

Spring, 1989
\$3.00

Healthsharing

Special Issue

A CANADIAN WOMEN'S HEALTH QUARTERLY

Healing Our Immune Systems

Epstein-Barr Virus

Infant Vaccination?

Overcoming Candida



INSIDE

Healthsharing

Vol 10:2 March, 1989

Collective Members

Susan Elliott, Amy Gottlieb,
Alice Grange, Ruth Kidane,
Lisa McCaskell, Katie Pellizzari
On leave: Deirdre Gallagher, Diana Majury

Administration

Amy Gottlieb, Jo-Ann Minden

Advertising

Susan Elliott

Circulation/Promotion

Amy Gottlieb,

Copy Editing/Proofing

Lisa McCaskell, Amyra Braha

Design/Production

Susan Elliott (coordinator), Pam Bristol,
Amyra Braha, Jill Cameron, Mary Margaret
Crapper, Alice Grange, Ruth Kidane, Lisa
McCaskell, Jo-Ann Minden, Katie Pellizzari

Editorial

Amy Gottlieb (coordinator), collective
members, Helen Armstrong, Linda
Rosenbaum

Typesetting

Lynne Fernie/Type A

Printing

Delta Web Graphics

Cover Photo

Ingrid Mayrhofer

Editorial & Advertising Offices

14 Skey Lane, Toronto, Ont. M6J 3C4
(416) 532-0812

Published quarterly by Women
Healthsharing, Inc. Anyone wishing to make
a tax-deductible donation (\$10 or more)
please send a cheque payable to Women
Healthsharing.

Subscription rates are \$12/year,
individuals; \$24/year, organizations and
institutions. USA add \$2 Cdn or US funds;
other add \$3, International Money Orders
only.

Women Healthsharing endeavours to print
material with which we agree; however not
every article or column reflects the opinion
of all collective members or of our funders.

Authors and artists retain copyright, 1989.
No part of this magazine may be reprinted
without prior permission. Unsolicited
manuscripts or artwork should include a
stamped self-addressed envelope. A writing
guideline is available upon request.

ISSN: 0226-1510. Second Class Mail
Registration: 5327.

Women Healthsharing receives partial
financial support from Women's Program of
Secretary of State, Employment &
Immigration and other sources.

Advertising rates are available upon
request.

Indexed in the Canadian Magazine Index
and available on-line in the Canadian
Business and Current Affairs Database.

FEATURES

10 Sick But Not Silenced

Candidiasis and the struggle for health
Maggie Burston

17 ABCs of Immunology

A primer on the immune system
Susan Elliott

20 Winning the Battle

Living with Epstein-Barr virus
Lorie Rotenberg

28 Shots in the Dark

The risk of infant vaccination
Anna Kohn



ALWAYS IN HEALTHSHARING

3 Collective Notes

Building the road to immune recovery

4 Letters

6 Update

15 Healthwise

Where to go for info and support

25 My Story, Our Story

Making my operation operate for me
Wendy Annand

33 Thematic Resources

Reading about the immune system

36 Resources and Events



COLLECTIVE NOTES

Building the Road to Immune Recovery

Have you noticed that everyone you know is either sick or knows someone who is struggling with mono or Epstein-Barr, or candidiasis, or shingles, or cancer, or skin problems, or environmental allergies, or AIDS. Many of our parents wonder at how much sicker young people are. And many of us try to understand why our children have endless ear infections or why our friends are succumbing to viruses when they're supposed to be in the prime of their lives. And every winter the media is full of reports about the rising number of viral and bacterial infections.

Despite an unmistakable increase in disease, most of us still think about illness as a personal and individual matter. When we're ill, we feel trapped and isolated inside our hurting, distressed bodies. But many of us confuse the experience of illness with how it is created. We assume that illness is a punishment for failing to take care of our bodies. In making illness our individual burden we fail to make the connection between sickness and our social/political environment. We fail to see the connection between widespread use of the birth control pill and the epidemic of yeast infections and Pelvic Inflammatory Disease among Canadian women. We may not connect the hazardous materials we are exposed to at work to the increase in women suffering from candidiasis or the increasing problem of infertility.

