# HEALTHMATTERS

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PUBLICATION OF THE VANCOUVER WOMEN'S HEALTH COLLECTIVE

## HI!

Welcome to the first issue of HEALTHMATTERS, a new quarterly publication by the Vancouver Women's Health Collective.

We hope to provide Canadians with women's health information which is not accessible through the everyday media. Articles will include information gleaned from other sources throughout the English speaking world, book reviews and original research. We welcome submissions.

Our apologies if you receive more than one copy of this first issue. Please pass extras on to other people who might be interested.



### INSIDE HEALTHMATTERS

Improved Condom Withheld

Ultrasound
A Growing Concern

Osteoporosis

DES

AND MORE...

### **ENDOMETRIOSIS**—

### Comprehensive Information At Last!

Julia Older, an established writer, could find no general information to answer questions about endometriosis, a condition which runs in her family. Endometriosis occurs when cells from the lining of the uterus grow elsewhere in the body. This can cause numerous symptoms, including abnormal bleeding and pain.

Older's curiosity unleashed, she began a journey "to unravel the popular myths and wind through the labyrinth of contradictory information amassed by doctors over the last decades."

<u>Endometriosis</u> is the product of her work. It is a well done book, interesting and easy to read, which presents a wide range of information about endometriosis gleaned from medical and alternative sources as well as from many women with the condition.

Older is at her best when challenging some of the most publicized myths about endometriosis. In response to the theory that this is a "career woman's" disease, she presents information about the rising number of teenage women with the condition. She skillfully questions the assumption that black women rarely get the condition by documenting cases in black women; quoting doctors who believe that it is often mistaken for Pelvic Inflammatory Disease in black women; and presenting information showing that poorer black women without medical care or in emergency wards in hospitals have not been studied for endometriosis. She postulates that many of the early studies were conducted by doctors with middle class white clients.

Older gives medical evidence doubting one of the most popular theories about endometriosis - retrograde menstruation. She states that all women have some retrograde menstruation and only in some women does it contribute to endometriosis. Doctors do not understand why this is so.

Older's approach is excellent in presenting information which is controversial within the medical profession. It gives any woman a wide ran-

ge of opinions within which she can place her own doctor's point of view.

She also stresses what kind of information and alternatives a doctor should be presenting and what tests and examination should be done. She is very strong when she tells the reader to seek another doctor if she isn't getting all of these.

Some of the information in this book is based on the work of the Endometriosis Association of Milwaukee, Wisconsin. This group of lay women does surveys of women with endometriosis and encourages support groups to form. It is some of their information which shows that hormonal therapies do not work as well as promoted.

Although the whole book is very informative, the section on prevention ends on a disappointing note. Ms. Older does not present a great range of information about nutrition or alternative methods for healing. Women we have heard from have had good results with acupuncture making menstrual cycles more regular and cutting down on abnormal bleeding. Several woman have reported easing of pain by cutting citrus fruits from their diets.

This is the only book about endometrosis written in easy to understand language. It is a must to read for anyone interested in the condition.

ENDOMETRIOSIS: A Woman's Guide to a Common but often undetected disease that can cause infertility and other major medical problems

By Julia Older Charles Scribner's Sons, New York, 1984



Science for the People (USA)

Lynn Ruberson

### **OSTEOPOROSIS**—

### What Is Really Going On?

The latest hit on the "pop" medical front is osteoporosis. The word is everywhere...and with it, dire warnings to women, all of whom, we are told, are inevitably at risk, after menopause.

Talk shows and best-seller lists are awash with claims that there are new and safe hormonal strategems which will guard against the development of a condition generally described as crippling, potentially life-threatening and irreversible.

Recommendations have been made at a U.S. National Institutes of Health Conference for the use of estrogenic drugs to guard against osteoporosis in women; the Food and Drug Administration has approved such use not only to prevent against osteoporosis (together with calcium and exercise) but to treat it.

What is really going on here? Is osteoporosis a new disease, or an old one that's reached epidemic proportions? Is it really a serious threat to all women? And why the sudden thrust of publicity now?

