

Media – December,
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Cancer patients frustrated with test wait times

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CBC News

Breast cancer patients say it is taking too long to get the results of a test that may affect their treatment, and possibly improve their chances of beating the disease.

In August, authorities discovered that tests that had been done in St. John's had produced false results.

The Eastern Health Authority sent samples to Mount Sinai Hospital in Toronto for retesting, but hundreds of women are still awaiting their results.

- FROM OCT. 14, 2005: Flawed cancer tests raise patients' concerns

The hormone receptor test determines if a breast-cancer patient might benefit from the drug tamoxifen.

Zita White, a Happy Valley-Goose Bay resident diagnosed with breast cancer a few years ago, was told at the time of diagnosis that tamoxifen would not help her.

White, who believes she is cancer-free, is anxious to find out if that test was right. "Waiting for possibly bad news – sometimes the waiting is worse than the news. It's very stressful," she said.

Samples from more than 800 women are being retested.

But more than three months after the problem was discovered, only about one quarter of the samples have been retested.

"We did not expect it would take this long and we are disappointed by the time frames," said Dr. Bob Williams, a vice-president with the Eastern Health authority. Williams said Eastern Health has been advised that all testing should be completed before the end of January.

Williams says the new tests are showing that about 10 per cent of the original tests were wrong.

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Product Summary:

CANCER SOCIETY SAYS WAIT FOR RESULTS COULD HAVE BEEN SHORTER: It's been several months since the Eastern Health Authority discovered a test done on some breast cancer patients in this province had been producing false results.

Monday, December 05, 2005 07:10AM Item # 07
CBC Radio St. John's

CANCER SOCIETY SAYS WAIT FOR RESULTS COULD HAVE BEEN SHORTER: It's been several months since the Eastern Health Authority discovered a test done on some breast cancer patients in this province had been producing false results.

Monday, December 05, 2005 07:10AM Item # 07
CBC Radio St. John's

JEFF GILHOOLY: It's been several months since the Eastern Health Authority discovered a test done on some breast cancer patients in this province had been producing false results. The test determines whether the person would benefit from a drug called Tamoxifen, it's been shown to help prevent cancer from coming back in some patients. Once the Eastern Health Authority discovered there was a problem it sent the results to a hospital in Toronto to be re-tested. Months later many patients are still anxiously waiting for word and now the provincial branch of the Cancer Society says that wait could have been shorter. Peter Dawe is Executive Director, he's on the line right now, good morning.

PETER DAWE: Good morning Jeff.

JEFF GILHOOLY: We've talked about Tamoxifen on this program before but just in case there's listeners who aren't quite sure what it is or aren't quite aware of it, could you remind us briefly what happened here and how many patients were effected?

PETER DAWE: Well there's about 350 patients a year who get tested for breast cancer in this province and when you have breast cancer they have to determine if you are ER or PR positive and what that means is that you're hormone positive, you have estrogen progesterone receptors on the tumour. And about twenty percent of people don't and that's a general rule anywhere in the world. So about twenty percent of those 350 were what was called negative and now what we're finding out over at Eastern Health is about...they had about ten percent of that twenty percent, it's a little bit complicated, but it was about 80 or 90 people a year over a several year period who should have been told they were negative when actually they were positive. And the big difference there is if you're positive, that means you can use the drug, it's not the only drug but Tamoxifen is the one that's well known and that can help you and your survival rate.

JEFF GILHOOLY: All right, that's a good job of explaining it because you can get tied up in the negatives and positives can't you?

PETER DAWE: But part of this...part of the problem with the story I think is that it is a little bit complex.

JEFF GILHOOLY: Yeah. How long did you expect it to take though to get the tests back from Toronto, this hospital in Toronto where they were redone?

PETER DAWE: Well just to be clear again you know we're the Canadian Cancer Society, we're not Eastern Health and we're there as advocates saying you know this should be quicker. But you know when Eastern Health looked at it, they looked at it this summer, they found out they had a problem. I'm sure they thought within a couple of months they'd have all of these test results back and anybody who should have been on Tamoxifen would have been given the opportunity to be on it. The problem that they have, they run into is that, and in hindsight you know maybe they should have seen it, maybe they could have done something a little bit differently. But the problem is that they're still only about halfway through so they had seven or eight...around 700 altogether they had to retest. They're only halfway through getting the test result back so there's still hundreds of people out there, women, who don't know if they had the proper treatment or not for their breast cancer.