Our worsening health is due in large part to our weakening body defenses, our inability to fight off infection. Immunity, the process of neutralizing and destroying harmful organisms which enter our bodies and the building up of resistance to repeat contact with these bacteria and viruses is something that most of us have given little thought to — until recently. Now it seems that this

process, which is still poorly understood by Western scientists, is failing.

Although people in North America are living longer, we are doing so in worse health than our grandparents. Instead of blaming ourselves, we must look at the forces which affect our health and our ability to cope with illness. We are under attack by the physical effects of the economic values and policies of our society — from environmental pollution, work speedup, widespread use of 'legal' drugs (like antibiotics and birth control pills) and poisoning of the food chain.

The relationship between physical illness and the social and economic policies of this society becomes apparent when we look at the four major causes of immunological breakdown:

- The fact that we have to work harder for wages which are worth less leaves us exhausted and angry, with little time to refuel and rest our bodies. This stress weakens our immune system.
- The widespread pollution of our water and air is well known. Drinking water in almost every major urban area in Canada is polluted with dioxin and other dangerous chemicals. Air pollution is getting worse. The steady accumulation of environmental poisons in our bodies, which businesses produce and dump into our water and air, is causing a deterioration of our health.
- The deterioration of our food system is also widespread. Our food is contaminated by antibiotics, additives and fertilizers, or refined, eliminating much of its nutritional value.
- Drug therapy is the single most important therapy that Western allopathic doctors use for treat-

ment. But often drugs don't solve the problems, they mask them, eliminating symptoms and pain but not their causes. In the guise of good treatment and usually in good faith, doctors prescribe drugs that often have worse side effects than our original problem, and many of which suppress our immune response.

The present health care system doesn't meet our growing needs. It doesn't seriously look at the real causes of our illness, rather it separates causes from effects. The reigning medical philosophy, allopathy, is systematically committed to drug therapy and surgical intervention.

The drug industry is one of the primary reasons that this kind of approach has evolved and persists against all the evidence of its limitations. With billions of dollars of drugs and hospital hardware being produced every year, the second largest industry on the continent has found a ready network of distributors and promoters among medical doctors. Doctors have increasingly become technicians and salespersons for drug companies. And this will only get worse when the Mulroney free trade deal becomes reality.

Even though many doctors are highly motivated and anxious to help their patients, they are part of a system which cannot look at people holistically. Medical schools, for the most part, concentrate on body systems, what can go wrong with them and how to fix them. Normal life events such as childbirth and menopause have become conditions needing treatment. Mechanical, sports and war imagery define the way illness and "cure" are understood. The language and philosophy of Western medicine makes it almost impossible to look at the whole person and the external factors which affect us. Even our system of medical insurance, while making medical care available to everyone, limits doctors' ability to treat the whole person. Rigidly defined schedules determine how much time a doctor can spend with each patient — usually 10 to 15 minutes per visit.

Governments facilitate the dominance of medical doctors within the

Mind as Healer, Mind as Slayer: A Holistic Approach to Preventing Stress Disorders, Kenneth R. Pelletier, Dell, New York, 1977, 366 pp. Defines the role of stress in four major types of illness: cardiovascular, cancer, arthritis and respiratory and presents practical advice on the prevention of stress-related disease through techniques such as meditation and biofeedback.

Minding the Body: Mending the Mind, Joan Borysenko, Ph.D., Addison-Wesley, Reading, Massachusetts, 1987, 240 pp. Offers a unique blend of mental and physical exercises to unlock the body's power to heal. Many of the common ailments — allergies, premenstrual syndrome, diabetes, asthma, can be drastically improved without drugs or invasive medical procedures.

No More Cravings, Douglas Hunt, M.D., Warner Books, New York, 1987. A practical guide to low-cost programs of vitamin and mineral supplements and food substitutes to

help people suffering from food allergies, hormone imbalances and phobias.

Nutrition and Vitamin Therapy, Michael Lesser, M.D., Bantam Books, New York, 1981, 239 pp. Case histories illustrate how environmental pollutants, food allergies, vitamin deficiencies affect us. A guide to good health through vitamins and nutrition.

