

Winter, 1984

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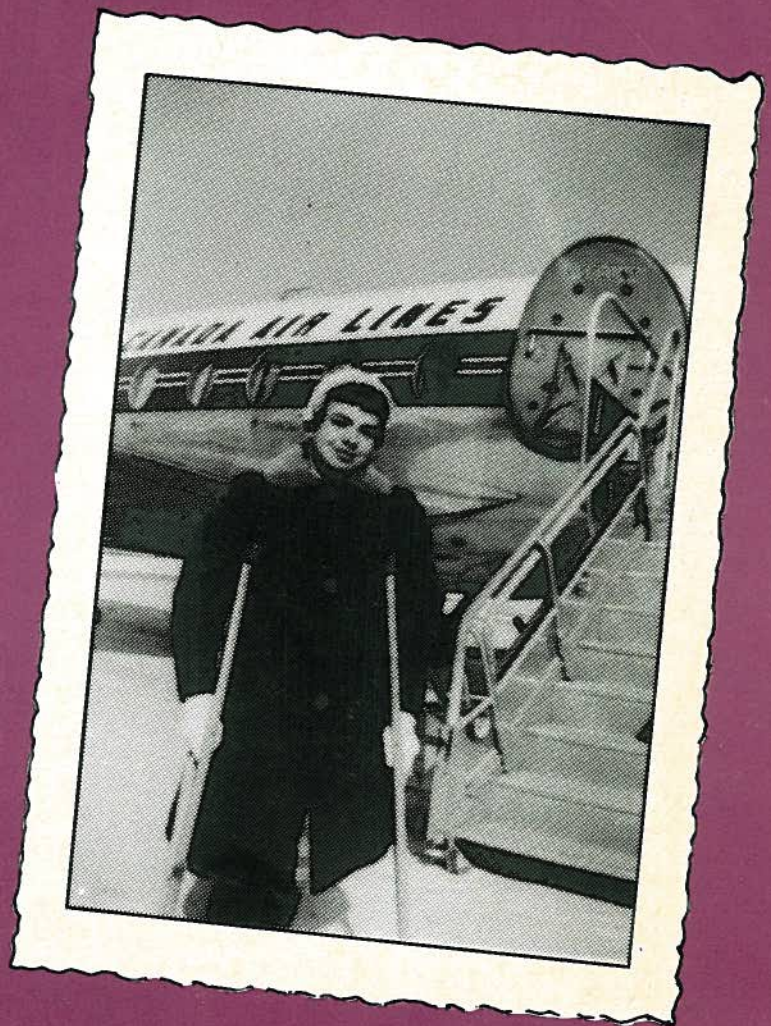
Healthsharing

A CANADIAN WOMEN'S HEALTH QUARTERLY

Life as the
Easter Seals Child

Population and
Politics

Turner's
Syndrome



Inside Healthsharing

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NEW from

KATHLEEN McDONNELL

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The Women's Press



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Healthsharing

Published by
Women Healthsharing



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Clarion Typesetting

Printer

Action Print

Healthsharing (ISSN: 0226-1510)
Volume VI, Number 1, December,
1984. Published quarterly by Women
Healthsharing, Inc., A Resource and
Writing Collective, Box 230, Station
M, Toronto, Ontario M6S 4T3.
Telephone: (416) 862-1791. Women
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Subscription rates are \$8.00/year,
individuals; \$15.00/year, institutions
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subscriptions, including subscriptions
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Looking Back Is Looking Forward

Since being involved in magazine publishing each *Healthsharing* collective member admits to the somewhat esoteric habit of reading mastheads. We watch the comings and goings of other magazine staffs and sometimes wonder how many *Healthsharing* readers do the same. If you are also a masthead reader you will have noticed both stability and change at *Healthsharing*.

This issue you'll notice that our collective is somewhat smaller than in former years with only six in all, and for the first time half of us are on leave. The return-to-school-syndrome has made its mark: Diana is doing a thesis on equality law far away in Wisconsin; Lisa is studying journalism and Jo-Ann nutrition, both here in Toronto. Among the three of us regularly attending fortnightly collective meetings, decisions about futures are also being made. Amyra has just started a book publishing programme, Elizabeth continues midwifery involvement and plans to apprentice next year, and Connie recently began job-sharing her family planning job.

In spite of the prominent spot occupied on the masthead, collective members are not the only women putting out this magazine — the many women who volunteer issue after issue for specific tasks and former collective members also influence and help produce the magazine. As the magazine grows older, the women who undertake specific tasks are more and more a part of our extended family. Long overdue, we are finally having social events — one upshot of which is that long-term copy-editors Sue Kaiser and Rona Achilles have finally met long-term designer/typesetter Linda Lounsberry! We fantasize a budget that will allow us to bring all regional reporters to Toronto for a party. In the meantime, resource guide staff have been lucky enough to meet several of them.

The women who have left the collective over the years continue to offer support and friendship. Nearly all are still in touch with us — they phone to share resources, review a book, staff a promotion table or come to paste-up. All our lives are busier than we would hope, and some former members have moved far from Toronto.

Gina Jones does community outreach with seniors in East Toronto, Sharon Zigelstein owns and manages Havana, a Cuban restaurant in Toronto. Kathy McDonnell is working for *Healthsharing* editing a women's health resource guide; a playwright and author, her new book is reviewed in this issue. Madeline Boscoe moved to Winnipeg a year ago where she is programme co-ordinator for the Women's Health Clinic. Jennifer Penney writes us regularly from Nicaragua where she is working as an occupational health educator. Anne Rochon Ford is run off her feet as field coordinator for DES Action/Canada. Susan Wortman lives in a farm house outside Hamilton and ekes out a living teaching Wendo. Bev Rodrigue, our office manager for two years, is a therapist in Toronto. Dorothy Cooper, our former promotion staff, moved east to Halifax a year ago. Betty Burcher has left to increase personal and family space in her life — she continues to work as a nurse at a community health clinic. Julie Wheelwright is somewhere between here and Nepal travelling overland with a group.

As we complete our fifth year of publication — a critical time for all magazines, and probably for small organizations — we reflect on how relatively healthy we have been over the years. Our average time of involvement among collective members has been a substantial 3½ years. Now we're in a time of transition when the founding mothers are moving on and new mothers are taking their places. Through the new energy, new skills, new friendships, as well as through the strength of the earlier enduring friendships, *Healthsharing* continues.

Elizabeth Allemang

Amyra Braha

Connie Clement

Making Changes

"Childbirth: Making Changes," a weekend of workshops, exhibits and films, was held in Regina October 13 and 14, 1984. More than 100 childbirth educators, nurses, physicians and consumers attended. The conference was sponsored by the Regina Childbirth Education Association, with assistance from the Regina Plains Community College and the Secretary of State Women's Program.

Many of the latest ideas and scientific findings in the field of childbirth with discussed in the workshops. The conference committee did a fine job in offering workshops on a wide variety of subjects. Valmai Howe Elkins, author of *The Rights of the Pregnant Parent and Birth Report*, was one of the better-known speakers. She called for the recognition of midwifery in Canada and a more humane, gentle approach to childbirth. Cynthia Carver, physician and author of *Patient Beware*, stressed that changes in medical practices most often come when the patient-consumer demands those changes. Visualization, the act of forming mental images or pictures, was the topic of a workshop led by Susan McKay. As a psychologist, nurse, and childbirth educator, she has found visualization to be a tool that can directly affect pregnancy and childbirth. She shared some techniques for guiding pregnant and labouring women through positive visualizations in order to enhance their experience. Workshops on positioning and movement during first and second stages of labour led by Penny Simkin were well attended. She used her own insights as a physiotherapist and childbirth educator as well as exhaustive research to formulate her theories.

The atmosphere of the conference was one of shared goals and ideals. Change is an ongoing process brought about by all of us. Plans for another Regina conference in 1986 are in the works.

by Pamela Woodsworth

UPDATE



Unity in Midwifery

TORONTO — Of the 210 member countries in the World Health Organization, Canada is the only industrialized country that does not recognize midwifery as a legalized health care alternative.

A five day conference held October 31 - November 4, 1984 at The Ontario Institute for Studies in Education, was hosted by the Midwifery Task Force of Ontario. Its theme, "Creating Unity" between health care professionals, midwives and parents, provided a strong air of mutual respect.

The conference coincided with a bill that was presented in the Ontario legislature at Queen's Park proposing "to establish midwifery as a self-governing health profession." Conference participants had the opportunity to leave theory behind and demonstrate their support. With strength in numbers they packed the gallery. However, the bill was defeated by the Conservative majority.

The Midwives' Alliance of North America (MANA) held its second annual convention during the conference, facilitating regional networking and open discussion of policy and standards

The energy and inspiration that were almost visible in the

atmosphere seemed to reach a peak on Friday night when the general public were invited to attend a forum entitled "Midwifery as a Women's Issue". The overflowing crowd of more than 600 people gave overwhelming support to the three speakers: Sheila Kitzinger, author of many books on childbirth and women's sexuality; Mary O'Brien, sociologist and author of *The Politics of Reproduction*; and Michele Landsberg, Toronto journalist and author of *Women and Children First*. This powerful evening was rich with shared memories, intense introspection and passionate demands for change. What had emerged throughout Friday's sessions were the themes of choice, care, and community. The three speakers took these crucial needs and wove them together into a strong identity for midwives and all women.

"Our own self doubts are as powerful an opponent as the male medical world", Kitzinger concluded. O'Brien responded by stressing the need to stop defining ourselves according to the male model and begin creating our own. This we are doing, she said, through our own form of revolution.

by Martha Bell

Canada Health Act Penalties Imposed

Almost \$10 million was deducted in the first dollar for dollar deductions imposed on provinces in July. Under the new Canada Health Act provinces violating extra-billing and user-charges conditions will be penalized monthly.

Ontario lost \$4.4 million, followed by British Columbia which was docked \$2.5 million. Newfoundland, P.E.I., Nova Scotia, The Yukon and the Northwest Territories were penalty-free.

The amounts deducted from federal cash transfer payments for insured health services will be held by the federal government for three years. Those provinces that satisfy the terms of the act by April 1, 1987 will receive the full amount of transfer payments withheld.

Who is Crazy?

EDMONTON — Alberta Hospital Minister Dave Russell thinks that offering free health care is as crazy as giving away free booze. He recently compared the operation of the health care system with that of the liquor control board. Russell suggested that we imagine the liquor control board tearing the price tags off the bottles, throwing the doors open wide and then at the cash register, informing customers that the government would pick up the tab. Crazy you say? Well, that, says Russell, is how we operate our medicare system.

