

My Journey with Breast Cancer: PAST, PRESENT AND FUTURE

By Barbara Heft, President, Canadian Breast Cancer Network

I am pleased to be the President of the Canadian Breast Cancer Network for 2002 and for the two years to come. I began my own personal journey with breast cancer nine years ago, but breast cancer has been part of my world for almost as long as I can remember. The true breast cancer journey really began with my mother Ruth, who was diagnosed in 1969 when I was 24; from that day my education really began.

My mother was courageous. She refused to give in to her illness, and fought the disease with experimental treatments anywhere she could find them as well as undergoing the traditional ones. She had both breasts removed with radical mastectomy. In those days there wasn't really much hope. She was radiated and burned by more primitive machines than are available now. She hung in, raised funds, and became President of the Cancer Research Society in Montreal before she died in 1976. Then the rest of my family started to die. My great-aunt and my mother's sister both died of breast cancer. Other cancers took my grandfathers, my Dad and so many women I knew that had been diagnosed with breast cancer.

Never in my life did I think I would ever follow in my mother's footsteps. I wanted to get away from cancer. But having breast cancer, a recurrence, and having been surgically and chemically rearranged and reconstructed by age 49, I knew that I had to do something. I was lucky; I live

in Toronto, and I had the best surgeons, oncologists, hospital(s) and resources of every kind, from support groups to therapy, to the best family and friends one could ask for. I was diagnosed early; I have outlived my mother by four years. She was 52 when she died. I am determined to have my 81.2 years, the life expectancy for Canadian women. Everybody who knows me knows my determination.

What am I going to do until then?

As I went through the stages of becoming a "survivor," a word that describes only part of the state we who come out the other end use to describe our status, I began to understand that I didn't have time to not become part of the solution. I sure knew the problem from the patient's perspective! What could I do? How could I help? As I looked around for some way to participate in the eradication of breast cancer, it became clear to me that I wanted to ease my terror of breast cancer for those I love, for my young daughter, my sister, my niece, and my friends, but mostly for me.

This work is very, very personal. To me – and to the women and men that I have come to know in "breast cancer" – this is a passion, a determination and an education as well as a need to do everything that we can possibly do, as soon as possible.

I joined Burlington Breast Cancer Support Services, one of the first support groups in Canada. During my illness, members of this group had reached out to help me,

and I was impressed. I was immediately drawn into the world of research and advocacy. At first we tried to pull together research information for our members, and very soon the Internet changed that landscape. It became apparent that the voice of women and men living with breast cancer and those who care about us needed a collectivity and focus. That seemed to me to be an important component for obtaining better treatment, drugs, quality of life, and funding for research and a cure. I felt I had been training for this all my life, in my career in human resources consulting, as a daughter, a mother, a Canadian and as a "survivor."

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In the mid 1990s, the Canadian Breast Cancer Network was just gaining momentum and I was asked to join the Board. I had heard that they were breast cancer survivors who had fought hard, and with the help of advocates in health care, medicine, industry and the federal government, were given a mandate to be that voice.

This is my fourth year with the Network, and it has been the experience of a lifetime.

My colleagues on the Board are from across Canada; we are all different and all the same. We are of different origins, religions, ages, and temperaments, not to mention geography and politics. However, we share one thing: a desire to rid the planet of this experience – to be part of creating "a world without breast cancer." This phrase I have borrowed from our partners at the Canadian Breast Cancer Foundation, who share our goals.

CBCN was created by a half dozen or so survivors who wanted to do something, and to make a difference in the lives of Canadians affected by breast cancer. Those wonderful people created an organization that has a solid foundation, and seven years later, we are part of the Canadian Breast Cancer Research Initiative (CBCRI), we have 53 partners, and we have 153 support groups as part of our Network.

We have been enriched by our partnerships. Health Canada, which has funded us up to now, is in the process of determining its priorities. They have been extraordinary in providing support, financial and otherwise. However, the Canadian Breast Cancer Research Initiative is only funded until March 31, 2003 – a date that looms large. We know through our consultations across Canada and surveys of the survivor population that the need for continuance is greater than ever. We are only getting started!

We have gained a seat at the table where decisions about breast cancer research are made. Survivors play a role in deciding research policy and direction – governments at every level have consulted us, and we have been heard. We must continue to strengthen our knowledge about problems that need to be solved as well as celebrate and share our victories.

What of the future?

There are approximately 175,000 of us living with breast cancer in Canada. Some have told us what they want the Canadian Breast Cancer Network to be, but others are not involved because they haven't been asked, or they don't know we are here. An important goal for CBCN is to reach those who have not yet found their voice or don't know it would matter. Together we can have an effect on the future of those who daily join the growing population who live with breast cancer. The death rate from breast cancer has decreased, but diagnosis is climbing, and the age of diagnosis is falling. We have plenty to be concerned about.

Next Steps Concern YOU!

Most importantly, it's you who we need help from. If you know of individuals living with breast cancer whose voices should be heard, encourage them to get in touch with us by calling our toll-free number, writing, or e-mailing. There is nothing they should be doing alone, and we can't do it without them.

Because so many breast cancer survivors never feel the need to join a support group, they may not know about us, and we certainly will not know about them. So how can we be the voice? Ask those you know and care about to let us know who they are. We will do the rest. 175,000 people living with breast cancer provide a great deal of important information for decision makers. It's as simple as that. ■



Early Detection: *An Unresolved Controversy*

By Karen DeKoning, Founding Member of the Breast Cancer Prevention Coalition, Member of the Board of Directors of the World Conference on Breast Cancer, Member of the Working Group for the Primary Prevention of Breast Cancer, Member of the Board of the Canadian Breast Cancer Research Initiative, Member of the External Advisory Committee of the Canadian Breast Cancer Initiative, member, Canadian Breast Cancer Network

During 2001, two scientific journal articles were published which showed that neither breast self-examination (BSE) nor mammography had any effect on the mortality of women from breast cancer. These are the only diagnostic tools for early detection, with the exception of a clinical breast exam performed by a highly trained nurse through the Canadian Breast Screening Programs. However, these are only administered to women aged 50 to 59, in conjunction with a mammogram. The only exception is British Columbia, where screening commences at age 40. Women who put their trust in a breast exam during an annual physical performed by a general practitioner may be given a false sense of security. The training GPs receive in medical school is minimal and it is not a procedure they perform daily. I know from experience that I never had a proper clinical breast exam until after I was diagnosed with breast cancer. Therefore, women have been left in a quandary as to benefits gained from any of the current methods of early detection.

Although newer methods for early detection in the testing stages, such as magnetic resonance imaging (MRI), are very accurate and involve no radiation, they are extremely expensive. Therefore, it is unlikely that they will ever be adopted as a mass-screening tool. Another screening device being tested is ductal endoscopy, where the ducts are examined with a fibre-optic camera. Ductal lavage, which

is being promoted by Dr. Susan Love, is also being studied. As well, there was a study published last month in the *Journal of the National Cancer Institute* (NCI), which indicated that cytological testing of breast fluid obtained through nipple aspiration might be useful in predicting breast cancer risk. However, there are ongoing problems with this procedure, such as insufficient harvest of diagnostic cells and an inability to pinpoint potential tumours.¹ Therefore, there are no accurate and affordable tools presently available for early detection to replace BSE and/or mammography.

These studies on the value of breast self-examination and mammography have caused a major uproar in the breast cancer community. Fifty percent of women find their own lumps, whether by BSE or while showering, or by their partner. Other women swear that mammography saved their lives by finding a tumour that was too small to feel. This controversy began with the publication of a new study in the June 26, 2001 *Canadian Medical Association Journal* (CMAJ) entitled "Preventative health care 2001 update: Should women be routinely taught breast self-examination to screen for breast cancer?" The study recommended that women between the ages of 40 and 69 no longer routinely be taught breast self-examination, as there has been no benefit shown in improving mortality. Also, BSE did not appear to make a significant difference in the size or stage of the tumours detected. The study also concluded that there was insufficient evidence to recommend that either women under 40 or over 70 be taught BSE.²

One of the most shocking statements made by the author, Dr. Nancy Baxter, was that breast self-examination actually causes harm. This is explained by "a significant increase in the number of visits to the doctors for benign breast lesions and significantly higher rates of biopsies for harmless lumps. Those biopsies can cause

permanent scarring and in some cases, significant breast deformity and emotional distress." In a commentary article in the January 22, 2002 *CMAJ*, I was quoted as contradicting this notion of harm. "The message of the study appears to be that women have no control or knowledge of their own bodies. If lives are saved, I believe that the cost is never too great."³ I also refuted Dr. Baxter's conclusions in an article I wrote for the *Toronto Star*, published June 29, 2001: "Most women would willingly undergo a needle biopsy or even an excisional biopsy for the reassurance that they don't have breast cancer. The wait-and-see approach can result in women being diagnosed with much more advanced disease, with fewer treatment options and perhaps a shorter life. The greatest emotional stress of all is not knowing if your lump is one of the 20% that are malignant."

My personal experience certainly reinforces this statement. In 1993, at age 48, I found a 3-centimetre lump between my yearly mammograms, which was followed by lumpectomy. I had been having them annually since my mother died of breast cancer in 1987. In 2000, I found a tiny hard spot just above my lumpectomy incision line. Surprisingly, the mammogram showed nothing. My oncologist thought that it was scar tissue. I was not willing to wait for my next check-up a year away to have this rechecked. I could not have lived with the uncertainty, and therefore, chose to have an excisional biopsy to remove it. It was lucky for me that I made that choice, because the tiny lump was malignant. Even if it had been benign, I would still not have regretted my decision.