The AIDS Challenge: Prevention Education for Young People, Marcia Quackenbush, Mary Nelson and Kay Clark (Eds), Network Publications, Santa Cruz, 1988, 526 pp. Provides educators, health professionals, and parents with guideposts for developing and implementing AIDS prevention education programs in school and non-school settings.

The Body Electric: Electromagnetism and the Foundation of Life, Robert O. Becker, M.D. and Gary Selden, William Morrow, New York, 1985, 364 pp. Explores the effect of electro-

magnetic fields on our health — from microwaves, computers, hairdryers, televisions, etc. Raises concerns about environmental pollution and exposes the politics of medical research.

The Miracle Nutrient: Coenzyme Q10, Emile G. Bliznakov, M.D., Gerald Hunt, Bantam Books, New York, 1987, 240 pp. Presents a powerful therapy to revitalize the immune system, reverse the effects of aging, protect and strengthen the heart, by supplementing your body's ability to supply CoQ10.

The Missing Diagnosis, C. Orian Truss, M.D., Birmingham, Alabama, 1982, 175 pp. Looks at different conditions caused by *Candida Albicans* overgrowth and examines the factors that produce and perpetuate it and the treatment that corrects and prevents it. Specific mention of depression, vaginal infections, premenstrual tension and cystitis.

The MS Diet Books: A Low-Fat Diet for the Treatment of MS, Roy Laver Swank, M.D. and Barbara Brewer Dugan, Doubleday, New York, 1987, 390 pp. A plan for balanced nutrition developed over a 35-year period of research with hundreds of people with multiple sclerosis.

Victory Over Diabetes, William H. Philpott, M.D., and Dwight K. Kalita, M.D., Keats Publishing, New Canaan, Connecticut, 1983, 294 pp. A nutritional guide to controlling diabetes based on enhancing and defending the body's own resources.

Women and AIDS, Theresa Dobko with help from Jared Mitchell and Carol Farkas, available free of charge from The AIDS Committee of Toronto, 1988, 24 pp. pamphlet. Essential information presented in an accessible form.

You Don't Have to Live with Cystitis, Larrain Gillespie, M.D., Rawson Associates, New York, 1986, 290 pp. First woman's guide to urological health. Shows how to alleviate and prevent a variety of urological problems including cystitis and incontinence and includes nutritional and vitamin information.

FROM THE NATIONAL FILM BOARD OF CANADA

Thursday Nights on VISION TV'S *THE CUTTING EDGE*

FEBRUARY 23



DOCTOR WOMAN:
The Life and Times of
Dr. Elizabeth Bagshaw

MARCH 23



DAISY:
The Story of a Facelift

MARCH 30



D.E.S.:
An Uncertain Legacy

Other new NFB releases to be presented include: *Sonia* (about Alzheimer's); *A Mother and Daughter on Abortion*; *What People Are Calling PMS*; *A House Divided* (about elder abuse); and *The Legacy of Mary McEwan* (about one of Canada's first feminist psychiatrists).

Video: \$2/day
16 mm: \$4-8 for five days



National
Film Board
of Canada

Office
national du film
du Canada

It is very necessary to be vigilant about racism. But we live in a society based on exploitation and alienation, with the poor being squeezed more and more. While it's certainly difficult to be poor and of colour, it's never easy to be poor, and a hierarchy of misery serves neither people of colour, nor the poor.

*Sandy Zeldheim
Montreal, Quebec*

Confusion and Disbelief

I read your Fall 1988 collective notes with growing confusion and disbelief. But what stopped me dead in my tracks was your announcement that from now on Healthsharing would pay women of colour for these contributions "in recognition of the specific obstacles they encounter" and "to encourage women to work for the magazine."

If a feminist magazine decides they can afford to pay writers, it should pay them all. It may choose to pay on a sliding scale to address differences in income (which may, don't forget, be a result of class, sex, or colour barriers). But to say only women of colour will be paid would be like saying only women will be paid while men must volunteer their labour.