Personally, I still haven't quite got the analogy figured out; but never mind. This week end I plan to book myself into a first class room at a major hospital for a holiday rest. If I inhale enough of the free laughing gas perhaps it will all come clear.

by Ellen Seaman

Breastfeeding Discouraged

Hospital care of Indian and Inuit mothers and newborns does not meet up to standards set out by the World Health Organization (WHO). This finding is revealed in a 1983 hospital policies and practices survey administered by the Medical Services Branch of Health and Welfare Canada. The survey, based on responses to a questionnaire distributed to the 312 Canadian hospitals reporting native births, indicates that many of these hospitals follow procedures that do little to promote breastfeeding and bonding among native women.

Despite the WHO recom-

mendation that breastfeeding commence as soon after birth as possible, 20 per cent of the surveyed hospitals do not allow newborns to remain with their mothers immediately following birth, even in the case of unmedicated delivery. Of those hospitals that do permit newborns to remain with their mothers following delivery, only 65 per cent allow breastfeeding at that time.

Over 80 per cent of the hospitals routinely supplement breastfeeding, most often with glucose and water; 30 per cent of Alberta hospitals more commonly supplement with form-

ula. Infant formula samples are distributed to breastfeeding mothers upon discharge in 42 per cent of reporting hospitals, although this practice varies widely from region to region (from 6.7 per cent of Saskatchewan hospitals to 82.3 per cent of hospitals in Alberta). Supplementary feeding of breastfed babies and distribution of formula samples to breastfeeding mothers likewise run counter to WHO recommendations.

The Canadian Pediatric Society has expressed concern regarding some of the hospital practices reported in the sur-

vey — excessive medication during labour, separation of mother and child, rigid feeding schedules, supplementary feeding and promotion of breastmilk substitutes. The society recognizes the detrimental effect of these practices on breastfeeding and bonding.

by Dianne Patychuk

Precedent Set

HALIFAX — For the first time, consumer participation is being formally included in the planning process of a health care facility in Nova Scotia. Six women were recently appointed by the Salvation Army to represent a "broad-based constituency of consumers" on the planning committees for the New Grace Maternity Hospital in Halifax. This is an important precedent for consumers in general, and for women in particular.

Because the concept of consumer participation is so new to the medical, administrative and planning staff of the hospital, the pioneer role these women face will be challenging. Their participation also represents considerable personal and financial sacrifice. With all this in mind, the Consumer Support Network was formed to provide an information and support network for the women.

The central goals of the network include the coordination of feedback to these consumer representatives and the acquisition of funding. Feedback from across the province will help the six women to be truly representative of consumer needs and make their input as credible and effective as possible. Two surveys related to childcare and research policies for the New Grace Maternity Hospital have been circulated throughout the province by the network.

For further information about the Consumer Support Network, contact: CSN, c/o J. Catano, 6246 Shirley Street, Halifax, N.S. B3H 2N6.

Newfoundland News Briefs

ST. JOHN'S — The Women's Health Education Project for Newfoundland and Labrador (WHEP) has come to an end after four years of research and field work that reached women throughout the provinces. WHEP is distributing resource kits and booklets to women in various communities in the province and a final report is being prepared. At present there are no plans for the formation of another women's health group to take over where WHEP has left off.

- The Women's Centre, a project of the St. John's Status of Women Council, has once again hired a full-time counselor. Anne Donovan, a social worker who recently moved to St. John's from Ottawa to take on this position will be responsible for individual and group counselling. Her plans are not yet complete; however, she soon hopes to organize several group counselling sessions.

- At last! It is almost unbelievable that until September 1, 1984 St. John's had no female

psychiatrist. Dr. Sheila Lynch opened her practice in an office on a busy downtown street. Dr. Lynch previously worked with the Transition House Project in St. John's.

- The September 21, 1984 Take Back the Night March in St. John's attracted 140 enthusiastic marchers despite a torrential downpour. A wonderful spirit of comradere and intense emotion moved the women and children participants.

by Pamela Hodgson

Silence Lifting

The Catholic Children's Aid Society of Metropolitan Toronto recently released a report showing a large statistical increase in reported child sexual abuse cases. Comparable six month periods in 1983 and 1984 show a 168 per cent increase (from 38 to 102 verified cases).

Estimates of the prevalence of child sexual abuse cases across Canada vary but it is generally agreed that at least one in four girls and one in ten boys will be sexually molested before they reach age 18. While the increase in cases handled by the Catholic Children's Aid Society (CCAS) may seem alarming, it likely suggests a growing awareness of the prob-

lem by social agencies and the public. Legal requirements for reporting also facilitate children getting help as early as possible.

In the CCAS report most child victims are females in early adolescence (mean age of 12.2 years). Although the abuse occurs within the family and has usually been ongoing for more than two years, treatment plans enable most victims to be treated and supported at home. In almost three-quarters of the cases reviewed in the report, treatment plans received the active support of the child's mother.

by Sue Kaiser



Photo: Clarion

Organizing in Saskatchewan

REGINA — The entrance of Grant Devine's conservative government to Saskatchewan in 1982 led Regina Healthsharing, Inc. to delay its original goal of establishing a women's health educational centre in Regina. Provincial funding for this project was unavailable. Health Minister Graham Taylor similarly rejected a secondary proposal to hire minimal staff to co-ordinate and facilitate self-help groups.

1983 and 1984 were rebuilding years for Regina Healthsharing. Grants received from the Secretary of State Woman's Program and the federal Health Promotion Directorate during this period supported the planning of a women's health conference, "Helping Ourselves." The central themes of the three day conference held in Regina in February 1984 were self-help and self-care.

"Helping Ourselves" was an important event. It inspired a resurgence of interest in

women's health issues and activism in Saskatchewan and it contributed to a regeneration of Regina Healthsharing. The board of Regina Healthsharing recently acquired several new members and its general membership has risen significantly.

Regina Healthsharing is presently exploring new structures in order to strengthen its accessibility and organization. It is operating collectively for the first time, and it is seeking new ways to integrate its members into its newly defined committee structure.

An equally exciting event in the province is the recent founding of the Saskatchewan Association for Safe Alternatives in Childbirth (SASAC). Groups are forming in Regina, Saskatoon and Nipawin to promote informed choices in childbirth and pregnancy. For further information contact: SASAC, Box 3301, Nipawin, Sask. S0E 1E0.

by Sue Cook

Safe Sterilization?

A new "safe" and "easy" method of sterilization is now being clinically tested in Canada. The procedure, called Femcept, involves injecting a small amount of a tissue adhesive chemical — methylcyanoacrylate (MCA) — into the fallopian tubes via the uterus. It initiates a chemical reaction that burns the tubal lining, scarring the fallopian tubes and resulting in permanent sterilization.

The failure rate of Femcept is reported to be 25 per cent after one application; the procedure can take up to four months before it is effective. An advantage of the procedure is that it can be done on an out-patient basis by paramedics.

Several prominent gynecologists are promoting Femcept in Canada as an easy, safe alternative to the risks of surgery, especially for women in Third World countries where

medical resources are scarce.

However, a recent study cited in the American Journal of Obstetrics and Gynecology (April 15, 1983) reveals that almost one quarter of the women studied who underwent the procedure experienced pelvic pain in the first month following the procedure and four per cent still had pain after the ninth month. Two per cent of the women had to be hospitalized, some with confirmed cases of pelvic inflammatory disease (PID).

One might wonder for whom Femcept is "safe" and "easy."

by Frumie Diamond

Diet Pills Unsafe

Trying to lose weight? Beware of simple solutions. They may not work and they may be dangerous to your health.

A number of easily available, over-the-counter appetite suppressants contain phenylpropanolamine (PPA). Two in particular, Acutrim, manufactured by Ciba, and Dexatrim, manufactured by Thompson Medical, are currently being promoted on U.S. television. Research shows however that PPA is neither effective nor safe.

Studies on PPA's effectiveness show subjects using PPA lost only one or two more pounds than subjects receiving placebos, and their weight loss was not maintained without the drug.

The side effects are significant. PPA is associated with severe hypertension, stroke and seizures, especially if taken with caffeine. Some of these reactions have occurred in teenage women as young as 13 years. Other side effects include nervous system disturbances, psychotic episodes, renal failure and cardiac arrhythmias. Deaths have been reported.

This drug is still on the market and easily available. It is also contained in decongestants and cold remedies.

by Frumie Diamond

Heightening Awareness

HALIFAX — The "International Congress on Women's Health Issues" was held in Halifax, October 3-5, 1984. This three day event attracted over 300 professionals and consumers from several countries. More than 140 papers were presented on a wide variety of topics. Organized by Phyllis Stern, Director of Dalhousie University School of Nursing, the congress was arranged to heighten awareness of women's health issues and encourage free discussion.

An international council was established at the conference to address women's health issues from an international perspective. The council will provide a forum for the exchange of information and support, and a mechanism for the publication and exchange of congress material. Organization of future congress sessions and the establishment of a centre for the study of women's health issues in Halifax are further goals of the council.



Photo: Claron

Congratulations and Thanks

As this issue goes to press, we are filled with satisfaction and pleasure because of court decisions made earlier in the week. Celebrations are in order. We congratulate:

- doctors Henry Morgentaler, Robert Scott and Leslie Smolling, all of whom were acquitted on charges of conspiring to

contravene the section of the criminal code dealing with therapeutic abortion;

- Colleen Crosbie, against whom charges of procuring an abortion were dropped;
- all those who assisted — politically, emotionally and financially — these four brave individuals.

Healthsharing

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M6S 4T3

Pornography Project

Inspired by a recent conference on pornography held at Queen's University in Kingston, Ontario, the Queen's Women's Centre is undertaking a project on women and pornography. They are preparing a series of video tapes based on the conference to be distributed with comment papers and an extensive bibliography.

They welcome submissions from feminists doing research on pornography, and they would like to hear from any women's groups active in this area. Contact: Queen's Women's Centre, Pornography Project, 51 Queen's Cres., Kingston, Ont. K7L 3N6.

PID Research

Maureen Moore is researching a book and resource guide on pelvic inflammatory disease (PID). She is interested in hearing from any women who have been cured of chronic PID. She would also like to know of any practitioners who can cure or improve the health of women with chronic PID.

Write to Maureen Moore, 4055 West 31 Avenue, Vancouver, B.C. V6S 1Y7, or phone (604) 228-8975. All replies confidential.

Self-help Book

Lynda Madaras, author of several books on women's health, is currently working on a book about the effectiveness of self-help and alternative therapies in women's health care. She would like to hear from women with medical problems (not strictly gynecological or obstetrical) who were unable or unwilling to be treated by orthodox medicine and who turned to self-help or alternative therapy. Extensive detail about the problem, diagnosis and treatment would be helpful.

Interested women can contact Lynda at 1341 Ocean Blvd., Suite 222, Santa Monica, CA 90401.



