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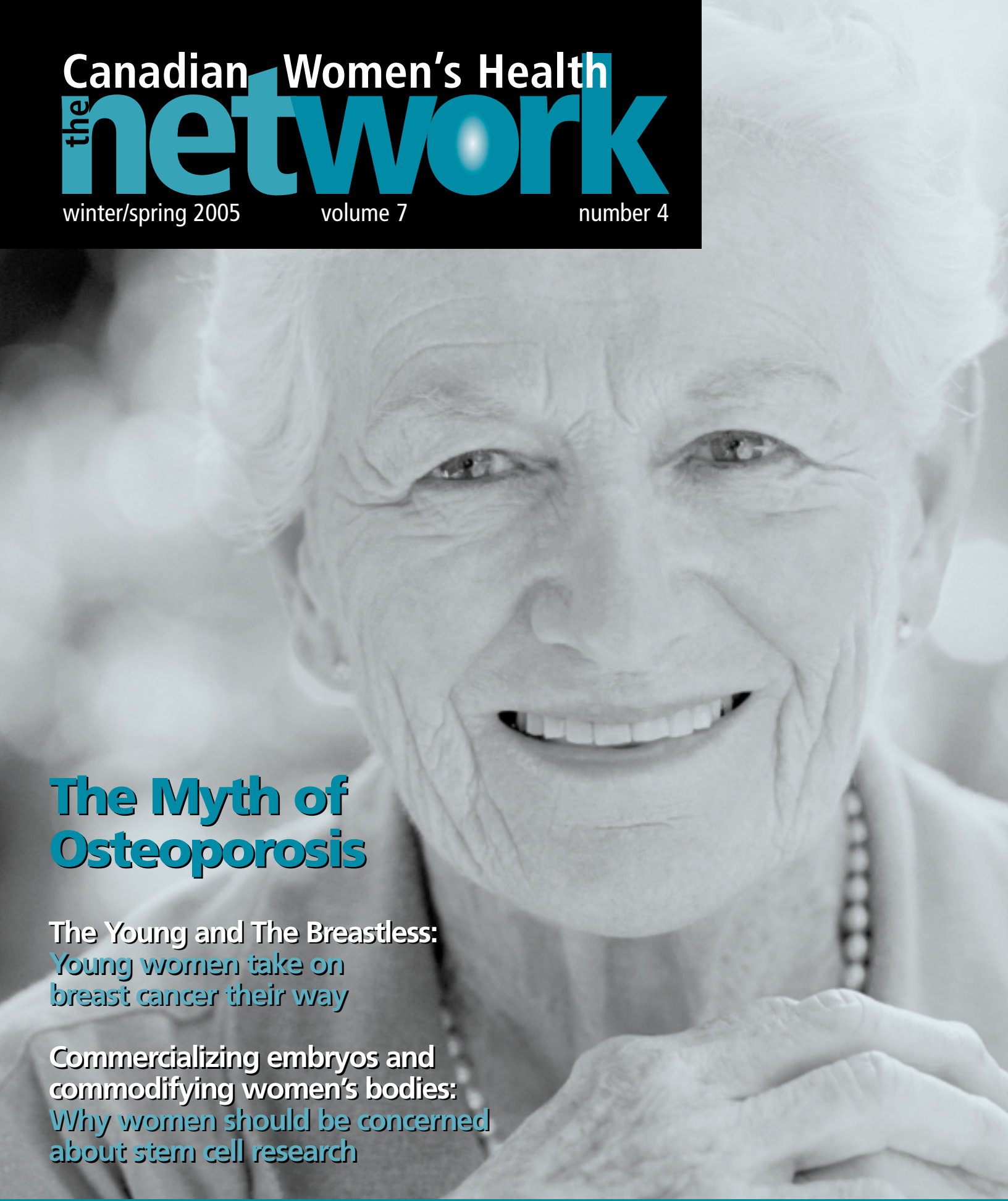

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Canadian Women's Health Network
Le Réseau canadien pour la santé des femmes

editor's note:

Thanks for having me!

For the last five months I have had the pleasure of serving as interim Director of Communications for the Canadian Women's Health Network (CWHN). It's been quite a ride. Every morning when I opened my computer, there was something new that had the potential to affect the health and well being of Canadian women. We need at least 10 times our current resources to respond to it all. And yet so much is accomplished thanks to the hard work and dedication of the women I have been working with these last few months. So I'd like to take this opportunity to acknowledge the staff, the board and the network of CWHN supporters. They are an inspiring group. Their commitment to advancing women's health and improving women's lives is formidable. It's been gratifying to be a part of the team.

Getting this magazine out has been the icing on the cake. I have learned so much from the women who produced these thoughtful and informative pieces. I want to thank them for being so generous with their time, their energy and their knowledge.

Please send us your comments, questions and concerns about this issue, and your ideas for the next. We want to hear from you. It's just one way that you can become part of the network.

Sincerely,
Gwynne Basen
Interim Director of Communications

WHAT'S INSIDE

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the YOUNG *and the* BREASTLESS

Melanie Gillis / Compliments of www.breastofcanada.com

Young women take on breast cancer their way

BY SUE RICHARDS

The woman beside me did bear a striking resemblance to celebrity Gloria Estefan, so I understood why she won the look-a-like contest. We arrived on the Sage Bistro balcony at the same time, needing fresh air. A balmy breeze, laced with sweet floral scents, carried the sound of waves washing up on Wreck Beach below. Gloria and I watch through the massive glass doors as dozens of women pack the dance floor, prancing and gyrating to the old pop favorite, "I Will Survive," arms waving madly in the air. I could have been at the Bullring or any downtown Guelph bar on a Saturday. Instead, I am in Vancouver at a breast cancer networking event called "The Young and the Breastless."

I can't say I've ever danced at a breast cancer conference before. Nor have I done yoga, art workshops or sing-a-longs. But this event is intentionally different. Created for young women, by young women, there is a freshness and vitality that honestly reflects the people whom it is designed to serve.

The multiple contests add another wacky edge and leave us all rolling in the aisles. One woman demonstrates how to improve posture by whipping out her prosthesis and placing it firmly on her head, then circling the room. Another sings the complete theme song to Green Acres with full impersonation and Broadway drama. People choke on their wine. I, too, am a contest winner thanks to a single butterscotch candy, blessed by the Dalai Lama and bequeathed to me by my yoga instructor, Jackie. The emcee excitedly declares me the recipient of the Auspicious Charm in Purse Award, after I exploded into the air like a rocket, wagging my precious candy like a flag. I am handed a martini-making kit, complete with a mickey of vodka. Should he find out, I trust that the Dalai Lama will appreciate the irony of the prize and not rescind my blessing.

Cancer conferences can be very raw events filled with heady, scientific content and an undercurrent of doom. So it is remarkable to me that we are laughing. These hundred women, ranging in age from late teens to mid-forties, are facing their own mortality with a modern-day pioneering attitude. Never before has there been a Canadian event dedicated to young women living with breast cancer. And just like life,

it's not all fun and games. The young moms, students, newly married, freshly separated, and women on the cusp of promising careers are seeking a connection and understanding so that they can continue living with some sense of joy and future. They also seek visibility in a society that prefers denial.