The scientific community has viewed the *CMAJ* study with caution. In a related commentary by two Harvard Medical School doctors, they warn that the recommendations of Dr. Baxter and her task force may be premature. They argued that

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her review of the Russian and Chinese studies involved women who were using BSE as the sole method of screening and that the women had not been followed long enough to demonstrate benefit.⁵

Dr. Cornelius Baines, a professor of medicine at the University of Toronto, also critiqued the study. "The recommendation is not based on an even-handed review of the literature. All they're doing is citing bad evidence. And when they cite good evidence, they basically are censoring the evidence that disagrees with them. For example, they fail to point out that the author of one of the foreign studies found women who performed self-examination well had a significantly decreased occurrence of advanced breast cancer, compared with women who performed it poorly, or not at all." Dr Baines also critiqued that some of the studies were not long enough. "It takes 13 years before you can see a benefit from reduced breast cancer deaths using mammography, so it's hardly surprising these studies have shown no benefit, as one only lasted five years."⁶

Dr. Barron Lerner, in an essay entitled "When statistics provide unsatisfying answers: revisiting the breast self-examination controversy," in the January 22, 2002 edition of the *CMAJ*, takes a less strident and more practical approach to the issue. "Because the stories of individual women have great resonance, and because they at times probably do represent exceptions to population-based generalizations, they constitute an alternative type of proof that should not simply be dismissed as unscientific. Similarly, we should respect BSE as a strategy that empowers women who are concerned with having healthy breasts. The lifesaving potential of BSE may be less important than its ability to give women some control in deciding what is best for their health and wellbeing. In this sense, the regular performance of BSE might itself become a desirable intermediate health outcome. If women clearly value breast examination, why is proof of lowered mortality in randomized controlled trials the only appropriate goal to study? Of course, continued support for BSE in the face of lacklustre data remains defensible because of its low cost and minimal reliance on technology (unnecessary biopsies notwithstanding)."⁷ I believe this to be a reasoned approach to the issue, despite the conclusions of Dr. Baxter's findings.

Ramifications from this study, however, have already impacted the cancer establishment. Dr. Verna Mai, director of the screening programs for Cancer Care Ontario, has stated: "I don't think it's responsible to disregard scientific evidence."⁸ The agency currently oversees the Ontario Breast Screening Program, which teaches breast self-examination at its 80 clinics to women between 50 and 69. "That approach will change now," Mai said. However, although instruction in BSE will not be routinely taught, a woman can still request to learn the proper technique. If women still wish to continue to practice BSE, which is their choice, or wish to learn, they need to be taught how to do it correctly.

The value of mammography was similarly denigrated in a Danish study published in *The Lancet* on October 20, 2001⁹. The authors of this new critique were two researchers at the highly respected Nordic Cochrane Centre in Copenhagen. The article was entitled "Systematic review of screening for breast cancer with mammography," in which the scientists reviewed seven mammography trials conducted over the past several decades. They concluded that five of them had serious flaws. Most glaring was a failure to ensure that women who were screened and the women in the control group were similar in age and other risk factors. They also cited factors that made previous studies more likely to blame breast cancer for deaths in the control groups than for deaths among the women who had been screened. Their conclusion was that mammography, which uses X-rays to detect tiny lumps in the breast before they can be felt by physical examination, has not been shown to reduce mortality from breast cancer or to prolong women's lives. Surprisingly, they suggested that mammography may actually lead to an increase in mastectomies, the opposite of the conventional belief that early detection leads to less aggressive treatment. They also supported the belief that radiation treatments cause an increase in deaths due to radiation-induced cardiovascular damage. This study has been endorsed by the editor of *The Lancet*, who stated: "At present, there is no reliable evidence from large randomized trials to support screening mammography programs."¹⁰

The reaction from the breast cancer establishment has been defensive. Some experts have found the study flawed and

guilty of even worse biases than it purports to find in the original mammography studies. Dr. Martin Yaffee, a senior scientist of imaging technology at Sunnybrook and Women's College Health Science Centre in Toronto, dismissed the research findings of *The Lancet* article. "They're analyzing experiments that other people have done. It's quite upsetting. They seem to have attacked this thing with a bias. They seemed to have focused on flaws in trials that show the benefit of screening and ignored flaws in studies that showed no benefit."¹¹ Dr. Yaffee again responded in a *Globe and Mail* article on January 15, 2002: "Those studies were all testing mammography that's being done now in terms of the quality, even the film mammography."¹² He also flagged that the Danish review ignored the fact that mortality rates for breast cancer have declined. He believes that part of this reduction is due to earlier detection, i.e., mammography.

The controversy surrounding this issue has once again provoked heated debate about the dangers of mammography. Scientists have known since its introduction that mammography has always been fundamentally flawed, as it exposes women's breasts to ionizing radiation. It also fails to detect 10-15% of tumours. Radiation is known as the only ultimate carcinogen, which directly causes cancer by mutating genetic data, causing tumour cells. Over time, these cells abnormally proliferate and gradually form a cancerous mass. Although women are told by their doctors that the amount of radiation in a mammogram is not harmful, radiation in the body is cumulative. Dr. Rosalie Bertell has been a strong advocate against radiation for many years in Canada. Surprisingly, Dr. Steven Narod, professor of public health sciences and chairman of breast cancer research at the Sunnybrook and Women's College Health Sciences Centre, has stated that early detection doesn't matter. "By the time the cancer is detectable by mammography, it already has the potential to spread and you can't catch it early enough. The other reason is that there are a certain number of lives that are saved by mammography, but it's balanced off by a certain number of lives lost to mammography, either through the acceleration of tumours that are already spread or through the induction of new tumours through the radiation."¹³

What has been the result of all this controversy? On the issue of BSE, it is already

known that screening programs in Canada will begin to abandon the routine teaching of proper breast self-examination techniques for women. Only if a woman specifically requests instruction will she be taught. The issue of mammography is a lot more complicated. Mammography in Canada and the United States is big business, is the only method of early detection for which there is a cost involved, and this cost is substantial. Recently, an independent panel of experts met in Rockville, Maryland, and concluded that there was insufficient evidence to show that mammograms prevented breast cancer deaths. The P.D.Q. (Physician Data Query) screening and prevention editorial board stated that while it was possible that mammograms were beneficial, it was also possible that they were not. This group, which writes information for the National Cancer Institute's on-line database, stated that it would rewrite previous statements to reflect this new view, which will be posted on NCI's website in April. Their conclusions, which contradict *The Lancet's* findings, are that not enough evidence currently exists to prove that mammograms reduce breast cancer deaths for any age group. The P.D.Q. also admitted that it is not going to be easy for women and doctors to decide what to do.¹⁴

Despite the recommendations from this committee, the National Cancer Institute, part of the United States' National Institutes of Health, has chosen to ignore this advice. In a press announcement on January 25, 2002, the Institute stated: "Women in their 40's should undergo regular mammograms to screen for breast cancer. NCI believes early detection is one of the most important approaches to cancer control. Mammograms are the best method currently available to detect breast cancer early, which could allow for more treatment options in women who have the disease."¹⁵ The American establishment has spoken! Although in Canada, women are not accepted into the screening programs until they are 50 (with the exception of British Columbia, where screening starts at age 40), you can be certain that the Canadian establishment will follow suit and continue to recommend mammography.

Probably the strongest advocacy statement regarding this controversy comes from the National Breast Cancer Coalition (NBCC) in the United States. Their view has long questioned the limitations of mammography screening. Their position posted on

their website states: "Mammography is not the answer to the breast cancer epidemic. There is no screening tool that finds breast cancer truly early. In addition, although aggressively promoted for many years, there is no scientific evidence to conclude that breast self-examinations help save lives. Unfortunately, breast cancer has been reduced to mammography and breast self-exams – simple, misleading answers to a complex problem. As breast cancer activists, we welcome the long overdue criticism and discussion of the effectiveness of existing breast screening methods. We must accept that we do not know how to detect breast cancer truly early, how to prevent or cure this disease, and focus our attention on getting those answers. Although it may be difficult to accept, it is vital that women know the truth about breast cancer screening and the false sense of security it provides. The goal is to focus research efforts on prevention, and on new, more accurate ways to detect and treat breast cancer."¹⁶

In conclusion, if we believe the results of these two studies on BSE and mammography, it leaves women and their doctors in an untenable position. If our current tools for early detection are flawed, and there is nothing viable on the horizon, what are women to do to? This is a very difficult question to answer, and it is certainly above my level of expertise to suggest a course of action to take. I assume that women will have to be assertive and make their own choices, as will I, based on current knowledge from the scientific community and our own instincts about our bodies. Until we have more conclusive evidence, it is critical that new and better tools be found.

However, we do need to come to terms with the fact that if early detection is a myth which cannot stop the epidemic, how do we stop women from dying from this disease? The best way, of course, would be to find a way to prevent the disease in the first place. We, as women, need to lobby government and the cancer establishment for more funding for a cure for breast cancer, and more importantly, for a way to prevent this disease in the first place. Prevention research has always been under-funded worldwide. Although I must commend the Canadian Breast Cancer Research Initiative (CBCRI) for recently announcing a \$10 million dollar RFA (research funding application) for breast cancer, this is still a small percentage of the overall research budget. We

need to fight for more research into the environmental links to breast cancer and for stronger messages from the cancer establishment, which involve the "precautionary principle." This means prudent avoidance of any substance that shows a possible link to the causation of breast cancer, even before science proves a definitive link. If publicly targeted health messages regarding the causes of lung cancer had waited until scientists had found benzo(a)pyrene, the exact chemical that caused lung cancer, the death toll from this disease would have been more horrific than it already was. Why should breast cancer, as a disease, be treated any differently? The precautionary principle saves lives! Ultimately, prevention will be the best way to stop the epidemic of breast cancer and keep women from dying from this horrible disease. ■

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- 16 National Breast Cancer Coalition: <http://www.stopbreastcancer.org/bin/index.htm>.

You, Your Breast Cancer Group and Prescription Drug Ads

"Now, predict your risk of breast cancer. And act on it. There is something you can do."

"Look at Diane now! The acne solution for women only."

"A LESSON in guys: never play hard to get. Be hard to get."

Sharon Batt is the 2001-2002 appointee to the Elizabeth May Chair in Women's Health and the Environment at Dalhousie University in Halifax. She is the author of Patient No More: the Politics of Breast Cancer and has been active in breast cancer advocacy since her diagnosis in 1988. She co-founded Breast Cancer Action Montreal and was a founding member of the Canadian Breast Cancer Network. Much of her recent advocacy has focused on Direct to Consumer Advertizing (DTCA). She was one of the creators of Ad/Vice, an art display critiquing DTCA, which was shown last spring in the library at Mount Saint Vincent University in Halifax, NS.