National Nutrition Project

Two nutritionists are investigating the possibility of establishing a national program concerning nutrition as a means to community development. Funded by the Health Promotion Directorate, the project will analyse and document existing resources and strategies, and recommend potential educational programs. Assistance is requested in identifying and prioritizing issues and programs with a nutrition education component.

Please contact: Sari Simkins, Nutrition Information Service, Ryerson Polytechnical Institute, 350 Victoria St., Toronto M5B 2K3, (416) 979-5000, ext. 6903 for Ontario and western Canada, and Catherine Maxwell, Montreal Diet Dispensary, 2182 Lincoln Ave., Montreal H3H 1J3, (514) 937-5375 for Quebec and eastern Canada.

Dalkon Shield

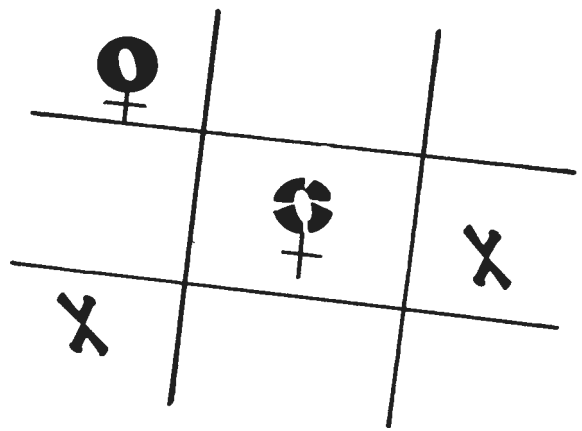
Over 9,000 claims are currently pending against the manufacturer of the Dalkon Shield in the United States. How many women in Canada have suffered from use of the Dalkon Shield?

If you are concerned about risks of this IUD such as pelvic inflammatory disease, or ectopic pregnancy, or if you are interested in class action suits brought against the company, please contact Elizabeth Fairley, 206 Wanless Ave., Toronto, Ont. M4N 1W6.

TURNER'S SYNDROME:

Not a Game of X's and O's

by Susan Charney
with Terry Hooven



I am one of five thousand females in Canada who have a chromosomal abnormality that only affects women and results in short stature. This condition is known as Turner's Syndrome or Gonadal Dygenesis. It is a relatively rare disorder, afflicting one in twenty-five hundred female births.

While most females have two X chromosomes in their body cells, women with Turner's Syndrome have one. Lack of secondary sex characteristics (breast development, pubic hair growth and menstruation) and infertility are common features of Turner's in addition to short stature. A variety of other medical problems are related to this syndrome. Ear, eye, heart, kidney and thyroid difficulties may occur as well as sugar diabetes, high blood pressure and keloids (especially firm, reddish scar tissue). Some women also exhibit low set ears, low hairlines, webbed necks, pigmented moles, bending out of the elbows and puffy hands and feet. Learning difficulties may include problems with spatial and directional abilities, mathematics and geography; however verbal skills are generally not impaired.

Not every Turner's woman exhibits all these characteristics. There are three different classifications of Turner's Syndrome. Monosomy is the classic form. A woman with this form is missing an X chromosome in all her cells. In isochromosome a woman's cells contain both X chromosomes but one is structurally different. Mosaicism is any combination of these two forms.

Through the procedure of amniocentesis, a diagnostic tool used to predict genetic fetal abnormalities, Turner's Syndrome may be identified; however this procedure is carried out only on pregnant women considered at risk for a screenable birth defect. At present, one third of cases are diagnosed in newborns. A medical practitioner may suspect a newborn has Turner's Syndrome if she is unusually short or if she shows other classic features. Another third are diagnosed during childhood when it is evident that the child is significantly shorter than what is considered normal. The remaining third are diagnosed during adolescence when the Turner's adolescent fails to undergo pubertal changes.

Although visible features associated

"If I hear one more person say 'Good things come in small packages,' I think I'll scream!"



*“When you look young,
you’re taken less
seriously ... You have
to try doubly hard in
school in order to
prove yourself.”*



with Turner’s Syndrome may lead a doctor to believe a young girl has Turner’s, conclusive verification is made through a procedure called karyotyping. In karyotyping, a photograph of the chromosomes is taken; the chromosome images are cut out and arranged on a sheet of paper according to their size and other criteria revealing abnormalities in chromosomal structure.

Because the ovaries of women with Turner’s Syndrome are usually streaks of connective tissue and are nonfunctioning, they are unable to produce ova (egg cells) or secrete estrogen and progesterone. In order to emulate the natural maturation process many Turner’s women choose to take a hormone supplement. Hormone replacement therapy using estrogen in combination with progesterone is beginning to replace hormone replacement therapy using androgen. In this new form of therapy, a very low dose of estrogen is administered at the age of 10. Evidence suggests that a low dosage at this point enhances the girl’s growth rate. At age 12 the estrogen dosage is doubled in order to promote breast development and pubic hair growth. At 14 the dosage is again doubled and is given in cycles; progesterone is given in combination with estrogen. Menstruation then begins; however ovaries and eggs do not develop.

The impact of long term daily use of estrogen is a concern to many Turner’s women. The benefits and risks of estrogen replacement therapy (ERT) need to be taken into consideration. While ERT among menopausal women has been associated with cancer of the uterus, recent evidence suggests that progesterone given in conjunction with estrogen provides a protective effect. Of the 10 cases of endometrial cancer reported in women with Turner’s, in all but one progesterone was not given. Estrogen is also believed to be effective in the prevention of osteoporosis, a disease affecting primarily elderly women in which bone brittleness can lead to height loss.

Of all the chromosomal abnormalities, Turner’s Syndrome is among the least severe. We do *not* suffer from mental retardation! Our life span is not shortened! *We can live happy, productive lives.* All of this is not to minimize the very real and sometimes painful psychological affects related to the medical and physical aspects of the disorder. The prominent features —

short stature and infertility — seem to be the hardest to deal with.

Women with Turner’s Syndrome are governed by the same genetic laws as the rest of the population. Therefore, those with tall parents tend to be taller. Their average height is that of an eleven year old, four feet, ten inches. A “normal” child is usually 20-21 inches at birth, and grows approximately 12-14 inches in the next two years. From two until puberty the average growth rate is about two and a half inches per year. At puberty there is a growth spurt which lasts until adult height is obtained. A child with Turner’s Syndrome is usually about 18 inches at birth, and does not go through the normal pubertal growth spurt.

Because age is frequently associated with height, Turner’s women often find themselves treated as younger than their chronological age, particularly in early childhood and adolescence. Adolescence is an especially difficult period. When you are 17 and look 11, socializing is awkward.

A common complaint adults express about their height is the lack of credibility they receive from their families and employers. They describe a feeling of having to try harder in many aspects of their lives in order to be taken seriously. As one woman told me, “It’s hard for a woman who is four feet, eight inches to look up to someone who is tall and be assertive.” Of course there are every day reminders of our short stature. Frequent annoyances such as sitting on a seat where feet dangle, struggling to see your full face in the mirror of a public washroom, and problems in fitting clothes remind us that the world is built for individuals who fall within the normal height range.

I have observed a tendency among many Turner’s women to see themselves as “little girls,” even as adults. The “little girl” self-image makes it difficult for some Turner’s women to overcome the barriers and prejudice they encounter.

Infertility is another painful aspect of Turner’s Syndrome. Female infertility is most commonly the result of blockage of the fallopian tubes. Turner’s related infertility results from incomplete development of the ovaries, resulting in failure to produce ova. I have been told that infertility is “not so awful;” that “many women choose not to have children.” This attitude pro-

*"I'm afraid that anyone
I'm involved with will
eventually throw me
over for someone
who is physically
more beautiful, that in
the end I'll always
lose out."*



vides little consolation to women who desire children. Loss of choice in child-bearing seems an unfair violation of our natural rights.

On a more positive note Turner's women understand why they are unable to have children. To us infertility is not a sudden shock which, under other circumstances, might cause enormous tension. We do not endure the agonies of fertility testing and the almost endless uncertainty of waiting for possible fertile periods.

Another source of concern for Turner's women is lack in development of secondary sex characteristics. Turner's women may feel that their sexuality and their capacities for achieving fulfilling, satisfying sexual relationships are limited as a result. Some feel that because they have developed differently, they will be rejected by potential romantic partners. Estrogen replacement therapy helps Turner's women develop physical features and secondary sex characteristics similar to other women.

Women with Turner's Syndrome need accurate, thorough information and support. For anyone afflicted with a rare disorder such as Turner's, isolation commonly results. Because only one out of every twenty-five hundred women are diagnosed with this condition, it is conceivable that a Turner's woman may go through life never meeting another Turner's woman.

A few years ago a woman approached her doctor with a request for assistance in organizing a Turner's support group in Toronto. He refused assistance on the grounds that she was not stable enough to undertake such a project. He neglected her personal needs and those of other Turner's women for such a group. The woman committed suicide.

This tragic incident and others like it illustrate the need for a group to address the concerns of Turner's women. The Turner's Syndrome Society of Canada was founded in 1981 to provide the Turner's population with a forum for mutual support. Staffed by Turner's women, the society offers educational sessions and self-help groups for women and their families. The central goals of the society are to reduce isolation, disperse medical information, establish medical support and undertake public education.

Small self-help groups have been effective in reducing our isolation. Misinformation can be corrected in the

informal, non-threatening atmosphere of self-help groups. We rely on peer counselling in our groups. There is no pretense of practicing psychotherapy, which is generally not necessary.

Gaining accurate medical information is important to Turner's women. A major complaint I hear from women and their families is that the medical terminology of much information written about Turner's is difficult to understand. The society has prepared a booklet, *The X's and O's of Turner's Syndrome*, a discussion of Turner's Syndrome. The booklet outlines medical and emotional issues in easily understandable terms.

Providing accurate information to the public is equally important. This became apparent to me recently when a woman who had learned she was carrying a Turner's fetus contacted the Society. She asked me, "Is my daughter going to be a monster?" and "Is my daughter going to hate me for the rest of her life?" I tried to explain that although we are all different, for the most part women with Turner's Syndrome are productive, happy adults. I told her problems often arise for Turner's women because of low self-esteem, but that with support and understanding these problems may be overcome. This woman chose to abort.

The first practitioner this mother saw gave her a list of the most severe medical and physical problems that could arise. It's no wonder she visualized a "monster." Parents deserve to be told of the positive aspects of Turner's Syndrome.