The normal menopause simply closes the circle of reproductive function. It is an expected, natural change of life, and signifies neither pathology, dysfunction nor deficiency... only age.

Abnormal menopause, on the other hand, is the termination of menstrual periods by some intervening force or event. The most common cause of an abnormal premature menopause is the surgical removal of the ovaries. Menopause, in these women, is a result, not a cause. For them, menopause, like osteoporosis, is just one in a long list of consequences. The lack of normal organs and normal organic function is their principal problem, and not the lack of estrogen alone.

Women whose ovaries have been removed premenopausally are considered to be at greatest risk for osteoporosis, with half of them destined to have both early onset and severe manifestations of the condition. Although in the normal population bone thinning is distinctly age-related, it is so rapid following castration that within a few years of operation the surgically menopausal woman in her mid-thirties may have less bone mass than a normal woman in her mid-fifties.

These women - and many who have undergone only hysterectomy - commonly suffer a variety of bone and joint disorders, including stiffness,

chronic backache, immobility, pain in the hips, kness, extremities and jaw, etc.

WHAT ABOUT EXERCISE, CALCIUM AND HORMONE REPLACEMENT THERAPIES?

Some studies suggest that overly strenuous exercise programs are responsible for the severe thinning of bone. But studies regarding the effects of exercise on healthy, intact persons have little applicability to the effects of exercise in castrated women, some of whom have their ability to exercise restricted.

Studies evaluating the effects of calcium on bone may have the same limitations. Even among normal populations such studies are inconclusive. The geographic variations in the incidence of senile osteoporosis do not support the importance of dietary calcium. The disease is less common in those populations in which the dietary intake of calcium is low such as China. High calcium intake is not without risk. Susceptible people may develop urinary stones as a consequence and some

proclaim the benefits of their hormone products, will enjoy a veritable bonanza if estrogens can be sold to every woman long past the contraceptive years, and long past menopause, in short, forever. The Wall Street Journal chronicles an estimated 10 million dollar advertising campaign by two leading calcium pill manufacturers projecting a 200 million dollar market by 1989.

Bone is a dynamic tissue affected by countless agents. Some are produced internally such as hormones and other metablolic agents. Others are external to the body such as diet and sunshine. But no single element can be isolated as the only one which affects bone. And, although bones become thinner with age, not all thin bones is osteoporotic, nor does it proceed to fractures.

Osteoporosis occurs in men also, and despite the fact that age and menopause are universal, in some countries the incidence of hip fracture (an assumed, but not proven index of osteoporosis) is greater in men than in women. In others the numbers are equal. Countries with the lowest overall incidence seem to have the lowest incidence among women. The United States, according to some data, has the highest incidence among women.



calcium supplements have been found to contain toxic elements.

But for some women calcium and exercise are simply not enough. Surgically menopausal women are in this category. Hormone therapy is seen as a final option. However, there are no carefully controlled studies of the risks and benefits of estrogen replacement therapy for women who have undergone surgical menopause.

Drug manufacturers, some of whom have funded the very studies which

The United States also has an extraordinary high rate of surgical removal of ovaries, and by the early 1960's it was estimated that a surgical menopause was imposed on about one-quarter of American women who were menopausal. Later estimates suggest that the figure may now be one-third or more. Therefore, if an osteoporosis crisis does exist, it may reflect the wholesale removal of female organs and is a medically predictable consequence.

(Source: HERS Newsletter, Vol. 2, No. 2)

# ABANDONING HIGH-TECH INCREASES SURVIVAL RATE IN COLUMBIA

San Juan de Dios hospital in Bogota, Columbia has moved away from reliance on expensive, high-technology incubators for premature babies. Instead, premature babies of 500-2500g. (1.1 - 5.5lbs) are now swaddled in an upright position close to their mothers' breast, and sent home within 2 - 12 days of birth.

The infant is packed like a small kangaroo in its mother's pouch, where it gets all the warmth, stimulation and food it needs. Since the method was first introduced, survival rates for the lowest birth weight babies have risen from 0 to 72%. Overall, survival rates for

preemies in the hospital are now almost 95%.