Acknowledging the growing incidence of breast cancer in young women is to admit that something is wrong with the world and that a groundswell of action is required.

Breast cancer has become a household word thanks to all the awareness-raising campaigns of the last dozen years. The average person recognizes breast cancer by name and nature. But the diverse range of women with breast cancer cannot be painted with one pink brush. Career trajectory, education, motherhood and relationships vary dramatically at different life stages. Throwing breast cancer into the mix at any point in time affects each of these life phases in profound and complex ways. Cultural and religious differences further complicate the ordeal. Sexual orientation adds yet another layer of intricacy to the experience.

Unlike other conferences where expert panelists discussed current medical trends while women sit, waiting to hear some good news, the Y and B organizers turn much of the stage over to the delegates. The women became the authorities of their own unique cancer process and share their stories directly with each other. The difference is profound and moving. I listen closely to the 29-year old, with three children under age nine, exhausted from treatment,

Cancer conferences can be very raw events filled with heady, scientific content and an undercurrent of doom. So it is remarkable to me that we are laughing.

Melanie Gillis / Compliments of www.breastofcanada.com

The 2005 edition of the Breast of Canada calendar is dedicated to young women. It can be ordered from www.breastofcanada.com

If you are a young woman living with breast cancer, please contact:

www.theyoungandthebreastless.ca

The organization is planning a second Young and Breastless Networking event in May 2006. Between now and then smaller scale one-day seminars and social events are in the works. If you have an event you would like to publicize, call or email them at: young_and_breastless@shaw.ca and they will publish it in the next e-News or on their website.

frustrated by her chemo-altered memory, with a supportive but equally burned-out husband. She quietly wonders what and how much to tell her kids. A single woman in her early thirties shares how she wants to date but feels terrified by the thought of revealing her disease and her missing breast. Epiphanies pop. Laughter ripples. Profanity pierces. Tears flow. Conversations focus on sex and sexuality. It is crystal clear to me that we are all part of a groundbreaking, think-and-feel tank, where both ideas and emotions are being intensely explored and will swell far beyond these walls and help thousands of people through a very challenging life experience.

Collectively, these women have found new support and they are going to nurture that support into something much bigger than themselves. My balcony companion merrily chats away, telling me the details of her Gloria Estefan look-a-like prize. Suddenly her face lights up. "Were you the woman who had her panties blessed by the Dalai Lama?" she inquires. "Panties?? You mean candy," I respond with a laugh. It seemed that Gloria's half of the room had misunderstood the emcee's excited description of my lucky butterscotch candy. Dozens of women left believing that I was carrying Dalai Lama-blessed panties in my purse! The DJ puts on "Celebration" and the song pulses from his sound system. Gloria and I join the throbbing mass of female energy on the dance floor. I am instantly smiling surrounded by all of this youthful, giddy energy. We were moving beyond pink ribbons awareness to bold, direct action.

Sue Richards lives in Guelph and publishes the Breast of Canada *calendar.*

Dr. Gabriele Helms

was born on May 15th, 1966. She was 38 years old when she died on New Year's Eve, 2004, three days after giving birth to her first child, Hana Gabriele Helms-Shore.

Gabi was an Assistant Professor of English at the University of British Columbia. She was also on the Board of Directors for the Canadian Breast Cancer Network.

I met her in October 2003, at the Canadian Breast Cancer Network's Annual General Meeting in Ottawa where she announced the plans for a new national event boldly called "The Young and The Breastless: A Networking Event for Young Women with Breast Cancer." I reacted by writing a single word in my notebook, "BRILLIANT." Then I introduced myself, showed her the Breast of Canada calendar and invited members of her support group to be models in my 2005 edition.

Gabi didn't miss a beat. Our cross-country photo shoot could not have gone more smoothly. Appropriately, on International Women's Day 2004, photos of six young women, all living with breast cancer, arrived in my mailbox. The incredible strength and beauty of the women took my breath away. These brave role models were making young women with breast cancer more visible.

I flew to Vancouver for "The Young and The Breastless" event last spring. After a warm reception, I watched and listened to Gabi as she spoke with confidence and tremendous grace, her vivacious energy setting the pace for this groundbreaking event. I remarked to "Dr. Helms" how I wished I was her student. Her compassion, courage and enthusiasm for life inspired me to no end. Leaders of such quality are in short supply in our world today.

The conference ended on May 15th, Gabi's birthday. I sang her well wishes with unrestrained gusto, as did the rest of the delegates. Tears streamed down my face, the kind of tears that come when my heart opens and I know that my soul is being touched by something rare and beautiful.

She was a daughter, a sister, a wife, a lover, a friend, a mother and an activist—taken far too young by breast cancer.

The family welcomes donations made in Gabi's memory to the BC Cancer Agency, www.bccancer.bc.ca

~ Sue Richards

The Myth of Osteoporosis

BY GILLIAN SANSON

When my friend Ann turned 45 she went for a bone densitometry scan. She is one of the healthiest women I know, but because she is small-framed her doctor recommended it. As she slid off the radiology table she was warned that she had "decreased bone density" and that by the time she is 80 she could be in "big trouble." Until that point, Ann had thought osteoporosis was a rare disease suffered by stooped elderly women who hadn't had enough calcium and vitamin D when they were children. Suddenly she was worrying about falling and splintering and wondering if she should take more care when she exercised. It never occurred to Ann to question the diagnosis or to wonder why osteoporosis is now more widespread than breast cancer, AIDS and heart disease combined.

A new epidemic?

Alarming fracture statistics, persuasive advertising, and conscientious physicians are directing millions of the world's "worried well" to osteoporosis testing and on to preventive medication. We are assured the tests are accurate and the drugs on offer are safe and effective, but we need to take a more critical look.

The statistics are certainly shocking. The Osteoporosis Society of Canada states that one in four (25%) women and one in eight men over the age of 50 has osteoporosis. The US Osteoporosis Foundation claims that half of all American citizens older than 50 will have an osteoporosis-related fracture, that at least 34 million individuals have the osteoporosis precursor "osteopenia" (low bone density), and that 20% of hip fracture victims will die within a year of the event. Yet, the Mayo Clinic says about 21% of postmenopausal women have osteoporosis and only about 16% have had a fracture, thus revealing widely diverging "absolutes" in the osteoporosis message.

A diagnosis of osteoporosis or osteopenia is a very frightening thing and there is little information available to help the consumer distinguish fact from hype before embarking on long-term drug regimes. Most of us are unaware that until it was re-defined as a measure of low bone mineral density (BMD) in 1994, osteoporosis was considered an uncommon disease of fragile bones afflicting mainly the very elderly. Everyone naturally loses bone density as they age, but the new definition does not account for that. The standard reference norm on the bone density machines is that of a young woman, making it almost impossible for an older person to have a normal diagnosis. The test categorises the disease from a single risk factor, yet it reveals nothing about the strength, micro-architecture, rate of remodelling,

size or shape of bone—all factors that contribute to bone fragility.

