

## ***Breast Density Websites: Where to Send Your Patients and Referring Providers for Information***

By Jennifer Harvey, MD, FACR, FSBI

**G**oogle “dense breasts” and at least 10 relevant websites will come up. Unfortunately, the best ones are not at the top of the list. This article provides a review of the content of multiple online sources (in alphabetical order) of information for radiologists and patients.

### **American College of Radiology**

The American College of Radiology has a PDF brochure (<http://www.acr.org/News-Publications/~media/180321AF51AF4EA38FEC091461F5B695.pdf>) that can be downloaded for patient use and also provides brief, clear, and reasonably balanced information.

### **American Cancer Society**

The American Cancer Society has a very clear 2-page PDF file (<http://www.cancer.org/acs/groups/content/@editorial/documents/document/acspc-039989.pdf>) on breast density. Patients are clearly the intended audience. No data are provided but pros and cons of ancillary screening are at least touched upon.

### **Are You Dense: Exposing the Best-Kept Secret**

This website (<http://www.areyoudense.org>) represents a 501(c) charitable organization founded by Nancy Cappello, PhD. Dr Cappello detected her breast cancer by palpation months after a normal screening mammogram. She went on to learn about breast density and advocate for patient education and notification, resulting in the first state (Connecticut) legislation on this issue. The website provides patient-level information about breast density and primarily focuses on masking through numerous patient stories. Most stories are from women with large or advanced-stage disease presenting shortly after a normal mammogram, presumably because of dense tissue. The site instructs women to talk with their doctors about more screening tests and states that these are covered in Connecticut. It then directs women to the advocacy site for more information for their state. The site is very passionate in its approach, but other websites provide more comprehensive information on breast density. The board of directors does not include any MDs.

### **Breastcancer.org**

[Breastcancer.org](http://www.breastcancer.org) is a comprehensive nonprofit site with a professional advisory board including radiologists. It is dedicated to all aspects of breast cancer, from diagnosis to treatment to survivorship. The site includes a single page ([http://www.breastcancer.org/risk/factors/dense\\_breasts](http://www.breastcancer.org/risk/factors/dense_breasts)) providing information on breast density. The information is limited and focuses on reducing risk through diet,



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healthy body weight, etc. Links to possible ancillary screening lead to general information on ultrasound and magnetic resonance imaging, rather than data or pros and cons. Not very helpful for this topic.

### **Breast Density Info**

This site (<http://www.breastdensity.info>) was organized in 2013 by the California Breast Density Information Group—composed almost entirely of radiologists from California—to provide information primarily to providers in response to their breast density notification legislation. Patients may benefit as well. The site provides a good review of breast density knowledge and is easy to navigate. The site has flowcharts for providers. Information about ancillary screening is provided but only in generalities. Numerical data to support decision-making would be helpful. The downside is that information does not appear to have been updated since it was first launched. For example, the website states, “Breast tomosynthesis (‘3D mammography’) is being offered in addition to screening mammography in some centers,” and no current data about tomosynthesis in dense breasts are provided. The most recent reference is from 2013. Overall this site is very user-friendly and has good information for radiologists and nonradiologist providers but could benefit from inclusion of numerical data and an update.

### **Dense Breast Info**

*I need to disclose that I am one of many scientific advisors for this site.*

This website (<http://densebreast-info.org>) is the most comprehensive and easy to navigate. It was created as a 501(c) and the advisors are all MDs. It is also supported by some breast imaging and biopsy-related vendors (<http://densebreast-info.org/educational-supporters.aspx>). In the center of the home page are tabs “For Patients,” “For Healthcare Providers,” “Technology,” and “Legislation.” The first 2 are similar in content, covering breast density knowledge and implications for care. The site includes a risk form that can be downloaded for patients to bring to their healthcare providers to help guide discussion. The site discusses ancillary screening but is not heavy-handed. I appreciate this statement: “You need to consider your own tolerance for false positives compared to the potential benefit of improved cancer detection when deciding whether or not to have additional screening.” Technology information is up-to-date and even includes evolving technologies such as contrast-enhanced mammography. The site provides a table that includes information on interval increase in



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cancer detection and false-positives. In addition, the legislation tab indicates which states have density notification laws and details of the legal nature and wording. For example, the recent law effective July 1, 2016, in Indiana has no specific language or criteria for notification. Navigation of the site is quite manageable. Of note, this website does not appear until page 3 of a Google search for “dense breasts,” so many people will not find it on their own.

### **Komen**

Komen (<http://ww5.komen.org/Breastcancer/Highbreastdensityonmammogram.html>) is familiar to all of us and is frequently the first website to be listed in a search. Although the site states that they support national legislation on breast density notification, they are very soft and even negative in the discussion of ancillary screening. For example, the site states, “Digital may offer screening benefits over film mammography for women with dense breasts.” No data are provided and several links are broken or lead to a different page. Not recommended.

There are many other sites that discuss breast density. Many are located within an institution, such as Memorial Sloan Kettering (<https://www.mskcc.org/blog/diagnostic-radiologist-carol-lee-discusses-what-women-should-know-about-breast-density>) and the Mayo Clinic (<http://www.mayoclinic.org/tests-procedures/mammogram/in-depth/dense-breast-tissue/art-20123968>). These sites are simple, with basic information that provides a good starting point for patients and providers. Others, such as Cancer Treatment Centers of America (<http://www.cancercenter.com/discussions/blog/breast-density-becoming-an-important-predictor-of-breast-cancer-risk/>), simply reiterate information from Komen.

In summary, the most up-to-date, comprehensive site for breast density knowledge is the Dense Breast Info site, with easy-to-navigate information for patients and providers. Again, note that this does not come up at the top of the search, so patients and providers will need direction to find it. Breast Density Info provides a comprehensive and well-written review of density in response to California legislation in 2013. It is aimed primarily at providers and could benefit from an update. For a starting point for discussion with patients, the American College of Radiology and American Cancer Society have nice PDFs that can be downloaded for distribution at your facility. ❖