The move away from high-tech equipment is one example of a hospital in a third world non-industrialized country discovering the imported technology of an industrialized nation to be inappropriate for their needs. This was particularly so as not enough incubators could be bought for all the premature babies born at the hospital and thus the technology itself suffered from overuse.

The alternative developed by the Columbians is promising for third world countries as it provides a

means of caring for premature infants cheaply and much more effectively. The alternative is also promising for the world at large. Instead of being incubated, isolated from human contact much of the time, premature infants would be able to get the physical contact, nurturing, warmth and stimulation all babies

The Columbian alternative would also provide a more humane option for the mother, who would no longer need to go through long periods of physical separation from her premature infant after its birth.

(source: Globe & Mail, Jan. 29, 1985)

### Contraceptive Sponge

### **Proceed with Caution**

One year after the introduction of the Today contraceptive sponge, clinical studies report "only" 12 cases of Toxic Shock Syndrome (TSS) among the estimated 600,000 women using the sponge. Numerous cases of vaginal irritation have also been reported.

According to the U.S. Centre for Disease Control, in four of the TSS cases women left the sponge in for longer than the six to eight hours advised by the manufacturer. In one case the woman was menstruating, a time when women generally are more at risk of developing TSS.

Introduced in June of 1983, the Today sponge contains the spermicide Nonoxynol-9 (N-9), which has been approved by the U.S. Food and Drug

Administration. Although it has not been tested for long-term toxicity and carcenogenicity, N-9 is commonly used in contraceptive foams, creams and jellies.

Since the introduction of the sponge the U.S. National Women's Health Network has been requesting stronger warning labels advising women that the product has not been tested for TSS. The Network recognizes, however, the important advantages of the sponge; it is non-prescription, can be used only when needed and contains no hormones.

A number of recent abortion patients report having become pregnant while using the sponge.

(Source: Irregular Periodical, Winter, 1984)



### PID Information Sought

A woman who has chronic pelvic inflammatory disease (PID), which is disabling, wants to hear from any woman who has been cured of chronic PID; any practitioner who has treated this disease with any success; or any women who have had total hysterectomy for PID. I would like

to know if the infection was cured and the pain relieved. I'd appreciate any information for myself and for the other PID victims I'm in touch with across the country. Write to: Maureen Moore, 2045 Trafalgar Street, Van., B.C. V6K 3S5. (604) 734-9206.

### Improved Condom Withheld

Improved condoms made from synthetic materials have been patented by major condom manufacturers for as long as 20 years. Manufacturers, however, have been taking no steps towards marketing the condoms.

The synthetic condom would allow for full transmission of body heat and moisture while preventing the passage of sperm. It is said to be virtually like another layer of human skin, unlike the rubber condoms currently available which interfere considerably with sensation for both women and men.

The condom industry consists of six large multinational corporations manufacturing the world's condoms. Condom manufacturers are not interested in marketing the new technology because it would require expensive replacement of existing equipment, and would not expand profits. Firms like Ortho, which manufacture both condoms and birth control pills, are not interested in cutting into their more profitable returns on the pill by producing attractive and less expensive alternatives.

Unlike the pill and the I.U.D., the condom poses no health risks to women or men. When used properly it is highly effective (96-97% when used alone, 99+% when used with spermicidal foam). Many women would welcome the existence of a condom which did not interfere with sexual sensation.

The continued promotion of harmful methods of birth control coupled with the suppression of safer methods is yet another example of how profits, rather than the needs of people, become the real priority of manufacturers.

(source: Globe & Mail, Sept. '84)

### **ULTRASOUND**

There is a growing concern among consumers and health care providers that the immediate benefits of diagnostic ultrasound in obstetrics may not outweigh the risks.

Ultrasound, originally developed as a sonar device in submarine warfare, uses high-frequency sound waves to get a picture or image of objects inside the body, such as a fetus, that are not clearly seen by x-rays. It has been widely used for the last five to eight years. Ultrasound can be used to tell if a woman has twins, detect a pregnancy occurring in the fallopian tube rather than the uterus, determine fetal age, evaluate bleeding during pregnancy or detect physical abnormalities. It is also used prior to amniocentesis.