Although extensive reviews of the evidence by independent academic organizations in Canada, the US, Sweden, Australia and the UK conclude that BMD testing does not accurately identify those people who will go on to fracture their bones, the new definition of osteoporosis as a widespread disease remains. In reality, the vast majority of the population never break their bones. Remarkably, an examination of the effectiveness of BMD screening by the University of Leeds found that people with higher bone density go on to have 63% of all fractures! All bones are designed to break when struck in a particular way. Low or high bone density makes so little difference that it is simply not worth measuring.

Most people under the age of 80 remain unaware that they have osteoporosis because it has no symptoms. Some 12% of women aged 50-79 experience spinal compression (vertebral fractures) but the majority are unaware of the fact. A small percentage do have symptoms, from which most make a full recovery. In the reassuring words of Californian osteoporosis expert Dr. Bruce Ettinger: "the osteoporosis that causes pain and disability is a very rare disease."

Debilitating hip fractures in the elderly are most likely to occur not as a result of low bone density, but because of dangerous home environments, immobility, dementia, medication such as corticosteroids, poly-pharmacy (effects of taking multiple medications), low levels of vitamin D, and existing conditions, such as hyperthyroidism, Crohn's disease and celiac disease. In other words, the older a person is, or the more unwell they are, the greater the risk of falling and breaking a hip.

Television ads, magazine articles, and fact sheets in doctors' waiting rooms greatly exaggerate the impact that osteoporosis can have on our lives. Even experts agree. Dr. Mark Helfand is a member of the US National Institutes of Health osteoporosis consensus panel. In his opinion, "I think even people who agree that osteoporosis is a serious health problem can still say it is being hyped. Most of what you could do to prevent osteoporosis later in life has nothing to do with getting a test or taking a drug."

A new "disease"—new "treatments"

The 1994 re-definition spawned a global "osteoporosis-preventing" juggernaut involving the pharmaceutical, bone density testing, dairy and calcium industries—the issue of fragile bones largely overlooked in the push to identify and influence bone density loss. Hormone therapy (HT) was the "gold standard" treatment for decades, with its bone mineral density maintenance effects seen as a side benefit of its main purported benefits of heart disease and stroke reduction. HT is now deemed too dangerous for long-term use because of breast cancer, stroke and heart attack risks. Other osteoporosis "preventing" drugs, in particular the bisphosphonates, Fosamax and Actonel, have been available for a decade and are increasingly popular following the demise of HT. But have they in turn been properly tested for safety and effectiveness?

"Most of what you could do to prevent osteoporosis later in life has nothing to do with getting a test or taking a drug."

Bisphosphonates are a potent class of drug that suppress bone remodelling or turnover. They are known as anti-resorptive treatments because they inhibit the action of the cells that are constantly breaking down or reabsorbing old bone. The cells that re-build bone are not initially affected so there is often an increase of bone density for the first year of use, then this slows or plateaus as remodelling stops.

Sales of bisphosphonates have reached unprecedented levels worldwide. Fosamax sales have rocketed from US$1 billion in 2000 to $2.7 billion in 2003. Meanwhile, the mechanics and effects of bisphosphonates are still not fully understood and many experts warn caution in prescribing, saying that more needs to be known about the long-term effects of slowing or halting bone turnover. Although treated bone can become more dense or mineralized, when remodelling doesn't occur, there are concerns it may become more brittle and prone to micro-fracture. Increased bone mineralization has been shown to increase micro-fracturing in animal studies. Bisphosphonates are long-acting and known to stay in the body indefinitely (in excess of 10 years), thus continuing their effect—for better or worse. It is considered unethical to study this medication in pregnant women or women who might become pregnant while the bisphosphonate is still in the bones.

Bisphosphonates can have very serious gastro-intestinal side-effects and are unpleasant to take. For all that,

they offer only marginal or very modest benefit. Fosamax may reduce hip fractures by just one percent (although even this is disputed). In real terms, this means that 90 at-risk women would need to be treated for three years to prevent one hip fracture in one of them. The remaining 89 would receive no benefit. It is estimated that hundreds of women aged 50 years with low bone density would need to be treated for more than three years to prevent one hip fracture in one of the groups.

Leading osteoporosis authority Professor Ego Seeman of the University of Melbourne, Australia, poses the question:

> Should we expose huge numbers of these women [age 50 and with low bone density] to a drug, its costs, inconveniences, side-effects, when most will not sustain a fracture had no treatment been given? That is, most who take the drug will be exposed to the risk of side-effects and costs and receive no benefit…This is the nature of preventive medicine; we have to treat large numbers to avert events in few. This is why the drugs we use must be safe—because most exposed do not benefit, and even a small number of adverse events can tip the balance of net benefit to net harm (www.medscape.com/viewarticle/443214).

Although a recent study showed that bone mineral density continued to increase with up to 10 years of Fosamax use, it is not clear that this means a reduction in fracture. Another recent study found that osteonecrosis (bone death) of the jaw following dental procedures is a new complication of bisphosphonate therapy. Dr. Ego Seeman warns, "We still need to answer the following question: Do drugs that suppress bone remodelling reduce or increase the risk of fracture in the long term?"

Unanticipated risks can surface long after a drug has been approved, as illustrated by the serious risks now associated with Hormone Therapy.

These days osteoporosis is no longer just a "women's disease." But the rush to provide costly and risky medical solutions for low bone density in large populations of healthy men and women who may never suffer from the disease draws attention away from the very important issues of preventing falls in the elderly and diagnosing genuine sufferers.

Alternative approaches

For most people it seems that a reasonably nutritious diet, healthy lifestyle and regular exercise are sufficient protection against future fracture. Since her diagnosis, my friend Ann has concluded that by staying informed, and keeping healthy and fit, she is doing everything she can to avert fracture when she is older.

What you can do:

- Educate yourself about bone health. Understand that a diagnosis of low bone density (osteopenia) or even osteoporosis is not sufficient reason to embark on a treatment regime. There are many other risk factors for osteoporosis, most importantly age, previous fracture and smoking, as well as prescription drug use such as corticosteroids and benzodiazepines. In fact, stopping drugs that increase risk of falls such as sedatives and hypnotics is likely a safer and more effective strategy than adding a drug that simply increases bone density. Your doctor can test you for secondary causes of osteoporosis.
- Make sure your diet covers the diverse nutritional needs of bone. Including calcium, magnesium, vitamin K, boron, manganese, zinc, copper, silicon and other nutrients is ideal. Fresh vegetables, fruits, nuts and seeds are good sources of these nutrients. Limit heavy protein and salt intake, reduce alcohol, don't smoke, and for essential vitamin D, get sunlight on your skin at safe times of the day. Note: too much supplemental calcium can be harmful and there is inadequate evidence that dairy foods protect against fracture.
- Exercise often! The force of muscles pulling against bone stimulates bone remodelling and formation. Higher impact activities like running, jumping and jogging are very effective, but regular aerobic exercise such as walking is also beneficial. Weight bearing exercises, resistance training, and flexibility and balancing exercises like Pilates, Tai Chi and yoga are also important. Research has demonstrated that we can benefit from exercise at any age—even centenarians will experience an increase in strength, stamina and muscle mass. Exercise programs have been found to reduce the frequency of falls in high-risk older people.
- Don't rush into taking drugs that may influence bone density but at present have little known benefit in terms of reducing fractures.