Sharon Batt, Chair in Women's Health and the Environment, Dalhousie University

If you've turned on your TV, read a magazine or looked at a billboard in the past few years, chances are you've seen one or more of the above slogans. You've probably also seen mysterious, sloganless ads, like the billboard of a couple in bed, with no explanation beyond, "Zyban? Ask your doctor." Whatever your reaction to the ads, you can't ignore the startling images. An ad in *Chatelaine* for the cholesterol-lowering drug Lipitor shows a dead body on a mortuary slab and asks: "Which would you rather have, a cholesterol test or a final exam?"

Ads for prescription drugs are at the eye of a health policy storm. Members of every breast cancer group in this country need to understand this controversy, and not only because some of the ads involve breast cancer drugs. Patients' organizations are influential players in a heated policy battle in which both sides are firing volleys across the thresholds of MPs' offices. Few people are neutral in this debate. Before joining the fray, patients' groups need to air the issue carefully with their members and ask: "Which side are we on?" Before you read any farther, a warning: *understanding the DTCA debate is vital to your group's health, but discussing these issues could be fatally divisive to your organization.*

The jargon term for prescription ads is DTCA, short for "direct-to-consumer advertizing." Every industrial country except the USA and New Zealand bans them, on the grounds that prescription drugs carry health risks that ordinary products don't. In the present system, doctors are the designated gatekeepers. Their role is to prescribe a drug when professional judgment tells them that drug is the best available course for the patient. Until recently, ads to influence consumers were off-limits, although drug companies can target physicians, via office visits, ads in medical journals, and an array of other methods.

The policy shift that opened the floodgates began in the United States in 1997. The American drug regulator, the Federal Drug Administration (FDA), had previously allowed DTCA but with heavy restrictions. Under pressure from industry, the FDA finally loosened the constraints governing ads on radio and TV. Ads like the first one quoted above, promoting tamoxifen (Nolvadex) to women at high risk of breast cancer, began to swamp the

American media. Although they are illegal here, the Canadian government did nothing to stop over-the-border "bleed" from US TV and magazines.

For the past two years, drug companies have lobbied governments, in Canada, Europe and elsewhere, to loosen the regulatory reins and allow US-style ads. With "just-watch-me" defiance of the ban, they have launched ad campaigns for drugs like Diane-35 and Alesse (see slogans above), Zyban, Lipitor and Viagra that they claim are legal – at least technically – under Health Canada's regulations.

As part of its strategy, the pharmaceutical industry sought allies in influential sectors, including the media. Newspapers, magazines and TV channels will enjoy a financial bonanza if the laws are relaxed. In the US in 2000, drug companies spent \$2.5 billion on DTC media ads. The drug industry has also identified patient advocates as highly desirable allies and has wooed groups to join their fight against government "paternalism" and "censorship." The industry claims prescription drug ads are essential educational materials for today's informed health consumer.

Durhane Wong-Reiger, an advocate who heads the Anemia Institute for Research and Education, has emerged as an influential voice in this strategy. In October 2000 she invited representatives from the pharmaceutical industry, the media and patient organizations to meet and discuss DTCA. This process spawned a Joint Working Group and the Consumer Advocare Network, which Wong-Reiger chairs. In consultation with her advisory group, she released a position paper last fall arguing for regulated DTC promotion of prescription drugs. Wong-Reiger argues that consumers have "**a fundamental right to information** about prescription drugs, which includes direct-to-consumer promotion of drugs" (boldface from the original).¹

Not all health consumer groups agree that the freedom to see ads for tamoxifen, Zyban or Lipitor is one of the great cornerstones of democracy. I belong to several coalitions whose members argue the opposite: that citizens have a right to **unbiased** information about prescription drugs; but ads, by definition, are inherently biased. Their purpose is to sell drugs. The drug companies' insistence that advertising is education chillingly evokes George Orwell's nightmare society, in which "War is Peace," "Ignorance is Strength" and "Freedom is Slavery." Pharmaceutical ad campaigns are so in-your-face and so well funded they overwhelm the modest capabilities of those who would truly educate the public about drugs. Because prescription drugs can have harmful or lethal effects, banning their promotion is no more paternalistic than banning child pornography or controlling the use of firearms.

Health advocates involved in breast cancer issues formed the coalition Prevention First², in which I am active, because we were concerned about the promotion of tamoxifen to healthy women. The FDA approved tamoxifen for healthy women at high risk of breast cancer in October 1998, and this approval gave AstraZeneca, the drug's manufacturer, the right under US law to mount a media campaign promoting tamoxifen to American women.

AstraZeneca launched its slick "Now, predict your risk of breast cancer. And act on it." campaign in early 1999. Our coalition analyzed the ads and concluded they violated FDA regulations. We filed complaints to the FDA, detailing the problems. The FDA concurred with our arguments and ordered AstraZeneca to stop the campaign. In its letter to AstraZeneca, the FDA said that the company had overstated the drug's benefits and downplayed its risks.³ By the time the ads were withdrawn, however, millions of women had been misinformed about tamoxifen's risks and benefits. The company was not required to run corrective ads.

Last December, the FDA required AstraZeneca to withdraw another ad promoting tamoxifen, this one aimed at women with breast cancer ("I **reduced** my chances for a recurrence of breast cancer **significantly**.") Again the company was found to have misled women by overstating tamoxifen's benefits and understating the risks.⁴

The Working Group on Women and Health Protection is a national coalition of Canadian health groups and academics that oppose DTCA.⁵ Organizations working under its umbrella include DES Action Canada, the

Canadian Women's Health Network, and Breast Cancer Action Montreal. We have filed complaints to Health Canada critiquing the Allesse and Diane-35 ad campaigns, organized a media campaign, and met with government policy makers urging them to uphold Canada's DTCA ban. To explain our position to the public, the Working Group and DES Action published a brochure by Vancouver researcher Barbara Mintzes, called *Direct to Consumer Prescription Drug Advertising: When Public Health is No Longer a Priority*.⁶

Groups in these two coalitions opposing DTCA differ from members of the Consumer Advocare Network on another important issue: they all refuse to accept pharmaceutical industry funds. The rationale for this policy is that, to maintain credibility as advocates for the public interest, the groups want to remain independent from powerful industry influences that could benefit from their advocacy. They also feel free to critique the pharmaceutical industry, a freedom that groups receiving industry money may forfeit. I share these views. Partnerships between pharmaceutical companies and advocates from the patient community make me extremely uneasy. Physicians and medical researchers are finally confronting the corroding effects of conflicts of interest; patients engaged in influencing public policy must do the same.

The future of DTCA in Canada is uncertain. As of this writing, DTCA promoters hold one trump card: DTCA opponents lack hard evidence of "death by advertising" – proof that prescription drug ads actually cause harm to health. However, the price tag to the health care system, through increased drug costs, has been demonstrated (yes, we pay for those glossy ads). Industry has made freedom of speech its centerpiece argument, for good reason. Courts have typically defended free speech unless the messages in question have done demonstrable harm. So far the evidence of DTCA's health harm is indirect.

A study by Barbara Mintzes, published in the *British Medical Journal*, moves the argument against DTCA closer to the goal post.⁷ When they prescribed a heavily advertised drug requested by patients, Mintzes found that physicians were more likely to be uneasy about the appropriateness of the prescription than when they prescribed a drug the patient had not

requested. Although evidence that advertising endangers health is still shy of proof, I believe bans on prescription drug ads must be maintained and enforced while more data is gathered.

Beyond the DTCA argument, this debate puts the question of industry partnerships squarely before the advocacy community. We now have in Canada two categories of patient groups: those that welcome pharmaceutical funds and partnerships, and those that reject corporate funding. Many groups have not yet formulated a policy on this question. The DTCA controversy offers a concrete example groups can use to explore the pros and cons of industry funds with their membership. Some breast cancer groups have corporate funding policies posted on their websites,⁸ and veteran health activist Anne Rochon Ford has written an excellent booklet to help groups navigate this potentially explosive discussion.⁹ ■

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- 1 Wong-Reiger, Durhane and Helen Stevenson-Smit, "A Case for Regulated Direct-to-Consumer Promotion of Prescription Drugs," Toronto, 2001.
- 2 Coalition members are the Boston Women's Health Book Collective, Breast Cancer Action, DES Action, the Massachusetts Breast Cancer Coalition, The Centre for Medical Consumers, the National Women's Health Network, the Women's Community Cancer Project, and the Working Group on Women and Health Protection (Canada), represented by Breast Cancer Action Montreal. Web address - <http://www.bcaction.org/Pages/LearnAboutUs/PreventionFirst.html>
- 3 Web reference: <http://www.fda.gov/cder/foi/appletter/1998/17970s40.pdf>
- 4 Web reference: <http://www.fda.gov/cder/warn/2001/10205.pdf>
- 5 Documents are posted on the DES Action Canada web site, <http://www.web.net/~desact/anglais/anglais.html> Go to "Health Protection Legislation" and from there to DTCA.
- 6 Available on the site listed above, under DTCA.
- 7 Mintzes, Barbara, et al. "Influence of direct to consumer pharmaceutical advertising and patients' requests on prescribing decisions: two site cross sectional survey", *BMJ*, Vol. 324, February 1, 2002, 278-279.
- 8 See, for example, Breast Cancer Action's policy, at <http://www.bcaction.org/Pages/LearnAboutUs/CorporateContributions.html> and Breast Cancer Action Montreal's at: <http://www.bcamm.qc.ca/news.htm>.
- 9 Ford, Anne Rochon, A Different Prescription: Consideration for Women's Health Groups contemplating Funding from the Pharmaceutical Industry, Toronto: National Network on Environments and Women's Health (NNEWH). To access the booklet on the NNEWH website, go to <http://www.yorku.ca/nnewh/english/nnewhind.html>.



Canadians Demand Regulated Direct-to-Consumer Advertising of Prescription Drugs

By Durhane Wong-Rieger, PhD, Chair of the Consumer Advocare Network

Limits of Canadian DTCA

Effective advertising of a product or service creates awareness and prompts the consumer to seek additional information. In the United States, both supporters and critics agree that direct-to-consumer advertising of prescription medication has increased awareness of medical conditions and prompted consumers to seek help.

Paradoxically, Health Canada regulations prohibit advertising of a prescription drug in conjunction with the treatment, prevention or cure of the medical condition for which it is licensed. As a result, Canadians who see an ad for a prescription drug are not informed about the condition being treated, unless, of course, they have seen the parallel American ads.