When an ultrasound is performed, the picture or scan is called a sonogram. Pictures are usually taken of the images and examined by a radiologist.

Ultrasound is also used in a device called a Doptone which is used during prenatal exams and in labor to listen to fetal heart tones. The Doptone delivers 99.9 times more energy than an ultrasound scan.

At present, a little over 50 percent of scans are used for only one medi-

### A Growing Concern

cal indication, the determination of fetal age.  $% \begin{center} \end{center} \begin{center} \end{center}$ 

Millions of pregnant women are being exposed to diagnostic ultrasound before the long-term effects on fetal development are fully understood. It will be 20 to 30 years before we know whether ultrasound will be the DES of the next generation. The occurrence of premature ovulation after ovarian ultrasonography is disturbing; as are its implications. If ultrasound can effect the adult ovary, what then is the effect on the ova of the female fetus?

Research has found evidence of growth anomalies and hereditary changes in the DNA of cells after ultrasound exposure. The U.S. Federal Drug Administration has called attention to research that suggests a tendency towards lower birth weight in infants exposed to ultrasound in utero (in the uterus). Preliminary data from the United Kingdom suggests a higher incidence of leukemia in children thus exposed. And though it is difficult to translate onto humans the effects of studies done on animals, it is important to note that some of the published animal studies suggest

ultrasound exposure can affect prenatal growth.

Recommendations from a U.S. National

Institute of Health panel include: informing patients of the specific clinical reason for the ultrasound; performing ultrasound only when clear specific benefit is apparent; informing patients of any potential risks and any available alternatives; and making patient education materials available (materials not produced by the manufacturers of sonography equipment.)

The recommendations were not clear regarding how much of a discrepancy for fetal age actually requires ultrasound. Is it two weeks, four weeks or does it matter if a pregnancy seems normal?

The U.S. National Women's Health Network suggests that women sign consent forms for obstetric procedures involving ultrasound. Such a procedure would help ensure an adequate exchange of information between the doctor, or midwife, and the patient, thereby enabling a woman to make an informed decision. (source: The NetWork News Nov., Dec. 1984; Womanwise Vol. 7 No. 4, Winter 1984)

### **HEALTH COLLECTIVE EXPANDS FOCUS**

Over the past year the Health Collective has researched and produced material on five health-related topics of concern to women: breast health; vaginal/cervical health; DES (diethylstilbestrol); menopause and premenstrual syndrome - PMS. This work was made possible through a grant obtained from the Health Promotion Directorate of Health and Welfare Canada which employed four women.

The focus of the project was to develop written materials that were comprehensive and understandable to present workshops on these topics in communities in B.C., Alberta and the Yukon. A packet of information was compiled for each topic. Some of the information included is original writing by the Health Collective; some of it is relevant material from other sources. The packets include physiological information about the topic, the conventional medical approaches taken to it and the alternative approaches available.

The packets also include information about the politics of the health care system - the profit motive behind the drug industry; the professional and sexist orientation of the medical system.

medical system.
The emphasis of the packets, generally, is on self-help: what we can

do ourselves about specific health problems and how forming self-help groups can be useful and supportive. Fourteen workshops on these five topics were conducted by project members in B.C., many of them in small cities in the interior and in northern B.C. Three workshops were conducted in Alberta and two in the Yukon. Women's groups in these communities co-sponsored the workshops.

Overall, the workshops were well attended and enthusiastically received. At some of the workshops women decided to get together again to form a self-help group. It was gratifying to us to have helped provide the setting for this to happen. The way we present workshops has evolved as a direct result of our experience. We heard many women's stories concerning particular health problems: their physical experience of the problem; their experience with the medical system; and their experience of discovering how their social and familial situations interacted with the problem. As a result, we attempt to view any medical problem in terms of its social, political and environmental context.

Issues raised in our workshops are broader than just how to deal with a specific health problem (although our written material is very detailed in that regard). Topic material is put in the context of the historical development of modern medical practices and structures, and how the women's self-help movement relates to this.

In January of this year we held a facilitators training conference. A couple of women from each of the centres where we had conducted workshops during the past year attended so they could learn more about facilitating workshops themselves on the five topics. Approximately sixty women attended the conference.