Gillian Sanson is the author of The Myth of Osteoporosis *(MCD Century Publications 2003).*
For more information visit her website at www.gilliansanson.com

For additional information on osteoporosis please visit www.cwhn.ca

SAME TUNE, DIFFERENT LYRICS
The Vioxx Story

BY ANNE ROCHON FORD
with Women and Health Protection

"Consumers should not have to second-guess the safety of what's in their medicine cabinet."

~ US Senator Charles Grassley, R-Iowa at the Congressional hearings on Vioxx, November 2004

After a quick survey of prescription drugs currently on the market, a visitor to planet Earth might well ask, "Don't these people ever learn from past mistakes?" They would be referring to the disturbing number of drugs that are approved for use and later withdrawn, or continue to be sold with warnings attached to them, long after "enough" harm has been done to the hapless scores who have been swallowing them.

Consider this sorry list. And while all of these treatments or products were found to have serious side-effects, not all of them were actually removed from the market:

- **Hormone Replacement Therapy**, prescribed to millions of women world-wide for the relief of menopausal symptoms and a reduction in the risk of bone fractures and cardiovascular disease, found in 2002 to increase the risk of heart disease, strokes, invasive breast cancer and blood clots.
- **Selective Serotonin Re-uptake Inhibitors (SSRIs)**, a class of anti-depressant drugs, where some of the most widely prescribed were later discovered to raise the risk of suicidal thinking and suicide attempts in teenagers.
- **Baycol**, a cholesterol-lowering drug (statin) manufactured by Bayer AG, withdrawn from the market in 2000 after some patients using it developed a severe and sometimes fatal muscle disorder.
- **Depo-Provera**, an injectable contraceptive drug given a black box warning label (a warning reserved for the most serious side-effects) by the United States Food and Drug Administration in November 2004 after studies showed serious loss of bone mineral density in young women, a concern raised by women's health advocates in the early 1980s.
- **Vioxx** (rofecoxib), a popular pain-killer for arthritis, withdrawn from the market internationally in September 2004 after studies showed an increased risk of heart attacks and strokes in users.

For women in particular, this list is even longer. Drugs and devices such as thalidomide, DES, the Dalkon Shield I.U.D. and the Meme breast implant have all been found to cause serious (and on-going) problems long after they had been unleashed on an unsuspecting public.

Both these recent and past examples point to serious flaws in our drug approval process and to an even greater problem with the surveillance of drugs once they have ▶

The Vioxx Story

been approved and are on the market.

The case of Vioxx is a stellar example of how warning signs of possible harm may be ignored, minimized or covered up, even when serious problems were revealed in the early stages of clinical trials. Despite the fact that studies from as early as 1999 showed the drug was dangerous (see side-bar, testimony by David Graham of the US Federal Drug Agency), sales of Vioxx were pushed by one of the heaviest direct-to-public marketing campaigns ever seen in the US, with a significant spill-over effect in Canada.

While Graham's testimony refers to the approval of Vioxx in the United States, the situation here in Canada is equally problematic; the federal government also knew of problems long before a decision to withdraw the drug from the market was made. In fact, research conducted by the Institute for Clinical and Evaluative Studies in Ontario found as early as 2001 that there were serious problems with the drug (*The Lancet*, 364, Dec 4, 2004: 2021-2029).

The flaws in the current drug regulatory system in Canada were highlighted in a report of the all-party Parliamentary Standing Committee on Health in early 2004. In "Opening the Medicine Cabinet: First Report on Health Aspects of Prescription Drug Use," the Committee recommended sweeping changes in the drug approval system. Their report focused on problems with secrecy on the part of Health Canada and was critical of their practice of allowing drug companies to maintain complete control over the data from clinical trials. The Committee also expressed concerns about the impact of direct-to-consumer advertising of prescription drugs and the weaknesses in adverse drug reaction reporting—all factors that contributed to the delay in withdrawing Vioxx.

Do we have any reason to be hopeful that things are changing for the better and that we will see a reduction in the approval of drugs that do more harm than good? The picture is mixed.

Some observers cite the intense focus on rapid approval for new drugs, in evidence in the US since the mid-1990s, as a major contributor to the present problematic situation. This same shift, whereby the regulator is more likely to bow to the economic interests of the drug companies than to protect the safety of the consumer, has also been happening in Canada. This was evident in the Throne Speech of 2002 (and the subsequent 2003 Federal Budget) which called for speedier approval of drugs without a comparable emphasis on post-approval safety surveillance.

On the positive side is the Parliamentary Standing Committee on Health report that questioned this fast tracking of drugs. The report was an important wake-up call. The Vioxx scandal is another. Health Minister Dosanjh calling for mandatory reporting of adverse drug reactions by health professionals in December 2004 is another small step forward. But there are many important changes that are still needed before we have a system that puts the health protection of consumers above all other imperatives and ensures that the drugs women take have more benefits than harms.

To see the Canadian all-party Parliamentary Standing Committee on Health report, "Opening the Medicine Cabinet: First Report on Health Aspects of Prescription Drug Use" (2004), visit www.parl.gc.ca/InfocomDoc/Documents/37/3/parlbus/commbus/house/reports/healrp01-e.htm

For more from Women and Health Protection, *visit: www.whp-apsf.ca*

From David Graham's testimony to the US Congressional hearings on Vioxx (Graham is the Associate Director for Science and Medicine in the US Food and Drug Administration, Office of Drug Safety):

Prior to approval of Vioxx, a study was performed by Merck named 090. This study found nearly a 7-fold increase in heart attack risk with low dose Vioxx. The labeling at approval said nothing about heart attack risks. In November 2000, another Merck clinical trial named VIGOR found a 5-fold increase in heart attack risk with high-dose Vioxx.

The company said the drug was safe and that the comparison drug naproxen, was protective. In 2002, a large epidemiologic study reported a 2-fold increase in heart attack risk with high-dose Vioxx and another study reported that naproxen did not affect heart attack risk. About 18 months after the VIGOR results were published, the FDA made a labeling change about heart attack risk with high-dose Vioxx, but did not place this in the "Warnings" section. Also, it did not ban the high-dose formulation and its use. I believe such a ban should have been implemented.

…The [drug approval] culture is dominated by a world-view that believes only randomized clinical trials provide useful and actionable information and that postmarketing safety is an afterthought. This culture also views the pharmaceutical industry it is supposed to regulate as its client, over-values the benefits of the drugs it approves and seriously under-values, disregards and disrespects drug safety.