Canadians Want Information about Prescription Drugs

Between two-thirds and three-quarters of Canadians polled believe that pharmaceutical companies should be allowed to advertise prescription drugs.¹ Indeed, Canadians consider access to information about therapeutic options, including prescription drugs, to be a fundamental right.

Canadian consumers expect to take an active role in making decisions about their healthcare.² Patients are more likely to follow their treatment regimen when they

have participated in making decisions about the choice of therapy.³ These treatment options increasingly include prescription medicines, which play a significant role in treating a disease or condition, controlling symptoms, and improving quality of life.

Health Canada's Concerns

The *Food and Drugs Act and Regulations* that govern DTCA date from 1953. Health Canada has acknowledged the need for update, but has been reluctant to implement proposed revisions because of one overriding concern: ***DTCA may cause patients to request specific drugs and physicians to prescribe them, thus increasing drug expenditures.***

This concern actually reflects broader controversies surrounding healthcare costs, drug costs, drug utilization, and the value of drugs. Healthcare systems everywhere are struggling with spiraling healthcare costs, and drugs represent the fastest growing component. Drug costs are influenced by many factors, including an aging population, newer drug therapies, and less hospitalization.⁴

There are no data substantiating the fear that DTCA, per se, increases drug expenditures. More importantly, investing in drug therapies may be beneficial to both patients and overall healthcare costs. A \$1 investment in drug expenditures results in \$3.65 savings in hospitalization costs.⁵

Rheumatic fever, measles, heart disease, ulcers, and emphysema are all examples of illnesses that have experienced dramatic declines in hospitalization and death rates as a result of new drug developments.⁶

Impact of Direct-to-Consumer Information

Surveys in both the United States and Canada show consumers are aware of DTCA and are prompted to discuss their medical condition and drugs with their physician. However, there is no evidence that DTCA has increased inappropriate prescribing.

The following summarizes the key findings from key surveys and studies.⁷

1. American and Canadian consumers see DTC ads.

Americans now see an average of nine prescription ads per day on television. Canadians are seeing the same ads on American cable stations, probably on average two to three a day **in addition** to exposure to print ads in American magazines.⁸

2. Patients visit their doctors as a result of drug ads.

According to the US Food and Drug Administration (FDA) survey, about half of those seeing an ad sought more information from their physician and one-quarter sought help for a medical

Your opinion is important to us!
Let us know what YOU think about DTCA!

Should direct-to-consumer advertising be legalized in Canada? Write to CBCN at 602-331 Cooper Street, Ottawa, ON K2P 0G5, fax (613) 230-4424, or e-mail your response to cbcn@cbcn.ca. We will print a sampling of comments in the Fall 2002 Network News, and all responses will be posted on our website (www.cbcn.ca). Only responses that contain your name and contact information will be considered for publication.

condition that they had not previously discussed.⁹ About four-fifths of physicians surveyed responded that they welcomed the request from their patient. The elderly and those in poor health condition were even more likely to talk to their doctor as a result of seeing a DTC ad, though no more likely to actually receive a prescription for the medication.¹⁰ As importantly, DTC promotion does not appear to significantly increase the number of physician visits, since about 80% of those who discussed an advertized drug did so at their next scheduled visit.¹¹

3. Physicians believe drug-related questions are appropriate.

In a Prevention magazine survey, about one-third of patients recalling ads asked their physician about an advertized drug. Similarly, about one-third of Canadian patients requested a specific product.¹³

More importantly, about 80% of American patients surveyed who asked about an advertized drug reported that their physician had welcomed the question and discussed the drug. Similarly, half of the Canadian physicians surveyed responded that the majority or all of the product requests were appropriate. More than four-fifths said that at least some requests were appropriate.¹⁴

4. Patients do not necessarily receive the drugs requested.

The survey by the US FDA found that about half of physicians prescribed the drug requested, while one-third prescribed a different brand and about 15% prescribed no drug. In a recent Kaiser survey, 44% (representing 13% of the public overall) say that the doctor gave them the prescription medicine they asked about.¹⁵ In contrast, the Prevention survey found that of those people who requested a specific drug, 85% received it, while 11% were prescribed no drug.

5. DTC promotion may benefit patients and the healthcare system.

DTCA appears to play an important role in prompting patients to ask their physicians about medical conditions not previously discussed. For example, DTCA has played a significant role in raising awareness of the risks of high cholesterol and the need for regular testing, and this remains a very important need given the new guidelines from the

National Heart, Lung and Blood Institute which nearly triple the number of adult Americans who should be taking cholesterol-lowering drugs.¹⁶ If DTC promotion helps appropriately targeted patients gain access to new medicines, this will result in better disease management, fewer side effects, and lower mortality.¹⁷ However, research is needed to determine the impact on the overall "burden of health" and public dollars.¹⁸

Status Quo Not Tenable

Clearly, despite Canadian regulations, DTCA is happening in Canada. Moreover, Canadian manufacturers, in the absence of clear guidelines and a pre-clearance advisory board, have experimented with "made-in-Canada" ads that test the boundaries. Examples include Pharmacia's Rogaine (hair loss) help-seeking ads, the toe fungus ads (from Xenna Corporation), a morning sickness ad (sponsored by Duchesnay Inc.), the widespread "Diane-35" acne ads (from Berlex Canada), and Wyeth-Ayerst's "Alesse" birth control ads.¹⁹

While some of these ads have been highly creative in their attempt to generate awareness without running afoul of Canadian restrictions, in some cases, the messages have been ambiguous and not helpful. For example, Pfizer's US Viagra ad clearly identifies the condition and treatment, as compared to the Canadian-generated ad that does not specify what is being treated. Similarly, Pharmacia's US ads for Detrol (overactive bladder medication) discuss the treatment and how it works, whereas the Canadian ad is unclear as to whether the treatment is a medication, pad, or psychological support.

Call for Action

Canada's Food and Drug Act must be updated immediately to allow responsible direct-to-consumer promotion of prescription drugs. While regulatory changes are being addressed, guidance should be issued to allow for DTCA within the current regulations.

It is recommended that advertizing directed to consumers be subject to the same type of review and advertizing standards clearance process as advertizing directed to physicians. Overall, despite some criticisms,²⁰ the Pharmaceutical Advertising Advisory Board has effectively managed this process.

Finally, it is important that manufacturers who place direct-to-consumer ads also fund comparable levels of education to consumers through consumer associations or other third-party entities. ■

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Cult, Kitsch or Political Movement: Breast Cancer Activism in the 21st Century

Jennifer Keck is a woman living with breast cancer and a member of the Circle of Strength Breast Cancer Support Group in Sudbury, Ontario

A prominent American feminist, journalist and social commentator, Barbara Ehrenreich was diagnosed with breast cancer shortly after the release of her most recent book, *Nickel and Dimed in America*. In her article *Welcome to Cancerland* in the November 2001 issue of *Harpers' Monthly* magazine, she weaves her personal experience with cancer into a hard-hitting critique of America's mainstream breast cancer culture. Ehrenreich asks how the American breast cancer movement, with its roots in the progressive women's health movement, could have become so bland and complacent over a relatively short period of time. She points to the movement's success in taking breast cancer from a position of relative invisibility to the "biggest disease on the cultural map."

Ehrenreich finds little that is feminist in the breast cancer movement that dominates popular culture. Perspectives on treatment, she claims, are mostly grateful and universally upbeat. Where is the rage? Where is the passion? Why aren't there marches in the streets to protest the high rate of mortality over this disease? Why are resources directed at treatments and very little at environmental causes? Why isn't the movement more honest about the limitations of mammography and not-so-early detection methods? Why isn't there more criticism of the pharmaceutical industry's strategy to push pills as a form of chemoprevention? Why are the experiences of survivors idealized when more and more women are dying from this disease?

This critique is not for the faint-hearted. There is relatively little about mainstream breast cancer culture that does not fall under the critic's eye. From the "infantilizing images" of teddy bears to the cult of cheeriness, she argues women are encouraged to be "good patients" while corporations are given the green light to shape the movement's image. Generous corpo-

rate support has increased the resources available for research and services, but it has also shaped the overall direction and messages of the movement.

I am not sure why this article is so disturbing. Certainly little of this analysis is new. Sharon Batt's *Patient No More* was one of the first books to develop a feminist critique of the Canadian breast cancer movement. Many of us who are active at the grassroots have used her book as a backdrop for our organizing work for years. One needs to exercise caution before transposing a critique of American culture to the Canadian experience.

Still, the article strikes close to home. In what seems to be another life I am an academic, a writer and the mother of a 12-year-old son. I was active with the women's movement long before I was diagnosed with breast cancer in the spring of 1997. After a regimen of surgery, radiation, chemotherapy and three years of tamoxifen, I was diagnosed with metastatic disease last January. For the most part, I have avoided the institutional politics of breast cancer, preferring to remain active with our local support group. I am also the primary researcher on a participatory action research project investigating why women attend support groups led by breast cancer survivors. I am left wondering if I am part of the sisterhood under attack here.

Yet I, too, resent that corporate logos have become the symbols of a movement supposed to be rooted in the struggles of women affected by this disease. I resent the fuzziness and perpetual cheeriness that has become a predominant theme of this movement. During last October's Breast Cancer Awareness Month, I spoke publicly (to anyone who would listen) about the dearth of images or materials for women with metastatic disease. Most of the books available are personal accounts about how women conquered breast cancer. This is a preppy message for a movement representing women with a life-threatening illness.

However, I am full of contradictions. I

have never really been able to develop a coherent critique of treatments and the pharmaceutical industry. I remain skeptical of an industry where profit is the guiding light for research and treatment and I am critical of the connection between pharmaceutical development and pesticide production. Still, I find myself vulnerable to the message that I need these drugs to survive. There are relatively few choices available, but for the most part I am thankful for the time and relief that drugs provide. Also, I am reminded that the last two drugs that were prescribed to me were not available to women five years ago.

Still, it is hard to envision this as success. The treatments are more or less the same. The mortality rates have not changed substantially over a thirty-year period. How can we describe this as winning?

Part of the problem with Ehrenreich's critique is the women – and activism – that she dismisses. It is one thing to critique the cancer establishment and its corporate ties, quite another to take on the women that make up the rank and file of mainstream breast cancer culture. One is left with the impression that the only "real" activism has to do with challenging the medical and scientific establishments and the institutions that make up the larger cancer industry. More demonstrations and picket signs.