Disclosure is another important issue we deal with in our work at the Society. Because imperfections and sexuality are generally taboo subjects in North American culture, disclosure does not come easily to families of Turner's women and to those with the condition. Parents major concern often centres around what age to tell their children and in how much detail. At the Turner's Syndrome Society the general consensus among the parents we see is that information should be gradually shared early on, so that the child can begin to understand her condition. We feel a suitable age to ensure the child grasps the *full* implications of her condition is in early adolescence when female bodies undergo rapid change so that she may begin to make an informed choice about her course of treatment. We urge parents *not* to wait

until their child asks questions about her short stature or lack of development. The manner in which the child is told is important. We recommend an informative, supportive approach.

Whom the woman chooses to tell is her prerogative. Confiding in friends and relatives may be difficult. The Turner's woman needs support and acceptance, and recognition of her feelings of anger, frustration, sadness or grief.

The Turner's Syndrome Society is also involved in activities to increase our organizational visibility and accessibility. We sponsor an annual conference at which current medical research is presented by healthcare researchers and practitioners. We utilize small group discussion, videotapes and slide-tape shows at these conferences, as well as at other public forums and educational sessions. In addition to our booklet, we publish a quarterly newsletter to keep our members informed of the society's activities and medical developments, and to provide a forum for the sharing of emotional concerns. Readers often send in responses to one another's articles. We also have a library that

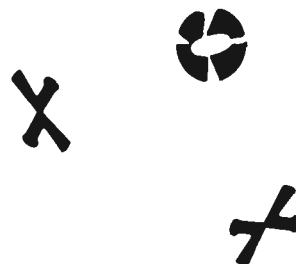
contains material on assertiveness training, women's issues, self-help and medical information.

While Turner's women are finding ways to support one another and increase social acceptance, medical changes may soon have an equal or greater impact on our lives. With the advent of in vitro fertilization and embryo transfers a Turner's woman may someday be able to carry a child in her womb. And experimentation with growth hormones may help to increase our final height.

Susan Charney is the co-ordinator of the Turner's Syndrome Society in Toronto.

Terry Hoooven is a freelance writer and a volunteer with the Turner's Syndrome Society.

For further information about the Turner's Syndrome Society of Canada contact: Susan Charney, the Turner's Syndrome Society, Administrative Sciences Building, Room 006, York University, 4700 Keele St., Downsview, Ont. M3J 1P3, (416) 667-3773.



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CENTRE STAGE:

Life as Little Miss Easter Seals



Today Lina Chartrand works for Pelican Players, a multicultural, neighbourhood theatre troupe in Toronto. Pelican Players dramatically links the personal and political in its plays. The personal-political connection is not new in Lina's life.

The article which follows reflects Lina's experience as a child with polio. In 1949, at the age of 16 months, Lina developed polio; 11 years later she had the dubious honor of being one of Canada's "Miss Easter Seals." She was encouraged by Easter Seals campaign officials to use her crutches, even when she didn't greatly need them; her responsibility was simply to "look crippled."

I nursed her till she was five months old but I never liked it so I put her on a bottle after that. They say a breastfed baby has more resistance to disease. It's a wonder I did it at all, I hardly breastfed the boys, just a few weeks.

She was strong. She was so smart, she could walk at 12 months and she was out of diapers. There was no holding her back, she was everywhere. She was a bit chubby, chunky little legs, she was so cute. My husband played with her, god how he played with that one.

I was lonely in Timmins. My husband had brothers and sisters here but I had no sisters, nobody here, just old Madame Blanchard, my mother's cousin. She was good to me. I can never repay her for what she did.

The year Lina got polio there was a big

flu going around. At first I thought that's what she had. I called the doctor, Docteur Clairmont. He was being run off his feet with sick babies. I was sure there was more wrong with her than just flu.

It started like a bad flu, she slept a lot, she felt hot and feverish. After three days she stopped walking, she couldn't hold her neck up.

This time I was crying when I called the doctor, the telephone operator wouldn't talk to me in french; in those days they weren't allowed to talk french even if they could. She kept saying the line was busy and I kept trying to say it was an emergency in english.

Finally I called the police and they came over with the doctor. He knew right away she had polio. We rushed her to Toronto by airplane.

Mother's Monologue



She was afraid of everything. In Toronto, she wouldn't let them X-ray her. It took about six people to hold her still. She was afraid of that X-ray machine; it was big. She screamed and screamed like they were trying to kill her. I couldn't stand to hear it. She was impossible.

She just wouldn't calm down. Even after when she re-learned to walk, even though it took a long time, she crawled and skittered about so fast, she was always getting loose from me.

The polio paralyzed her. Slowly she got back the control over her muscles, but some stayed weak. The Toronto doctors gave me exercises to make her do in Timmins. She always refused to do them.

The doctor said it was important. Who knows, she might not have needed to have operations, she might not have gotten so crooked in the spine if I could have got her to do those exercises.

What could I do? She said it hurt and she was so hard to control.

I was dead, I was nervous, I had the big liver operation. I missed my mother that year.

I wonder why she got polio when she was such a healthy baby and I did everything good for her. I remember once I caught her eating peaches that hadn't been washed. I thought that might be how she caught it. She got needles and boosters, she had got them all. Other kids in town who got polio ended up in wheelchairs or blind, she was lucky to be able to walk.

Over the Rainbow



In 1960 I was chosen to be Little Miss Easter Seals and to go on a tour of the Porcupine area with Whipper Billy Watson. When the campaign was announced, he flew up to Timmins for a TV interview in our living room on Preston Avenue.

He sat beside me on the old green couch, beside my mother's beautiful big fern. The camera and sound crews were all over the room and pouring out the front porch.

The Whipper talked about giving the handicapped more opportunities for jobs and education. I did very well answering the questions about my age, school grade and how I felt grateful to Easter Seals. My foot was in a cast and my crutches leaned against the couch beside me. I was shy but proud, slightly precocious and I had a beautiful sweet smile.

The Whipper never spoke to me privately. We played our roles. No one ever told me what to say or how to smile.

Easter Seals funded the Kiwanis Club in Timmins. This organization paid the train fares for my mother and I to travel to

Toronto for my operations. The Easter Seals campaign lasted several months, covering many events including a Christmas party, a tour of high schools, a banquet at the Empire Hotel.

The Whipper flew up to the Porcupine twice, first to do the TV interview to launch the campaign and several months later for a couple of days of speeches and banquets. I handled the other gigs on my own, assisted by my mother, Public Health Nurse Miss Collins and Kiwanis volunteers. I never really had to do much but smile, answer questions about my age and grade and say something like 'Please give to Easter Seals,' or even just 'Please give' was fine.

An event I especially remember is a Kiwanis-sponsored fundraising variety show of local talent at the Dante Club. There were cute little girls tap-dancing, teenagers who played the violin or the piano, and a men's barbershop singing group. Each act had its own sets of backdrops, white benches, flowers. Everyone was english; I was french.

I made my first stage appearance with the Krakana Sisters. The three sisters wore identical long bouffant dark hair with an Annette Funicello flip and flared dresses. They sang a number of songs appropriate to sister singing groups like *Sugartime* and it was while they belted out *You've Gotta Have Heart* that I came on stage on my crutches and sat on the white bench near them. The Krakanas then moved to the other side of the stage and sang *Somewhere Over The Rainbow* and sang *Somewhere Over The Rainbow* to me amid multi-coloured light effects. It was a hit and the applause lasted a long time.

They never said a word to me backstage. Maybe they thought I didn't speak English, that all I could say in English was "please give to Easter Seals." I told them their singing was nice but all they said was "oh, thanks."



No Union

On one of my first train rides, Maman was afraid of the black porters. She'd only seen one or two black people. We couldn't get hot water in our roomette so she buzzed for the porter. He ran the hot water for a long time feeling the temperature with his fingers. Maman was trying not to giggle. She imagined he was trying to wash away his blackness but he never got any whiter.

I was afraid. People stared at me when I walked to breakfast on my crutches. I wouldn't look at them. I tried to be quiet. Maman complained about how much the food cost on the train. It drew attention to us. I hated it.

I'm sleeping in an upper train berth. I can hear people walking back and forth on their way to breakfast. The night has been long. I can't tell if it's light or dark, no window up here. The butter-scotch soft blanket keeps me cozy, the

rocking keeps me snoozing. I'm in disguise. No one knows who I am. I'm an Eaton's catalogue model. I'm a child actress. I'm travelling by myself. If Maman talks to me, I won't answer her. She just wants to ruin my fun. If Maman wasn't here, they wouldn't know I'm French, they wouldn't know I'm from Timmins.

The train forms a tunnel between two realities for me now. Along the way there are shelves of experience leading out of the old way of life. It is a maze. You could end up right back where you started. There is little to see out the window: snow covered trees, desolate huge empty lots frozen with dead cars, small cabins dilapidated so you don't want to look inside, shabby motels, rocky roadsides with blast scars. Cold, 50 below.

No union.

I am interested in hearing from other women who have had polio. I can be contacted through Healthsharing.

Lina Chartrand has been an administrator for Pelican Players for three years. She is currently writing a performance piece about her experiences as Little Miss Easter Seals, funded by Canada Council. She lives in Toronto.

Tonight I put Maman on the train to Timmins and I walked away, out of the station, to my home in Toronto.

I walked out of Union Station, away from Gate 9, along the other departure gates, past the line-ups, up the ramp leading to the main part of the station, past the magazine kiosk, towards the big clock in the middle. The loudspeaker voiced the names — Gravenhurst, Noranda, Kirkland Lake, North Bay, Cochrane, Timmins.

Between Gate 9 at Toronto's Union Station and the Timmins train station, the world is transformed. In between is lots of darkness, sometimes rocky bedpans, motion sickness, chocolate bars. Early in the morning when I hear a long train whistle, I am back on that train between Timmins and Toronto, between home and Sick Children's Hospital.

Population and Politics

by Anne Marie Smart
drawings by Ruth Jones

In August, I was one of nearly 3,000 government and non-government people who attended the Second International Conference on Population, a United Nations-sponsored event held in Mexico City.

I thought the conference would be my first opportunity to see feminists and government delegations from around the world, including Canada, grapple with a wide range of population problems — women and health, reproduction, fertility, maternal and child mortality, to name a few.

My euphoria at being a bit player on this international stage quickly evaporated. As I sat in one of the eternal traffic jams in Mexico with pillars of black smoke spewing more pollution into a city which ranks among the most polluted in the world, I realized that most of the crucial population issues were, for the most part, being subsumed by political grandstanding.

As the eight-day conference wore on, bickering on issues ranging from settlement policies, nuclear disarmament, free market versus state controlled economies and abortion threatened to derail the conference and deflected world attention from population issues.

The conference opened auspiciously. On a rainy Sunday afternoon about 150 non-governmental organizations (NGOs) gathered for the first briefing from UN officials. Crowded in a small room was a cross-cultural blend of faces from many races. Some name

tags were familiar —the Pakistan Women's Association, Associated Country Women's Association, and a whole range of population institutes, for example.