Frankly, that's discrimination. And, dressing it up as a carrot to the forces which challenge you is insulting to me as a feminist and a writer who has never been paid for her work with feminist journals, nor (until recently) for her work in combatting racism and sexism.

I don't expect to be always paid for my work, or for even developing and supporting my personal beliefs, but I don't

ever expect to be exploited, particularly by my own sisters.
*Martha Muzychka
St. John's, Nfld.*

Job Well Done

I wanted to thank you for the article "We Are Not Immune," by Lisa McCaskell, in the Fall issue. The personal approach made for interesting and informative reading, a combination not easy to come by. Congratulations on a job well done!

*Caroline Soles
Toronto, Ont.*

Kaufert's Excellent Article

I do enjoy every issue. Pat Kaufert's article, *Through Women's Eyes*, was excellent. Her examples that personified the problems she identified were all recognizable by me. As a 58 year old woman, I strongly witness her point that

Our Cover



The cover photograph of Maggie Burston, founder of Candida Research and Information Foundation was taken by Ingrid Mayrhofer.

"women have always shared knowledge among themselves."
*Janice Boyes
Vancouver, B.C.*

An experience that lasts a lifetime.



Barbara McCann

CUSO NEEDS

Health Lecturers/Researchers

Two community health teaching positions are now available with the Pan African Institute for Development.

In **Zambia** an English-language lecturer is needed to teach, and to design and carry out research in rural health programs for women.

In **Cameroon**, a French-language lecturer/researcher is needed to train agents and supervisors of health nutrition and family planning services.

Both positions require a masters in public/community health and several years experience.

CUSO offers you a challenge. The chance of a lifetime. Two years living in another culture and an opportunity to work with others who are striving to improve their lives.

It's hard work, but rewarding.

We need someone special. Someone who wants more than 9 to 5. Someone willing to try something different.

If you have skills and experience and can live on a modest salary, we probably have a job for you.

Join other Canadians working in the Third World. Join CUSO.

For further information send your resumé to
**CUSO, BH-25, 135 Rideau Street,
Ottawa, Ontario K1N 9K7.**



UPDATE

Birth Centre

The Ontario Government is withholding support for a proposed free-standing birth centre in Toronto.

But originators of the concept still plan to open the centre, even if it must be done privately. To open without a licence or government funding is expensive — \$150,000 for start-up costs plus funds for cash flow in the first year.

"We've raised only a small percentage of that," says Karen Walker, President of Toronto Birth Centre Inc.

She and the other centre members are frustrated by the government's changing position on a free-standing centre. Her group has worked to realize their ideas for ten years. "Back during the NDP-Liberal accord, Murray Elston was health minister. We had up to six meetings with his bureaucrats from 1985 to 1987. He said he was looking for a way to fit us into the health

system." Elston proposed a semi-autonomous relationship with a hospital, and the group sought and received the go-ahead from Doctors Hospital in downtown Toronto.

But after the 1987 provincial election, Elinor Caplan was appointed health minister and a host of new government bureaucrats took over the centre's portfolio. Caplan proposed four new hospital-based birth centres, but no free-standing ones.

The government's proposed independent health facilities act, which the birth centre would fall under, has gone through first reading and is expected to go through committee hearings this winter. Caplan has announced that all independent facilities in existence as of June 1988

The government's proposed independent health facilities act, which the birth centre would fall under, has gone



through first reading and is expected to go through committee hearings this winter. Caplan has announced that all independent facilities in existence as of June 1988 when the legislation received first reading would be allowed to stand as legal when the legislation passed. Walker wrote Caplan saying that they had been ready to go ahead with their proposed centre as of June 1988. But Caplan didn't change her mind. She

also refuses to meet with Walker and other centre proponents until after the legislation is passed.

"We decided to go ahead on our own, similar to the community midwives, and charge a fee. This will be free enterprise in essence. This has been a bitter pill for us because philosophically we felt people should not have to pay for this," says Walker.

She remains committed to free-standing birth centres, believing they provide less medical intervention than hospitals, are consumer controlled and less bureaucratic, and provide a much more comprehensive package of prenatal and postnatal care.