The Morning After

Emergency Contraception Access in Quebec

BY NATHALIE PARENT

with the Fédération du Québec pour le planning des naissances

As of December 2001, women in Quebec can purchase emergency oral contraception (EOC) medication at a pharmacy without a prescription from a doctor, but only after a compulsory consultation with a pharmacist.

Negotiations between the pharmacists and the government over who would pay for this service dragged on for nearly two years. During this time women themselves had to pay for the consultation.

Finally, in December 2003, the government signed an agreement with the Association québécoise des pharmaciens propriétaires du Québec (Quebec Association of Pharmacists) that the Régie de l'assurance maladie du Québec (Quebec Health Insurance Board) would cover the costs of the EOC consultation. For any woman with a valid Quebec healthcare card this obligatory consultation would be free of charge.

A Little Known Agreement

Last spring, three months after the agreement came into effect, the Fédération du Québec pour le planning des naissances (FQPN) learned that many pharmacists in Quebec either did not know about the new arrangement or were choosing not to honour it. They were continuing to charge a $10 to $30 consultation fee directly to women seeking emergency contraception. In fact, after making several calls to pharmacies in the Montreal and Sherbrooke regions, we discovered that there was enormous confusion surrounding the terms of the agreement and that very few pharmacists were accurately applying it.

The FQPN contacted both the Régie de l'assurance maladie du Québec and the Association québécoise des pharmaciens propriétaires du Québec. The Association responded by sending a memo to its members reminding them that the EOC consultation was now available free of charge for all women in Quebec.

But even after this letter was sent out, members of the FQPN learnt that some pharmacists were still charging consultation fees. Something had to be done and so we asked our members for assistance in conducting a province-wide inquiry into the situation.

What We Learned

With the help of our members we telephoned 54 pharmacies in 27 cities in 11 regions in Quebec. The pharmacists were asked the following questions: How much does EOC cost? Do you, as a pharmacy, charge a consultation fee? If so, how much? Is the consultation carried out in privacy? And what do you see as the purpose of the consultation? The women conducting the survey also made note of the type of reception and the quality of the information they received.

Out of 54 pharmacies contacted during September and October 2004, 10 pharmacies, 19%, were making women pay for the consultation. That meant that almost one out of five pharmacists were not respecting the right of a woman to have this service free of charge. The fees charged varied between $10 and $25. Some pharmacists believed that the insurance companies would reimburse them; others thought that payment depended on a woman's drug insurance plan. Some believed that the consultation was free only with a doctor's prescription. Others knew absolutely nothing about the agreement. During our calls, some pharmacists checked up on the information we gave them. One even called the Régie de l'assurance maladie du Québec, and ended up apologizing to us when he confirmed that the consultations should, indeed, be free.

The great majority of pharmacists assured us that consultations were held in privacy and most reported having office space for this purpose. But that wasn't always the case. One respondent ▶

in the Eastern Townships said he did hold his consultations at the counter, but first made sure there were few people around. A pharmacist in Charlesbourg mentioned that she would consult with a client away from the counter if she felt her client was uncomfortable otherwise. Another said he spoke to women in his office if sexual abuse was involved. Two pharmacists said that they had no place at all for a private consultation.

The most commonly prescribed emergency contraceptive pill in Quebec is Plan B. A progesterone-only pill, Plan B has far fewer side-effects than Ovral, the other leading emergency contraceptive medication. The price of Plan B varies between $20 and $29.99. Ovral involves taking four tablets of high-dose estrogen and progesterone and costs $5 to $25. All insurance plans reimburse the costs of EOC and the final amount paid by a woman will vary, based on her plan. EOC is completely free for women 18 years old or younger, and for full-time students under 25 years of age.

When asked about the purpose of the consultation, the answers the pharmacists gave us were quite varied. Some said they asked for the date of the women's last menstrual period to confirm that there was a real risk of pregnancy. Others said they used the consultation to determine the best method of EOC and to explain the side-effects. Still others wanted to discuss the woman's overall health and explain any possible side-effects. One pharmacist even talked about checking a woman's vital signs, which surprised us since Plan B has no risks associated with it.

Many of the pharmacists said that they used the consultation to inquire about the possible risk of sexually transmitted diseases. Some questioned women to find out if there was any sexual abuse involved so they could refer them to the appropriate resources. Others used the consultation to talk about contraception. A pharmacy in Asbestos had clients fill in a questionnaire that could take 10-15 minutes to complete. That was somewhat excessive we felt.

The final results of our inquiries are quite troubling. Too many pharmacies do not respect the fact that EOC-related services are free. The FQPN will contact the Association québécoise des pharmaciens propriétaires du Québec as well as the Régie de l'assurance maladie du Québec to demand changes to the current situation. Along with the Coalition pour la santé sexuelle et reproductive (Coalition for Sexual and Reproductive Health), we are considering other demands, the most important being that EOC be sold as an over-the-counter drug, with no requirement to consult with a pharmacist.

EOC Over The Counter

The FQPN supports the position taken by the Canadian Women's Health Network (CWHN) that would see over-the-counter sales of EOCs. We believe that forcing a woman to consult with a pharmacist creates an absolutely unnecessary obstacle to obtaining EOC. In the case of women who live in small communities, it can also mean a serious invasion of privacy.

The CWHN has stated that there is no medical argument to justify a mandatory consultation with a healthcare professional before obtaining emergency contraception. The World Health Organization has declared Plan B risk-free and not requiring a physical examination. The United Kingdom, Norway, Sweden, Finland, Israel, France, Belgium, Denmark, Morocco and Portugal already offer Plan B over the counter.

In their instruction manual on EOCs, the Quebec Order of Pharmacists states that "there is no absolute medical contra-indication for using EOC" (pg. 23). "The risks for its use are non-existent and any side-effects are reversible without serious consequences" (pg. 24). It also mentions that there are many benefits to using EOC, since it is fast, short term, non-invasive and has a high success rate. Lastly, it specifies that any questions asked by the pharmacist "should be limited to ones that will allow him or her to evaluate the need for taking an EOC or the possibility of an existing pregnancy" (pg. 27).

The FQPN and the CWHN believe that women, given the appropriate information, can decide for themselves if EOC is right for their situation. Without a mandatory consultation, access to EOC, which has been proven to be a safe and effective drug to prevent unwanted pregnancies, would greatly improve.

More Accessible, But More Expensive?

The one disadvantage of selling EOC as an over-the-counter drug is that it would no longer be covered by drug insurance plans and women would have to pay the full price. The FQPN intends to take steps to ensure that the drug remains free of charge for certain groups of women, such as young people, even if sold over the counter. One solution would be establishing distribution centres where EOCs could be provided at a wholesale price or free. It is clear that there is still much that remains to be done.