Others were less expected. What role would Couple to Couple League, Club of Life, International Federation for Family Life Promotion, International Secretariat of Catholic Technologists, Agriculturalists and Economists or the Inter-American Association of Broadcasters play at this conference?

I was one of a group of seven Canadians representing a wide diversity of 11 Canadian NGOs interested in population, from Planned Parenthood Federation of Canada, the Ontario Conservation Council, the Manitoba Council for International Co-operation to the National Survival Institute.

As the briefing in the airless room wore on, however, the first ominous signs emerged. We were strictly told that this conference was an inter-governmental affair and that our presence and participation was neither wanted nor needed. In short, we were to be grudgingly accommodated in Mexico.

This attitude differed sharply from the experience in Bucharest in 1974 at the First International Conference on Population. There, NGOs and women from around the world lobbied to influence the outcome of the conference. Headlines from the 1974 conference told how women "through determined lobbying and political finesse succeeded in inserting a strong women's

liberation clause in the cornerstone document of the conference, the World Population Plan of Action."

Government and UN officials alike viewed '74 as a positive experience. In growing shock I listened as the rules for the '84 conference were outlined. There were stringent guidelines on the dissemination of information. For example, we would not be allowed to distribute "propaganda," public relations documents or materials that criticized a government by name or were likely to be offensive to governments. That rule led to a ban on distribution of my publication, *Tellus*. I protested the proposed censoring of a single offending sentence that mildly criticized the UN Fund for Population. Assisted by a little media clout and backing from the Canadian government, UN officials relented and allowed the magazine to be distributed.

Further, we were told that seating space for NGO representatives was virtually non-existent. For the main plenary, where each nation delivered its policy statement, names were drawn from a hat for the few seats at the back of the room. In the main committee, where most of the slogging work to write the 88 eventual recommendations was carried out, we were allowed to sit on the floor at the back of the room without translation services for any of the dozen languages heard in the room.

This attitude continued throughout the conference. In a statement to the Canadian embassy, Marilyn Wilson,

co-ordinator of the Canadian Task Force on Population and Executive Director of Planned Parenthood Federation of Canada, asked why NGOs were blocked. "We are puzzled by a seeming contradiction. Many governments, our Canadian delegation included, have paid tribute to NGO activities and acknowledged our role, stature and expertise in population. Yet neither government nor the United Nations has encouraged a full participation in this conference.

"Why is there so much paranoia on the part of the United Nations to our participation when the previous experience in Bucharest (in 1974) is seen as positive?"

In the opening statement to the plenary, Canada placed NGO involvement first. "Canada recognizes fully that NGOs have unique contributions to make to development," Senator Lorna Marsden told the delegates. "Their innovative capacity and their understanding of issues and constraints at the grassroots community level enhance their vitality in the planning and implementation processes." Canada's voice and those of a few other

specific reference to improving the role and rights of women.

Laura Sundberg, a Woman in Development project officer with the Manitoba Council for International Cooperation, chaired what she describes as a "determined group of over 50 women and men" who milled in the hallways button-holing any government delegate they thought might be sympathetic. Zimbabwe was the first to propose an amended recommendation putting population issues in the wider context of women's concerns; Canada was among the first countries to support it. Recommendation 5 approved by the conference reflects the efforts of the group and reads in part:

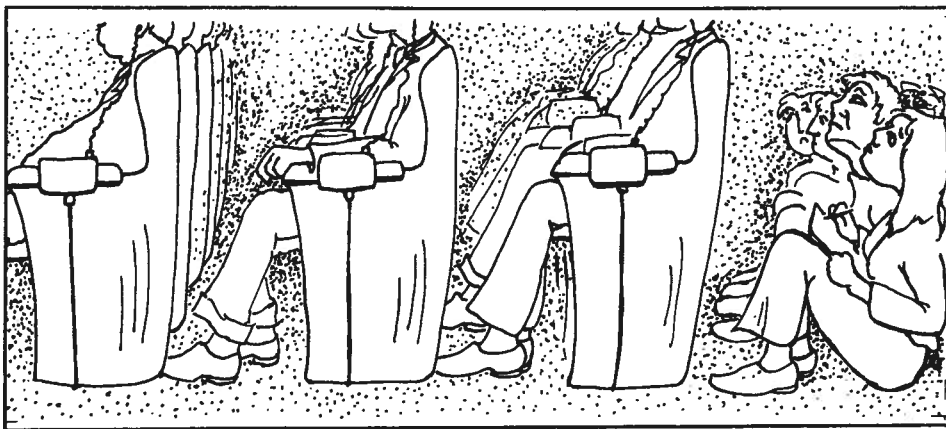
"Governments are strongly urged to integrate women fully into all phases of the development process, including planning, policy and decision-making. Government should pursue more aggressively action programmes aimed at improving and protecting the legal rights and status of women through efforts to identify and to remove institutional and cultural barriers to women's education, training, employment and access to health care."

role of women and participation by women in decision-making are prerequisites to the development of appropriate and effective policies."

Yet neither Canada nor other countries pointed out the seeming contradiction of this particular conference — if women were most directly affected by all the issues at this conference, why were so few women present to debate the issues?

Canada's 10-member government delegation, led by Marsden, was one of the few delegations from either developed or developing countries with a woman representative. In fact, only 51 women were among the 333 delegates from the 76 countries sampled by "NewsMexico '84," the NGO tabloid published throughout the conference. It added: "Of the 76, 41 had no women representatives at all and on only eight do women equal or outnumber men."

The federal election took Marsden back to Canada after only two days, leaving behind a delegation made up primarily of government bureaucrats from the departments of External Affairs, Statistics Canada, Health & Welfare and Status of Women, most of them men.



We were allowed to sit on the floor at the back of the room without translation services.

nations, however, did not extend to protesting the treatment of NGOs at the conference.

Despite the obstacles, NGO women managed some small victories. In draft versions of the conference report, "Status of Women" was only mentioned in the context of procreation and family formation in a section entitled "Reproduction, the Family and Status of Women." The other 87 recommendations in the document relating to health, nutrition, family planning, education, contraceptive technology and aging contained no

One similarity that struck me was that in '74 feminists waged a hard battle to get one small mention of status of women in the population plan. Now, nearly 10 years and supposedly many gains later, women were again struggling against the odds to get official acknowledgement of the link between population, economic development and equality.

Canada's statement at the conference attached great importance to the status of women: "Women are directly affected by all the issues on our agenda at this conference," Marsden noted. "Recognition by policy-makers of the

By mid-week of the conference, the victory on status of women seemed to have gone unnoticed and attention shifted to the roadshow provided by the U.S. delegation. As too often occurs at conferences, journalists and delegates alike became enmeshed in the machinations of the anti-choice movement.

The six-member all-male U.S. delegation, led by Republican Congress representative, James Buckley, vowed to curtail funds to countries that "promote" abortion. Further, it called U.S. efforts of the past two decades an "overreaction" and said the real cause of population problems is "governmental control of economies" and the solution is free-enterprise capitalism — "the natural mechanism for slowing population growth in problem areas."

If implemented, the U.S. policy would cut as much as \$100 million from the \$240 million the U.S. now contributes worldwide to family planning programs. It could also signal other budget-cutting governments to adopt similar policies.

Not only was this position a complete reversal of long-standing U.S. com-

mitment to assist family planning in the developing world, it was viewed by many papers as President Reagan's pancea to the anti-choice movement in preparation for the upcoming election.

"The final irony," said U.S. columnist Georgie Anne Geyer, "is that the poor mother in the hut in Mexico, looking for some help, has more sense — immeasurably more sense — than the ignorant people Ronald Reagan plans to send to Mexico. Birth control and abortion may be criminal to his representatives; but they approach the truly criminal in far more profound ways."

The U.S. managed to shunt the population issue aside for most of the week. One week into the conference a second U.S. delegation arrived and threatened to prevent the Reagan administration from carrying out its policy. The second group of six included a Democratic representative from the Congressional Women's Caucus who voiced her "distress" that no women were included in the Buckley group.

Canada appeared to take issue with the U.S. but, in fine Canadian fashion, did not take on the U.S. directly. In her speech, Marsden reaffirmed the right of sovereign governments to develop their own national policies in relation to family planning. "The Canadian Government supports a voluntarist approach to family planning in both its foreign policy and international assistance," she said. "Canada has funded projects containing family planning elements and will continue to do so."

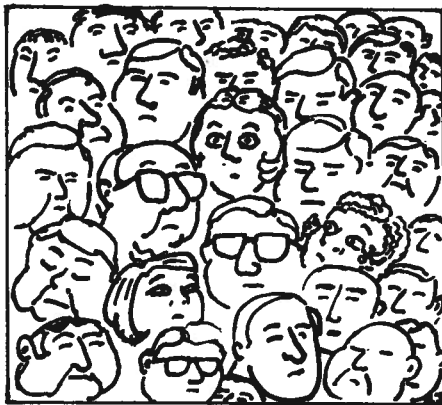
Later, at a news conference, Canada lost another opportunity to make an international pro-choice statement. Asked repeatedly by Canadian journalists whether Canada was criticizing the U.S., Marsden was firm. "Abortion is not really an issue (for Canada) at this conference," she said. "We see other aspects such as clean water and education as far more fundamental than abortion when it comes to population control and economic development. These have been Canadian positions for decades."

Perhaps the only feminist statement at the conference came from the Swedish Minister of Health, Gertrud Sigurdson. In a strongly worded speech, she called for access to safe contraception. "Effective contraception liberates women from unwanted

pregnancies and induced abortions and improves considerably the health of both mothers and children. Prevention of unwanted pregnancies must always be our aim."

Then, in what appeared to be in direct opposition to the U.S., she added: "I note, however, that illegal abortions, performed under unsafe medical conditions, is a very serious health problem in many countries today. Therefore I would like that all women in the world have access to legal and safe abortions."

It was by far the strongest feminist and anti-U.S. statement I heard at the conference. Perhaps the Third World



Why were so few women present to debate the issue?

felt they had too much to lose if they criticized the U.S., but developed countries also shied away from confronting the U.S. head-on on this issue. Not once during the conference were the word "feminism" or issues of concern to women and health discussed.

Feminist principles were absent in part because women didn't attend the conference, but also because no forum was allowed for NGOs or individual feminists. As the conference wore on, some NGO delegates turned to their colleagues to see how they felt. It turned out that many groups were in Mexico with their own agendas.

Behind those innocuous looking name tags I'd noticed at the first briefing lurked many anti-choice groups. Couple to Couple and Club of Life grabbed an overwhelming amount of attention with their staged demonstrations outside the conference centre.

Club of Life delegates marching through Mexico City to a shrine outside the city protested that the conference was taking place at all. "We don't think population is the real problem of development. What we need is technology and credit," one delegate told reporters.