Why should we expect the breast cancer movement to be monolithic? Surely our experience with the broader women's movement teaches us to anticipate differences and the value of forming coalitions. Should we expect women to be any more unanimous about their politics because they share a disease? There are huge barriers to building a progressive breast cancer movement. The problem isn't simply one of resources and financial support. Women in this movement die! Until I was diagnosed with breast cancer, I had never been a member of a social movement where the stakes were so high.

The women I meet with on the first Tuesday of every month have been a criti-

cal part of my support since I was diagnosed four years ago. Sometimes I look around the room and try to imagine how we would have come together without the curious tie of a disease. We certainly do not all share a common political worldview. But the women who call with messages of support, who are there when my world is collapsing and who want to help other women get through the worst part of this disease form an important part of my life. These women *are* my sisters.

I am caught by the phrase at the end of Ehrenreich's article. This is *not* her sisterhood. I want to ask her what contact she has had with grassroots women. What does she know of the organizations that are slugging away on these issues outside of the larger centres, where women are demanding to be taken more seriously by their physicians, where women who have never considered themselves political are challenging local charities to find out how the money is spent, where women are facing their own fears of mortality to hold the hand of other women who are dying from this disease? Has she received a phone call from a woman panicking over a recent diagnosis? Has she mourned the loss of a friend and activist?

Yes, let's bring back RAGE. Let's rail against the injustice of a disease that has taken on epidemic proportions. Let's say that it is not OK to have this disease. Let's take on the corporate agendas of pharmaceutical companies and challenge the commercialization and corporatization of our movement. Let's confront corporations who insist on having their logos – and agendas – dominate our events and organizations. While we are at it, let's refuse to make one more cheery speech for causes that do not represent our interests.

However, let's not forget the sense of community that formed part of the early breast health movement. My experience with the women's movement taught me the importance of analysis and resistance. It also taught me the importance of a culture that respects diversity and the need to build solidarity and sisterhood.

I agree that it is time to bring the progressive voice of the breast cancer movement out of the closet, to return to an in-your-face politic, to develop an analysis that challenges the way things are and looks at how things could be. We need to ask

the question, who benefits? We need to build alliances with other political movements, but with a healthy dose of sisterhood and respect. Ehrenreich is a relative newcomer to this movement. Her rage is refreshing. I hope she too finds the sisterhood.

If you have not read Barbara Ehrenreich's recent article, *Welcome to Cancerland*, you should.

Jennifer Keck would like to thank the women from across the country who took part in an informal e-mail conversation to develop this article. A long-time admirer of Barbara Ehrenreich's work, she plans to send her a copy of this article along with a Canadian care package including Gerry Rogers' film, My Left Breast, Laura Sky's How Can We Love You, the environmental film Exposure and Sharon Batt's Patient No More. This is a gift of politics and creativity – from her sisters across the border. ■

Canadian Breast Cancer Network Partners

National Partners

Canadian Breast Cancer Foundation
 Canadian Breast Cancer Foundation
 Community Research Initiative
 Canadian Breast Cancer Foundation,
 Ottawa Branch
 Canadian Breast Cancer Research Initiative
 Canadian Cancer Society
 Breast Cancer Society of Canada
 National Cancer Institute of Canada

Provincial/Territorial Networks

Alberta Breast Cancer Network
 Alliance for Breast Cancer Information
 and Support, British Columbia and
 Yukon
 Breast Cancer Action Saskatchewan
 Manitoba Breast Cancer Information and
 Support Network
 New Brunswick Breast Cancer Information
 Partnership
 Northwest Territories Breast Health/Breast
 Cancer Action Group
 Ontario Breast Cancer Information and
 Exchange Project (OBCIEP)
 Prince Edward Island Breast Cancer
 Information Partnership
 Purple Lupin Partnership (Newfoundland)
 Qullit, Status of Women Council
 Réseau d'échange d'information du
 Québec sur le cancer du sein

Provincial/Territorial/Regional/Local Partners

Action for Breast Cancer Calgary
 Breast Cancer Action Kingston
 Breast Cancer Action Manitoba
 Breast Cancer Action Montreal
 Breast Cancer Action Nova Scotia
 Breast Cancer Action (Ottawa)
 Breast Cancer Centre of Hope (Winnipeg,
 Manitoba)
 Breast Cancer InfoLink (Calgary)

Breast Cancer Prevention Coalition
 Breast Cancer Support Services Inc.
 (Burlington, ON)
 Breast Health Centre of the Winnipeg
 Regional Health Authority
 Breast of Canada Calendar
 Manitoba Breast Cancer Survivors Chemo
 Savvy Dragon Boat Team (Winnipeg)
 Miles to Go Healing Circle – Six Nations
 (Ontario)
 New Brunswick Breast Cancer Network
 Prince Edward Island Breast Cancer
 Support Group
 Souders-Matthey Foundation for Breast
 Cancer Research
 Sister to Sister: Black Women's Breast
 Cancer Support Group (Halifax, NS)
 Willow Breast Cancer Support and
 Resource Services (Toronto)
 Yukon Breast Cancer Navigator
 Yukon Circle of Hope

Key Partners in Other Sectors

Canadian Health Network
 Canadian Hospice Palliative Care
 Association
 Quality End-of-Life Care Coalition
 Canadian Prostate Cancer Network
 Canadian Science Writers' Association
 Women's Centre of Montreal
 Disabled Women's Network Ontario
 HPV and Cervical Health Society
 National Council of Jewish Women of
 Canada
 National Council of Women of Canada
 Newfoundland and Labrador Women's
 Institutes
 Women and Rural Economic Development

International Partners

National Breast Cancer Coalition
 (Washington, D.C.)
 Philippine Breast Cancer Network

Gene Patenting: *Is It Too Late To Stop It?*

By Lynn Macdonald

Gene patenting, along with the closely related issues of human cloning and stem cell research, has preoccupied ethicists, theologians, scientists and many others stakeholders for the last decade. Even before the completion of the Human Genome Project in 2000, genes had become the latest hot commodities in a scramble at patent offices around the world. To date, more than 1,000 human genes have been patented, and tens of thousands more are awaiting patent approval by patent offices in each country. The test case that allowed patenting of genes was the landmark 1980 United States Supreme Court decision *Diamond v Chakrabarty* that granted a patent for an oil-dissolving microbe.¹

A patent is a legal agreement between the inventor and a government in which the inventor agrees to disclose publicly what he or she has "invented" in detail, and in turn can stop others from using this process or drug. Patent owners have exclusive rights for twenty years in Canada and the United States. The patent can however, be bought, sold, rented or hired.

There are two classes of biotechnological inventions that can be patented. The first class consists of gene and protein sequences that have been isolated from the body and that are useful as a pharmaceutical drug, assay (a chemical test), or other application. The second class relates to a gene process that has already been patented. In this case, a second or third inventor can obtain a new patent if he/she invents a new use or drug for that process.

Specific sequences of genes are patentable if they meet the three criteria of the United States Patent and Trademark Office² of being **novel, well described and useful**. In Great Britain, the UK Patent Office issues patents, but Great Britain has also signed the European



Lynn Macdonald

Patent Convention, which essentially patents inventions under the 19 other European countries that are governed by the European Patent Office. In any event, the Trade-Related Intellectual Property Right (TRIPS) agreement basically ensures similar standards around the world.

The argument used to justify this process is that it rewards the inventor, helps her or him recoup the millions of dollars that have been invested in developing the invention, and stimulates the flow of scientific and technological knowledge. Pharmaceutical companies argue that that cures for many diseases are on the way, such as Alzheimer's, breast cancer, and arthritis, to mention but a few.

Gene patenting has become an issue in the breast cancer community because in July 2001, Myriad Genetics Laboratories Inc. of Salt Lake City, Utah, patented the process of testing for BRCA 1 and BRCA 2 in the United States, Canada and Europe. Five to 10% of breast cancers are positive for BRCA 1 and 2 genes. They are very common but not exclusive to Ashkenazi Jews, and most North American Jews are of Ashkenazi descent. Breast cancers that are caused by BRCA 1 and 2 mutations will likely be diagnosed before the age of 50, and by the age of 70 most will have

developed breast cancer. Women positive for BRCA 2 mutation also have a high risk for ovarian cancer. Knowing their hereditary status allows women to make decisions, such as having prophylactic mastectomies and removal of their ovaries. Up to last summer, provincial and territorial cancer agencies were performing BRCA 1 and 2 tests in their own laboratories, at a cost of \$800 each. MDS Laboratory Services, the Canadian subsidiary of Myriad Inc., is now charging \$3,850 for BRCA 1 and 2 full sequencing, \$600 for Ashkenazi panel, including mutations on 3 genes, and \$525 for Single Site BRCAAnalysis®.

The British Columbia Ministry of Health withdrew funding for the tests due to their exorbitant costs. Then on July 11, the British Columbia Cancer Agency stopped performing the tests, leaving patients who were waiting for testing through the Hereditary Counselling Program no choice but to pay the full cost themselves or not to have the test. All other provinces have maintained their hereditary testing programs, but Premier Mike Harris of Ontario announced that Ontario would challenge the "rights of private companies to patent genes, then control, and profit from, diagnostic and medical treatments using the patent."³ He was supported by Dr. Ron Carter of the Canadian College on Medical Genetics, who said, "This is a very important issue... there will be hundreds of genes where patents will be brought into action. If this action sets a precedent, we will not be able to afford our health care system."⁴ Premier Harris subsequently raised the issue with other premiers at their August 2001 meeting, and also challenged the Federal government to get involved in the issue. The January 24-26, 2002 meeting of Canadian Premiers on Health Care has put this issue on the back burner, as it is clear that governments across Canada are planning to make substantial changes to the health care system.

The United States and Europe allowed patenting of the genetically altered

Harvard mouse that is useful in cancer research. Canada, while issuing patents on genes, proteins and cells, has drawn the line on higher life forms, such as human cloning. Last year, Canada's Federal Court of Appeal ruled 2 to 1 that the Canadian Commissioner of Patents was wrong to deny the patent of the Harvard mouse.⁵ Is this a small step away from human cloning?