JEFF GILHOOLY: All right does that speak to another problem with...that the fact that when these I guess whole batches of tests went up to Toronto they weren't prioritized?

PETER DAWE: Well you know and as we've dug through this and spoken to the people at Eastern Health to figure out what was going on, indeed when they figured out they had a problem they batched all the samples together and believe it or not Eastern Health, you know they've still got samples of the tumours going back to 1997. So they've bundled up all of these samples and sent them all up together to try to figure out you know the extent of the problem. They didn't know the extent of the problem that they had then and in hindsight if you look back at it you know there could have been a prioritization process put in place where you know maybe your most recent diagnosis would have been tested first or as it turns out I mean there's even people that were sent up or samples that were sent up from people who were deceased because it was so long ago.

JEFF GILHOOLY: Really?

PETER DAWE: Well you know I mean that's what happens, if you send all of the samples back and you're not sure if...you know there was no contact made with any of these people prior to the samples going back up. And again in hindsight the Cancer Society would have said gee whiz guys, if you got a problem of this magnitude and it's effecting people this way the first step you should do is you know contact all these people and have a direct communication about what the issue is.

JEFF GILHOOLY: So if I understand you then is it possible that the family of a patient who is deceased could be getting test results before a living patient?

PETER DAWE: Well I think they're trying to fix the problem now but certainly they...

JEFF GILHOOLY: Has that happened?

PETER DAWE: Their original plan was not to contact people until the test result came back. And if that's your plan then you're going to get a test result back not knowing whether the person was you know in the province, out of the province. You don't know you know where they are in their progress in the fight against cancer. So obviously you're going to get situations like that. The problem they have now is they're so far into this process and they've committed themselves to Mount Sinai in Toronto to get these test results back and all the results have been sent up, to try to do anything with it now, it would probably cause more delay than is necessary and if it is keep with the process you know no matter how long it took it's going to be quicker than trying to do some type of priority work with it now, right.

JEFF GILHOOLY: So maybe you should have spent more time at the beginning sorting through the results eh?

PETER DAWE: Well if you look at you know what the lesson learned you know from my...it's easy for me to say it, I'm not working in that system but from outside the system and advocating for people with cancer you're going to say look you know your first response has got to be can we protect life here, you know whose life is it that we can you know put a priority on to literally save their life. And if you go through that process, if you think through that process first then you know you're going to come up with some different decisions that were made right.

JEFF GILHOOLY: Okay how are patients reacting to this, are you getting much feedback from them?

PETER DAWE: We've been in contact with a number of people you know, at first when the story broke and it came out in the media first you know, the first response was you know what does this mean, what does this mean? So now we're at the point I think where people understand what it means but now they're getting very anxious, they've been you know up to three and four months that the system has known that there's a problem and they're sitting there you know, some people react differently than others but for the most part there's a lot of anxiety and for the most part there's a you know a little bit feeling of powerlessness because you know they can't control the process. You know and you think about our health care system you know there's a lot of complaints but you know in general the general rule of thumb is that you get things done when you get them...need them done and we've got a great system. I mean you know believe it or not I mean that's the normal for the average person going through, is going to experience it that way. And so you've got a group of women now who are sitting there who can't control the process and are feeling quite helpless about it.

JEFF GILHOOLY: All right we appreciate your time this morning, thank you.

PETER DAWE: Anytime Jeff.

JEFF GILHOOLY: All right, bye now. Peter Dawe, the Executive Director of the provincial branch of the Canadian Cancer Society.

PATIENTS STILL WAITING FOR TEST RESULTS: *The Canadian Cancer Society is critical of the amount of time its taking to review batched results for breast cancer tests.*

Tuesday, December 06, 2005 01:43PM Item # 03
VOCM Radio St. John's

GERRY PHELAN: The Canadian Cancer Society is critical of the amount of time it's taking to review botched results for breast cancer tests. Some of those tests done since 1997 may have given the wrong results. Up to 800 women in Newfoundland and Labrador are affected. Peter Dawe, Executive Director of Canadian Cancer Society for this province says the retesting should have been done by the end of October. He says only about half of the 800 women have had their tests looked at for a second time.