HELEN ARMSTRONG

Breastmilk enhances immunity

It is well-known that maternal antibodies passed through breastmilk protect infants from infection. There is new evidence, however, that proteins found in breastmilk may actually stimulate an infant's own immune response as well. As reported in *Mothering* (Summer, 1988), researchers at McGill University found breastmilk

proteins accelerate the growth of B-lymphocytes and scientists at the University of Texas have discovered that breastmilk can activate macrophages — white blood cells that complement B-lymphocytes in the immune system.

WHS

CALGARY WOMEN'S HEALTH COLLECTIVE



Feminist Therapy Offered

265-9590

316, 223 - 12th Avenue S.W., Calgary, Ab. T2R 0G9

20th century tax deduction

A new tax deduction for people suffering from "environmental sensitivity," which is also known as 20th century disease, will be allowed by the federal government according to a Canadian Press report. The tax break, applicable in the 1988 tax year, will cover certain equipment such as air

filters and water purification systems. To qualify for the deduction, a doctor's certificate stating that you suffer from a chronic, multi-system disorder must be included in your tax return. It is estimated that at least 3,000 Canadians have this disorder.

WHS

Homecare for those who can pay?

Homecare service users in Quebec, the majority of whom are elderly women, may now have to pay for their care following a superior court decision in the summer of 1988.

The question of user-pay service was raised in the courts through a class action suit against a Local Community Service Centre (CLSC) in Candiac, Quebec. The CLSC collected a total of \$26,147 for homecare services between 1976 and 1987.

The suit was launched on the grounds that citizens of Quebec have a right to free homecare services. The judge didn't agree, ruling that social services are not a guaranteed right under Quebec legislation. Had the suit been won, the CLSC would have been obliged to reimburse those people who had paid for services.

According to the judge's interpretation, the law provides the right for all people to receive health and social services but doesn't state that these services have to be provided free.

In 1980, the Minister of Health gave directives to its



Dawna Gallagher

health and social service institutions, stating that homecare services must be provided for free to the people of Quebec. However, in court it was judged that these directives were not upheld by law and therefore, there were no grounds for a class action suit.

The outcome of this case puts into question a major principle underlying the Quebec health and social services system which, up until now, had been taken for granted. Legally, there is nothing preventing other CLSC's from charging user fees for homecare services.

Elderly women would be the hardest hit by widespread user fees. Although an average woman's life expectancy in Quebec is 78 years, compared to 70 years for men, she can expect to live her last 18 years with a serious

health problem. The fact that the majority of elderly women live alone and in poverty means they have the greatest need for homecare and the least means to pay for it.

Quebec government reports have recently outlined the need for increased homecare services to reverse the trend of over-institutionalization. Allowing elderly persons to stay in their home environment longer makes more sense from a human and economic point of view. Unfortunately, the recent judgement concerning homecare service fees could decrease women's access to these services and adversely affect their autonomy and well-being.

MARION LOKHORST

Multivitamin protection

A new report from the U.S. Centres for Disease Control confirms preliminary findings that multivitamins can prevent serious neurological defects. The study showed that women who took multivitamin pills around the time of conception have less than half the number of babies born with neural tube defects, which include spina bifida (the incomplete closing of the bony casing around the spinal cord) and anencephaly (an absence of

major parts of the brain). Spina bifida can cause paralysis and anencephaly is potentially fatal. Women who have given birth to infants with neurological problems are at increased risk for similar difficulties in subsequent pregnancies. That these serious birth defects could be prevented by taking daily multivitamins is an encouraging possibility.

WHS

Healthsharing is growing!



We are looking for women interested in working with Healthsharing. Become a collective member or help out with:

- regional reporting
- editing
- design
- office maintenance
- paste-up

Help strengthen the women's health movement — help our voices be heard.

Call Amy at (416) 532-0812 or write to Healthsharing, 14 Skey Lane, Toronto, Ontario M6J 3S4.

Reviewing the drug system

A provincial inquiry is reviewing Ontario's prescription drug system. Changes are needed to ensure that essential drugs are provided to those who need them and to protect consumers from unnecessary, overpriced, ineffective and

harmful products.