While politicians make blanket statements, as did former American President Bill Clinton and British Prime Minister Tony Blair in calling for free access to the human genome map, there remains no clear body in charge of determining the future of patenting of genetic material. As Richard E Gold, who holds the BCE Chair at the Faculty of Law at McGill University, said, "We must rethink the nature of patent protection over human biological material. These are not widgets. Most of us regard them as highly personal. Besides, they offer the only means by which a person can evaluate his or her future health status."⁶ In a Letters to the Editor in the *Globe and Mail*, noted Toronto lawyer Clayton C. Ruby suggested that the approval of the Harvard mouse leads us one step closer to human patenting.⁷

Has the horse already been let out of the barn? Perhaps. The Canadian College on Human Genetics and similar bodies around the world must raise the ethical and moral implications of gene patenting. We need to wake up to the dangers implicit in corporate control over genetic material, and let our governments know that we don't want our genes used for profit. ■

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My *Clinical Trials* Training

By Lynn Macdonald

In 1996, the Washington, DC based National Breast Cancer Coalition (NBCC) established a novel program to fight breast cancer – the **Clinical Trials Project**. Their assumption was that clinical trials are needed to help find the best drugs to treat breast cancer. Trial design, access and accrual to clinical trials are the three highest priorities of NBCC.¹ Currently, fewer than 3% of adult patients in the United States are in clinical trials.² As a result, NBCC developed a four-pronged approach: legislative, education and training, clinical trials clearinghouse and research partnerships.

It was my very great honour to have been one of 22 people selected to attend the July 12-15, 2001 Clinical Trials training, and to be the only participant from Canada. Dr. Molly Mead, who has led all 25 previous sessions, conducted the meeting, which was held in Washington, DC. As usual, there were materials to be read prior to the course, and upon arrival, we were given a three-inch thick binder with presentation handouts and other reference materials. All the speakers were outstanding in their knowledge and astonishing in their ability to convey complex material to lay consumers. Class discussion was prolific and rigorous, as all the attendees were carefully selected and not "shy." I was surprised to see many other advocates I knew, having met them at the United States Department of Defence Peer Review, Project LEAD, or the San Antonio Breast Cancer Symposium. The one limitation for me as a Canadian was that they used the American system in their examples, and clinical trial processes are somewhat different in Canada. However, my Canadian education was completed at the recent Canadians for Best Medicine Conference, 2nd Summit on Reform of Canada's Drug Review system, January 25-27, 2002 in Aylmer, QC.

This education strategy for advocates was designed to give delegates the scientific

knowledge and tools we will need to participate at all levels of the clinical trials process, from evaluating trial design to serving on Institutional Review Boards (IRBs) and Data Safety Monitoring Boards (DSMBs). The current policy of NBCC is that no drug should be given to breast cancer patients outside of a clinical trial. NBCC hopes that graduates will represent the organization in its research partnerships. For example, in 1996 NBCC partnered with the biotechnology company Genentech, Inc. to design and implement a Phase III clinical trial of the drug Herceptin. NBCC helped design an expanded program for the drug, served on the DSMB and on the Steering Committee of the trial. NBCC used its contacts in the breast cancer community to raise awareness about the trial and facilitate patient accrual. This partnership helped bring a life-prolonging but very expensive drug to market.

NBCC is currently working with Biomira Inc. to implement a Phase III clinical trial of Theratope vaccine in women with metastatic breast cancer. Theratope is a therapeutic cancer vaccine designed to stimulate the body to develop an immune response directed against cancer. NBCC is also involved in a BCIRG³ clinical trial of Herceptin in the adjuvant setting and in Genentech, Inc.'s Anti-VEGF⁴ clinical trial. ■

- 1 National Breast Cancer Coalition Foundation, "NBCC Clinical Trials Project Research Partnership. Criteria for Trial Evaluation," p. 1.
- 2 Ibid.
- 3 BCIRG stands for the Breast Cancer International Research Group – the first academic global cooperative intergroup of oncology researchers dedicated to the global strategic development of promising new therapies for women with breast cancer. Contact them at <http://www.bcirg.org/internet/default.htm>.
- 4 Anti-VEGF stands for vascular endothelial growth factor. VEGF is a protein that is known to stimulate growth in new blood vessels and hence increase tumours. Anti-VEGF tries to prevent new blood vessels from growing. It is a novel cytostatic form of chemotherapy. <http://www.macular.degeneration.org/Drugs/antiangiogenicdrugs.html>.

Challenges and Hopes in

Clinical Trials

By Lynn Macdonald

Clinical trials are studies to determine whether new drugs or interventions are both **safe** and **effective**. They represent the fastest way to find treatments that work. Often the idea for a clinical trial begins with an unplanned or alert observation by the physician. Trials usually begin with laboratory and animal evaluations of new therapies or procedures that get promising results. They are not given to live human subjects until extensive testing has been done. At this point the **Clinical Trial Protocol (CTP)** is developed, which describes the background/rationale, patient eligibility, schedule of tests, procedures, medications and doses, length of the study, and scheduled visits to monitor safety and effectiveness.

An important concept at this point is **clinical equipoise**; that is, the investigators must have a state of genuine uncertainty as to whether drug or treatment "A" or drug or treatment "B" is superior in "X" population. This justifies randomization in the clinical trial as well as the establishment of a null hypothesis – that is, that both treatments or drugs have an equal chance of proving effectiveness. Equipoise must be present in all arms of the clinical trial, whether they are single arm, randomized, placebo-controlled (a sugar pill or other action that is not specific to the disease being studied) or blinded. Often when trials lose equipoise, the study must be halted, as clearly one drug/treatment has proven to be superior to the other.

A second but closely related consideration must be given to the **ethical aspects** of the study. All studies have ethical implications. Emanuel et al, in their groundbreaking article on ethics in clinical research, state seven requirements that must be part of all studies. These are: 1) **value**: clear improvement in health or knowledge must be demonstrated; 2) **scientific validity**: the study must be rigorous methodologically; 3) **fair subject selection**: the study must have clear inclusion

criteria; 4) **favourable risk/benefit**: benefits must outweigh risks; 5) **independent review**: a separate body must review the research on an ongoing basis, amend and terminate where necessary; 6) **informed consent**: the benefits and known risks to patients must be described, and researchers must get the **voluntary** consent of the patient (the Mayo Clinic's model template is an excellent example of informed consent); and 7) **respect for enrolled subjects**: privacy, opportunity to withdraw and must be well monitored. Additionally, three further principles often discussed in terms of ethics are: 1) **autonomy**: respect for persons; 2) **beneficence/nonmaleficence**: appropriate balance of harms and benefits; and 3) **justice**: burdens and benefits of research are distributed fairly.

In the United States, all clinical trials must have both an **Institutional Review Board (IRB)** which is local and hospital/university/industry based, and a **Data Safety Monitoring Board (DSMB)**. In Canada **IRBs** are often called Ethics Committees. The **DSMB** is an independent committee composed of three to 10 members. Members might be statisticians, physicians, ethicists, epidemiologists, patient advocates, and sponsor/industry representatives. They review outcome data; cumulative toxicity data and trial performance; determine whether and to whom outcome results should be released prior to the reporting of the results; review related studies; and review major proposed modifications prior to their implementation – for example, termination of the trial, dropping an arm based on toxicity results or other reported trial outcomes, increasing target sample size. Essentially, **DSMBs** are safety nets for patients participating in clinical trials. Study administrators are by law required to report **Adverse Effects (AEs)** within 24 hours of occurrence to the **DSMB**. In addition, with the increase in multi-site trials, **Central Review Boards (CRBs)** are increasingly being established in both the United States and Canada. Consumer reviewers can participate on all three.

Canadian institutions are increasingly participating in **CRBs**.

When a new cancer drug is ready to be tested in humans in the United States, the investigator must submit an **Investigational New Drug (IND)** application to the **Federal Drug Administration (FDA)**. With FDA approval, testing in humans, or **Phase I Clinical Trials**, may begin. The main purpose of Phase I is to determine **safety**. Researchers test a new drug or treatment in a small group of 20 to 40 people, not only to determine safety, but also to determine a safe dosage range, as well as any side effects. Initial clinical trials also begin to clarify what happens to a drug in the human body, such as any changes, how much of it gets into the bloodstream and various organs, how long it stays in the body (half-life), and how the body gets rid of the drug and its effects. An example would be using a modified Fibonacci progression (a mathematical formula), which would provide for dose increments until the **maximum tolerated dose (MTD)** is reached. Three to six patients are included at each dose level.

Phase II Clinical Trials have some short-term safety purposes, but the focus is on **effectiveness**. The study treatment is given to a larger group of people (30-100) to see if it is effective for a particular disease and to further evaluate its safety. An example would be a trial of drug A for patients with Stage II breast cancer. These patients would be followed for a period of time, three months, for example, when their tumours would be re-evaluated.

The purpose of **Phase III Clinical Trials** is to determine **safety, effectiveness and dosage**. The study drug or treatment is given to large groups of people (500-3,000). The goals are to confirm effectiveness, monitor side effects and compare it to commonly used treatments. An example would be a Trial of drug A versus drug B for patients with Stage III breast cancer.

In the United States, the sponsor of the new drug or treatment is usually an academic institution, hospital or a pharmaceutical or biotechnology firm. They must apply to the Federal Drug Agency for an Investigative **New Drug Application (NDA)**. The **NDA** must include all the pre-clinical data that support the application. In addition, the researchers must include a **Clinical Trial Protocol**, which describes background/rationale, patient eligibility, schedule of tests, procedures, medications, dosages, and the length of the study. It must also include scheduled visits for monitoring to determine safety and effectiveness. A new drug application also contains the following: pre-clinical studies, human clinical studies, manufacturing details, labelling and additional information such as **endpoints** and **surrogate endpoints** (how outcomes will be measured, such as **Time to Progression [TTP]**). Once an agent is approved (licensed for sale by the FDA), a range of relevant studies becomes possible. These are **Phase IV Clinical Trials (Post Market)**, which are large studies over a long time (five to 20 years). These studies are often multi-site, comparing multiple drugs.