Even more upsetting was the omnipresence of the Holy See. My initial surprise that the Catholic Church was given a seat as an equal to other countries was replaced by rage and frustration as the Holy See "consented" to attend the daily morning NGO briefings.

By taking more than the allotted 45 minutes of the meeting to explain the Catholic views on contraception, abortion and sterilization, no time was left for the NGOs to exchange views or share strategy for strengthening the plan of Action, the conference's main legacy for the next decade. Disturbingly, not one NGO in the daily briefings complained about this shabby stifling.

I walked out of the briefings in disgust, wondering why equal time was not given to other major religions from around the world. I was not surprised to discover that the Moslem faith, for example, did not have status equal to that of the Catholic Church. Was it not a conflict of interest for the Catholic Church to participate in a population conference, I wondered?

I emerged from the conference drained, with a document containing 88 vague recommendations couched in UN jargon and a Mexico Declaration equally as vague. We were instructed to return to our countries, filter the information to our groups, construct programs for addressing population programs and urge our national governments to become involved.

Judging from the politics played in Mexico, this would be an impossible task.

Anne Marie Smart is the managing editor for Tellus, the publication of the Planned Parenthood Federation of Canada. She lives in Ottawa.

MY STORY, OUR STORY

My story. our story is every woman's experience — our collective experience — with health.

Coming Home

by **Connie Clement**

I am home. *Really* home. And goodness, how good that feels. After years without roots, years without a home, daily now I return to my home, a tiny cottage surrounded by water, enough water to hold the city at bay, and I marvel. I am flooded with thanksgiving as I pause between the dock and my front door to listen to the water lap the shore. I sigh with pleasure.

As I begin to understand the importance of home, I think about what it has meant in my life to be homeless. All my life I've used the word "home"; I've used it lightly, casually, used it to mean anywhere I've been temporarily parked. Anywhere from the office after lunch, a hotel during a conference or a comfortable and warm apartment which housed me for years. None, I now realize, were home.

Oh, I didn't recognize that I was homeless, and I have never been homeless in terms of being on the street. Rather, I share with many people of our time an absence of roots. I grew up in only three houses, few by current standards: an old, rambling house with a porch big enough to hide children underneath and all the garter snakes we could hope to catch, a tiny post-war bungalow where I could watch the drive-in from across the freeway after my parents put children to bed, and from the age of ten onward, a suburban house surrounded by trees and quiet. Armed with Consumers Reports and a Yankee frugality my parents sought durable comforts neither of them had as children. They succeeded, for their house is both friendly and attractive. Yet I have no sense of special personal belongings; I do not know what either parent would grab in case of a fire. My mother's home lies in her dogs; my father's home lies in nature and more recently in painting; and, for each of them, in each other, in children and in friends.

And that is what my home has always been. Friends. Ten months after moving to Ontario, I went overseas for an indefinite period. I remember the sheer terror in me at going — not because of going, but from knowing that if upon my return to Ontario I did not find a welcome then I would be without a place in the world. Holly Near's song, "Coming Home," always stirs the memory of that fear. When friends move away the walls of one's emotional home are weakened. Now those walls are buttressed by the existence of a geographical spot in the world to which I can come home to roost.

The ocean, perhaps my most encompassing, life-long friend and lover, always has offered a space for solace, for healing — a temporary home. Salt water flows within the rich red of my blood. A dozen years ago I wondered how my newly-made Ontario friends who had never seen the ocean had managed to continue living so long. Now, as I begin to know the lake around my home, I know it will become the little sister, the less passionate friend who will give me pleasure each day. And I learn that I might stay alive without the ocean here.

I am lucky enough to have had a spiritual home for much of my life. A retreat out of Nirvana, sitting on the edge of the ocean in Maine. Thanks to the generosity of a dear friend, I have known absolute peacefulness and safety for several weeks a year. But always I must travel there; always I must leave there long before my heart can bear it.

Home has been transient, a state of being known for moments, for hours, for a three week stretch. Now as I settle into home full-time, I watch my body relax, I can see a part of my future beyond a couple of years. I am offered a stability that allows me to centre my days, my soul, my politics.

Exploring my new-found stability with friends, I have been asked if my sense of longevity does not stem simply from ownership. Without doubt, private ownership entails status and achievement in Western cultures. Culturally speaking, ownership is a home-coming of sorts. But is it for me?

To think that this value might be so embued in my thoughts and desires

as to be invisible frightens me. As a feminist I have been forced to soul search. Ownership, I have concluded, was not central to discovering home. Although at the moment my home is centred in the particular house I am rebuilding with my close friend and co-owner and in which I hope to live for many years, when I think of getting old I think of living on the island; I do not think of my particular house.

The irony is that I should have found my home now and that home should be on Toronto Island. I wasn't even looking for a home — I moved to the island because Alison was determined we would live here. Oh, don't get me wrong; I thought it would be lovely to live here, but exactly where in Toronto we lived wasn't critical to me during house-hunting time. As well, the winters, the travel, the legal instability of the houses and community all made me hesitant.

The surprise was on me! Within weeks of living here I was home, home for the first time in my adult life.

The irony is doubled because of the legal and political struggle for the island community to survive. Unjustly the courts recently decided that Alison and I, and all our island neighbours, don't own the home we have bought and are repairing; basic renovations, which we are legally responsible to make, have put us in debt; the Metropolitan government is entering arbitration to set rents on land and houses. Obviously my sense of longevity reflects belief more than objective reality.

Yet, home has come into my life this year. I did not create this home; a home has opened up around and in me. And I find a health settling in even as I struggle to balance the magazine, a full-time job, renovating and friends.

I am home. A ship has come in. And I will fight to keep this ship in harbour and grow old in my new-found home.

Connie Clement is a member of Women Healthsharing who moved in September, 1983 to one of 250 houses on Toronto Island, a ten minute ferry ride from downtown.

REVIEWS

Abortion Re-Examined

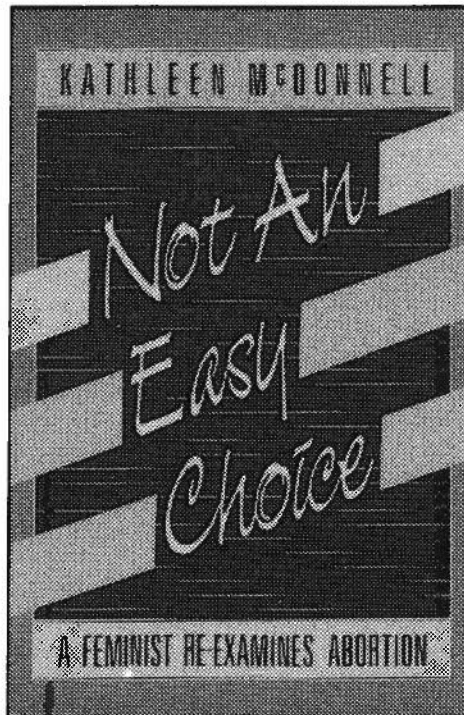
Reviewed by Ellen Monk

Not An Easy Choice: A Feminist Re-examines Abortion, Kathleen McDonnell, *The Women's Press*, Toronto, 1984. \$8.95, paperback

My logic sometimes differs with my intuition on the topic of abortion. Even after arriving at a carefully thought out pro-choice position, I still have doubts. For me, Kathleen McDonnell's book is a burst of relief. It is a brave book which tackles issues many pro-choice feminists have not allowed themselves to speak of. McDonnell talks about what makes us uneasy about abortion and strengthens the pro-choice position where it has always been weak.

For too long women's grief and doubts about abortion have been discussed mainly by the anti-choice movement. Many pro-choice people have been so busy fighting the opposition that they have not gone beyond the issue of "choice" to look more deeply at the moral aspects of aborting a conceptus. And for good reason, as this is an area which the anti-choice movement has used to attack women's freedom to choose. But admitting that abortion is an experience which causes grief to some women is not a weakness in the pro-choice argument. McDonnell looks at this aspect of the abortion issue which has traditionally been the domain of the anti-choice movement and makes the base of feminist reasoning, which supports choice, broader and stronger.

The lack of acknowledgement and discussion of the moral aspects of abortion on the pro-choice side of the issue probably stems from the nature of the abortion debate. As McDonnell points out, the two sides are uncompromisingly polarized. While one side argues apples, the other argues oranges. The basic reasoning of the choice position is that a woman's rights outweigh those of an embryo or fetus and that women can and must be trusted to exercise their own moral judgement on the issue. The central theme of the anti-choice ethic is that from conception the conceptus is the equivalent of a human being and should not be destroyed under any circumstances. In both cases, the reasoning is



limited to one dimension — "rights" of the fetus on one side, and the woman on the other.

Obviously, as McDonnell points out, our ethic of abortion must be re-examined. Women experience post-abortion grief and this is not being addressed by feminists. Their feelings have been exploited by the opposition who define the grief as mental illness or regret. McDonnell links the wide range of emotions women go through after childbirth with the same ambivalent feelings some women experience after an abortion.

When feminists like Emma Goldman and Simone de Beauvoir included the pro-choice idea in their argument that women could not improve their status until they controlled their fertility, a woman couldn't see a fetus on an ultrasound screen and the technology for "selective abortion" wasn't available. Their reasoning is still the bottom line on the issue, but McDonnell expands feminist thought on reproductive choice to include changes in science and society which are making the abortion issue increasingly complex.

Before technologies such as ultrasound came into widespread use, abortion was something of a non-decision. The embryo or fetus was not tangible and it was easy to argue that a woman's rights should be respected above the rights of this potential life. Fetal rights are not the only concern in the abortion issue, as the opposition claims,

but we must begin to look at the fetus as more than just a blob of tissue.

How does our concept of choice fit in with the decision to abort "defective" fetuses for example? McDonnell answers this by pointing out that we have been asking the wrong question on these issues. Instead of asking if the fetus *should* be aborted, we must ask ourselves how we can ensure that a genuine choice exists for women in these circumstances. A feminist ethic on abortion must include the right to choose to keep a pregnancy. Women should not feel coerced into terminating a pregnancy because they want a child but don't have the money to support it or feel that there is not enough financial and emotional support to bring a child with Down's Syndrome into the world.

Abortion is an issue of self versus other and women have traditionally been made to feel that they must put their needs second to those of others. McDonnell makes no bones about the underlying attitudes toward women which the right to life movement entails.

But we cannot ignore the fear some right to lifers express that by allowing abortion, we are chipping away at the intrinsic value of life. McDonnell doesn't offer any solutions to these fears but it is good to see her acknowledging them.

Feminists must maintain their independence but at the same time make room to include the fetus and the father. Women are encouraging men to take more responsibility in contraception and childcare. McDonnell points out that there is no role for men whose partners are going through an abortion experience other than the "supportive male" role.

