15.0766.04000

#### FISCAL NOTE Requested by Legislative Council 02/05/2015

Amendment to: HB 1370

1 A. State fiscal effect: Identify the state fiscal effect and the fiscal effect on agency appropriations compared to funding levels and appropriations anticipated under current law.

	2013-2015 Biennium		2015-2017	Biennium	2017-2019 Biennium	
	General Fund	Other Funds	General Fund	Other Funds	General Fund	Other Funds
Revenues						
Expenditures						
Appropriations						

1 B. County, city, school district and township fiscal effect: Identify the fiscal effect on the appropriate political subdivision.

	2013-2015 Biennium	2015-2017 Biennium	2017-2019 Biennium
Counties			
Cities			
School Districts			
Townships			

2 A. Bill and fiscal impact summary: Provide a brief summary of the measure, including description of the provisions having fiscal impact (limited to 300 characters).

Engrossed House Bill 1370 creates a new section of NDCC relating to mammogram result notices and the notification of registered owners of mammography equipment, provides an expiration date and declares an emergency.

B. Fiscal impact sections: Identify and provide a brief description of the sections of the measure which have fiscal impact. Include any assumptions and comments relevant to the analysis.

The amendment to the original HB 1370 requires the Department of Health to notify all registered owners of mammography equipment of the changes included in the legislation, along with the state board of medical examiners, the North Dakota medical association, the North Dakota board of nursing, and the North Dakota nursing association. This bill will have minimal fiscal impact as the Department of Health communicates with all entities included in this bill on a regular basis.

- 3. State fiscal effect detail: For information shown under state fiscal effect in 1A, please:
  - A. **Revenues:** Explain the revenue amounts. Provide detail, when appropriate, for each revenue type and fund affected and any amounts included in the executive budget.
  - B. Expenditures: Explain the expenditure amounts. Provide detail, when appropriate, for each agency, line item, and fund affected and the number of FTE positions affected.

C. **Appropriations:** Explain the appropriation amounts. Provide detail, when appropriate, for each agency and fund affected. Explain the relationship between the amounts shown for expenditures and appropriations. Indicate whether the appropriation or a part of the appropriation is included in the executive budget or relates to a continuing appropriation.

1

Name: Brenda M Weisz Agency: Department of Health Telephone: 328-4542 Date Prepared: 02/06/2015 15.0766.03000

#### FISCAL NOTE Requested by Legislative Council 02/05/2015

Amendment to: HB 1370

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	2013-2015 Biennium		2015-2017	Biennium	2017-2019 Biennium	
	General Fund	Other Funds	General Fund	Other Funds	General Fund	Other Funds
Revenues						
Expenditures						
Appropriations						

1 B. County, city, school district and township fiscal effect: Identify the fiscal effect on the appropriate political subdivision.

	2013-2015 Biennium	2015-2017 Biennium	2017-2019 Biennium
Counties		· · · · · · · · · · · · · · · · · · ·	
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School Districts			1 Aurt
Townships		A Alternation	

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Name: Brenda M Weisz Agency: Department of Health Telephone: 328-4542 Date Prepared: 02/06/2015

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## 2015 HOUSE HUMAN SERVICES

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HB 1370

# 2015 HOUSE STANDING COMMITTEE MINUTES

Human Services Committee Fort Union Room, State Capitol

> HB 1370 1/28/2015 Job #22732

□ Subcommittee □ Conference Committee

Committee Clerk Signature

Explanation or reason for introduction of bill/resolution:

Relating to mammogram results notices.

Minutes:

Testimonies 1-5

Chairman Weisz opened the meeting on HB 1370.

Rep. Pamela Anderson: From District 41 introduced and supported the bill. (See Testimony #1)

3:11

Rep. Mooney: Is there high propensity in dense breast tissue?

Rep. P. Anderson: Yes. There is information available when they have their mammograms. There are four levels of density.

Rep. Mooney: Once a baseline is established then a person can identify that and know that is part of their history and moving forward would be the idea?

Rep. P. Anderson: Absolutely.

4:14

Rep. Kathy Hawken: From District 46 in Fargo testified in support of the bill. Breast cancer is the leading cause of death for women. This gives the patient the knowledge base to be able to advocate for their good health. This is one of the pieces that can bring down healthcare costs over time. Because you are aware of it, looking for it and can catch it early. There is an issue of how ND looks at females and we don't come out real high on that. There is no cost to this bill. It is strictly making a law that women are to be informed of their results of their test. This could save some lives. I hope you will support this legislation.

House Human Services Committee HB 1370 January 28, 2015 Page 2

7:22

Rep. Porter: Are we sending a letter to a patient that says they have dense breast tissue that creates more questions, problems or concerns for them? Wouldn't we be better off if we have the physician discuss this with them rather than sent out in a letter? Are we setting ourselves up for a lot of unanswered questions that should be a required part of the follow up?

Rep. Hawken: I agree with you. This legislation was passed in 21 states. Our intent is for them to have the conversation with their doctor. We don't want to legislate how, but to send the information to the patient.

11:46

Cynthia J. Eggl: Testified in support of the bill. (See Testimony #2)

22:10

Rep. Fehr: You made reference to 4 types of breast tissue density. What are those for?

Eggl: Fatty tissue, scattered fiber granular tissue, dense tissue, extremely dense tissue. They couldn't see I had two tumors. This is not only a woman's disease, but men's also.

Rep. Fehr: It is also true for men that they have the 4 types of dense breast tissue?

Eggl: I can't speak from that point. This information is from the radiologist association.

Rep. Rich Becker: If the breast looks like looking at mud and the doctors miss it what other steps could they have taken to diagnose this earlier?

Eggl: That is why so many women are being diagnosed at a much later stages of breast cancer. The secondary testing I went through was ultrasound. Most women that have breast cancer don't have symptoms. Disclosure of the breast tissue type can be made as part of the letters that go out following mammography. I'm hoping based on the legislation that has been introduced that that would afford women and some men to catch their breast cancer at their earliest stage. They most likely would go forward for additional testing.

Rep. Rich Becker: You are implying that doctors are not communicating this information if dense breast tissue is present?

Eggl: Exactly about 50% of the facilities providing mammography are disclosing. My sister went in for her test and was informed of dense breast tissue and did a follow-up with her doctor. I am now on long term disability

Rep. Mooney: As you describe all of this, is a part of this not just dialogue between the doctor and patient, but the doctor and radiologists who are reading these tests?

Eggl: Right. The radiologist reading those reports determines one of those classifications. In 21 states now the radiologist has to the letter to the patient disclosing the type of breast tissue and recommend if they need to go for further testing.

House Human Services Committee HB 1370 January 28, 2015 Page 3

## 31:14

Dan Hanaher: Representing Sanford Health (who is neutral on the bill) passed out a letter from Michael Bouton, MD. Sanford Health is following the practice of this bill now. (See Testimony #3)

#### 34:34

Rep. Fehr: Can you tell us how Sanford Health is handling this notice in sensitive way?

Hanaher: The have standardized forms. Once the radiologist decides there is dense breast tissue the options to the patient are articulated in written form to them. Nationwide the definition of dense breast tissue is not clearly defined. Each radiologist may have a different opinion as to what is dense and what is not.

Rep. Fehr: If we pass this bill and put it in the century code, are you aware of any discussion of a year or five years from now that the testing is so advanced, this would become obsolete?

Hanaher: That is an ongoing concern of ours.

Rep. Mooney: It doesn't do any damage until this technology advances?

Hanaher: I agree.

Vice-Chair Hofstad closed the hearing on HB 1370.

Handed In Testimony

Patty Johnson (See Testimony #4)

Sanford Health (See Handout #5)

# 2015 HOUSE STANDING COMMITTEE MINUTES

# **Human Services Committee**

Fort Union Room, State Capitol

HB 1370
2/3/2015
23124

□ Subcommittee □ Conference Committee

Committee Clerk Signature

# Explanation or reason for introduction of bill/resolution:

A BILL for an act to create and enact a new section to chapter 23-01 of the North Dakota Century Code, relating to mammogram result notices.

### Minutes:

Chairman Weisz took up HB 1370.

Rep. Porter: My wife is a mammo-tech, so she is well read on mammography results. This bill is about 4 or 5 years late. The issue is fixing itself with technology & current medical practices. If we pass this, it should have an expiration date to come out of the century code the day the federal law hits so that it is not duplicated. I don't believe it is necessary based on the fact that it is happening already.

Chairman Weisz: How does that get around the issue regarding breast density.

Rep. Porter: With the technology of the 3D mammograms, the doctor can see much better the dense, fatty tissue and see if there is a possibility a tumor. They can do ultrasounds and MRI's ten times better now.

Rep. Mooney: I would be on board with an expiration date, and want a do pass on this legislation. It should be a standard practice.

Rep. Porter: There is no requirement that says that they will tell you that you don't have dense breast tissue.

Rep. Rich Becker: Dr. Bolton from Sanford said this is a national issue and should be dealt with as a federal issue. It appears that you are confirming that the federal government has something in the works. Any legislation of medical practice is a slippery slope for the government. Whether we pass this or not, a solution seems to be rapidly evolving.

Rep. Hofstad: I'm concerned about this slippery slope also. To suggest that this legislative body can put those procedures into code is dangerous. I think we should be cautious of putting things in code that we don't have the expertise or business in doing.

House Human Services Committee HB 1370 February 3, 2015 Page 2

Rep. Seibel: I don't think we should wait. I'm going to support this bill.

Rep. Fehr: Between federal law and new techniques, is there a way we can put something out that would automatically expire in two years without being renewed? I am expecting that to the major breakthroughs that this bill is going to be a short term issue.

Chairman Weisz: If you are looking to do that, then there are two ways, the first you can just put a sunset on it and have it last two years, the other way would be to say that it sunsets whenever federal regulation comes down. The simplest way would be to end it after two years.

Rep. Porter: This is old news, we are behind the curve of technology. The practice of medicine is 80% caught up to what we are thinking. This bill is not going to change the practice of medicine, they have already changed and they have already adopted this as a standard practice.

Rep. Mooney: I don't disagree that the expiration might be a really useful way to go with this. If there is even one doctor or patient who still isn't quite there, then that person's health could cost us more than this bill. **Makes motion to amend HB 1370.** 

Rep. Fehr: Seconds the Motion.

Voice Vote: The amendment carries.

Rep Seibel: motions for a Do Pass as Amended.

Rep Mooney: Seconds the motion.

Roll Call vote: 5 Yes, 8 No, 0 Absent.

Motion fails.

Rep. Porter: motions for a Do Not Pass as amended.

**Rep Hofstad: Seconds the motion** 

Roll Call Vote: 8 Yes, 5 No, 0 Absent.

Motion for a Do Not Pass as Amended carries.