Public hearings were held throughout the province in October and November and a final report will be released in December 1989. However, several recommendations have already been made. In December, the Minister of Health voiced approval for the inquiry's recommendation that drug costs for people with cystic fibrosis and thalassemia be covered by the province. With drug bills as high as \$1,000 per month, many adults with cystic fibrosis are forced to go on welfare in order to receive their drugs for free. This change in coverage is one step forward in making essential drugs available to all those in need.

On no other health issue is the conflict between profits and health care more clear. The federal government in

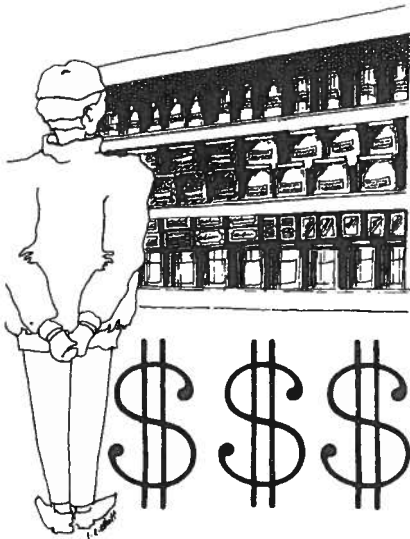
passing Bill C-22 last year extended market protection of drug companies and showed that it stands on the side of drug company profits. Governments have been unwilling to regulate the drug industry adequately to protect the public.

Provincial drug benefit plans which provide free drugs to people on social assistance or over age 65 are becoming a focus of government accountability for public health. In 1988, Ontario seniors groups were alarmed to discover that up to 30 per cent of seniors' admissions to hospitals were a direct result of drug reactions or interactions. Ontario seniors are the most drugged population of all industrial

countries. The "benefits" of the Ontario Drug Benefit Plan are being seriously questioned.

Other serious problems with the prescription drug system are yet to be addressed. Mechanisms are needed to ensure that drug industry pressures do not affect the drug approval process. Drug approval criteria must be based on acceptable safety, ability to meet real health needs and cost effectiveness when compared with alternatives. Getting at the root of the problem will challenge the system which makes us passive consumers, and which provides little support for the development of alternatives.

DIANNE PATYCHUK



Health education project in Montreal

A new project is in the making at le Centre de sante des femmes de Montreal, a non-profit community health organization operated by and for women. The centre will soon be offering discussion groups and lectures as part of the already-existing documentation centre.

The centre initiated the project after a survey of Montreal women's groups revealed a striking need for health information and knowledge of the body.

Ten information binders have been developed on topics such as menopause, cervical cancer and sexually transmitted diseases. The binders will be available for individual use in the centre or

can be used as tools in biweekly discussion groups. These informal sessions, covering a variety of topics, will be held at the centre or among community groups and organizations. As well, lectures on women's health will be scheduled on a regular basis.

Le Centre de sante des femmes has been offering services to women for more than ten years, including: referrals, cervical cap fittings, abortion counselling and services, and use of the documentation centre. The centre can be reached at (514) 842-8903.

MARION LOKHORST

Depo-Provera injections rejected

The Canadian Government has refused to approve Depo-Provera for use as an injectable contraceptive.

Health and Welfare Minister Jake Epp informed Upjohn Company of Canada in September 1988 that its application didn't have enough evidence of the long-term safety of the drug.

"This action was taken after consultation with our Special Advisory Committee on Reproductive Physiology," said Epp. He called for the results of additional safety studies before approval is reconsidered.

Studies in Costa Rica and Thailand have raised serious concerns about links between Depo-Provera and increased risk of breast cancer and birth defects. The ethics of administering the drug to

disabled women and others without informed consent have also been raised.

The Manitoba Coalition on Depo-Provera commended Health and Welfare for its decision and urged it to inform doctors across the country of its action. The coalition has also asked that strict guidelines be adhered to when doctors prescribe the synthetic hormone for its approved use in treating endometriosis and certain forms of cancer.