Her comments on artificial reproduction are very insightful. Technologies like in vitro fertilization, embryo transfer and artificial wombs, will free us from the limited concept of the traditional nuclear family. But leaping toward new reproductive technologies may also be an indication of our fear and distaste of biological nature. In artificial reproduction, abortion, birth control and childbirth, women's bodies are on the line. McDonnell points out that women don't want the capacity to reproduce taken away. They simply want control over reproduction themselves.

McDonnell raises some thought-provoking questions, most of which can't be answered. Her discussion on

issues such as fetal viability and male involvement are well thought out but it is in the final chapter, where she makes her ideas concrete, that the book becomes most exciting.

McDonnell makes a strong case for control over our bodies in birth, abortion, and contraception. She suggests establishing reproductive health centres run by women. Such health centres would include services such as lay abortion and midwifery. Childbirth, abortion and contraception are all part of our mental and reproductive health. If women are going to accept and consider the new aspects of abortion which she discusses in this book, then they must have a supportive atmosphere where they can make genuine choices about these issues.

Ellen Monk lives in Ottawa and is the English editor of Tellus, the journal of the Planned Parenthood Federation of Canada.

Transcending Cultural Boundaries

Reviewed by Barbara Lamb

Abortion: Stories From North and South, Produced by Gail Singer, 16mm, colour, 55 minutes, 1984. Distribution information available from the National Film Board of Canada.

"I think it is something which women press down and hide, because you can't share the experience." This is a Japanese woman's description of the experience of abortion. She and a group of friends speak of the isolation of women in their society, bound as they are by ancient traditions of formality, deference and silence. But the silence has been broken. In Gail Singer's remarkable new documentary, *Abortion: Stories from North and South*, women around the world speak eloquently of pain and of courage. They tell stories of abortion.

Like *Loved, Honoured and Bruised*, Singer's moving account of one woman's struggle to leave an abusive husband, *Abortion Stories* upholds the mandate of Studio D of the National Film Board of Canada to produce films from the perspective and experience of women.

Abortion is a subject with which all women are intimately involved; if we

have not had an abortion ourselves, we usually know someone who has. But often the immediacy of the experience is lost or overlooked. We sacrifice our subjectivity when we consider abortion solely as a political issue.

And therein lies the freshness and value of Singer's film. It both expands and personalizes. The anthropological view of abortion allows us to lift our vision from the confines of the inequitable Canadian situation (though it is in fact featured in this film). We see abortion as a global event which occurs 30-55 million times a year and which has transcended race, religion and boundary to remain one of the oldest forms of population control.

The film also treats abortion in an anecdotal manner. We cannot help but be touched by the candour and courage of each woman as she tells her own story, an approach which makes the subject ultimately accessible.

One of the most striking points of the film is that abortion continues to be practiced, despite moral and legal constraints. This is illustrated by vignettes of women's lives in Ireland, Peru, Thailand, Japan, Canada and Columbia, all countries where abortion is either illegal or strictly controlled.

In Ireland, where paradoxically both abortion and contraception are unlawful, Gina Oxley kneels before a statue of the Virgin in the Church of the Immaculate Conception before seeking out a referral to an abortion clinic in

London. While being counselled Gina is fearful of exposure; her courage in re-enacting her story for the film is striking.

In urban Peru, backstreet abortions are common. Juana Alvarado tells of police visits to hospitals to arrest women following treatment. There is a scene of a women's prison, where children accompany their mothers because there is no one to care for them outside. A toddler stares impassively at the camera from behind the bars of a cell.

Tension builds in the film. In Japan we see twisting teenagers in leather jackets juxtaposed against an ancient tea ceremony. Women on the street circulate petitions while male politicians proclaim that "economic reasons no longer justify abortion." In Canada, Henry Morgentaler strokes a patient's head following her abortion at his illegal Montreal clinic, and describes to a Toronto audience the inhumanity of the present-day law in this country.

The final scenes of the film are of Columbia, where the death rate from backstreet abortion is one of the highest in the world. The images are unforgettable. There is a look of disbelief on the face of Savarina Sanchez, a community health worker, when asked if there is a birth control program in the barrio. There is the horror of the scene in a Bogota garbage dump where searchers look for the several infants who are abandoned there each week. We

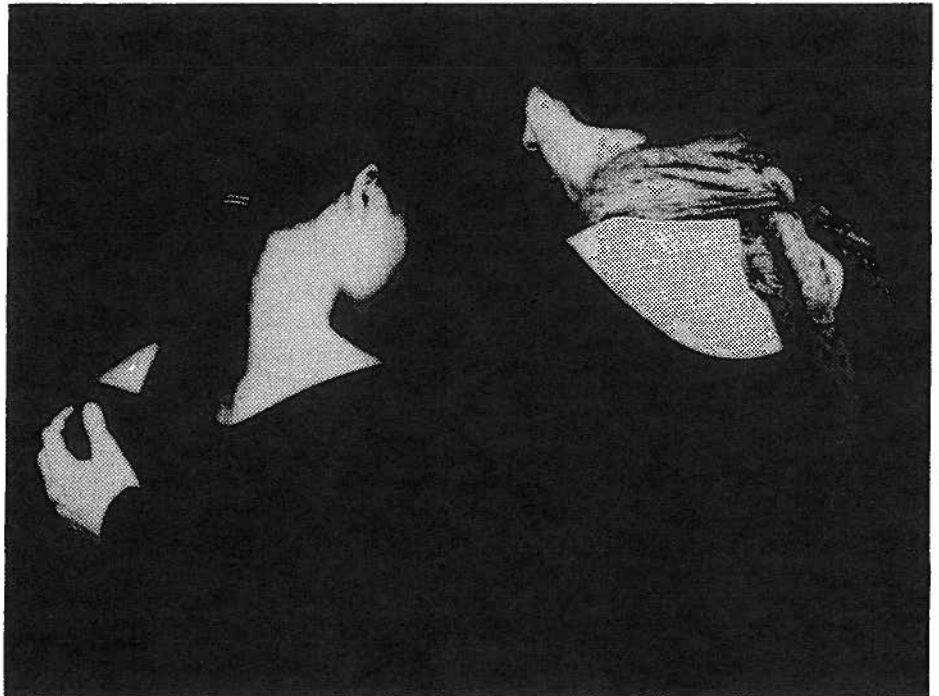


Photo: NFB

are struck by the fact that desperation is part of the heritage of our gender.

This film demands grief: for the women led from a raided Toronto abortion clinic with blankets over their heads; for guilt-ridden Japanese women who buy statues to house the souls of aborted fetuses; for Peruvian women who raise their children in jail; for the Columbian woman, hospitalized after trying to abort herself with an onion, not knowing whether her uterus has been removed. And this film demands we honour these women.

This is a film of tribute, a testimony to the courage and determination of women, and for our hope in the future.

Barbara Lamb is a counsellor at the Birth Control and V.D. Information Centre in Toronto.

Reluctant Awareness

Reviewed by Lou Nelson

Falling from Grace, Elly Van de Walle, Press Gang Publishers, Vancouver, B.C., 1984, \$5.95 paper, 52 pages.

Falling from Grace is a short, aptly titled collection of poems exploring one woman's experience of mastectomy. Written over a period of six years, it focuses particularly on Elly Van de Walle's life after the removal of her breast, and the effect the operation has on her self-image and her psyche. The chronological organization of the poems takes us through her operation and recovery, to grief and anger, another pregnancy, and the death of a friend (from cancer). She describes her feelings in clear and direct images, successfully evoking the tension she lives with daily: the possibility of recurrence. While the threat is inescapable, Van de Walle is not immobilized. She is tenacious in her exploration of the emotional changes wrought by the operation.

At age 28, with one child, she discovered the lump in her breast. When she entered the hospital for an exploratory operation, the lump was diagnosed as malignant and her breast was removed while she was still under anaesthetic. She describes waking after the operation:

Break the water.
My head bobs amidst the waves
consciousness tugging at me like a
child, insistent.

Is it off? I ask.
The roar of ocean.
Try again.

A bottle drifts by.
Inside, a message saying: yes.
Seawater runs on my face, stings my
breast.
It's not true, is it?

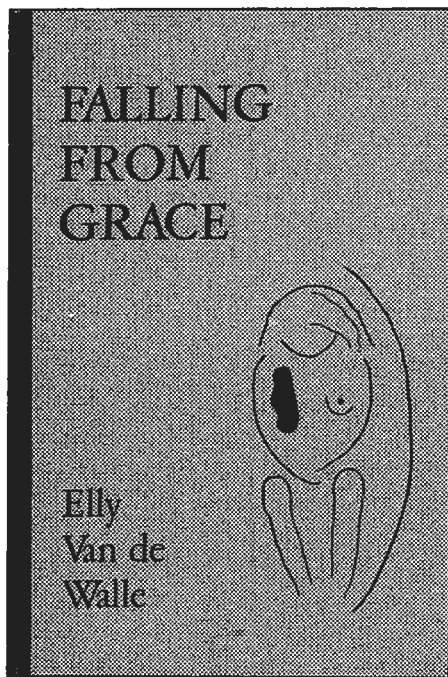
(A sinking feeling, p. 17)

From that first moment of reluctant awareness, Van de Walle moves into an assessment of her situation. When she leaves the hospital following her mastectomy, the sense of loss she feels is immense. It is coupled with awareness of death:

Much of what is scattered in winter
can never be regained in spring.
The bird rots in the soil
the bones no longer shape its frame
no longer provide
the evidence of song and flight.

(February song, p. 21)

Following her initial grief comes the



awareness that she can at any time be again betrayed by her flesh:

The body's laughter
torn out of it
as surely as its breast
with flesh forever suspect
a treacherous necessity
never to be trusted again.

(Check up, p. 22)

She cannot evade the reminder of death that her brush with cancer brings

so close. It irrevocably alters her sense of the future:

Tomorrow's shadow
extends for evermore
seeds
ashes in my mouth.

(Spring, again, p. 40)

Yet she continues to fight to maintain control of her life, to understand thoroughly what has taken place in her body and not be overcome by the mutilation. In her poem "On grief and its relative value," she finds room for somewhat ironic detachment from her situation in contemplation of more devastating death and destruction that exists elsewhere in the world. Humor comes to her rescue. Eyed by a strange man, she imagines exposing her remaining breast and confronting him with:

I excel
at archery
as well.

