to call the Congressperson. FindItEarlyAct.org.

00:47:56 **Adele Costa**

Thank you. Yes, we're on notice.

00:47:59 **Denise Hyater-Lindenmuth**

And since there is an increase of breast cancer diagnosis with people of color, African American women, I would particularly guide them to the Triple Negative Breast Cancer Foundation, because that is a common diagnosis that we see particularly in African American women. It was with triple negative breast cancer. So go to that foundation, go to that website, look at what they have available for clinical trials, and they are very open to talking to you about what's available.

00:48:32 **Adele Costa**

Great. Thank you so much. Well, thank you all for joining us today. We will be transcribing this, and we will be posting the recording for this event next week. And anybody who registered will get it in

their inboxes, along with a feedback survey. We really appreciate you taking the time to get educated with us today. I'm going to hand it right on over to the two executive directors if they want to end it with anything. But I think we're good. Are we good?

00:49:06 **Denise Hyater-Lindenmuth**

Thank everyone for attending this and listening to this panel discussion. I think it's important that we continue do to educate everyone around this issue. But just looking at women's health in general, we are here to know the advocates for that. Thank you, JoAnn, for joining us.

00:49:26 **JoAnn Pushkin**

Thank you for having me. This was such an opportunity.

00:49:29 **JoAnn Pushkin**

Thank you.

00:49:31 **Adele Costa**

Take care, everybody. This is us signing off.