Workshop emphasis was on the 'how to' aspect of facilitating workshops on the specific topics researched by the Health Collective rather than on the topic material itself. Other workshops dealt with the five health topics and with developing research skills. The conference was very successful and there are women who attended who are already doing workshops in their own communities.

Funding for this project ends June 30, 1985. The Health Collective has only one salaried grant position until that time. Some workshops will be done in the Lower Mainland and follow-up work will be done with groups that are now facilitating workshops in their own areas.

### **DES Update**

DES (diethylstilbestrol) is a synthetic estrogen given to millions of women in pregnancy in the 1940's, 50's and 60's. The drug has been linked to numerous health effects in women and men exposed before birth.

Two recent studies have added to the existing knowledge of health problems for women exposed to DES. A study of DES mothers published in the November 29, 1984, issue of the New England Journal of Medicine indicates that DES mothers have one and a half times the risk for breast cancer of unexposed women. (DES mothers include any woman given the drug during pregnancy, whether or not she gave birth to a live infant). The increased risk for breast cancer is only apparent more than 25 years after a woman has been exposed to DES.

A previous study on DES mothers had indicated a similar increase in risk for breast cancer, but the New England study is the first to have

surveyed a large enough number of women to who a statistically significant increase in risk. This adds validity to the link between DES and breast cancer.

The increased risk reported in the New England study is not considered a large increase compared, for instance, to the much higher risk for breast cancer a woman faces if she has a) certain types of family histories of breast cancer, or b) has been exposed to a lot of radiation. However, the study does add weight to the need for DES mothers to do regular breast self-examination and to avoid other substances which may initiate or promote breast cancer, such as hormonal drugs (progesterone or estrogen replacement therapy).

Another new study, published in the <u>Journal of the American Medical</u>
<u>Association</u>, Dec. 7, 1984, looks at whether DES daughters are more likely to have abnormal Pap smear results than unexposed women. This study involves a 7 year follow-up of DES daughters enrolled in the DESAD project. The DESAD project is the only large-scale follow-up of DES daughters. In this study, the authors report twice the number of

abnormal results from Pap smears and biopsies (tissue samples from the cervix and vagina) in DES daughters compared to unexposed women.

DES daughters had biopsies taken much more frequently than unexposed women. Therefore, the comparison of biopsy results is likely to be inaccurate. However, when the results of Pap smears alone are compared, DES daughters were still found to be one and three quarter times as likely to have abnormal cells found than unexposed women.

Earlier studies of DES daughters and abnormal Paps carried out by the DESAD project did not show any relationship between abnormal Paps and DES exposure. It may be that as DES daughters reach their 30's and 40's there is an increased risk for abnormal Paps.

The increased risk for abnormal Pap smears reported in this study is not huge; it is most frequently limited to mild dysplasia, or mildly abnormal cells, a condition which can be unrelated to cervical cancer. DES daughters need to have regular medical exams, during which Pap smears are taken, with a doctor knowledgeable about DES exposure.

### DES Daughter Wins Lawsuit

Andrea Goldstein, a DES daughter from Boston, was awarded \$50,000 in damages against Eli Lilly for injuries related to her DES exposure.

Andrea suffered two ectopic pregnancies (for which DES daughters are at higher than usual risk) and was found to have the T-shaped uterus found in many DES daughters. It is impossible for her to have children.

This is the first lawsuit verdict on pregnancy problems related to DES exposure. All previous lawsuits won by DES daughters against the pharmaceutical companies manufacturing DES have been won solely on the basis of the DES daughter having developed DES-related vaginal cancer (vaginal adenocarcinoma).

Although vaginal cancer is an extremely serious health effect of DES exposure, it is also quite rare. Between 1 in 1,000 and 1 in 10,000 women exposed to DES before birth will develop vaginal cancer.

Pregnancy problems, on the other hand, are experienced by approximately 50% of DES daughters. These include higher risks of miscarriage and premature birth, ectopic pregnancy, and higher likelihood of infertility.

(source: <u>DES Action Voice</u>, issue #23, Winter 1985)

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