**Rep Porter Carries the bill** 

# 2015 HOUSE STANDING COMMITTEE MINUTES

# **Human Services Committee**

Fort Union Room, State Capitol

ΗB	1370
2/4/	2015
23	225

□ Subcommittee □ Conference Committee

Committee Clerk Signature

Explanation or reason for introduction of bill/resolution:

A BILL for an act to create and enact a new section to chapter 23-01 of the North Dakota Century Code, relating to mammogram result notices.

## Minutes:

Attachment 1

00

Chairman Weisz took up the reconsideration of HB 1370.

Rep. Porter: I would move to reconsider our actions regarding a Do Not Pass on HB1370.

Rep. Hofstad: Seconds the Motion.

Voice Vote: the Aye's have it.

### Motion passes HB1370 is brought back.

Rep. Porter: (See Attachment 1) We had plenty of discussion on HB 1370 yesterday, and plenty of the discussion focused on the fact that a lot of what is being don is going to happen through the federal regulations. I was informed that Mammography is the only federally regulated medical procedure. It is not going to take an act of congress to accomplish the goal this bill is trying to reach. I Move to Amend line 20 and add the proposed text.

### Rep. Hofstad: Seconds the Motion.

Chairman Weisz: Can section 1 and 2 stay as well as subsection 3?

Rep. Porter: That is correct.

Rep. Seibel: would the sunset, July 30, 2017 still remain?

House Human Services Committee HB 1370 2/4/2015 Page 2

Rep. Porter: Yes.

Voice Vote: The Aye's have it.

Rep. Seibel: I move for a Do Pass HB1370 as Amended.

Rep. Mooney Seconds the Motion.

Rep Fehr: The amendment and everything will go into the century code, but it will disappear in two years?

Chairman Weisz: That would be correct.

Roll Call Vote: 12 Yes, 0 No, 1 Absent.

Rep. Porter Carries the Bill.

15.0766.01002 Title.03000



February 5, 2015

#### PROPOSED AMENDMENTS TO HOUSE BILL NO. 1370

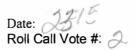
- Page 1, line 2, after "notices" insert "and the notification of registered owners of mammography equipment; to provide an expiration date; and to declare an emergency"
- Page 1, line 20, after the first underscored period insert "<u>The state department of health shall</u> notify all registered owners of mammography equipment of these changes, along with the state board of medical examiners, the North Dakota medical association, the North Dakota board of nursing, and the North Dakota nursing association. The state department of health shall encourage these boards to include information about these changes in the next publication of their professional journals.

**SECTION 2. EXPIRATION DATE.** This Act is effective through July 30, 2017, and after that date is ineffective.

SECTION 3. EMERGENCY. This Act is declared to be an emergency measure."

Renumber accordingly

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	ROLL	CALL	IG COMMITTEE /OTES D./370		
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2015 HOUSE STANDING COMMITTEE
ROLL CALL VOTES
BILL/RESOLUTION NO. 1370

House Human Services				_ Committee
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Amendment LC# or Description:		15	5,0766.01001	
Recommendation: <ul> <li>Adopt Amendre</li> <li>Do Pass</li> <li>As Amended</li> <li>Place on Cons</li> </ul> Other Actions: <ul> <li>Reconsider</li> </ul> Motion Made By	Do No	endar	Without Committee Rec Rerefer to Appropriation C conded By	
Representatives	Yes	No	Representatives	Yes No
Chairman Weisz		$\overline{V}$	Rep. Mooney	VZ
Vice-Chair Hofstad		V/	Rep. Muscha	V/
Rep. Bert Anderson		V/	Rep. Oversen	V
Rep. Dick Anderson		V/	/	
Rep. Rich S. Becker		V/		
Rep. Damschen		V	/	
Rep. Fehr	V		/	
Rep. Kiefert		XI		
Rep. Porter	/	V		
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House Human Services			V	Com	mittee
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Chairman Weisz Vice-Chair Hofsta Rep. Bert Anders Rep. Dick Anders	ad on son	Yes No	Rep. Mooney Rep. Muscha	Yes No
Chairman Weisz Vice-Chair Hofsta Rep. Bert Anders Rep. Dick Anders Rep. Rich S. Bec Rep. Damschen Rep. Fehr	ad on son	Yes No	Rep. Mooney Rep. Muscha	Yes No
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Vice-Chair Hofstad	-		Rep. Muscha		
Rep. Bert Anderson Rep. Dick Anderson			Rep. Oversen		
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Recommendation: Adopt Amendment Do Pass Do Not Pass Without Committee Recommendation As Amended Rerefer to Appropriations						
Other Actions:						
Motion Made By						
Representatives	Yes No	Representatives	Yes No			
Chairman Weisz		Rep. Mooney				
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#### **REPORT OF STANDING COMMITTEE**

- HB 1370: Human Services Committee (Rep. Weisz, Chairman) recommends AMENDMENTS AS FOLLOWS and when so amended, recommends DO PASS (12 YEAS, 0 NAYS, 1 ABSENT AND NOT VOTING). HB 1370 was placed on the Sixth order on the calendar.
- Page 1, line 2, after "notices" insert "and the notification of registered owners of mammography equipment; to provide an expiration date; and to declare an emergency"
- Page 1, line 20, after the first underscored period insert "<u>The state department of health shall</u> notify all registered owners of mammography equipment of these changes, along with the state board of medical examiners, the North Dakota medical association, the North Dakota board of nursing, and the North Dakota nursing association. The state department of health shall encourage these boards to include information about these changes in the next publication of their professional journals.

**SECTION 2. EXPIRATION DATE.** This Act is effective through July 30, 2017, and after that date is ineffective.

**SECTION 3. EMERGENCY.** This Act is declared to be an emergency measure."

Renumber accordingly

#### **2015 SENATE HUMAN SERVICES**

HB 1370

# 2015 SENATE STANDING COMMITTEE MINUTES

**Human Services Committee** 

Red River Room, State Capitol

HB 1370 3/4/2015 24300

□ Subcommittee □ Conference Committee

**Committee Clerk Signature** maly Muller

Explanation or reason for introduction of bill/resolution:

A bill relating to mammogram result notices and the notification of registered owners of mammography equipment; to provide an expiration date; and to declare an emergency.

Minutes:

Attach #1: New Screen Tests for Hard-to-Spot Breast Cancers, by Wall Street Journal Attach #2: Testimony by Rep. Pamela Anderson Attach #3: Written testimony by Cynthia J. Eggl Attach #4: Written testimony by Nancy Cappello Attach #5: email from Fred LaVenuta

**Chairman Judy Lee** distributed the article, "New Screening Tests for Hard-to-Spot Breast Cancers," by The Wall Street Journal (attach #1)

**Representative Pamela Anderson**, District 41, introduced HB 1370 (attach #2) (ends 4:32). Representative Anderson provided additional written testimony:

- Cynthia Eggl (attach #3)
- Nancy Cappello (attach #4)
- Fred LeVenuta (attach #5)

**Chairman Judy Lee** stated this not only impacts women, but can also occur with men. Chairman Judy Lee further mentioned that the survey from North Dakota is much more favorable than the national survey. She stated that she does not support legislation that dictates medical care that physicians should supply. Chairman Judy Lee's research indicates that there is a tremendous of support in the years that have intervened since Ms. Eggl's diagnosis. Chairman Judy Lee believes the technology and medical practice has evolved and physicians inform their patients of the issue.

**Representative Anderson** responded that this is a mandate for information. Until this started in the state of Connecticut in 2001, women didn't have this information at all.

Chairman Judy Lee stated that is 14 years ago.

**Representative Anderson** continued, stating that she had a mammogram one year ago at Sanford and was not provided the information. It is now becoming a standard of practice. She believes this will make a difference in women's lives. You may get the information at

large clinics, but it may not be available at all clinics throughout the state. You have to be your advocate of your own health, do if you don't know if you have dense breast tissue, you can't be an advocate for early detection. Until this law is passed, no one gave the information to women.

**Chairman Judy Lee** asked can you demonstrate a causal relationship in the 14 years since the effort began and how it caused the additional information to be provided, or do you not think that physician's continuing education and evolving practices may have also contributed to the fact that more people know about the issue than before.

**Representative Anderson** stated that only one-in-ten women found out from their physician that they had dense tissue.

Chairman Judy Lee asked in which year.

Representative Anderson responded based on Ms. Eggl's letter.

**Chairman Judy Lee** indicated that Ms. Eggl's discussion is based on her experience starting seven years ago. The point is that there has been an evolution-of-care and medical providers recognize the importance of this.

**Representative Anderson** explained that she is on her 4<sup>th</sup> provider at Sanford in the past 5 years. If she didn't have that information herself, she doesn't know how she can be her own advocate if she has to rely on the healthcare providers.

**Senator Warner** asked if there are objective measures of density. Is there a number that indicates fatty tissue, dense tissue, extremely dense tissue? Is it one number for the entire organ or are there mapping possibilities, areas of greater or lesser densities which could be mapped and provided opportunities to measure change over time.

**Representative Anderson** responded that there are four levels of density of breast tissue. Fatty tissue and dense tissue mammograms are considerably different. This is the information you get. The radiologist reads the test, but it was never in the report - they would state the mammogram was normal and not identify the level of density. Further, the tissue in your breast doesn't change over time.

**Senator Warner** understands that the density masks the condition, it doesn't contribute to condition.

Representative Anderson that is correct.

**Senator Axness** reviewed the original bill and amendments from the House. Senator Axness asked why they decided to put an expiration date on this bill.

**Representative Anderson** stated the idea was that within the two year period, everyone would be doing this, so then it no longer needed to be in statute. The House also added the emergency clause.

OPPOSITION TO HB 1370 No opposing testimony.

NEUTRAL TO HB1370 No neutral testimony.

**Chairman Judy Lee** invited **Ms. Courtenay Koebel** to the podium, asking what her membership may do regarding the notifications.

**Courtenay Koebel**, representing the North Dakota Medical Association, stated this is a difficult and emotional issue. When this was discussed with the members of the medical association, they responded that they already inform their patients of the density. There may be special cases where it is not appropriate, but in general, we support patients being aware of their healthcare and being their own advocate. They are concerned that it is another mandate, so they do have concerns.

**Chairman Judy Lee** asked who is going to let the people know that aren't part of the big healthcare network to tell people about it. How will you even know the law was even passed?

**Ms. Koebel** responded they do advocacy after session, releasing notices, the hospital association does and other specialty societies do. Sometimes when bills like this pass, there is a surprise element that "this is the law?"

**Senator Howard Anderson, Jr.** recommended comment from the Department of Health on section 3 of the bill, where it states the Health Department may establish forms and notify clinics.