PETER DAWE: Well we noticed 700 or 800 samples were sent away to be retested and ideally you know, that could have been done in six or eight weeks, everybody would have been happy to get the results back and women could have found out if they should have been on tamoxifen or not. You know the problem now is there are only about halfway through getting these samples retested. So you've got a group of women that are sitting there knowing that they're going to be retested, they don't even know when it's going to be done and you know, if there's about 10 percent rate of changing from a negative to a positive then that means there's about 10 percent should have the opportunity to go on a drug like tamoxifen. So there's women sitting there knowing that you know, gee whiz it might be me that should be going on tamoxifen and can't even really figure out when we're going to get the tests results back.

GERRY PHELAN: What's the problem is that normally how long it would take to get these 700 or 800 women tested or did they mess up somewhere along the line?

PETER DAWE: The problem is that Mount Sinai was running at pretty well full capacity and then they were approached by Eastern Health to do you know these 700 or 800 more tests and they thought they could do it on weekends and then on over-time and get through it. You know what they discovered was that they just didn't have the capacity and to get 700 or 800 more tests done was taking a lot longer than they thought. And it's not even a money solution, you know, it's not like oh, we'll give you more money and you guys do it, it's a capacity up in Mount Sinai you only have so many lab technicians, you only have so many pathologists to read the results. So you know, that's the problem now is that, you know, there's no clear path for it to say well you know if we did this we could get through them all. And you know, so that's the frustrating part, the frustrating part is you don't see the solution either.

GERRY PHELAN: So is there no way to speed this thing up in the foreseeable future?

PETER DAWE: Mount Sinai apparently, has purchased a particular machine that can do this automatically a certain piece of it automated and they think that will speed it up but now, you know that's not the regular process. I mean the regular process is this test might take a week at the most, you know that would be the norm, that would be the expectation, the problem is that they've got this bulk of tests that they've got to get through and so it's clogged up the system up in Mount Sinai.

GERRY PHELAN: God forbid but are we putting some women in danger because of these time delays?

PETER DAWE: Well there's no doubt that if you look at the entire group of women and if you look at the experience they've gone through and the delays of getting on a drug like tamoxifen. Tamoxifen in the clinical trials has shown one particular clinical trial a 33 percent increase in survival rate over a two year period and so there's no doubt that you know taking a group of people, you can't pick out which one and it's almost impossible on an individual basis but you know if you take a group of people almost a thousand women and then you know 100 of them should have been on tamoxifen, there's no doubt that lives were and have been endangered and will be endangered unless this process is hurried along.

