

# JoAnn Pushkin

By Danielle Sharek, MD

Ms. JoAnn Pushkin is the executive director of DenseBreast-Info.org, a website centered on developing comprehensive, medically sourced educational resources to objectively inform patient and health care professional discussions around breast density. Ms. Pushkin has coauthored educational courses, articles, and grants and given talks and interviews on the topic of breast density. Her advocacy efforts were prompted by her own personal experience of self-detecting a palpable breast cancer that was masked by dense breast tissue on mammography (<https://densebreast-info.org/about-us/our-team/>). This interview has been edited for clarity and length.

## DS: Please tell me about yourself and your background.

**JP:** I spent most of my career in stock research with a side consulting business in marketing/writing. At age 45 I was diagnosed with invasive breast cancer. At nearly the same time, in early 2006, a lifelong dream came true and a children's story I wrote was published. I had hoped to focus on writing for children full time. While my dream to write was realized, my published work is now entirely on the topic of breast density.

## How were you diagnosed with breast cancer?

Several weeks after a "normal" mammogram I felt a lump during a self-exam. Though large enough to feel, it did not show on a diagnostic mammogram, but that same day it was easily seen on an ultrasound. I learned I had breast cancer, I learned it was missed due to dense tissue, and I learned I had dense breasts, all within 10 minutes of each other.

## How did you feel when you learned of the news?

At first diagnosis, numb. Then devastated. Then incredulous. Then angry. Then motivated to effect change.

After a recurrence 5 years later, I remember thinking, in that split second before my body physically reacted to hearing the devastating news, "Well, I am apparently very good at growing breast cancer."

## What was your treatment process? Did you face any treatment obstacles? How did you overcome them?

Surgeries, chemo, more surgeries. Despite a mastectomy, a recurrence 5 years later, and then radiation.



Danielle Sharek, MD

## What motivated you during your diagnosis and treatment process?

My daughter was 15 when I was diagnosed. I remember negotiating with the universe, "Please let me at least get her off to college and then you can have me."

## What did you learn from your experience?

That patients need to be informed about tests they are being sent for—and should specifically ask what the benefit and realistic limitations are for those tests in their personal situation.

If I had known I had extremely dense breasts and that cancer detection on mammography was so compromised due to it, I *certainly* would have initiated a conversation about supplemental screening with my provider. But you can't have a conversation about something you aren't even aware that you need to. That lack of knowledge effectively denied me the opportunity for an early-stage diagnosis.

## How has this diagnosis impacted your life? How have you used your diagnosis to impact others?

After learning that Connecticut had just enacted a law to provide women some limited information about breast density, in 2010 I initiated efforts for a New York state "inform" law, a federal law for national notification, and an FDA/MQSA [Food and Drug Administration/Mammography Quality Standards Act] rule change to require that standardized information about breast density be included in the patient lay letter.

New York's law was the first to actually inform women if they have dense breasts and served as a template to many other state laws that followed. On the national level, the FDA did update its dense breast reporting requirement, and that goes into effect in September 2024. I am also currently a consumer representative to the FDA National Mammography Quality Assurance Advisory Committee.

And to address educational needs created by density informing and supplemental screening discussions, in 2015 I cofounded, with Dr. Wendie Berg and rad tech Cindy Henke, the [DenseBreast-info.org](https://DenseBreast-info.org) website. This medically sourced educational resource on the topic is clearly needed; in 2023 alone, the website hosted 810,000 visits.

### Are there any lessons that you think the breast imaging community can learn from your experience?

Nearly every state inform law was fought for by a woman who was screened annually by mammography, did not know she had dense breasts, detected a lump, learned it had been missed on the mammogram due to density, and was floored to learn that this "missed-due-to-density" cancer was not a rare occurrence to medical providers. When everyone a patient is relying on for medical direction doesn't share this one very important thing that results in a cancer detected that is no longer early stage, it results in a feeling of betrayal and crisis of faith in the medical system.

### You have worked very hard to advocate for women with dense breasts. What achievement is most meaningful to you, and what are your plans for future work in the field of breast cancer?

#### Three achievements:

- Website: [DenseBreast-info.org](https://DenseBreast-info.org) is now the world's leading website on the topic. The educational website provides medically sourced, peer-reviewed, evidence-based educational content for patients and providers. Our medical advisory board consists of internationally recognized, published experts in breast imaging and obstetrics/gynecology.
- National reporting standard: The FDA reporting rule going into effect in September 2024 creates a single baseline level of dense breast information for women across the United States and solves the dilemma of varying levels of "inform" created by 38 individual inform laws. Though I was relieved, it was a bittersweet accomplishment (see my March 2023 public statement).

- Find It Early Act: The new FDA reporting standard will mean that all women will be told whether their breasts are "not dense" or "dense." And for those who have dense breasts, that "...other imaging tests in addition to your mammogram may help find cancers."

But once women are informed that they have dense breasts or are at higher risk and may benefit from supplemental imaging to *complete* breast screening, can they afford it? For those individuals for whom a mammogram screening is not enough, expanded insurance coverage for breast imaging beyond the mammogram is needed. The next legislative front is continuing work on state insurance laws and the federal [Find It Early Act](#) (FIEA). The FIEA would ensure all health insurance plans cover screening and diagnostic breast imaging with no out-of-pocket costs for women with dense breasts or at higher risk for breast cancer, close loopholes inherent in state insurance laws, and cover all private and public plans, including TRICARE and Veterans Health Administration plans.

#### A statement from Executive Director JoAnn Pushkin

It's been over ten years since my request to the FDA to consider the requirement that women be informed about their breast density after their mammogram, and over ten years since an FDA advisory committee agreed that women certainly should be.

Too many patient "density inform" advocates are no longer with us to join me in an exhale of relief that all U.S. women will now be told about their breast density. That their tragedies - of hidden cancers finally found when no longer early stage - may be prevented from wreaking havoc on other families.

So, while we all share a hallelujah! that this has finally come to pass, to quote songwriter Leonard Cohen, for some of us, "it's a cold and it's a broken Hallelujah." But a hallelujah it is.