**Chairman Judy Lee** invited a representative from the Department of Health to comment. There was no one available to do this, so this will be discussed further in committee work.

Closed public hearing.

# 2015 SENATE STANDING COMMITTEE MINUTES

# **Human Services Committee**

Red River Room, State Capitol

HB 1370 3/4/2015 24330

□ Subcommittee □ Conference Committee

Umald Mueller

Committee Clerk Signature

Explanation or reason for introduction of bill/resolution:

A bill relating to mammogram result notices and the notification of registered owners of mammography equipment; to provide an expiration date; and to declare an emergency.

## Minutes:

No attachments

The Senate Human Services Committee met on March 4, 2015 at 2:05 p.m. for HB 1370.

**Chairman Judy Lee** recapped the earlier discussion from the hearing earlier today. The committee invited the Department of Health to comment on Subsection 3, bottom of page 1, regarding establishing a standardized form for use by a facility for notification of breast density.

**Susan Morman**, Director for the Women's Way Program with the Department of Health, indicated that in section 3, the "State department of health *MAY* establish a standardized form". The department does not have the intent to create a standardized form. The intent is to inform the facilities that they need to notify the women. The department would provide suggested language as to what they should be saying along with additional information regarding breast density.

**V. Chairman Oley Larsen** discussed with mobile mammogram testing procedures, they go through a process of screening, so they automatically move to the next step, or do they have to send the patient to a different location for more advanced equipment for follow-up.

**Ms. Morman** indicated that in most instances, they are not sent to another facility. A woman may have dense breasts, but she may not be informed about the situation and may not understand that she may need to come in for another procedure or go to a different level of review.

**Chairman Judy Lee** asked doesn't the newest equipment reflect enhancements in technology so repeated procedures aren't necessary.

**Ms. Morman** indicated yes, but with the dense breasts it becomes more difficult, and so sometimes they require additional testing.

**Senator Howard Anderson, Jr.** explained the way mammogram works is information is reported to physician who then interprets the findings to the patient. The follow-up test would be an ultrasound if they couldn't see with the mammogram.

**Ms. Morman** confirmed that is correct. The Radiologist provides the report which goes back to the provider and the patient. This bill would require that dense breast information is provided to the patient. The patient may not get the report today.

**Chairman Judy Lee** thinks it's odd that we ask the Department of Health to create a new form when it doesn't seem that difficult to add a sentence from the reports that come out from the clinics.

**Ms. Morman** restated that the Department of Health does not intend to establish the form. The bill states "may" develop a form.

**Chairman Judy Lee** asked if Ms. Morman has a suggestion on language changes to the bill. Chairman Judy Lee suggested removing the first sentence in Section 3.

Ms. Morman indicated that would make sense to her as they don't plan to develop a form.

**Chairman Judy Lee** indicated further that more language could be removed, as it seems rather detailed for statute. But she would favor removing the first sentence.

**Ms. Morman** confirmed. The Department of Health is already including the information as detailed in subsection 3, so there is no problem with leaving this in the bill.

**Chairman Judy Lee** asked if there should be a phrase or a mandate that states the provider must provide the information to the patient. That is the real intent.

**Ms. Morman** indicated it is already stated in subsection 2, "the facility shall include in the summary of the written report that is sent to the patient a notice that the patient has dense breast tissue..."

**Senator Dever** offered his opinion that the introduction of this bill suggests that health care providers do not follow-up on a diagnosis of dense breasts. If they transmit that information to the patient, then do they have an obligation to follow-up and leaving that to the patient.

**Daniel Hannaher**, Sanford Health, testified neutral at the House committee hearing for HB 1370. They do not see the necessity of the legislation because they are currently doing everything that it mandates. The hospital association also testified that in surveying the hospitals in the state, upwards of 85% were already doing it, and the 15% missing simply aren't in the business of providing the service. It is good intent, it will not cost them anything, so they praised the intent of the bill but also stated it is not necessary.

**Chairman Judy Lee** stated she had conversation with Ms. Eggl and she is passionate of the bill, but Chairman Judy Lee struggles whether this bill is necessary.

**Mr. Hannaher** indicated that the State of Minnesota implemented this last year, so any hospital serving patients to the neighboring state has undertaken this.

**Chairman Judy Lee** indicated that for no other reason, any facility doing mammography would do it from a liability standpoint. It is a commonly discussed issue, so notification would protect these facilities.

**Mr. Hannaher** stated it is good medical practice to discuss with the patient. This has evolved with 3-D mammography and technology.

Senator Dever asked what the term "heterogeneously dense breasts" applies to?

**Chairman Judy Lee** indicated the density levels would be different. **Mr. Hannaher** indicated he is not a doctor so could not define the term. He believed it could mean this could occur with males as well as females.

**Senator Dever** stated the benefit of a standardized form is that it would indicate what your level of concern should be if diagnosed with dense breast tissue.

**Chairman Judy Lee** offered her opinion that the clinicians will have that same level of expertise if it is required. It would be part of the letter they send out anyways.

**Senator Dever** so mammograms are done at hospitals, mobile centers, cancer centers, etc. The committee confirmed.

**Chairman Judy Lee** voiced her concern that she doesn't want to leave the impression that the State Department of Health "MUST" establish a form so they are sitting around waiting for them to do this, when they have no intent to do this.

**Senator Warner** moved the Senate Human Services Committee ADOPT AMENDMENT to remove the first sentence of Subsection 3 requiring the Department of Health to establish a form. The motion was seconded by **Senator Dever**.

# Roll Call Vote to ADOPT AMENDMENT

<u>6</u> Yes, <u>0</u> No, <u>0</u> Absent. Motion passes.

**Senator Warner** moved the Senate Human Services Committee DO PASS the Amended Engrossed HB 1370. The motion was seconded by **Senator Axness**.

# **Discussion**

**Senator Dever** stated he may not support the motion because he thinks it is unnecessary, although he is sympathetic to the intent. **Chairman Judy Lee** agreed.

Roll Call Vote to DO PASS AS AMENDED 2 Yes, 4 No, 0 Absent. Motion fails.

**Senator Dever** moved the Senate Human Services Committee DO NOT PASS AS AMENDED. The motion was seconded by **V. Chairman Oley Larsen**.

### Discussion

**V. Chairman Oley Larsen** indicated that as sonograms evolved, the medical industry evolved with that. As new technology moved along, such as 3-D technology, it is the procession of this. He does not believe anyone is being left behind. Legislatively, we should not get in the way of that process.

<u>Roll Call Vote to DO NOT PASS AS AMENDED</u> <u>4</u> Yes, <u>2</u> No, <u>0</u> Absent. Motion passes.

Senator Dever will carry HB 1370 to the floor.

15.0766.03001 Title.04000 Adopted by the Human Services Committee

March 4, 2015

7) 3/4/15

## PROPOSED AMENDMENTS TO ENGROSSED HOUSE BILL NO. 1370

Page 1, line 20, remove "<u>The state department of health may establish a standardized form for use by a facility</u>"

Page 1, line 21, remove "in compliance with this section."

Renumber accordingly

- ....

Date: 03/	64	2015
Roll Call Vote	e#:	/

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Date: 03/04	_2015
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2015 SENATE STANDING COMMITTEE ROLL CALL VOTES BILL/RESOLUTION NO							
Senate Human Services				_ Com	mittee		
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Senators	Yes	No	Senators	Yes	No		
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Senator Oley Larsen (V-Chair)		V	Senator John M. Warner	$\checkmark$			
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Absent \_\_\_\_\_\_ No \_\_\_\_\_ Floor Assignment \_\_\_\_\_

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Senators Senator Judy Lee (Chairman)	Yes	No	Senators Senator Tyler Axness	Yes	No		
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#### **REPORT OF STANDING COMMITTEE**

- HB 1370, as engrossed: Human Services Committee (Sen. J. Lee, Chairman) recommends AMENDMENTS AS FOLLOWS and when so amended, recommends DO NOT PASS (4 YEAS, 2 NAYS, 0 ABSENT AND NOT VOTING). Engrossed HB 1370 was placed on the Sixth order on the calendar.
- Page 1, line 20, remove "<u>The state department of health may establish a standardized form</u> for use by a facility"

Page 1, line 21, remove "in compliance with this section."

Renumber accordingly

## **2015 TESTIMONY**

HB 1370

1-28-15

Testimony On HB 1370, Pamela Anderson, District 41

Chairman Weisz and members of the House Human Service Committee, my name is Pamela Anderson, I represent District 41.

#1

House Bill 1370 is an information bill. A breast density notification law requires that women are notified who have undergone mammography and were found to have dense breast tissue. It can be more difficult to detect early breast cancer in dense breast tissue.

The intent of this law is to give health information to the patient and her health care provider. What they do with the information will be up to them and their insurance company.

I have attached a map showing the states that have passed this law, introduced or working on a bill. Minnesota has passed a similar law.

The North Dakota Hospital Association, Jerry Jurena, graciously did a survey of health care providers in North Dakota. I have included the survey which had an 83.4% response rate. The good news is 50% already report breast density. The 50% that report breast density probably covers 80% of the mammograms done in the state.



\* -

So, you might ask, do we need this law at all? I would say "yes" because all women in the state should have this information given to her no matter where she receives her healthcare.

Ms. Eggl sent all committee members an email and is here to testify as well. Dr. Fred LaVenuta sent an email to the Committee Chair asking support of House Bill 1370 which I have included with my testimony. He calls this information a "wake-up" call.

I urge you support this bill. Thank you.





## Breast Density Notification Laws by State — Interactive Map

January 16, 2015 | Breast Imaging, Mammography By Marijke Vroomen Durning, RN

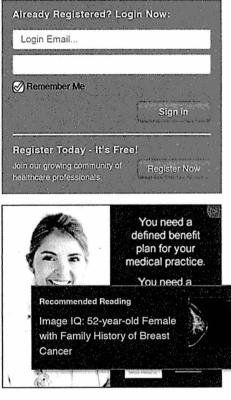


Breast density notification laws have been put into effect in 21 states. A breast density notification law requires that physicians notify women who have undergone mammography and were found to have dense breast tissue.

The intent of such a law was to give women the necessary information to decide on further action if they had dense breast tissue. Dense breast tissue makes it harder to identify cancer on a mammogram and may also be associated with an increased risk of breast cancer, according to the American College of Radiology (ACR). Women with dense breasts are encouraged to discuss with their physicians their possible increased risk of breast cancer and the difficulty that mammography may have in detecting tumors. Critics of such a law or of how such a law is Implemented believe that women may receive the information in less than ideal circumstances, which can lead to increased anxiety, as well as additional medical procedures.