Upjohn voluntarily withdrew its application to the U.S. government due to certain regulations in effect. The U.S. Food and Drug Administration had rejected Upjohn's application in 1978 and again in 1984.

HELEN ARMSTRONG

Bring birth back

A group of midwives has been working since 1986 to bring birth back to the Northern communities surrounding Hudsons Bay.

In a rare exchange between two cultures, southern-educated midwives teach Inuit apprentices within their own domain at the Povungnituk Maternity. The project has provided a much needed alternative to the practice of flying pregnant women south to give birth.

Inuit apprentices are nominated by their communities, and once this honour has been received, they begin on-the-job training in Povungnituk. Complete training is given for pre and postnatal care of new mothers and infants. One apprentice must be present at each labour and birth.

The Povungnituk Maternity relies on a team approach to decision-making, a welcome difference in a land where the sole responsibility for decision-making can be frightening for a lone nurse in an outpost nursing station. A committee comprised of the midwives, apprentices and health care practitioners reviews all prenatal cases to determine the place of birth and a general care plan. They employ a holistic approach to prenatal decisions; if a woman is considered high-risk, she will be advised on nutrition, hygiene and exercise or provided with the necessary health services to lower her risk status.

The job is high-profile because of its community health mandate. The midwives' activities include

family planning and sex education, development of public education programs through a video series and radio phone-in programs, development of texts and teaching of perinatal care for local health care and community workers in the villages, and participation in conferences.

Essential to the Povungnituk midwives' formula is the community's mandate for autonomy and control over its health care, the Inuit commitment and the ongoing process of public education.

Jennifer Stonier, a Povungnituk midwife, says the project never ends. "The process is like life (and birth). . . it is always ongoing."

JOANN LOWELL



Joann Lowell

The wrath of grapes

The United Farm Workers of America (UFW) recently began their third international boycott of California table grapes.

The UFW has also released a powerful and provocative video *The Wrath of Grapes*. This sixteen minute video presents a strong case for supporting the grape boycott to protect farm workers, consumers and the environment from the effects of toxic pesticides. Eight million pounds of pesticides are annually used in the production of grapes; one-third of the pesticides used are known to cause cancer and birth defects.

The video reveals some startling facts: in 1985, the Governor of California vetoed a bill which required posted signs warning farm workers

when a field has been sprayed. The Governor stated that California's 14 billion dollar a year grape industry could not afford the signs. One worker died in 1985 after the field he entered has just been sprayed. Three years later, in 1988, California finally has a law requiring that signs be posted after pesticide spraying.

After exposure to these dangerous toxins, some women farm workers have had multiple miscarriages and have given birth to deformed children. Dozens of children are stricken with cancer in the heart of grape country in California. McFarland, one of the three officially-declared "child-cancer-clusters" in the state has 11 children in a six block area diagnosed with cancer — 6 have already died.

For consumers, the health

risk comes primarily from the pesticide residues on the fruit, most of which do not wash off. For people who live in grape country, pesticide-contaminated water supplies threaten their communities.

The objective of the farmworkers union is to show that the greatest threat posed to workers, consumers and the environment is the pervasive use of deadly pesticides. The

UFW hopes that consumer boycott of table grapes will put increased pressure on the growers to stop using deadly pesticides.

For more information, contact: David Martinez, 600 The East Mall, Suite 401, Toronto, Ontario M9B 4B1. (416) 626-6332.

SHARON KLEIN



Smokefree

Teaches Women to Quit Smoking

(416) 465-1323

Phyllis Marie Jensen, R.N., Ph.D.

also FEMINIST PSYCHOTHERAPY
and DREAM ANALYSIS

Maggie Burston

SICK BUT NOT SILENCED

Women are not "alive and well" in Canada today, and the fault is not their own. They are suffering from the effects of environmental pollution, work speed-up and contemporary medical practices. These practices are entrenched in the control that medical doctors and the drug industry have over the public health purse. But women's cries of anguish are not being heeded by the medical establishment. That is why the women's movement needs to become more knowledgeable, politicized and aggressive about women's real health needs.