When most cancer patients think of chemotherapy, they usually think of **cytotoxic drugs**, such as Adriamycin or Cyclophosphimide. These drugs aim to destroy tumours within the body. In fact, there is a whole range of **cytostatic** drugs, which are much more specific in their action. Of all oncology compounds in development today – about 374, all in Pre-clinical Phase III studies, cytotoxic drugs comprise 22% of studies, gene therapy 5%, vaccines 8%, supportive care 7%, monoclonal antibodies 9%, antiangiogenic 6%, hormones 6%, signalling transduction pathways 8%, others 10%, and novel agents 19%.

The main hope for the future is in the area of molecular biology, which is in the process of identifying and developing many novel therapeutic targets. Advances in drug developments are providing increasingly successful ways of inhibiting such targets. Unprecedented numbers of new agents are in clinical trials today. **Oncopharmacogenomics**, as the area is known, will measure mutations in key genes, measure expression patterns in biological systems tumour cell lines through immunochemical assays or tests, xenograft models (animal to human transplants) or anti-tumour response, and

tumour specimens from patients in prospective clinical trials. They will combine data and use computer algorithms to sort genes of interest and correlate these with outcomes. The future of the "post-genomic" anti-cancer drug discovery will hopefully lead to personalized and targeted medicines, whereby diseases will be reclassified based on biologic markers. An individual will receive a therapy tailored to his/her biologic markers. Finally, biologic markers will be used to identify disease predisposition (chemoprevention).

Progress in methodology and the philosophy of clinical trials is making the process more productive, more reliable and more beneficial for us all. The fact that a new vanguard of trained consumer advocates is now prepared to participate at all levels of the clinical trial process – the IRB, the DSMB, and actual clinical design process – increases hope that breast cancer survivor advocates will once again lead us to sit at the research table, and influence how the table is set. ■

- 1 Ezekiel J. Emanuel, D Wendler and C. Grady, "What Makes Clinical Research Ethical", JAMA, May 24/31, 2000, Vol. 283, No. 20, pp.2701-2711.
- 2 Grateful acknowledgement is given to Dr, Edith Perez of the Mayo Clinic in Jacksonville, FL for her outstanding power point presentation in preparing this document and for her mealtime clarification of many concepts.

The Canadian Breast Cancer Network

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Every Director on the CBCN Board is a breast cancer survivor

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Support CBCN's Friends Remembered Fund!

By Lynn Macdonald

In 1995, Jan Morrow died from breast cancer. Jan, who was an original member of CBCN's Board of Directors, believed strongly in the need for a national organization that would be the voice of breast cancer survivors. Her family requested in her obituary that a fund be established by CBCN to help achieve this goal. Shortly after, Leah Lovestead, a brave young woman who was also from British Columbia, succumbed to breast cancer, and her family and friends added to this fund. Subsequently, other monies have been received in memory of other talented and remarkable women whose lives have been taken by the devastating disease we know as breast cancer. There is currently about \$5,000 in this fund.

The purpose of the Friends Remembered Fund is to give something back to the breast cancer community by supporting an activity or award that fits with our mission, vision, goals and values (advocacy, education, information and linkage). However, to fund worthwhile projects, we must increase the amount of funding available.

Please consider giving to the Friends Remembered Fund in memory of a loved one or friend. Or make a donation to the Friends Remembered Fund to support the Canadian Breast Cancer Network and its work.

PLEASE HELP US REACH OUR \$25,000 GOAL!

Since 1993, Avon Canada's Sales Dealers have raised more than \$7,000,000 for Breast Cancer Research

As a company that has had women's best interests at heart for over one hundred years, Avon is tremendously proud of the way in which our Sales Dealers have made this cause their own.

In the 140 countries around the world where Avon does business, our Sales Dealers are an integral part of the communities in which they live and sell our products. Through the Flame Crusade, they have strengthened that time-honoured relationship and made an invaluable contribution to the lives of their neighbours and fellow citizens.

As one of the seven partners of the Canadian Breast Cancer Research Initiative, Avon Canada remains firmly committed to the ongoing fight against breast cancer and looks forward to the day when the result of all our efforts is an end to this deadly disease.

What's Next?

Pucker up, our next fundraising campaign comes in September!

A V O N
www.avon.ca

The NETWORK ON THE MOVE



By Jackie Manthorne, Executive Director

Rural Consultations

Since I last reported on our activities in the Summer 2001 issue of *Network News*, we have formed a partnership with the Canadian Breast Cancer Foundation Community Research Initiative (CBCFCRI) to evaluate and analyze the results of the 17 consultations held with rural women with breast cancer in 2000. The resulting report, entitled *Perspectives of Rural Women with Breast Cancer*, offers an important opportunity to increase awareness about the experiences of women living in isolated and remote communities while struggling with a breast cancer diagnosis. The report is now being used to formulate a National Strategy to better meet the information and support needs of rural women with breast cancer. This National Strategy will be implemented over several years in collaboration with CBCN's partner and member groups. If you would like to receive a copy of the report, or to partner with CBCN on this initiative, please contact Roberta Lloyd,

National Programs Coordinator, at 1-800-685-8820, ext. 221, or rlloyd@cbc.ca.

Consultations with Young Women with Breast Cancer

In the spring of 2002, CBCN held 10 focus groups in Halifax, Montréal, Toronto, Winnipeg and Vancouver with 80 young women with breast cancer to discover their information and support needs. CBCN is again partnering with the CBCFCRI to analyze the results, with the goal of creating a National Strategy to improve services to young women, which will be implemented over the next decade. If your group would like to be involved in this initiative, please contact Roberta Lloyd.

www.cbc.ca

Check out our new, improved website, with a News Section, a listserv for volunteers and staff of breast cancer organizations, and an enhanced and expanded database of breast cancer groups in Canada. Contribute to the Bulletin Boards, suggest new links, or browse through hundreds of links and other resources.

Outreach

Those of you not already receiving *Outreach* should get in touch with us to sign up for this free resource. Four to six pages in length, *Outreach* is published by CBCN every two months and is distributed in the text of an e-mail message, on our website, and by mail. It contains information on CBCN, upcoming events and conferences in the breast cancer community, and interesting websites, books, and other resources. Groups can send material for *Outreach* to Michelle Kowlessar, National Communications Coordinator, at 1-800-685-8820, ext.226, or mkowlessar@cbc.ca.

Web Pages for Canadian Breast Cancer Groups!

CBCN is providing free hosting services for web pages for Canadian breast cancer groups. If your group is interested in this service, please contact Michelle Kowlessar.

Resources for Sale at CBCN

Comfort Heart: A Personal Memoir

Comfort Heart: A Personal Memoir, by Carol Ann Cole with Anjali Kapoor, is a memoir by former CBCN Board member Carol Ann Cole, also known as the Comfort Heart Lady. The story of the Comfort Heart Initiative is as inspiring as the power of the Comfort Hearts themselves. Carol Ann was born in Annapolis Valley, NS, and eventually left for North Bay, where she was hired by Bell Canada. As she began to climb the ranks of the company in the early 1970s, she realized the obstacles that faced a single woman in the corporate world, especially a single mother. But she continued to persevere and became one of the first female vice presidents of one of the country's largest corporations. Then her world came crashing down. Within days, both Carol Ann and her mother were diagnosed with breast cancer. While Carol Ann was able to beat it, the loss of her mother later that year had a monumental impact on her life. When she walked into a pewter store and discovered the Worry Hearts, small hearts that you would rub in times of stress, she knew she had found the way to give back to the cancer community. By altering the design and renaming them Comfort Hearts, Carol Ann created the Comfort Heart Initiative that to date has raised over one million dollars for cancer research. *Comfort Heart: A Personal Memoir* is a story of determination and courage, and how you can accomplish your goals if you put your mind – and heart – to it. You can order *Comfort*



Carol Ann Cole, the Comfort Heart Lady and author of *Comfort Heart: A Personal Memoir*

Heart: A Personal Memoir from CBCN for \$17.95 plus \$5.00 shipping and handling. You can also order Comfort Hearts by calling 1-800-407-4436 or from The Comfort Heart Initiative, Box 27013, Halifax, NS B3H 4M8.

How to Ride a Dragon: Women with Breast Cancer Tell Their Stories

How to Ride a Dragon is an inspirational book for anyone who has done battle with dragons. It relates the stories of 22 women who have experienced breast cancer and have gone on to "ride the dragon" as dragon boaters. The book depicts the cancer journey as a mythic battle with the dragon – and explores what is required to slay the adversity of a life-threatening disease. Drawing from the story of Beowulf and dragon myths from east and west, the book reveals the mythic dimension of the women's deeply personal experiences with breast cancer. In the course of their disease, the survivors experienced both sides of the dragon – the dark and the light – and eventually came to peace with their wounds and losses. Those survivors who live to "ride the dragon" in dragon boating are playing out the myth of the dragon in every dragon boat race. They fight with all their might to win and then they ritually honour those who have lost the fight in the "pink flower ceremony" that follows the race. While this book focuses on the stories of breast cancer

survivors, it is a book for everyone who has met major adversity – and like the dragon boating women themselves, it generates hope. Proceeds from the sale of *How to Ride a Dragon* are being donated to the Canadian Breast Cancer Research Initiative through the Canadian Breast Cancer Foundation and the Canadian Cancer Society. This is a project of Dragons Abreast, the Toronto survivor dragon boat team, with input from fellow paddlers across the country. Order from CBCN for \$19.95 plus \$5.00 shipping and handling.

The Ottawa Folklore Centre 25th Anniversary Album

The Ottawa Folklore Centre has released a compilation CD to celebrate its 25th anniversary. The CD, produced by Ian Tamblyn, is a collection of great listening music. The album is dedicated to Terry Penner, co-owner of the Ottawa Folklore Centre and Director of the School of Music at the Folklore Centre, who died of metastatic breast cancer in November 2000. \$15.00 plus \$5.00 shipping and handling.

My Left Breast

My Left Breast, the award-winning documentary film directed by Gerry Rogers and produced by Paul Pope of Pope Productions, won two Gemini Awards for Best Documentary/History, and Best Direction in a Documentary. *My Left Breast* has garnered many awards to date,

among them Gold for Best Canadian Documentary at Hot Docs; Best Canadian Film and Best Female Director at Inside/Out, the Toronto Gay & Lesbian Film Festival; and a Silver Hugo at the Chicago International Television Festival. *My Left Breast* is a co-production of CBC Newsworld and Pope Productions. Prices for *My Left Breast* are: Individuals: \$24.95 plus \$5.00 shipping and handling. Institutions: \$99.95 plus \$5.00 shipping and handling.