"The manner in which the information is shared is important," Richard Frank, MD, PhD, chief medical officer for Siemens Healthcare North America and founding member of the Quantitative Imaging Biomarkers Alliance of the Radiological Society of North America, told *Diagnostic Imaging*. "There might be value in not just sending a letter through the mail, but giving it to her. She then has an opportunity to actually talk about it." In most cases, the letters are mailed, so the content of the letter is paramount. The letter's text varies considerably across the states. Frank believes that women would be better served with a single informed letter issued from the federal level.

An example of ineffective language used in some states is one that raises more questions than it answers, according to Frank. Such letters say, "If you have dense breasts, and then what the options are. So the woman is going to look at that letter and say, 'why did I receive this letter?" It doesn't tell her if she does or doesn't have dense breasts, nor bes it inform her of her particular situation, Frank explained. A letter that says "if" you have dense breasts, is a good



MAKING SENSE OF BREAST DENSITY LEGISLATION - OUR INTERACTIVE MAP



Use our interactive toolto help you navigate breast density notification legislation across the country.

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example of one that might only raise concerns and not be helpful, he said.

In process Legislation passed No action

For a more effective letter, Frank liked the one by physicians in Michigan: "It says, 'your mammogram shows that your breast tissue is dense.' There is the opening line, a clear statement," he stated.

"You're receiving this letter because your breast tissue is dense. Dense breast tissue is very common and is not abnormal. However, dense breast tissue can make it harder to find cancer through a mammogram" is a common explanation in some state's notification letters. Frank pointed out that these lines explain why it might be a good idea for this woman to undergo other imaging techniques. "And then the letter goes on to say something else: also dense breast tissue may increase your risk for breast cancer."

The letter continues: "This information about the results of your mammogram is given to you to raise your awareness. Use this information to talk to your physician.' So now they are giving specific instructions for what you should do with this," Frank said. "There is no question in the mind of the woman. 'What is my status, what is there relevance and what should I do about it?"

The ACR has provided some resources for physicians who would like to learn more about the breast density laws. In addition, they have some sample lay report letters for physicians' use or adaptation.

The first state to pass breast density notification legislation was Connecticut in 2009. Many states have followed since then. Check out our interactive map to see which states have passed breast density notification legislation (and their recommended text), what states are in process and what states haven't approached the controversial topic yet.

## Doctors are people too.



Mixed Messages About Breast Density As Risk Factor

Technologists Affect How Radiologists Read Screening

Risk-Based Screening Misses Many Breast Cancers

Mammography

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1/17/15, 3:41 PM Page 2 of 3

# Mammography Survey

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and the second set of	your facility information:	17 facilities completed survey
ber	Facility Name:	City:
	Jamestown Regional Medical Center	Jamestown
	West River Health Services	Hettinger
3	Altru Health System	Grand Forks
	Southwest Healthcare Services	Bowman
5	CHI St. Alexius Garrison Hospital	Garrison
	CHI Mercy Health	Valley City ND
	Sanford Health	Fargo, ND
8	CHI Lisbon Health	Lisbon
9	St. Andrews Health Center	Bottineau
10	St Lukes Hospital	Crosby
	Linton Hospital	Linton
	Jacobson Memorial Hospital Care Center	Elgin
	presentation medical center	rolla
Contract of the second s	McKenzie County Healthcare Systems	Watford City, ND
	TIOGA MEDICAL CENTER	TIOGA
	Sakakawea Medical Center	Hazen
	Mountrail County Health Center	Stanley
2. Does y	our hospital/clinic provide mammograms?	
Answer	Response Percent	
Options		
Yes	82.4%	
No	17.6%	
		-
s. If yes, v	vho reads/reviews them?	
Answer	Response Percent	
Options		
f done in-	37.5%	
f	81.3%	
	If done in-house, identify name and/or dept:	If outsourced, identify who outsourced to:
	In house radiologists (Wade, Reddy)	
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4. Is brea	st density reported?	
Answer Options	Response Percent	
	50.0%	
	25.0%	
N/A	25.0%	
5. If yes,	tojwho:	
Number	Response Text	
	to ordering provider via report	
2	Main Provider for Patient, and Mammographer,	
2	Patient if heterogenously or extremly dense and	
3	referring physican	
4	the provider	
5	On final report, so information goes to primary physician	
	In the repor	
	On the report - one goes to provider and one to patient	
8	On the radiology repor it indicates dense versus fatty tissue	

6



## Anderson, Pamela K.

From: Sent: Dject: Fred LaVenuta <fredlave@cableone.net> Monday, January 26, 2015 12:04 PM Weisz, Robin L. House Bill 1370

I am writing to encourage your support passage of House Bill 1370. In summary, this bill provides for notification to a patient undergoing mammography if her X rays show dense breast tissue according to accepted standards. Women with dense breast tissue are six times more likely to develop breast cancer and conventional mammography may miss small tumors. This bill does entails no costs but it is a wake-up call to those concerned that alternatives to conventional mammography for early diagnosis should be considered. Fred LaVenuta M.D.

Fargo, ND



Are DENSE? ADVOCACE because your life matters

January 26, 2015

The Honorable Robin Weisz Chairperson, ND Human Services Committee 2639 First Street SE Hurdsfield, ND 58451-9029

Re: House Bill 1370 – Mammographic Results Notice Testimony of Nancy M Cappello, Ph.D., Founder, Are You Dense Advocacy, Inc.

Dear Chairman Weisz, Vice Chairman Hofstad and ND Human Services Committee:

My name is Nancy Cappello and I reside in Woodbury CT. I am founder of two global breast cancer organizations whose mission is to educate the public about the impact of dense breast tissue on missed, delayed and late-stage cancers. I write to you in support of **HB 1370** and request that this correspondence be included in the record of the Public Hearing on January 28, 2015.

In 2004, I was diagnosed with advanced stage IIIC breast cancer after a decade of 'normal' mammograms. I first learned about my dense breast tissue <u>after</u> my cancer diagnosis, which was within weeks of what I refer to as my "happy gram" report which stated that the results of my mammogram were "normal."

My physicians informed me that **my years of mammography screening failed to detect my cancer because of my dense breast tissue.** My cancer was the size of a quarter and has spread to 13 lymph nodes -remember a normal mammogram weeks before. Six surgeries, 5 months of chemotherapy, 24 radiation treatment, life-long medications, countless tests, massive medical costs and a greater likelihood of dying prematurely from this disease; this is the reality of my advanced stage cancer.

Searching the scientific journals, I was stunned to discover that my story, while compelling, is common as 40% of women have dense breast tissue. **National surveys report that less than one in 10 women learn about their breast density from their physician.** For more than two decades, research demonstrates that women with dense breast tissue have less than a 50% chance of having their cancer detected by mammography alone. There are additional screening tools, when added to mammography, that significantly increase detection of small, invasive cancers invisible by mammogram. **Dense Breast Tissue is also an independent risk factor for breast cancer.**<sup>1</sup>

<sup>1</sup> Cappello, N. Journal of American College of Radiology (10:903-908), December, 2013



Are You Dense Advocacy, Inc.

96 Rowley Road • Woodbury, CT 06798 • (203) 232-9570

AreYouDenseAdvocacy.org

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The Honorable Robin Weisz Re: HB 1370 Mammographic Results Notice Page Two



Armed with these startling scientific facts, I started working with the Connecticut legislature and, in 2009, Connecticut became the first state in the nation to standardize density reporting to women through their mammography report.

Compelled to action because of the **inaction of the medical community to inform women about this fatal flaw in breast cancer screening**, I founded two nonprofit organizations, **Are You Dense**, **Inc. and Are You Dense Advocacy**, **Inc.**, which **has fueled a global movement of patients turned advocates -** a testament to the fact that there is no shortage of women harmed by their dense tissue.

Following CTs leadership, legislative champions, inspired by advocates, enacted breast density legislation in **21** states (Texas in 2011; Virginia, New York, California in 2012, Maryland, Hawaii, Nevada, Oregon, North Carolina, Tennessee, Alabama, Pennsylvania in 2013, New Jersey, Arizona, Missouri, Massachusetts, Rhode Island, Ohio and **your border state, Minnesota in 2014** and Michigan in 2015. An additional **8 states**, including **North Dakota**, have introduced or are awaiting introduction of density reporting bills in 2015.

Women can only rely on what their doctors choose to reveal to them. Unless density reporting is standardized, too many women will falsely have confidence in their "normal" mammography report and yet in reality their report is far from normal. Later stage cancers are more costly to treat, convey fewer treatment options and poorer survival outcomes.

Your affirmative support of **HB 1370 will give women of North Dakota critical information about their dense breast tissue so they can make an informed decision as they participate in discussions** with their health care providers about their personal breast screening surveillance.

I applaud Representatives Anderson, Hawken, Mitskog, Strinden and Senator Nelson for supporting this critical women's breast health bill. It **will improve life outcomes** for women of North Dakota. I ask the committee for its support of **HB 1370**.

Nancy M. Cappello, Ph.D. Director and Founder Are You Dense Advocacy Inc.



# 2

### CYNTHIA J. EGGL 2701 12<sup>th</sup> Street South, #14 Fargo, ND 58103 (701) 234-1706

January 28, 2015

Rep. Robin Weisz, Chairman ND Human Services Committee 2639 First Street SE Hurdsfield, ND 58451-9029

RE: House Bill No. 1370 – Mammography Result Notices

Dear Rep. Weisz:

Thank you for allowing me to testify at the hearing on House Bill No. 1370 on Wednesday, Jan. 28, 2015. My name is Cynthia J. Eggl and I reside in Fargo, ND. I am the author of a book entitled, "Boundless Blessings and God's Grace: My Journey through Breast Cancer." I am testifying in support of the proposed North Dakota legislation. 21 states in the U.S., including North Dakota's border state Minnesota, have legislated density reporting to women, starting in Connecticut in 2009 - a testament that there is no shortage of women harmed by their dense breast tissue with missed, delayed and late stage breast cancer.

I want to share my personal experience with you. I completed monthly self-breast exams, a baseline mammogram at age 35, annual mammograms starting at age 40, and annual physicals, all with no indication of breast cancer – all my exams and reports were "normal." From January, 2011 to April, 2011, I experienced excruciating breast pain in my lower left breast which radiated out under my left arm. The pain finally forced me to my doctor's office on April 5th, 2011 for an exam.

On that day, a physician's assistant at Sanford SouthPointe Family Practice completed my exam and marked three areas of concern on or near my left breast which she felt needed to have further testing. She left the exam room, returning about 10 minutes later to tell me I was not going back to work that day, and that I was to proceed immediately to the Breast Imaging Clinic at downtown Sanford Clinic. She indicated the staff at the Breast Imaging Clinic would be working me into their schedule for a breast ultrasound. I remember thinking to myself that I should not be afraid because I had done everything I possibly could to try to catch potential breast cancer at its earliest stage.

