

Denise Dunn

From: Deborah Thomas-Pennell
Sent: Monday, December 05, 2005 11:18 AM
To: Susan Bonnell; George Tilley; Dr. Robert Williams; Dr. Donald Cook; Denise Dunn; Heather Predham; Nancy Parsons
Subject: FW: 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 07:10AM Item # 07



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FYI...on CBC Morning Show this am.

-----Original Message-----

From: 709News@bristolgroup.ca [mailto:709News@bristolgroup.ca]
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Product Summary:

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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.