(On preconceptions, p. 34)

The wide span of time over which these poems were written gives an episodic quality to the book, each poem telling its own story, revealing a different aspect of the author's process of adjustment. It is not a dramatic collection, but rather one that describes the ordinary details of life lived under the shadow of cancer's possible recurrence. Elly Van de Walle speaks for hundreds of women who have undergone mastectomies, who cannot write the stories themselves. I am sure many would recognize themselves in her poetry. She makes her experience accessible to others who have not lived with that cruel knowledge. Her work is part of the growing tradition of naming women's experience, and slight though the volume is, it speaks powerfully of one woman's courage and determination.

The book includes an annotated list of further readings, a selection of 15 non-technical books on the subject of breast cancer. These resources increase our ability to deal with cancer when it confronts us, but as Van de Walle says in her introduction, "Few women ever totally resign themselves to such mutilation. We may adjust to it, we may live with it, we may even laugh about it. But we can never accept it."

Lou Nelson is a printer turned student living in Montreal. She is currently active in the Concordia University Women's Collective.

LETTERS

We reserve the option to print letters to *Healthsharing* with minor editing for length, unless they are marked "not for publication."

Research on Ponstan

The review of *The Real Pushers* in your Fall 1984 issue refers to serious adverse reactions to the drug mefenamic acid (Ponstan), but it does not say what these are.

I wrote the review and felt uneasy about not saying more about this drug which is increasingly prescribed for menstrual cramps. I set out to find more about its risks.

The difficulty I had getting information about Ponstan and the contradictory nature of the evidence are, I suspect, typical of such searches. The Toronto field office of the Health Protection Branch of Health and Welfare Canada (Drug Inquiries) referred my request for information to the Ponstan manufacturer, Parke-Davis, and to the *Compendium of Pharmaceuticals and Specialties* (CPS). The Bureau of Prescription Drugs in Ottawa also referred me to the manufacturer for their product monograph (which is what the CPS is based on). They said if I wasn't satisfied with the information provided by the manufacturer, I could request Drug Regulation Affairs to research the drug and pay an hourly research fee for this "public service."

When I called Parke-Davis and asked for a product monograph, my call was transferred to the marketing department. With a follow-up letter and a second call to Parke-Davis, I was assured that my request was being answered; it never did arrive.

Information available about mefenamic acid is conflicting and variable. Health and Welfare Canada, and health care practitioners and recipients cannot trust the manufacturer to provide critical information or evaluation.

The 1984 CPS recommends using Ponstan in acute and chronic conditions and belittles its side effects. Other sources do not agree.

The 1984 *Physicians Drug Reference* (PDR), an American version of the CPS, advises caution in the use of Ponstan and

outlines contra-indications and side effects in detail. Although gastrointestinal symptoms are commonly associated with Ponstan, more serious reactions — blood disorders and renal failure — are also reported. The *Medical Letter* cautions that some of these effects have occurred in people who have used the drug for as little as three days. The *Medical Letter*, in addition to *AMA Drug Evaluations*, Goodman and Gilman's *Pharmacological Basis of Therapeutics* and Charles Medawar's *The Wrong Kind of Medicine*, do not recommend Ponstan because of its toxicity and lack of conclusive evidence of its superior ability to relieve pain when compared to less dangerous drugs. If it is used, *The Medical Letter* recommends its use should not exceed one week.

An article in the June 1984 *Contemporary Obstetrics and Gynecology* recommends Ponstan for cramping associated with IUD's as well as for menstrual discomfort. The recommendation is based on a study of 34 women who used the drug for three menstrual periods; their reactions were compared to those of women who used a placebo.

Parke-Davis funded a study which rates mefenamic acid as the most effective drug in a comparative study with two other drugs. The sample size of this study is also small, 26 women. In both studies there is considerable subject drop-out (23 per cent in the first study and 48 per cent in the second). The incidence of illness and side effects from the drug among both dropouts and women who completed the study raises serious questions about the drug's safety.

All drugs have side effects. We may be willing to accept the risks associated with taking one or two capsules once a month, but the use of Ponstan for prolonged IUD related cramping is a more serious choice. The unavailability, inadequacy and contradictory nature of the evidence makes an informed choice difficult.

As a first step in our struggle for alternatives, we need to go to independent sources of informa-

tion. Most of us do not have easy access to the limited amount of material produced. The women-sharing of research and ideas promoted through magazines such as *Healthsharing*, discussion and action groups, women's health centres and networks are important beginnings in our ongoing struggle to have truly informed choice, safe alternatives and control over decisions about our health.
Dianne Patychuk
Toronto, Ont.

Anti-Medical Bias

A friend of mine who is concerned about the health and survival of your magazine — it being a Canadian publication representing an important viewpoint on matters of concern to us all — has urged me to explain why I am not continuing my subscription.

As a physician concerned with the manner in which my profession offers its services to people, I welcome the opportunity to display an "alternative" viewpoint in my office waiting room (and to read *Healthsharing* myself). But I find too often that your magazine presents an opinion that is insensitive to the complexities of the professional's dilemma and disrespectful of the high ideals that guide the efforts of many of my colleagues; in effect, separating "us" (your readers) and "them" (doctors). I feel that I am being personally abused by many generalities you publish without contest.

I contrast this kind of journalism with that of *Medical Self-Care*, for example, which makes the effort to express the highest aspirations of the medical viewpoint when it suggests weaknesses in certain patterns of practice.
A. Shoichet
Mission, B.C.

Repetition or Alternatives?

In her article *Transforming Erotic Power* (Fall 1984), Mariana Valverde appears to suggest that were aggression and passivity not gender-linked they would be desirable, even complimentary, behaviours. The article is peppered throughout with the vocabulary of pornography ("transforming," "surrender,"

etc.), and although the term sado-masochism itself does not appear, the euphemisms have the effect of assuring that its message is gotten across.

It is incomprehensible to conceive of sexuality as a process and then, as Valverde does, banalize the concept by endorsing role-playing. It is precisely because sexuality in patriarchy is male-defined and used as a vehicle for male power that we must recreate sexuality rather than imitate the masculine model of opposing forces. Valverde seems to propose that it is in our interest as women to perpetuate the dehumanizing masculine vision of human (including sexual) relations. It is the pornographic eye — the eye which despises sexuality — that views nudity and egalitarian, tender relations as being anti-erotic.

Rather than endorsing sado-masochism, would it not be sensible for us to develop a real alternative to it.
Susan De Rosa
Montreal, Que.

Author Responds

Susan De Rosa claims that words such as "transforming" and "surrender" are euphemisms for pornography and sado-masochism. Well, I am speechless. "Transforming" (as in "transforming society") is part of the vocabulary of feminism, not of pornography. And as for "surrender," my point was that both the urge to engulf and the urge to surrender are integral part to sexual love; our task as feminists is not to try and drain all the power out of sex but rather to create a more egalitarian context, so that power is no longer harmful.

I never said that "egalitarian, tender relations" were "anti-erotic." What I did say was that egalitarian sex does not have to confine itself to mere tenderness. To believe that lust and sexual power are inherently male and politically incorrect is to fall into traditional stereotypes about women's sexuality as light, tender, and cute.

Feminist sexuality must move beyond these traditional polar opposites, and incorporate both the tenderness and the power, the sweetness and the strength.
Mariana Valverde
Toronto, Ont.

RESOURCES & EVENTS

Health Education Resources on Women's Health

This British catalogue has up-to-date listings on all aspects of women's health and includes information on society and social conditions, work, health and welfare rights, contraception, maternity, and mental health. Each section lists leaflets, posters, resource packs, films, videos, slides, and books. Also included are contact addresses for further information.

Copies may be obtained at a cost of £2 from the Victoria Health Education Department, 1A Thorndike Close, London, England SW10. Send cheques or postal orders, payable to Victoria Health Authority

Self-Help for PMS

Self-Help For Premenstrual Syndrome by Michelle Harrison, an American physician, is a comprehensive booklet dealing with many aspects of PMS. Symptoms, causes, diagnosis, alternative treatment, and social and political factors are covered. This booklet also contains guides to menstrual charting and an extensive bibliography.

It is available from your local women's bookstore at the cost of \$5.95, or through Matrix Press, P.O. Box 740, Cambridge, Mass. 02238. (Write for cost and availability before ordering.)

Women and Aging

Too Old Yet Too Young: An Account of Women In Limbo is a report recently published by the Council on Aging of Ottawa-Carleton. It explores the situation of single women between the ages of 55 and 65 in the Regional Municipality of Ottawa-Carleton. This report is a useful resource guide for all communities.

The report is available at no cost from: The Council on Aging of Ottawa-Carleton, 256 King Edward Ave., Ottawa, Ont. K1N 7M1.

Women In Science

The Canadian Association for Women in Science has produced an audio-visual presentation entitled "Touching the Unknown," a profile of four prominent Canadian women scientists—an astronaut, a biogeneticist, a computer specialist and a nuclear medical researcher. The 10 minute program is designed to promote careers for women in science and technology.

For information regarding the association or their presentation, contact Canadian Association for Women in Science, Box 6054, Station A, Toronto, Ont. M5W 1P5.

Sexual Abuse Counselling

"Counselling the Sexual Abuse Survivor: A Conference on Clinical and Social Issues," sponsored by Klinik Community Health Centre, is scheduled for February 20-22, 1985 in Winnipeg. The conference will focus on working with adolescent and adult survivors of childhood sexual abuse. Workshops will address varying treatment approaches and models, current research and therapeutic issues.

Contact Diane Issac, Klinik, 54 Broadway Ave., Winnipeg, Man. R3C 0W3, or call (204) 774-9004.

Black Women's Health

Spelman Messenger, the Spelman College alumni magazine, has published a special issue featuring the *First National Conference on Black Women's Health Issues* held at Spelman earlier this year.

For information about cost and availability of the magazine write: *Spelman Messenger*, Spelman College, 350 Spelman Lane S.W., Atlanta, Ga. 30314.

Women and Pharmaceuticals Theatre Event

Side Effects is a unique play about women and pharmaceuticals in Canada and the Third World co-sponsored by the Great Canadian Theatre Company and Women's Health Interaction. The play can provide a focus for conferences, workshops and discussions, and it is adaptive to theatres, community centres and auditoriums. A well researched guide has been designed to accompany the performance. *Side Effects* is scheduled for a national tour during 1984 and 1985.

For information about bringing *Side Effects* to your community, contact Women's Health Interaction, c/o Inter Pares, 209 Pretoria Ave., Ottawa, Ont. K1S 1X1, (613) 563-4801.

Audio-Visual Resources on Sexuality

The Planned Parenthood Federation of Canada has prepared a comprehensive catalogue of audio-visual resources on sexuality. Resources are listed under such diverse categories as homosexuality, infertility, and sexuality and violence. A critique of each resource and a recommended target audience are provided.

The catalogue is available at the cost of \$5.00 from Planned Parenthood Federation of Canada, 151 Slater St., Suite 200, Ottawa, Ont. K1P 5H3.