Three hours after I arrived at the Breast Imaging Clinic, I was called back for the test. It took the technician about 20 minutes to complete my breast ultrasound. She indicated she would be showing the scans to Dr. Janine Carson, the Radiologist on call at the Breast Imaging Clinic, to see if there was anything further she needed to see before letting me leave the clinic. About 10 minutes later, both the technician and Dr. Carson came back in the room. Dr. Carson stood by my bed and said, "Cynthia, looking at your breast scans is like looking through mud. Your breast tissue is so dense, I cannot see what I am looking for on the scans." She indicated she was in the room to help guide the technician as they did a second breast ultrasound. Following the second ultrasound, she turned back to me and said, "We need to schedule three needle biopsies as soon as possible." I got dressed and proceeded to the scheduling office, where I made appointments for my biopsies the following Monday.

I endured three needle biopsies on April 11, 2011. Dr. Carson indicated I should know my biopsy results in the next day or two. The following day, April 12, 2011, at 2:30 p.m., Dr. Carson called to confirm I had breast cancer in all three of the biopsied locations. She told me I had ½ hour to call my family and my

employer, and then I needed to be off the phone so I could receive a call from the Sanford Roger Maris Cancer Center regarding appointments they were already scheduling with a medical oncologist, radiation oncologist, a breast surgeon, and for other tests. I have survived a 9+ month breast cancer battle.

Breast cancer doesn't run in my family – I'm the first to be diagnosed with this disease. I was stunned to learn I had Stage 2b breast cancer which had moved into my lymphatic system. Several of my physicians told me my breast cancer had most likely been growing undetected for a period of 2-4 years.

I also discovered additional information regarding dense breast tissue after my journal was published as a book in December, 2012. From the <u>www.areyoudense.org</u> website, I learned that nearly half of our population worldwide has dense breast tissue. Two-thirds of women pre-menopausal and one-third of the women post-menopausal have dense breast tissue. Breast density is one of the strongest predictors of the failure of mammography screening to detect cancer. If you have dense breast tissue, there is a much greater risk of having breast cancer which will go undetected, even within months of undergoing a normal mammogram. Knowledge about your breast tissue composition is an important part of your breast health records. The more "dense" tissue a woman has, the higher the chance that cancer might be missed and that cancer might develop in the first place. While mammogram detects 98% of cancers in women with fatty breasts, it finds ONLY 48% in women with the densest breasts. Cancer turns up 5 times more often in women with extremely dense breasts than those with the most fatty tissue.

Dense breast tissue is comprised of less fat and more connective tissue which appears white on a mammogram. Cancer also appears white on a mammogram thus tumors are often hidden behind the dense tissue. As a woman ages, her breasts usually become more fatty. A radiologist determines the density of a woman's breasts by examining a mammogram.

I use every opportunity to encourage women to request a copy of their mammography report from their doctor - to make sure it is the report that is generated from the radiologist and not a form letter. I ask them to read the report carefully, looking for descriptions of their breast tissue. If they do have dense breast tissue, I strongly encourage them to talk to their doctor about having a breast ultrasound, breast MRI, 3-D imaging or whatever additional testing options that may be available to them to find potential breast cancer at its earliest stage.

I have gained knowledge about the risks associated with dense breast tissue while battling for my life after no one told me about my dense breast tissue. Knowing would have afforded me a chance to find my breast cancer at an earlier stage by undergoing additional testing. I know personally how profoundly my breast cancer battle has affected my quality of life for the long-term.

Prior to my breast cancer battle, I was diagnosed with Hashimoto's Disease, an autoimmune disease of the thyroid, which in and of itself, is difficult to manage. Following a double lumpectomy, removal of 9 lymph nodes from beneath my left arm, 16 chemotherapy treatments using three different chemotherapy drugs, and 33 radiation treatments, I have now been diagnosed with a total of five (5) autoimmune diseases – Hashimoto's Disease, Rheumatoid Arthritis, Fibromyalgia, Pre-Diabetes bordering on full blown Diabetes, and a rare autoimmune disease of the skin recently diagnosed by The Mayo Clinic.

Additionally I have peripheral neuropathy (nerve damage) which has affected my ability to drive – I have driven only three times in the past year because of disorientation and dizziness. I cannot feel the bottom of my feet and my little toes are numb. I cannot sit in a darkened room because it feels like I am going to fall right out of my chair. I have lymph edema throughout my left breast, degeneration of bones in my knees, feet, and shoulders, severe disabling muscle spasms, and swollen ankles if I sit for periods longer then several hours. My fatigue is overwhelming and I have overall body aches each day. Because I have a suppressed immune system following my formal breast cancer treatments, there are limitations to what type of prescribed drugs I can use to help manage my autoimmune diseases and other health issues. I

make each day that I have been granted the best it can be, regardless of my health issues, because I am quite simply grateful to be alive. Prior to my breast cancer diagnosis, I was working 50-60 hour work weeks for Dakota Medical and Impact Foundations as the Executive Assistant to the President, boards, committees and members. I was also managing a home-based business and teaching private voice lessons, where I drove to the homes of my voice students for their lessons.

During my 9+ months of formal breast cancer treatments, surgery, and for one year following those treatments, I worked 40-hour work weeks for my employer. On January 9, 2013, I filed for personal long-term disability, and was forced by our private insurance carrier to file for Social Security Disability Insurance (SSDI) so they could offset their payments to me. After being denied twice by SSDI in a written application and an appeal, I appeared at a formal hearing in front of an Administrative Law Judge on Sept. 13, 2013. Five days later, Sept. 18, 2013, the judge ruled I was permanently disabled for a period of 5-7 years.

My physical health has been diminished, but my mental health, thank God, has remained intact. I was encouraged by many people and finally published my personal journal written while I underwent my formal treatments and recovered from my breast cancer battle into a book entitled, "Boundless Blessings and God's Grace: My Journey through Breast Cancer" by Cynthia J. Eggl. My book is available worldwide, and is a positive, uplifting journal from my perspective as a patient, encouraging others should they ever be diagnosed with cancer or another challenging medical condition. I promised myself that I would make the path for individuals diagnosed with breast cancer in the future smoother than my journey.

This legislation, through education alone, could help save lives, save trauma to future breast cancer patients, and could save millions of healthcare dollars because breast cancer is diagnosed at its earliest stage. Passing this legislation and having it signed into law will be the most important thing I do in my life to positively impact others.

I have felt a sense of betrayal being diagnosed with a later stage breast cancer following 12 years of supposed "normal" mammograms and yearly exams by my family physician. It is especially troubling knowing that some of the very medical doctors who purport to have the best interests of their patients in mind, who fail to disclose that your dense breast tissue could prevent your mammogram from finding your breast cancer situation at its earliest stage, and who fail to even discuss additional testing with you, are the same physicians who think that how they are fulfilling their medical oaths today is perfectly fine when it comes to this medical issue.

Beyond my personal goal of wanting to do better for future patients lies my hope that North Dakota's legislators would have the best interests of their constituents at heart - affording them every opportunity to survive a breast cancer battle. Since we do not have a cure for breast cancer, the most obvious way we can affect breast cancer's grip is to find it at its earliest stage. But that is not possible unless your medical doctor discloses to you that your breast tissue is dense and the associated risks of dense breast tissue. Education and additional testing are key, and you could help affect change and educate North Dakotans through this specific legislation. I ask for your support in recommending passage of House Bill No. 1370 so that it can be signed into law in North Dakota as soon as possible. Thank you!

Sincerely nia J. Eggl

cc: Rep. Curt Hofstad, Vice Chairman, ND Human Services Comm. Dist. 15 - chofstad@nd.gov Human Services Committee Members: Rep. Bert Anderson, Dist. 2 - bertanderson@nd.gov Rep. Dick Anderson, Dist. 6 - dickanderson@nd.gov Rep. Rich S. Becker, Dist. 43 - rsbecker@nd.gov Rep. Chuck Damschen, Dist. 10 - cdamschen@nd.gov Rep. Alan Fehr, Dist. 36 - afehr@nd.gov Rep. Dwight Kiefert, Dist. 24 - dhkiefert@nd.gov Rep. Gail Mooney, Dist. 20 - gmooney@nd.gov Rep. Naomi Muscha, Dist. 24 - nmuscha@nd.gov Rep.Kylie Oversen, Dist. 42 - koversen@nd.gov Rep.Todd Porter, Dist. 34 - tkporter@nd.gov Rep.Jay Seibel, Dist. 33 - jayseibel@nd.gov

Sponsors of House Bill No. 1370:

Rep. Pamela Anderson, Dist. 41 - pkanderson@nd.gov Rep. Kathy Hawken, Dist. 46 - khawken@nd.gov

Rep. Alisa Mitskog, Dist. 25 - amitskog@nd.gov

Rep. Marie Strinden, Dist. 18 - mjstrinden@nd.gov

Sen. Carolyn C. Nelson, Dist. 21 - cnelson@nd.gov

# 1/28/15

> Bill No. 1370 Testimony to the House Human Services Committee

Whereas House Bill 1370 has been introduced in the sixty-fourth Legislative Assembly of North Dakota, the Sanford Health, Edith Sanford Breast Center Physicians have reviewed and discussed the contents of the bill. This is an important issue we have dealt with across our system over the past few years. We are proud to convey that we are currently providing the information to patients outlined in the bill consistent with professional standards of practice. We remain proactive to the concerns and health of our patients. The issue of dense breast stratification to the degree of risk for breast cancer, and the additional testing required to follow these patients carefully and appropriately is in transition. While we have incorporated this into our standards of practice we take a position of neutrality related to this bill consistent with Sanford standards. We do remain committed to staying in the fore front of this and other issues related to the health of the citizens of North Dakota.

SANF: RI

HEALTH

Sincerely,

Michael Bouton, MD, MA, FACS

HB1370

~

Patty Johnson 3906 10<sup>th</sup> St. N Fargo, ND 58102 (701) 793-6017

January 2**9**, 2015

Dear Rep. Robin Weisz,

My name is Patty Johnson and I have been asked to share my Breast Cancer story with you on behalf of House Bill #1370 to mandate the reporting of dense breast tissue to patients.

My story starts in Aug of 2006 at the age of 46, when at my yearly physical exam; I expressed concern of breast tenderness and the feeling of fullness in my left breast with my then physician Dr. Charlene Card. During the exam Dr. Card asked if I was doing monthly exams and I replied I was, and that although I could not feel any changes in my breast tissue I was having a feeling of tenderness and fullness in my left breast. She also could not feel anything of concern and reassured me that my previous mammograms had never shown any concern. She stated to me that I was getting to "that age" and that I should expect to have changes in my breasts. I asked, if the tenderness was due to hormone changes wouldn't I then feel tenderness in both breasts? She recommended that I follow up with another mammogram. I followed through with the mammogram and the report came back as negative.