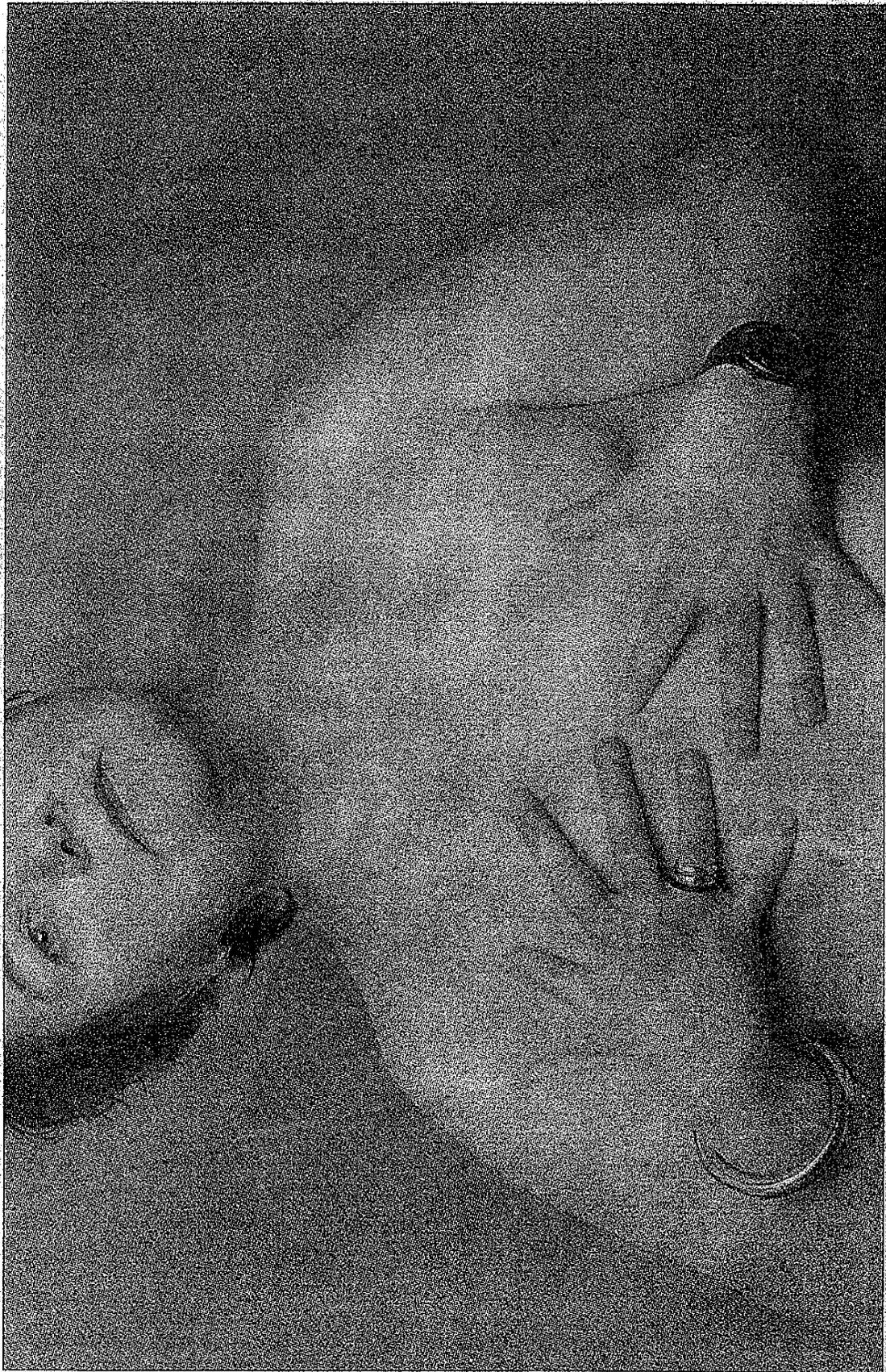
GERRY PHELAN: Peter Dawe.

January

29/06

Independent

Still in the dark



Paul Daly/The Independent

Gerry Rogers lost her breasts to cancer.

Some breast cancer patients still waiting for results of retesting

BEN
CURTIS

The results are in, but Newfoundland's most famous breast cancer survivor is still wondering if her test was accurate.

Gerry Rogers, director and subject of the Gemini Award-winning documentary *My Left Breast*, says her doctor is almost certain the tests carried out to help determine her course of breast cancer treatment were among those sent back by the Eastern Health Board to Toronto's Mount Sinai Hospital for review.

But information is hard to come by. "They haven't told me anything," Rogers tells *The Independent*. "Nobody has contacted me about anything. But when I saw my oncologist in late December, she said 'Gerry, looking at the test results that are coming back and looking at your initial test results, I'm 99 per cent sure that yours would be one of the ones that were falsely negative.'"

In May last year, Eastern Health, which oversees hospitals in the St. John's area, sent away test results (Canadian Cancer Society spokesman Peter Dawe pegs the number at 1,000) from as far back as 1997 after determining that between five and 20 per cent of the results may have been inaccurate.

The outcomes of the tests, which examine hormone receptors in breast cancer cells for estrogen and progesterone, help physicians determine the

course of treatment that a patient should undergo.

The last of the retest results came in last week, but Eastern Health officials have yet to issue a public statement on the issue, electing to wait until they have assessed the retests and notified

patients on an individual basis.

"I'm not sure what the strategy will be at that point until we get them all finished and I guess we'll decide at that point what we're going to do publicly," says Deborah Pennell, spokeswoman for Eastern Health.

When *The Independent* broke the story in October, Eastern Health officials said they had kept it quiet because they didn't want to cause mass hysteria.

But Rogers is angry that she had to learn about the testing errors from the media.

"I think as soon as they knew that something was wrong they should have told us immediately, rather than the information coming out because somebody in the media got wind of somebody who

See "*Rumblings*," page 2

‘Rumblings and rumours’ of legal action

From page 1

knew something,” she says. “They should have done it immediately and explained what they did and didn’t know, because we’re not children. We’re health-care consumers, and this is a system that we all own.”