Reprinted from À notre santé …sexuelle et reproductive*, the newsletter of the Fédération du Québec pour le planning des naissances, www.fqpn.qc.ca*

For more information on emergency oral contraception and the position of the Canadian Women's Health Network visit our website at: www.cwhn.ca/resources/cwhn/ec.html

commercializing EMBRYOS and commodifying WOMEN'S BODIES

Why women should be concerned about stem cell research

BY ABBY LIPPMAN
with the Canadian Women's Health Network

An end to chronic disease. Treatments individualized for your injured body parts. Lifespans extending beyond 120 years—or longer. Sounds like the claims of some 21st Century snake oil salesperson, doesn't it? In fact, these are just some of the miracles being promised by scientists and politicians seeking to gain support for embryo stem cell cloning research. And in case medical marvels don't convince us that this research "MUST" be done, we are also told how the products of this work will lead to untold economic growth of the economy.

Separating fact from fiction

All this hype and more was in evidence in recent months, with stem cell research becoming a headline grabbing topic during the recent American elections. It was propelled by Proposition 71, on the ballot in California as part of the November 2004 US presidential election. Proposition 71 sought and won voters' support for a multi-billion dollar public expenditure to underwrite embryonic stem cell and embryo cloning work in both public and private research facilities. The bill opens the door for biotech companies to become enormously wealthy using public dollars, with no guarantees that any therapies that might be developed would be truly accessible to citizens. The proposition passed (about 60% for, 40% against) despite opposition from feminist and social justice groups and individuals, including the California Nurses Association, the Boston Women's Health Book Collective/*Our Bodies Ourselves*, the National Women's Health Network, and an ad hoc coalition called Pro-Choice Alliance Against Proposition 71.

The topic didn't escape attention in Canada. Many in this country, including the Canadian Women's Health Network, joined with feminist, social justice and human rights critics in the US to try and defeat Proposition 71. The *Globe and Mail*, on the other hand, took up the cause for research cloning. It regularly ran unsigned editorials warning that Canada will either fall behind in research, lose our scientists to the lure of lucre south of ▶

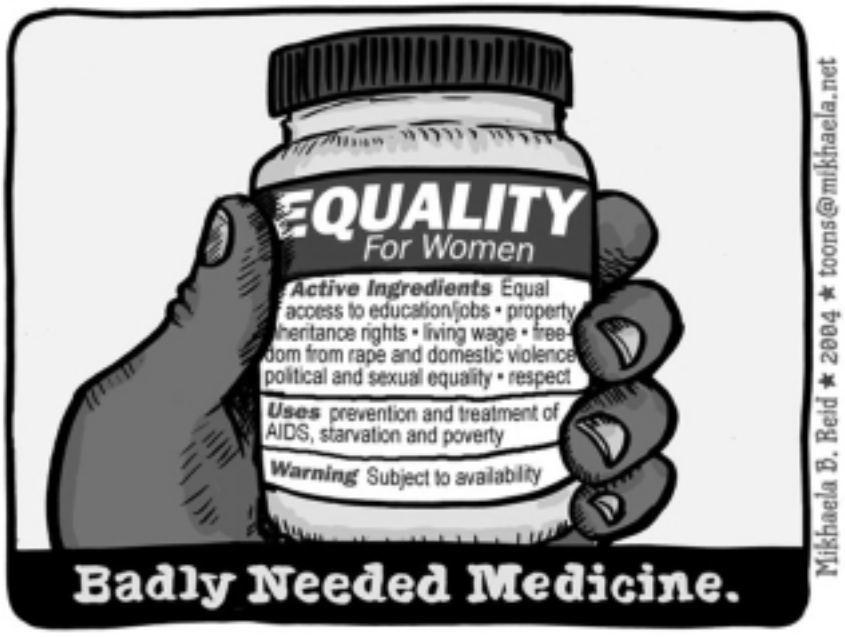
the border, fail to provide "cures" to just about every ailment we may develop, or all of the above if we don't get on with research cloning in this country.

So what's going on here? Is embryo stem cell research really the most important health issue or medical technology facing North America these days? The golden ring we must be sure to grab? Why are feminists seeming to take a position most often associated with the religious right? And is embryo stem cell research an issue for women in Canada to address?

Legislating limits

Stem cells come from a variety of sources, but the ones that cause the most debate are those from embryos. More precisely, from embryos created via cloning techniques. At the present time, Canada has legislation (*An Act Respecting Assisted Human Reproduction and Related Research* (AHR Act), passed March 29, 2004) that prohibits the creation of embryos for research purposes. It also bans all cloning, for either research or reproductive purposes. This same legislation will eventually put into place a regulatory agency that will be empowered to oversee how embryos created in in-vitro fertilization programs, but not implanted, are managed. If the donors of the egg and sperm used to create these embryos give their informed consent, some of these embryos, and the stem cells derived directly from them, may be used for research purposes. This is an activity that the AHR Act allows—and that most feminists and social justice activists accept. Fundamental understandings of biology and of disease processes—perhaps someday, even cures—can come from research that uses cells from these embryos.

The AHR legislation now in place allows Canadian researchers to study umbilical cord cells, adult stem cells, and other material that may someday provide treatments and cures. This material offers more than enough challenges and potential rewards to keep scientists in Canada productively working without any need to emigrate to California, as the *Globe and Mail* implies may happen. The AHR Act is a well-founded piece of legislation concerned with protecting the health of women and children in Canada. Moreover, the research doors opened by the AHR Act attempt to take human rights and social justice for women seriously, thanks to the efforts of women and groups who repeatedly called attention to these concerns whenever the "new" reproductive technologies were discussed during the past two decades. It was the absence of any such attention to the health and safety of women in Proposition 71 that generated much of the feminist opposition to it. Those same concerns fuel feminist objections to research cloning here in Canada.



What are the risks to women?

Feminists and other critics of an open door to embryo stem cell research share a number of concerns regarding the impact of the research on women. Research cloning—what Californians will now be paying for and what Canada prohibits—currently requires treating thousands of young women hormonally with powerful drugs in order to obtain their eggs, eggs that are the necessary "ingredient" in all embryo stem cell cloning approaches. These drugs have both known and unknown harmful side-effects. In fact, the most commonly used drug, Lupron (used primarily for women with endometriosis and men with prostate cancer), has never been approved for the purpose of "harvesting" eggs, and has a questionable safety record.

For example, in the one published research study on cloned embryos to date, 176 human eggs produced just one embryo. Thus, if a researcher wants to study (as one said he did) cell death in Parkinson's disease, and if he would need (as he said he did) multiple embryos to do so, it could involve exposing many

thousands of women to unknown risks to obtain the needed eggs.

If we then think about ALL of the researchers who want to study just this disease, and then about the many other diseases thought to be embryo-stem-cell responsive that others want to investigate, it becomes apparent why so many women's health activists oppose cloning.

Feminists and social justice advocates are concerned with the rights of these women: can they give truly informed consent for this research if the health risks from treatment to obtain eggs are unknown? As well, there exists a strong possibility of coercion (by offers of large amounts of money) and commercialization (creating a market in eggs). Even if a "safe(r)" way of obtaining eggs were developed than the methods currently used, serious concerns would still remain, since this could paradoxically lead to turning women who provide their eggs into "workers" in a booming industry.