A Chance for Life

A Chance for Life was written by the late Suzanne Giroux and published by ecw Press (www.ecwpress.com). Susanne, a Board member of the Canadian Breast Cancer Network and an honorary member of the Board of the Saunders Matthey Foundation for Breast Cancer Research, succumbed to breast cancer on June 10, 2001 in Cornwall, Ontario, at the age of 34. \$17.95 plus \$5.00 for shipping and handling.

Order *Comfort Heart*, *How to Ride a Dragon*, the *Ottawa Folklore Centre CD*, *My Left Breast* and *A Chance for Life* from CBCN by sending a cheque to 331 Cooper Street, Ottawa, Ontario, K2P 0G5.

You can also use your VISA by calling 1-800-685-8820 or e-mailing cbcn@cbcn.ca.



Left to right: United Parcel Service Ottawa representative presents a cheque to Jackie Manthorne, CBCN Executive Director, to cover the cost of couriating free mastectomy bras and breast prostheses across Canada.



Breast Cancer Network Nova Scotia Launched!

On the weekend of December 1st, 2001, women from across Nova Scotia met to discuss establishing a provincial breast cancer network. Over 40 women, representing the District Health Authorities (DHA) in Nova Scotia, discussed breast cancer issues that were of concern throughout the province. The majority of participants were breast cancer survivors, and many hold leading roles in support groups and other breast cancer organizations. During the weekend everyone worked to produce a map of community assets and to identify gaps and needs for each DHA. Activities to meet these needs were then discussed, and an action plan and structure for the newly formed Breast Cancer Network Nova Scotia (BCNNS) were envisioned. For more information, please contact Kathleen Barclay, (902) 465-2685, or e-mail kathleen@bca.ns.ca.

On the Road with How Can We Love You?

How Can We Love You? is the documentary story of Mary Sue Douglas and Jan Livingston, two women living with metastatic breast cancer who travelled across North America with a community theatre troupe performing the play *Handle with Care?* The documentary film, aimed at women with breast cancer, their families and health care professionals, went on the road in 2001, thanks to Transamerica Life Canada and the Ontario Trillium Foundation. *How Can We Love You?* visited 44 communities in a highly successful cross-Canada tour. *How Can We Love You?* was produced and directed by Toronto filmmaker Laura Sky. For information on the 2002 tour, visit www.laurasky.org. To book a screening or workshop, contact Sky Works at (416) 536-6581 or info@laurasky.org.



The How Can We Love You team on tour in Sudbury, Ontario.

Increasing Breast Health Awareness in Calgary Workplaces

Workplace health promotion programs are on the rise and have been shown to benefit both employees and employers, yet relatively few of these programs focus on the early detection of breast cancer. To help workplaces increase breast health awareness and promote early detection of breast cancer among their employees, the Breast Health Education Coalition of Calgary (BHECC) developed the Workplace Breast Health Education Package. This Package consists of a comprehensive resource binder called *A Gift to the Women in your Workplace and Those Who Care About Them*. It includes breast health messages, activity ideas, resource lists, sample newsletter articles, posters, and other information related to breast health education. After being pilot-tested, the Package was distributed to 38 companies in Calgary that had over 100

employees each. Contact Patricia DeWitt, Manager, Grace Women's Health Centre, Calgary Health Region, Tel.: (403) 670-2180; E-mail: Pat.Dewitt@calgaryhealthregion.ca.

Hope Air

Hope Air is a national charitable organization that arranges free air transportation for Canadians who must travel from their home communities for recognized medical care, but who cannot afford the cost of flight. In 1999, Canadian Airlines donated 7,000,000 points to the Canadian Breast Cancer Foundation (CBCF), matching the dollars raised at the annual *Run for the Cure* event. The points were designated for use by breast cancer patients who needed help with the cost of flying for medical care associated with their illness, but to date, *Hope Air* has received few calls for assistance from breast cancer patients. Contact *Hope Air*, Procter & Gamble Building, 4711 Yonge Street, North York, ON M2N 5K8; Tel.: (416) 222-6335; Toll-free 1-877-346-4673; Fax: (416) 222-6930; E-mail: corrie@hopeair.org; Website: www.hopeair.org.

Questions and Answers on Breast Cancer

The second edition of *Questions and Answers on Breast Cancer – A guide for women and their physicians* is now available. Sponsored by the Canadian Breast Cancer Research Initiative (CBCRI) and based on the Canadian Clinical Practice Guidelines for the Care and Treatment of Breast Cancer, *Questions and Answers* contains 13 guidelines, including investigation of a breast lump that can be felt and investigation of an abnormality that is discovered by mammography. Several guidelines have been revised, and there are two new guidelines: the management of persistent pain after breast cancer treatment, and the management of lymphedema related to breast cancer. Order copies of *Questions and Answers* from the Canadian Cancer Society's Cancer Information Services, 1-888-939-3333, or

from Publications Health Canada, Tunney's Pasture, Ottawa, ON K1A 0K9, tel.: (613) 954-5995, or consult them on line at <http://www.cma.ca/cmaj/vol-158/issue-3/breastqa/index.htm>. Health care professionals can consult the Clinical Practice Guidelines at <http://www.cma.ca/cmaj/vol-158/issue-3/breastcp/>.

Paddle to a Cure: Journeys of Hope

Paddle to a Cure is a Canadian kayaking expedition designed to raise funds for the Canadian Breast Cancer Foundation (CBCF) for breast cancer research, education, diagnosis and treatment. The expedition will be led by women and will promote a non-competitive, community-based learning model. There are a total of nine different Journeys of Hope – two on Lake Superior, one in the North Channel, four on Georgian Bay, and two on the West Coast. The trips take place throughout July and August, with 10 participants joining the leaders on each trip. *Paddle to a Cure: Journeys of Hope 2002* hopes to raise \$500,000. To take part, participants must collect a minimum of \$2,500 in donations. *Paddle to a Cure*, CBCF, Suite 1000, 790 Bay Street, Toronto, ON M5G 1N8, or call (416) 596-6773, ext. 544 or 1-800-387-9816, ext. 544, or e-mail elalonde@cbcf.org. You can also visit <http://www.paddletoaacure.com>.

New Resources from Breast Cancer Action Nova Scotia

Breast Cancer Action Nova Scotia (BCANS) is pleased to announce the availability of the booklets *Breast Cancer Online: In Our Own Words* and *Breast Cancer Online: How We Told Our Children, In Our Own Words, Part II*. The booklets were written and lovingly compiled by women who have "been there." Hope, wisdom and even laughter are recurring themes. Their purpose is to share the experiences of women who take part in BCANS' online discussion forum with women newly diagnosed with breast cancer. The second and newest edition recounts women's experiences in telling their children about their cancer diagnosis. Booklets are available by con-

tacting BCANS at (902) 465-2685 or by visiting their web site at <http://www.bcans.org>.

Creative Fund Raising Idea!

In the summer of 2001, CBCN Board member Catherine Mooney organized the first **Five-Mile Yard Sale for Breast Cancer** in Souris West, PEI. Everyone within a five-mile radius held their yard sales on the same day, with a \$10 fee for each household to participate. The fee paid for advertizing and for pink balloons as driveway markers. Catherine also collected donations of used goods from people who did not want to hold sales, and put up a sign in her yard explaining that the proceeds of the **Five-Mile Yard Sale** would be used to buy breast health/breast cancer books for the local library. The Sale coincided with the Bluegrass Festival, a large event in the area. **The Five-Mile Yard Sale** raised \$1,000 in just a few hours, and not only were they able to contribute books to their local library, were also able to help three other libraries. For more information, contact Catherine Mooney through CBCN.

Book Launched as Husband Turns Anguish into 180 Days of Inspiration

The Canadian Breast Cancer Foundation (CBCF) Atlantic Chapter launched the much-acclaimed *Rise & Shine* during Breast Cancer Awareness Month in October 2001. Copies of the book are available in all Lawtons Drugs Stores in Atlantic Canada, or by calling the CBCF Atlantic Chapter office (902) 422-5520, ext. 4 (or 1-866-273-2223 in Atlantic Canada). The author of the book, Wayne Fiander, painstakingly searched for inspirational quotes to help his wife Bertha Etter go through 180 days of chemotherapy after she was diagnosed with breast cancer. Bertha decided to share his gift with the world and gave the CBCF Atlantic Chapter the privilege of publishing this very private collection. *Rise & Shine* sells for \$19.99 (plus shipping) with 100% of the profits going to breast cancer research. To find out more about *Rise & Shine*, visit www.cbcf.org/atlantic.

Atlantic Breast Cancer Net (ABCN)

The Atlantic Breast Cancer Net (ABCN) is a new online resource for Atlantic Canadians. Along with a wide variety of interactive services, the site will provide breast cancer groups and organizations free web development services. The website is a repository of Atlantic Canadian breast cancer links, information and resources. The site has two unique features. The first is **The Buddy Database**, an interactive feature that will allow you to search a database for a "buddy," or someone who shares a similar diagnosis. The second is **My Mother Has Breast Cancer**, a section of the web site devoted to children and their reactions to a parent's diagnosis. Information, resources and links are available at this address as are the BCANS' booklets *Breast Cancer Online: In Our Own Words* and *Breast Cancer Online: How We Told Our Children, In Our Own Words, Part II*. Visit ABCN at <http://www.abcn.ca>.

Manitoba Breast Cancer Survivors are Making Waves all across the Province

Make Waves is a special water exercise and support program designed for women post breast surgery that has been in operation in Winnipeg at the YMCA-YWCA (downtown) and the Misericordia Health Centre since 1989. In the fall of 2001, Louise Shoenherr, an active member of Breast Cancer Action Manitoba, struck a planning committee to expand **Make Waves** to rural and northern women. With financial support from the Canadian Breast Cancer Network and the Canadian Breast Cancer Foundation and in-kind donations from other groups, training sessions for instructors were held in November 2001 and January 2002. Nineteen instructors in 14 rural/northern communities received training to provide the **Make Waves** program, and three rural areas have successfully launched programs. For more information, contact Dianne Brown, Community Liaison Coordinator, The Breast Cancer Centre of Hope, at (204) 779-8384.