In December of 2007, my next physical exam was with Dana Stegmiller, P.A. Dana asked if I had any changes in my breast and I replied no, in her exam she also could not feel any lump and recommended another mammogram. This mammogram also came back as negative.

Then 6 months later on Sunday, June 15<sup>th</sup> 2008 after working in the yard and undressing to shower I noticed a black spot on the nipple of my left breast. Thinking it was dirt I brushed it off and was shocked to see a green fluid drain from my breast. Dana Stegmiller P.A. saw me the next day; she was able to express some fluid to culture and ordered another mammogram, which was to be more diagnostic. The culture

came back negative for any bacteria and again the mammogram was negative. She then referred me to the MeritCare breast clinic which was scheduled out 6 weeks before I could be seen. I had requested to be called in on a cancellation and was seen the next week by Dr. Carol Grimm. During this exam she expressed some fluid and placed it on a card and said it looked clear reassuring me that a premenopausal woman that had breast-fed could have this green drainage. She reviewed my previous mammograms and said they all looked good. She also could not feel anything to be concerned about. I then pointed out to her the area that I had the tenderness and she placed a black X on the spot and said we could go across the hall and have an ultrasound done on my breast. As we were leaving the exam room she had the card with the green fluid in her hand and said she wanted to do one more thing to reassure me that everything was ok. She explained that if she were to put a drop of dye on the fluid and if it were to change blue then she would be concerned. In doing that it immediately turned blue. We then proceeded with the ultrasound and when the doppler was placed on the black X a dark mass was seen measuring the size of a small bean. I questioned how could this not be seen on the mammograms and was told it was because I had dense breast tissue. This was the first time I was ever made aware that my breast tissue was dense. The next day a biopsy was done and three days later I was told I had ductal carcinoma in situ.

The following week we met with Dr. Kubalak who recommended that I have a lumpectomy with removal of a few lymph nodes to determine the stage of my cancer. My husband Tim (now deceased from tonsil cancer) had found a study recently completed on dense breast tissue that recommended additional diagnosing and treatment options. The study indicated the use of MRI for diagnosing breast cancer and before surgery or treatment. Dr. Kubalak confirmed the study and scheduled an MRI. At the follow-up exam he explained due to the density of my breast tissue the MRI is unable to see the tumor. The titanium marker (that was placed at the time the biopsy was done) could be seen but they were unable to clearly see the tumor. He then said he had to change his recommendation for a lumpectomy, and recommended that I have a bilateral mastectomy instead, because due to the inability to appropriately screen my dense breast tissue.

Following my bilateral mastectomy and removal of several lymph nodes I was happy to hear that the lymph nodes were clear of any cancer. My oncologist Dr. Tate informed me the pathology revealed ductal carcinoma in situ with a second tumor an encysted noninvasive papillary carcinoma that was adjacent to the ductal carcinoma in situ. This second tumor was not revealed on mammogram or MRI.

I am here 8 years later to share this with you and hope that you will consider supporting House Bill #1370 that will mandate men and women be told what their breast tissue density is and be given additional options for breast screenings.

In closing, I want to thank you for your time and commitment to your service for the people of North Dakota. I ask that you pass House Bill #1370. My prayer is that you will be the one that brings this information forward to a future breast cancer survivor like my husband Tim had done for me. Please feel free to contact me if you any questions.

Sincerely

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Patty Johnson

#5



Breast Health Services 2400 32ND AVE S FARGO, ND 58103 701-234-7100

12/17/2014

1-28-15 HB1370

Dear :

**Results:** 

RE: Your breast imaging exam done on: December 13, 2014 Interpreted by: Report sent to:

Thank you for choosing Sanford for your breast health care needs. We are pleased to inform you that the results of your breast imaging exam appear normal. A report of your results were sent to your doctor. If you have not already done so, please schedule a breast exam with your doctor.

#### Next recommended exam: December 15, 2015

The mammogram shows that your breast tissue is dense. Dense breast tissue is very common and is not abnormal. But dense breast tissue can make it harder to find cancer on a mammogram. Also, dense breast tissue may increase your breast cancer risk. This information about the result of your mammogram report is given to you to raise your awareness. Use this report when you talk to your doctor about your own risks for breast cancer, which includes your family history. At that time, ask your doctor if more screening tests might be useful, based on your risk. More information on breast density can be found at http://www.breastdensity.info/.

Current American Cancer Society Guidelines recommend yearly mammograms starting at age 40 and continuing for as long as a woman is in good health. Even though mammograms are the best method we have for early detection, not all cancers are found with mammograms. If you feel a lump or have any other reasons for concern, you should tell your health care provider.

Your report will be kept on file at Sanford as part of your permanent medical record. It is your responsibility to inform any new doctor of the date and location of this examination. If you have problems obtaining your breast images, we can be contacted at (701) 234-7100 or (800) 437-4010, ext. 7100

Sincerely,

Sanford Breast Health Services

15.0766.01002 Title.03000 Adopted by the Human Services Committee

February 4, 2015

#### PROPOSED AMENDMENTS TO HOUSE BILL NO. 1370

- Page 1, line 2, after "notices" insert "; and the notification of registered owners of mammography equipment;"
- Page 1, line 2, replace the second "and" with "to provide an expiration date; and to declare an emergency"
- Page 1, line 20, after the first underscored period insert "<u>The state department of health shall</u> notify all registered owners of mammography equipment of these changes, along with the North Dakota Board of Medical Examiners, the North Dakota Medical Association, the North Dakota Board of Nursing, and the North Dakota Nursing Association. The state department of health shall encourage these boards to include information about these changes in the next publication of their professional journals.

**SECTION 2. EXPIRATION DATE.** This Act is effective through July 30, 2017, and after that date is ineffective.

SECTION 3. EMERGENCY. This Act is declared to be an emergency measure."

Renumber accordingly

[.]

HBISTO 03/04/15

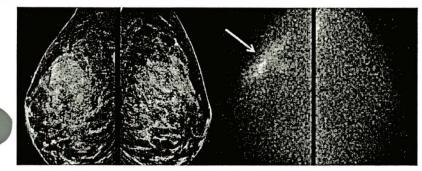


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http://www.wsj.com/articles/new-screening-tests-for-hard-to-spot-breast-cancers-1424731497

# New Screening Tests for Hard-to-Spot Breast Cancers

For women with dense tissue, mammograms can be less accurate so new tests offer better detection but often more false alarms



A 7 cm breast cancer was obscured on the mammogram, left, but became visible with a technology called molecular breast imaging, right; arrow. *PHOTO: MAYO CLINIC* 

By MELINDA BECK February 23, 2015

Millions of women in 21 states will get an ominous note with their mammogram results this year. Even if everything seems fine, they'll be informed that they have dense breast tissue, which can raise their risk for cancer and hide abnormalities, making their mammograms less accurate.

The question is: now what?

A host of new breast-imaging technologies promise to detect more cancers in these women. But many of the methods bring more false alarms as well, subjecting women to Iditional tests and biopsies unnecessarily. Some are also more expensive than mammograms and haven't been widely studied yet. AND SHOW

1,2

Laws in 21 states require doctors to tell women they have dense tissue. Similar bills are pending in eight more states and a national bill was introduced in Congress earlier this month.

"It's a very confusing time," says Emily Conant, chief of breast imaging at the University of Pennsylvania Medical Center. "This legislation has happened before we have a medical consensus about what to tell women."

Some experts say telling women they have dense breasts would make them anxious unnecessarily.

"Of course you might be anxious. But I'd trade a false positive for a false negative any day," says Nancy Cappello, who started the campaign for density-notification laws and the organization Are You Dense? after numerous mammograms failed to spot her advanced breast cancer. Doctors had noted her dense breasts for years, but never told her that her mammograms might not be showing potential problems.

As of now, mammograms are the only breast-screening technology proven to save lives, experts say. Every year, some 40 million U.S. women undergo a mammogram, in which their breasts are compressed between metal plates and X-rayed from top to bottom and side to side. Cancerous tumors and even tiny calcifications that can indicate early cancers show up as white areas on the images, distinct from fatty breast tissue. But breast tissue that is glandular and fibrous appears white, too, and can obscure such abnormalities.

About 50% of women under age 50 and 33% of older women have breasts dense enough in some spots or throughout to interfere with mammograms, studies show. Mammograms can miss up to half of early cancers in such women.

Digital mammography—in which images are stored digitally rather than on photographic film—are more accurate, because the images can be enlarged and enhanced. But they still miss about 20% of cancers in women with dense breasts, studies show.

The Options: Mammogram	to MBI
<b>Mammogram:</b> Takes X-rays of the breast, from side to sid recorded either on film or digitally	e and top to bottom,
Pros: Quick, inexpensive; can find very early cancers before	
<b>Cons:</b> Compression and dense breast tissue can hide tumor positives	s and generate false
<b>Cost:</b> \$50 to \$200; fully covered by insurance	
Tomosynthesis: Takes multiple X-rays from different angle dimensional image	es to create a three-
<b>Pros:</b> Finds more cancers; fewer false positives	
<b>Cons:</b> Uses more radiation; some cancers still obscured in c <b>Cost:</b> \$50 to \$75 over mammograms; covered by Medicare	
Ultrasound: Creates images using high-frequency sound	waves
Pros: No radiation; widely available; can distinguish solid lu	imps from cysts
<b>Cons:</b> More false positives; can be hard to interpret <b>Costs:</b> \$50 to \$200; some states require insurers to cover	for women with
dense breasts	TO WOMEN WILL
MRI (Magnetic resonance imaging): Uses magnets an provide multiple cross-section images mainly used for diagi Pros: Can evaluate palpable masses not visible on ultrasou Cons: Costly; time-consuming; more false positives Cost: \$500 to \$1,500; limited insurance coverage	nosis, not screening
<b>MBI (Molecular breast imaging):</b> A radioactive tracer m highly visible with a special camera	
<b>Pros:</b> Finds more cancers, with fewer unnecessary biopsies faster than MRI	, than other methods
<b>Cons:</b> Some radiation; not yet widely available <b>Cost:</b> \$400 - \$500; limited insurance coverage	

More hospitals and imaging centers now offer a new form of mammogram called 3-D tomosynthesis. It starts like a regular twodimensional mammogram. Then the X-ray arm rotates around the patient in an arc, taking additional images at different angles that can be assembled into a three-dimensional view. Radiologists liken 3-D tomosynthesis to taking pictures of the individual pages of a book, rather than trying to see what's inside by just

the front and back.

In a study of nearly 500,000 women at 13 centers published in the Journal of the American Medical Association last year, 3-D tomosynthesis found 41% more instances of invasive cancer than regular mammography, and had 15% fewer false positives.