In much of the discussion about research cloning to create embryo stem cells, this focus on women is lost. Rather, proponents are portrayed as caring saviors of the sick, while opponents are all squeezed together and labeled "pro-life," leaving the impression that a clash of values about the moral status of the embryo is the root of all differences. (In California in November, the discussion was also often reduced to an anti- vs. pro-Bush split.) But this manipulation of what is a badly needed democratic debate hides some important ethical and health concerns about the responsible use of powerful new technologies and about the best use of public funds for health promotion and disease prevention. And perhaps for Canadians, at the top of this list of concerns is the need for explicit and thoughtful attention to women's roles.

Keeping the focus on women

Debates over embryo stem cell research and research cloning are likely to heat up over the next 2-3 years as Health Canada holds consultations across the country to help it develop the details about permissible practices laid out in the AHR Act. It will be important that this debate not be hijacked into one that focuses on the status of the embryo or into setting up artificial pro-research/anti-science divides. The focus must remain on women. And women need to become engaged in this discussion.

Today, women in Canada are fortunate to have the AHR Act between them and the many with financial interests in research cloning and the creation of embryos for research purposes. But to remain protected, women—individuals and groups—will have to mobilize. The passage of Proposition 71 in California, and the rapid introduction of similar legislation in many American states since then, suggest that the prohibitions in the AHR Act will be under increasing attack in Canada as researchers and others try to find places on the stem cell/cloning bandwagon. We need to remain active not only to ensure that the agency the government will be putting in place to oversee future developments in assisted reproductive technologies is transparent, accountable, and licenses only those activities that are of proven safety and effectiveness, but that when the Act is reviewed—as it must be in about three years—the protections for women and children remain firm.

Let's avoid snake-oil promises, protect women's health, and stick with exploring stem cells from adults and from embryos already in in-vitro fertilization clinics not used for reproduction.

Abby Lippman is the co-chair of the Canadian Women's Health Network and Professor of Epidemiology, McGill University.

For more information on the Assisted Human Reproduction Act *please visit www.cwhn.ca/resources/cwhn/billc6.html*

What are embryo stem cells?

Embryo stem cells are unspecialized cells that can become any cell type in the body and generate new cells and tissues. The stem cells are harvested from blastocysts, the growing group of cells that develops several days after an egg is fertilized.

What is embryo cloning?

The usual procedure for cloning—whether for research or for reproduction—involves what is called somatic cell nuclear transfer (SCNT). This is the procedure that was used in creating Dolly the sheep. In SCNT, the nucleus, which contains most of a cell's genetic information (DNA), is removed from an unfertilized egg cell. The nucleus from a body cell (any cell, from any person) is then introduced into this egg cell, which is then stimulated to start dividing. The resulting cells are the embryo stem cells that can be used for research, and they will contain the genetic material (DNA) from the donor of the body cell. If they come from a person with some disease, researchers then have a supply of material with which to study this condition.

WHAT WE'RE READING & WATCHING | recommended resources from our library

From Barbara Bourrier-LaCroix, Information Centre Coordinator

Surviving on Hope is Not Enough: Women's Health, Poverty, Justice and Income Support in Manitoba

Rhonda Wiebe and Paula Keirstead (Prairie Women's Health Centre of Excellence, 2004)
Available online at www.cewh-cesf.ca/PDF/pwhce/survivingOnHope.pdf
Large print: www.cewh-cesf.ca/PDF/pwhce/survivingOnHopeLP.pdf

If you are poor you are likely to experience more illness and have a shorter life expectancy than someone with a higher income. Women, especially women with disabilities, Aboriginal women and single mothers are more likely than men to live in poverty. Do publicly funded income support programs reduce poverty and improve health? How do women who rely on these programs experience them? The authors try to answer these questions by examining women's experiences with these programs as well as their access to the justice system. The authors' recommendations for change are based on the experiences of the women they interviewed and will be of particular interest to community workers and activists.

Women, Peace and Security

Sheri Gibbings (Canadian Research Institute for the Advancement of Women, 2004)

Since September 11, 2001, national security has been defined in terms of the threat posed by terrorism. But who and what are genuine threats to our security? The Canadian government has responded to these perceived threats by spending more on defence, diverting money away from important social programs, making life more difficult for the poor. The authors of this fact sheet make the case that women are at particular risk. They are more likely to experience poverty, and the chauvinistic and violent culture that is often allowed to flourish in the military, leading to increased attacks on women as well as on visible minorities or racialized groups.

First Stage Trauma Treatment: A Guide for Mental Health Professionals Working with Women

Lori Haskell (Centre for Addiction and Mental Health, 2003)

Many women seeking treatment for depression, chronic anxiety, substance-use problems, difficult or abusive relationships and self-inflicted harm are actually experiencing complex post-traumatic stress responses associated with chronic abuse and neglect in childhood. While mental health professionals may be aware of their clients' early histories, they may underestimate the role of the trauma as the origin of their symptoms and fail to provide these women with the treatment they need. This guidebook has been developed to assist mental health workers and caregivers in understanding more about the impact of abuse and neglect in women's lives. The author outlines the basic components of first stage trauma treatment and offers specific tools and concrete strategies to use in beginning this difficult work.

Health Literacy: A Prescription to End Confusion

(Institute of Medicine of the National Academies, 2004)

Health literacy defines the degree to which individuals obtain, process and understand the information needed to make appropriate health decisions. It is essential to successful health care. As patients we convey our symptoms and medical history to health professionals who then convey back results, recommendations, information and instructions. But what if you don't understand what's being said to you? This report looks at the problems associated with low levels of health literacy, and recommends actions to promote a health-literate society. While written for an American audience, many, if not all, of the recommendations can be adapted for a Canadian perspective.

My Body, My Responsibility: A Health Education Video for Deaf Women

(University of Rochester, 2003) 62 minutes

There is a serious need for educational materials on reproductive health and this video helps fill that gap. It covers topics including puberty, menstruation, pregnancy and labour, birth control methods, and sexually transmitted diseases including HIV, and how to be tested for HIV. The film features deaf actresses in most roles and dialogue in American Sign Language throughout. It also has a spoken English voice-over and open captions (subtitles), so the film is accessible to hearing and hard-of-hearing people as well as sign language users.

Is It Safe for My Baby? Risks and Recommendations for the Use of Medication, Alcohol, Tobacco and Other Drugs During Pregnancy and Breastfeeding

(Centre for Addiction and Mental Health, 2003)

This booklet is for women who are planning a pregnancy, who are pregnant or breastfeeding. It gives information about the relative risks and safety to the fetus of prescription, over-the-counter and illegal drugs, along with alcohol, tobacco and other substances when the mother is pregnant, and to the baby, when breastfeeding. While the

Women Need Safe, Stable, Affordable Housing: A Study of Social, Private and Co-op Housing in Winnipeg

Molly McCracken and Gail Watson
(Prairie Women's Health Centre of Excellence, 2004)
Available online at www.cewh-cesf.ca/PDF/pwhce/housing.pdf

One in five Canadian women live in poverty. These women are at greater risk of living in unsafe and unhealthy environments and need support to achieve stable and affordable housing. This study looks at the effects of different housing policies on the economic security, health and well being of women in Winnipeg. Governments, policy-makers and community leaders can use the findings to learn which housing models and practices better meet women's needs.