Instead, Rogers has been forced to wonder what might have been.

According to Dawe, a positive result on the test, called an ER/PR test for estrogen or progesterone receptors, means the patient could respond to a hormone therapy treatment such as Tamoxifen. The faulty tests showed false negatives.

“In clinical trials, Tamoxifen has shown some great results of improving survival rates of women with breast cancer,” says the cancer society spokesman. “If you’re positive, and you get tested and they say you’re negative, you’re missing the opportunity to get the hormone therapy.”

The ramifications are not lost on Rogers, who could have been told about the five-year hormone treatment program six years ago.

“They might suggest now for me to take Tamoxifen, but it seems to me like closing the barn door after the horses are out,” says Rogers, who has lost both breasts.

“I’m well now, but if something were to happen, you would think could this have been prevented?”

“I’ve had some friends who have been diagnosed and who have died, who maybe weren’t supposed to die,” she adds. “I’m not making any kind of informed medical pronouncement here, but I had friends whose pathologies indicated they had a pretty good chance for survival, and they died. They were early stages, with no lymph node involvement, and they were estrogen negative; they weren’t on Tamoxifen. And then they got recurrences and died. I wonder if their pathology was wrong

too, you know?”

Pennell says it will take at least another month to know how many people may have been incorrectly treated.

“It’s all relative,” she says. “There’s a lot of treatment options and people may have gotten treatment anyway. It’s really hard to determine until we get down through every single case and take a look back.”

“For some people, it’s not going to mean anything,” agrees Dawe. “They may have been offered Tamoxifen or some other treatment anyway. For some people, Tamoxifen may not have been an option no matter what, because there are some side effects. It’s really individualized. Until I get some real good numbers I’m hesitant to talk about anything.”

Eastern Health officials wouldn’t discuss exactly what went wrong — though they have explained that new lab technology caught the errors and led to the retests.

The cancer society hasn’t been told.

“Eastern Health should answer that, but from what we’ve been told it’s a complicated process,” Dawe says. “They haven’t pinpointed exactly what went wrong. In any biological test there’s going to be a certain amount of false negatives. It just happens that their rate is up around 10 per cent. They’re trying to tighten up their quality control to the point that where they can say ‘We’re doing this test as well as anybody else.’”

Dawe says there have been lots of “rumblings and rumours” of legal action, but he’s heard nothing concrete. Pennell says Eastern Health hasn’t heard of any lawsuits either.

For Rogers, the errors would be a lot easier to swallow if they were explained.

“For the most part, people are not litigious,” she says. “They just want to be treated with respect and fairness. By handling it this way, it makes people

“I’m not making any kind of informed medical pronouncement here, but I had friends whose pathologies indicated they had a pretty good chance for survival, and they died.”
Gerry Rogers

angry enough to want to be litigious.”

Rogers phoned Eastern Health when she found out the results were in, and was directed to a “patient liaison” voicemail. She hadn’t heard back prior to *The Independent’s* press deadline. She says the silence is unfortunate, considering how well she has been treated by Eastern Health in the past.

“I’ve feel that I’ve had exemplary care,” she says. “Every step of the way I’ve been treated with compassion and respect, and this is totally disrespectful.”

Independent February 8/06

YOUR VOICE

'Test results haunt many of us'

Dear editor,

I recently started to receive *The Independent* through home delivery. I enjoy your paper and the fresh perspectives that you provide to your readers.

The front-page article headlined *Still in the Dark* by Ben Curties (Jan. 29-Feb. 4 edition) was very hard hitting and what a powerful photograph of the courageous Gerry Rogers. It is difficult but not impossible for me to imagine the fear and frustration that women such as Gerry and their loved ones must be experiencing. For all of us as health-care consumers the need for accurate information about our own health and related treatment options is paramount to making sig-

nificant life decisions. I recognize that no health-care organization wishes to cause "mass hysteria" on important health issues. However, the sharing of information regarding problematic test results must be handled carefully, with great sensitivity and speed.

Finally, the issue of problematic test results haunts many of us. For me, they relate to the death of my oldest and best friend who died of breast cancer during the time period in question. She was a vibrant woman and dedicated professional.

Her life ended far too soon.

*Geoff Chaulk,
St. John's*