"We do tomo on every woman who comes into our center. It's definitely becoming the standard of care," says Dr. Conant, one of the investigators on the JAMA study. Still, she notes, that study didn't look specifically at women with dense breast tissue.

Y.H

Ultrasound does find more cancers—but about four times as many false positives as well. An analysis in the Annals of Internal Medicine in December estimated that ultrasound screening, in addition to mammograms, would avert four breast cancer deaths for every 10,000 women aged 50 to 74 with dense breasts. But it would also result in 3,500 biopsies that didn't find cancer and cost an additional \$10 million. The authors, including breast-cancer researchers at 14 major medical centers, concluded that supplemental ultrasound would increase costs substantially while producing relatively few benefits.

Some doctors—and many women with dense breasts—disagree, and say ultrasound found life-threatening cancers that mammograms routinely missed.

"Women are strong. We need this information," says Claudia White, 48, of Durham, Conn., who credits the state's first-in-the-nation notification law with prompting the ultrasound that found invasive cancer in both of her breasts. Connecticut's law also requires insurers to cover the cost of supplemental ultrasound (generally \$50 to \$150) for women with dense breasts.

"I'd rather be scared for a couple of days than dead," says Jan Kritzman, 67, of Newington, Conn., whose cancer was also diagnosed on ultrasound thanks to the state's law.

MRI—magnetic resonance imaging—finds even more cases of breast cancer, with fewer false positives, than ultrasound. But because it is time-consuming and costly—as much as \$1,500 in some centers—it is generally recommended only for women who are at high risk for breast cancer.

Some researchers are testing whether an abbreviated version—called "fast MRI"—can achieve the same results by taking only a few images, in far less time, and cost just \$200 to \$300, about the same as ultrasound.

Molecular breast imaging or MBI, also holds promise. It involves injecting a radioactive tracer into the patient's vein. Cancer cells readily absorb the substance and "light up" when viewed with a special camera.

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Past versions of MBI exposed patients to too much radiation to use for regular creenings. A new version developed at the Mayo Clinic in Rochester, Minn., uses a lower dose. In a study of 1,585 women with dense breasts published in the American Journal of Roentgenology this month, Deborah Rhodes, a Mayo Clinic internist, and colleagues found that MBI detected nearly four times as many invasive breast cancers as mammography, with fewer unnecessary biopsies. As of now, only about 100 hospitals offer the newest MBI technology, which is made by GE Healthcare and Gamma Medica Inc. But with costs as low as \$300, it could grow rapidly, particularly if additional studies yield similar results. Mayo receives royalties from one manufacturer, Gamma Medica Inc.

Doctors say that a large, randomized clinical trial comparing all the options for women with dense breasts would be helpful. Meanwhile, they can help women understand the pros and cons and decide for themselves whether to seek additional tests.

Some say that given the uncertainties, they wish they didn't know their breasts were dense. Denice Newton, 52, had a biopsy last year after getting a notice under North Carolina's new law. Even though it was negative for cancer, she hated the ordeal. "Mentally, I was planning my funeral," she says. "Now, every time I feel an itch or oreness in my left breast, I think, 'Cancer.' "I do not want to go back in six months, but I'm afraid if I don't, I might regret it."

Write to Melinda Beck at HealthJournal@wsj.com

## Corrections & Amplifications:

An earlier version of this article said tomosynthesis found 41% more breast cancers than regular mammography, but failed to note that these were invasive breast cancers. The earlier version also incorrectly said tomosynthesis found 10% fewer false positives than regular mammography. The correct figure is 15%. (Feb. 25, 2015)

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Testimony On HB 1370, Pamela Anderson, District 41



Chairman Lee and members of the Senate Human Service Committee, my name is Pamela Anderson, I represent District 41.

House Bill 1370 is an information bill. A breast density notification law requires that women are notified who have undergone mammography and were found to have dense breast tissue. It can be more difficult to detect early breast cancer in dense breast tissue.

The intent of this law is to give health information to the patient and her health care provider. What they do with the information will be up to them.

I have attached a map showing the states that have passed this law, introduced or working on a bill. Minnesota has passed a similar law and we used their language.

The North Dakota Hospital Association, Jerry Jurena, graciously did a survey of health care providers in North Dakota. I have included the survey which had an 83.4% response rate. The good news is over 50% already report breast density.

So, you might ask, do we need this law at all? I would say "yes" because all women in the state should have this information given to her no matter where she receives her healthcare. This bill does have a sunset clause.

I have included the written testimony of Ms. Eggl, Fargo, ND, that she gave before the House Human Services Committee, a letter supporting House Bill 1370 from the Director and Founder of the "Are You Dense Advocacy Inc." and an email from Dr. Fred LaVenuta in support of this legislation. He calls this bill a "wake-up call" to those concerned that alternatives to conventional mammography for early diagnosis should be considered.

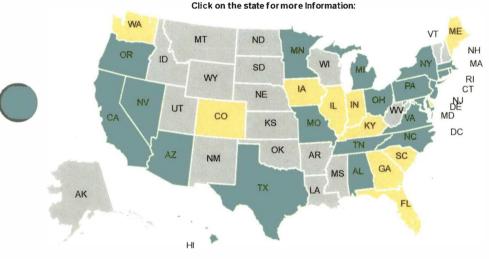


Thank you Chairman Lee and members of the Committee, I am asking you to support this bill.



## Breast Density Notification Laws by State — Interactive Map

January 16, 2015 | Breast Imaging, Mammography By Marijke Vroomen Durning, RN



Breast density notification laws have been put into effect in 21 states. A breast density notification law requires that physicians notify women who have undergone mammography and were found to have dense breast tissue.

The intent of such a law was to give women the necessary information to decide on further action if they had dense breast tissue. Dense breast tissue makes it harder to identify cancer on a mammogram and may also be associated with an increased risk of breast cancer, according to the American College of Radiology (ACR). Women with dense breasts are encouraged to discuss with their physicians their possible increased risk of breast cancer and the difficulty that mammography may have in detecting tumors. Critics of such a law or of how such a law is implemented believe that women may receive the information in less than ideal circumstances, which can lead to increased anxiety, as well as additional medical procedures.

"The manner in which the information is shared is important," Richard Frank, MD, PhD, chief medical officer for Siemens Healthcare North America and founding member of the Quantitative Imaging Biomarkers Alliance of the Radiological Society of North America, told *Diagnostic Imaging*. "There might be value in not just sending a letter through the mail, but giving it to her. She then has an opportunity to actually talk about it." In most cases, the letters are mailed, so the content of the letter is paramount. The letter's text varies considerably across the states. Frank believes that women would be better served with a single informed letter issued from the federal level.

An example of ineffective language used in some states is one that raises more questions than it answers, according to Frank. Such letters say, "If you have dense breasts, and then what the options are. So the woman is going to look at that letter and say, 'why did I receive this letter?" It doesn't tell her if she does or doesn't have dense breasts, nor does it inform her of her particular situation, Frank explained. A letter that says "if" you have dense breasts, is a good



LEGISLATION - OUR INTERACTIVE MAP



Use our interactive tool to help you navigate breast density notification legislation across the country.

#### ▼ RELATED ARTICLE

Image IQ: 52-year-old Female with Family History of Breast Cancer

Add Ultrasound or Tomosynthesis to Mammography For More Detection

# Mammography Survey

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7	On the report - one goes to provider and one to patient	
8	On the radiology report it indicates dense versus fatty Itissue	





CYNTHIA J. EGGL 2701 12<sup>th</sup> Street South, #14 Fargo, ND 58103 (701) 234-1706

ULACH #3 HB 1370 03/04/15

January 28, 2015

Rep. Robin Weisz, Chairman ND Human Services Committee 2639 First Street SE Hurdsfield, ND 58451-9029

RE: House Bill No. 1370 – Mammography Result Notices

Dear Rep. Weisz:

Thank you for allowing me to testify at the hearing on House Bill No. 1370 on Wednesday, Jan. 28, 2015. My name is Cynthia J. Eggl and I reside in Fargo, ND. I am the author of a book entitled, "Boundless Blessings and God's Grace: My Journey through Breast Cancer." I am testifying in support of the proposed North Dakota legislation. 21 states in the U.S., including North Dakota's border state Minnesota, have legislated density reporting to women, starting in Connecticut in 2009 - a testament that there is no shortage of women harmed by their dense breast tissue with missed, delayed and late stage breast cancer.

I want to share my personal experience with you. I completed monthly self-breast exams, a baseline mammogram at age 35, annual mammograms starting at age 40, and annual physicals, all with no indication of breast cancer – all my exams and reports were "normal." From January, 2011 to April, 2011, I experienced excruciating breast pain in my lower left breast which radiated out under my left arm. The pain finally forced me to my doctor's office on April 5th, 2011 for an exam.

On that day, a physician's assistant at Sanford SouthPointe Family Practice completed my exam and marked three areas of concern on or near my left breast which she felt needed to have further testing. She left the exam room, returning about 10 minutes later to tell me I was not going back to work that day, and that I was to proceed immediately to the Breast Imaging Clinic at downtown Sanford Clinic. She indicated the staff at the Breast Imaging Clinic would be working me into their schedule for a breast ultrasound. I remember thinking to myself that I should not be afraid because I had done everything I possibly could to try to catch potential breast cancer at its earliest stage.

Three hours after I arrived at the Breast Imaging Clinic, I was called back for the test. It took the technician about 20 minutes to complete my breast ultrasound. She indicated she would be showing the scans to Dr. Janine Carson, the Radiologist on call at the Breast Imaging Clinic, to see if there was anything further she needed to see before letting me leave the clinic. About 10 minutes later, both the technician and Dr. Carson came back in the room. Dr. Carson stood by my bed and said, "Cynthia, looking at your breast scans is like looking through mud. Your breast tissue is so dense, I cannot see what I am looking for on the scans." She indicated she was in the room to help guide the technician as they did a second breast ultrasound. Following the second ultrasound, she turned back to me and said, "We need to schedule three needle biopsies as soon as possible." I got dressed and proceeded to the scheduling office, where I made appointments for my biopsies the following Monday.



I endured three needle biopsies on April 11, 2011. Dr. Carson indicated I should know my biopsy results in the next day or two. The following day, April 12, 2011, at 2:30 p.m., Dr. Carson called to confirm I had breast cancer in all three of the biopsied locations. She told me I had ½ hour to call my family and my

employer, and then I needed to be off the phone so I could receive a call from the Sanford Roger Maris Cancer Center regarding appointments they were already scheduling with a medical oncologist, radiation oncologist, a breast surgeon, and for other tests. I have survived a 9+ month breast cancer battle.

Breast cancer doesn't run in my family – I'm the first to be diagnosed with this disease. I was stunned to learn I had Stage 2b breast cancer which had moved into my lymphatic system. Several of my physicians told me my breast cancer had most likely been growing undetected for a period of 2-4 years.