Voices: Women, Poverty and Homelessness in Canada

Rusty Neal (National Anti-Poverty Organization, 2004)
Available online at: www.napo-onap.ca/en/resources/Voices_English_04232004.pdf
The number of homeless women in Canada has increased dramatically since the 1990s. Political realities such as changes in transfer payments to the provinces and the failure to deliver a national housing strategy have played a part. In this report the author traces the personal stories of homeless women in Halifax, Ottawa and Vancouver. Funded in part by the National Network on Environments and Women's Health, it is the result of a multi-year project analyzing the causes and conditions of homelessness. The report includes a list of recommendations to both the federal and provincial/territorial governments.

information in the booklet is a good starting point to address the questions of safety, it is also a great way for a woman to prepare herself for more in-depth talks with her doctor, midwife or pharmacist.

Damaged Angels: A Mother Discovers the Terrible Cost of Alcohol in Pregnancy

Bonnie Buxton
(Alfred A. Knopf Canada, 2004)
Fetal Alcohol Syndrome Disorder (FASD) describes a range of physical and developmental problems affecting some children born to women who drink alcohol during pregnancy. While the damage is permanent and irreversible, early diagnosis and intervention can prevent common secondary disabilities such as mental health and behavioural problems. The author writes from her personal perspective as she learns to understand her daughter Colette's disability. She describes how a diagnosis of FASD can change everyone's attitude towards the person affected and that a person who is seen as mean, defiant, lazy and uncooperative becomes someone with a neurological disability who needs a special approach to care, education and treatment.

Diabetes in Women: Adolescence, Pregnancy, and Menopause, Third Edition

E. Albert Reece, Donald R. Coustan and Steven G. Gabbe (Lippincott Williams & Wilkins, 2004)
Diabetes affects approximately five to ten percent of Canadians and nearly half of those with the disease are women. This book provides an educational and therapeutic resource for health care workers who care for women who have diabetes.

Visit our website to see more resources in women's health: www.cwhn.ca

Pharmaceuticals in our water: A new threat to public health?

A new fact sheet released by Women and Health Protection warns about a new health and environmental concern. Tests on water in North America have found trace amounts of antibiotics, painkillers, anti-inflammatories, hormones, tranquillizers, chemotherapy drugs and drugs used to treat epilepsy and blood cholesterol. A family of chemicals called phthalates, found in many cosmetics, perfumes and hair products, has also been detected. Scientists and policy makers have begun to worry about their possible harm to human health and the environment.

We are exposed to this toxic mix of PPCPs (pharmaceuticals and personal care products) on a daily basis. Adding to the concern is the fact that we are using more drugs than ever before, setting the stage for increased contamination over time.

Women have a particularly strong connection to PPCPs. Exposure to minute quantities of certain chemicals while a woman is pregnant can harm the developing fetus. Women are most often responsible for the purchasing and disposal of drugs and home-use products. There are many drugs that are prescribed more often to women than to men and women experience adverse reactions to drugs more often than men do.

The fact sheet describes what individuals, governments and industry can do to reverse the threat these products pose to our health and to the environment. Women and Health Protection believes the federal government should take a "green pharmacy" approach to the problem that would include an emphasis on prevention through reduced use of drugs and other PPCPs.

All of us can play a role by reducing drug and cosmetic use, disposing of these products safely and pressuring governments and drug companies for change.

For more information on PPCPs, see Full Circle: Prescription Drugs, the Environment and Our Health, *written by Sharon Batt, on the website of Women and Health Protection, at: www.whp-apsf.ca*

Reflecting on the midwifery way

In July 2004, the Atlantic Centre of Excellence for Women's Health and the Prairie Women's Health Centre of Excellence hosted "The Midwifery Way: A National Forum Reflecting on the State of Midwifery Regulation in Canada" at Dalhousie University.

Access to the full conference programme, which includes the abstracts of the presentations, is available on the website of the Atlantic Centre of Excellence for Women's Health, www.acewh.dal.ca

The conference proceedings were prepared by the Prairie Women's Health Centre of Excellence and will soon be available on their website, www.pwhce.ca

about us:

Canadian Women's Health Network | Le Réseau canadien pour la santé des femmes

CANADIAN WOMEN'S HEALTH NETWORK

INFORMATION • COMMUNICATION • ACTION

The CWHN was created in 1993 as a voluntary national organization to improve the health and lives of girls and women in Canada and the world by collecting, producing, distributing and sharing knowledge, ideas, education, information, resources, strategies and inspirations.

We are a far-reaching web of researchers and activists, mothers, daughters, caregivers, and family members, people working in community clinics and on hospital floors, at the university, in provincial and federal health ministries, and in women's organizations, all dedicated to bettering women's health and equality.

We are guided by a woman-centred vision of health and wellness and believe that in order to improve the health status of women we must address social and economic conditions such as education, housing, environment and gender which all impact on health.

We recognize and respect the diverse needs and realities of women's lives, and take an active stance to prevent discrimination based on gender, race, religion, sexual orientation, age, ability, language and geographic region.

We function in English and French, and endeavor to provide access to materials in other languages and alternative formats.

CANADIAN WOMEN'S HEALTH NETWORK PROGRAMS:

www.cwhn.ca

Our website is one of Canada's top bilingual sites for women's health information with over four million hits per year. It is updated regularly to give you easy access to valuable information and resources on women's health, including breaking news, feature articles, an on-line database and links to other useful sites.

Publications:

Network Magazine

Our bilingual magazine is the Canadian front-runner for the latest on health issues that affect women, as well as topical debates, national and international health news and reliable resources. Available in print and electronic formats.

Brigit's Notes

Our free monthly bilingual e-mail bulletin keeps you up-to-date on hot issues related to women's health.

Women's Health Information Centre:

Our comprehensive and always-expanding bilingual collection of women's health publications and resources from across Canada and the world is catalogued on our website. This gives you – free of charge – access to some 10,000 documents, reviews, projects and organizations covering a wide range of information on women's health and women's lives. Aiding searches in the database is CWHN's unique bilingual and Canadian women's health thesaurus. A list of over 4000 key words and terms allows quick and easy access to topics related to women's health. We also answer requests to help find health information through our national toll-free numbers (including TTY) or our website.

E-mail Discussion List:

CDN-WOMEN is a moderated discussion list that joins together and strengthens links among organizations, individuals and groups across Canada involved in women's health.

Community Outreach and Networking:

Our network is a trusted source of women's health information for individuals, organizations, the media, policy makers and key health planning groups across Canada.

We participate in regional and national conferences, consultations, events and workshops and distribute credible women's health information materials. We also help people come together for action on women's health by supporting and building networks, coalitions and joint projects.

Media Relations:

Our comprehensive bilingual communications, media and public relations program has resulted in the CWHN being an important choice for journalists seeking information on women's health issues in Canada.

THIS IS YOUR NETWORK – JOIN US!

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