I also discovered additional information regarding dense breast tissue after my journal was published as a book in December, 2012. From the <u>www.areyoudense.org</u> website, I learned that nearly half of our population worldwide has dense breast tissue. Two-thirds of women pre-menopausal and one-third of the women post-menopausal have dense breast tissue. Breast density is one of the strongest predictors of the failure of mammography screening to detect cancer. If you have dense breast tissue, there is a much greater risk of having breast cancer which will go undetected, even within months of undergoing a normal mammogram. Knowledge about your breast tissue composition is an important part of your breast health records. The more "dense" tissue a woman has, the higher the chance that cancer might be missed and that cancer might develop in the first place. While mammogram detects 98% of cancers in women with fatty breasts, it finds ONLY 48% in women with the densest breasts. Cancer turns up 5 times more often in women with extremely dense breasts than those with the most fatty tissue.

Dense breast tissue is comprised of less fat and more connective tissue which appears white on a mammogram. Cancer also appears white on a mammogram thus tumors are often hidden behind the dense tissue. As a woman ages, her breasts usually become more fatty. A radiologist determines the density of a woman's breasts by examining a mammogram.

I use every opportunity to encourage women to request a copy of their mammography report from their doctor - to make sure it is the report that is generated from the radiologist and not a form letter. I ask them to read the report carefully, looking for descriptions of their breast tissue. If they do have dense breast tissue, I strongly encourage them to talk to their doctor about having a breast ultrasound, breast MRI, 3-D imaging or whatever additional testing options that may be available to them to find potential breast cancer at its earliest stage.

I have gained knowledge about the risks associated with dense breast tissue while battling for my life after no one told me about my dense breast tissue. Knowing would have afforded me a chance to find my breast cancer at an earlier stage by undergoing additional testing. I know personally how profoundly my breast cancer battle has affected my quality of life for the long-term.

Prior to my breast cancer battle, I was diagnosed with Hashimoto's Disease, an autoimmune disease of the thyroid, which in and of itself, is difficult to manage. Following a double lumpectomy, removal of 9 lymph nodes from beneath my left arm, 16 chemotherapy treatments using three different chemotherapy drugs, and 33 radiation treatments, I have now been diagnosed with a total of five (5) autoimmune diseases – Hashimoto's Disease, Rheumatoid Arthritis, Fibromyalgia, Pre-Diabetes bordering on full blown Diabetes, and a rare autoimmune disease of the skin recently diagnosed by The Mayo Clinic.

Additionally I have peripheral neuropathy (nerve damage) which has affected my ability to drive – I have driven only three times in the past year because of disorientation and dizziness. I cannot feel the bottom of my feet and my little toes are numb. I cannot sit in a darkened room because it feels like I am going to fall right out of my chair. I have lymph edema throughout my left breast, degeneration of bones in my knees, feet, and shoulders, severe disabling muscle spasms, and swollen ankles if I sit for periods longer then several hours. My fatigue is overwhelming and I have overall body aches each day. Because I have a suppressed immune system following my formal breast cancer treatments, there are limitations to what type of prescribed drugs I can use to help manage my autoimmune diseases and other health issues. I



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make each day that I have been granted the best it can be, regardless of my health issues, because I am quite simply grateful to be alive. Prior to my breast cancer diagnosis, I was working 50-60 hour work weeks for Dakota Medical and Impact Foundations as the Executive Assistant to the President, boards, committees and members. I was also managing a home-based business and teaching private voice lessons, where I drove to the homes of my voice students for their lessons.

During my 9+ months of formal breast cancer treatments, surgery, and for one year following those treatments, I worked 40-hour work weeks for my employer. On January 9, 2013, I filed for personal long-term disability, and was forced by our private insurance carrier to file for Social Security Disability Insurance (SSDI) so they could offset their payments to me. After being denied twice by SSDI in a written application and an appeal, I appeared at a formal hearing in front of an Administrative Law Judge on Sept. 13, 2013. Five days later, Sept. 18, 2013, the judge ruled I was permanently disabled for a period of 5-7 years.

My physical health has been diminished, but my mental health, thank God, has remained intact. I was encouraged by many people and finally published my personal journal written while I underwent my formal treatments and recovered from my breast cancer battle into a book entitled, "Boundless Blessings and God's Grace: My Journey through Breast Cancer" by Cynthia J. Eggl. My book is available worldwide, and is a positive, uplifting journal from my perspective as a patient, encouraging others should they ever be diagnosed with cancer or another challenging medical condition. I promised myself that I would make the path for individuals diagnosed with breast cancer in the future smoother than my journey.

This legislation, through education alone, could help save lives, save trauma to future breast cancer patients, and could save millions of healthcare dollars because breast cancer is diagnosed at its earliest stage. Passing this legislation and having it signed into law will be the most important thing I do in my life to positively impact others.

I have felt a sense of betrayal being diagnosed with a later stage breast cancer following 12 years of supposed "normal" mammograms and yearly exams by my family physician. It is especially troubling knowing that some of the very medical doctors who purport to have the best interests of their patients in mind, who fail to disclose that your dense breast tissue could prevent your mammogram from finding your breast cancer situation at its earliest stage, and who fail to even discuss additional testing with you, are the same physicians who think that how they are fulfilling their medical oaths today is perfectly fine when it comes to this medical issue.

Beyond my personal goal of wanting to do better for future patients lies my hope that North Dakota's legislators would have the best interests of their constituents at heart - affording them every opportunity to survive a breast cancer battle. Since we do not have a cure for breast cancer, the most obvious way we can affect breast cancer's grip is to find it at its earliest stage. But that is not possible unless your medical doctor discloses to you that your breast tissue is dense and the associated risks of dense breast tissue. Education and additional testing are key, and you could help affect change and educate North Dakotans through this specific legislation. I ask for your support in recommending passage of House Bill No. 1370 so that it can be signed into law in North Dakota as soon as possible. Thank you!

Sincerely, Cvnthia J. Egg



Are DENSE? ADVOCACY because your life matters



January 26, 2015

The Honorable Robin Weisz Chairperson, ND Human Services Committee 2639 First Street SE Hurdsfield, ND 58451-9029

Re: House Bill 1370 – Mammographic Results Notice Testimony of Nancy M Cappello, Ph.D., Founder, Are You Dense Advocacy, Inc.

Dear Chairman Weisz, Vice Chairman Hofstad and ND Human Services Committee:

My name is Nancy Cappello and I reside in Woodbury CT. I am founder of two global breast cancer organizations whose mission is to educate the public about the impact of dense breast tissue on missed, delayed and late-stage cancers. I write to you in support of **HB 1370** and request that this correspondence be included in the record of the Public Hearing on January 28, 2015.

In 2004, I was diagnosed with advanced stage IIIC breast cancer after a decade of 'normal' mammograms. I first learned about my dense breast tissue <u>after</u> my cancer diagnosis, which was within weeks of what I refer to as my "happy gram" report which stated that the results of my mammogram were "normal."

My physicians informed me that **my years of mammography screening failed to detect my cancer because of my dense breast tissue.** My cancer was the size of a quarter and has spread to 13 lymph nodes -remember a normal mammogram weeks before. Six surgeries, 5 months of chemotherapy, 24 radiation treatment, life-long medications, countless tests, massive medical costs and a greater likelihood of dying prematurely from this disease; this is the reality of my advanced stage cancer.

Searching the scientific journals, I was stunned to discover that my story, while compelling, is common as 40% of women have dense breast tissue. **National surveys report that less than one in 10 women learn about their breast density from their physician.** For more than two decades, research demonstrates that women with dense breast tissue have less than a 50% chance of having their cancer detected by mammography alone. There are additional screening tools, when added to mammography, that significantly increase detection of small, invasive cancers invisible by mammogram. Dense Breast Tissue is also an independent risk factor for breast cancer.<sup>1</sup>

<sup>1</sup> Cappello, N. Journal of American College of Radiology (10:903-908), December, 2013

## Are You Dense Advocacy, Inc.

96 Rowley Road • Woodbury, CT 06798 • (203) 232-9570

AreYouDenseAdvocacy.org



501(c)(4) Public Charity

The Honorable Robin Weisz Re: HB 1370 Mammographic Results Notice Page Two

Armed with these startling scientific facts, I started working with the Connecticut legislature and, in **2009**, **Connecticut became the first state in the nation to standardize density reporting to** women through their mammography report.

Compelled to action because of the **inaction of the medical community to inform women about this fatal flaw in breast cancer screening**, I founded two nonprofit organizations, **Are You Dense**, **Inc. and Are You Dense Advocacy**, **Inc.**, which **has fueled a global movement of patients turned advocates -** a testament to the fact that there is no shortage of women harmed by their dense tissue.

Following CTs leadership, legislative champions, inspired by advocates, enacted breast density legislation in **21** states (Texas in 2011; Virginia, New York, California in 2012, Maryland, Hawaii, Nevada, Oregon, North Carolina, Tennessee, Alabama, Pennsylvania in 2013, New Jersey, Arizona, Missouri, Massachusetts, Rhode Island, Ohio and **your border state, Minnesota in 2014** and Michigan in 2015. An additional **8 states**, including **North Dakota**, have introduced or are awaiting introduction of density reporting bills in 2015.

Women can only rely on what their doctors choose to reveal to them. Unless density reporting is standardized, too many women will falsely have confidence in their "normal" mammography report and yet in reality their report is far from normal. Later stage cancers are more costly to treat, convey fewer treatment options and poorer survival outcomes.

Your affirmative support of **HB 1370 will give women of North Dakota critical information about their dense breast tissue so they can make an informed decision as they participate in discussions** with their health care providers about their personal breast screening surveillance.

I applaud Representatives Anderson, Hawken, Mitskog, Strinden and Senator Nelson for supporting this critical women's breast health bill. It **will improve life outcomes** for women of North Dakota. I ask the committee for its support of **HB 1370**.

Nancy M. Cappello, Ph.D. Director and Founder Are You Dense Advocacy Inc.



### Anderson, Pamela K.

om: Jent: To: Subject: Fred LaVenuta <fredlave@cableone.net> Monday, January 26, 2015 12:04 PM Weisz, Robin L. House Bill 1370

<u>HB 1370</u> 03/04/15 24300

I am writing to encourage your support passage of House Bill 1370. In summary, this bill provides for notification to a patient undergoing mammography if her X rays show dense breast tissue according to accepted standards. Women with dense breast tissue are six times more likely to develop breast cancer and conventional mammography may miss small tumors. This bill does entails no costs but it is a wake-up call to those concerned that alternatives to conventional mammography for early diagnosis should be considered. Fred LaVenuta M.D.

Fargo, ND