For more than two decades I have suffered from chronic bladder and yeast infections which are the result of medically-incompetent surgery I had 25 years ago. The constant use of increasingly powerful antibiotics for bacterial infections induced by the operation weakened my immune system tremendously. In 1983 my health had deteriorated to the point that I was allergic to most foods and most substances in the environment. I was dying from a combination of infection and starvation. The major culprit in my deterioration was something I now know to be candida albicans overgrowth, but at that time no doctor I knew in Toronto rec-

ognized it or knew anything about it.

I wish I could say that I am now well, but that is not the case. I live with the fact that I shall not be able to regain full health. But I am alive and this miracle is due only to the fact that I decided not to accept the medical opinions of doctors I consulted in Toronto — opinions that amounted to a death sentence, like "go home and live with it." Instead I searched for other insights and answers.

As a result of this search I obtained diagnosis and treatment, although this was in direct conflict with establishment medicine. I have been able to recover fairly well, to the point where I was able to establish the Candida Research and Information Foundation (CRIF).

It has been a long journey, whose successes came about because I was prepared to re-examine all the belief systems that underlie the practice of medicine in our society. Without a critical examination of the concepts which shape our understanding of disease and the way this understanding is institutionalized in our present health care system, I could not have understood and treated my illness. Without a re-evaluation of the standard expectations that we have of our

families and friends when we are ill, I would not have survived. A realistic appraisal of these factors is essential to all who live with chronic or critical illnesses.

The present philosophy underlying our concept of disease stresses the treatment of an affected organ or body system without paying full attention to the relationship between it and the body as a whole. Allopathic medicine's range of diagnostic tools to assess the affected areas detect disease only when it has reached an acute stage. Treatment consists of drug therapy, which essentially serves to suppress the symptoms of disease, and surgery which serves to contain the damage of disease. These therapies reflect a philosophy of emergency medicine that is disease- rather than health-oriented. As with every philosophy, the pursuit of some ideas has led to the neglect of others.

Let me be absolutely clear. There is a very important place for allopathic treatments within our health care system. I would have been dead a long time ago if they

had not been available. But drugs and surgery do not constitute all the help that is available nor are they without their hazards.

Antibiotic drugs used to combat infection eradicate the offending bacteria while simultaneously initiating a disease process by provoking an overgrowth of yeast. This imbalance of organisms in the body, if unchecked for a long period may induce toxicity, which then leads to crippling allergies and immune suppression. If taken infrequently and in short duration, the impact of antibiotics may be negligible. But if they are prescribed repeatedly, and their yeast-provoking effects not counteracted, the bacteria inevitably become drug resistant. Unchecked infections invariably lead to immune breakdown and possibly death.

The immune-suppressant nature of drugs is not limited to antibiotics. It is characteristic of the whole drug arsenal, though frequently the reactions and consequences of drugs are not seen until many years later. (Corticosteroids and birth control pills are two examples of drugs whose hazardous effects are not felt until years later.) That the impact of drugs is experienced individually leads us to the mistaken impression that their consequences are particular to us. We might even see their therapeutic failure as a reflection of our own inadequacy. Statistics on iatrogenic (treatment-induced) disease have shown this to be entirely false. One-quarter to one-third of all hospital misadventures are the result of drug therapy gone wrong. Unfortunately, we do not have access to this kind of information, and therefore can't use it to frame our own experience.

Nor is it commonly known that drug-induced disease and drug resistance exist outside the human population. Dr. Marc Lappe, a senior professor of health policy at the University of California at Berkeley, in his book *Germs That Won't die*, writes that "cattle can be major reservoirs of infection for other animals and people." He states further that, "the occurrence of multiresistant bacteria in cattle has increased in direct relationship to the use of antibiotics in feed." These resistant bacteria are found in meats and meat



Barbara Pasternak

products and "they are transmitted to and cause an increase in the antibiotic-resistant bacteria in human populations."

It's time we saw the writing on the wall. The combined ill effects of drugs in humans and animals is telling us that something must be done. The ever-increasing rates of viral, bacterial and chronic disease are chilling testaments to the poverty of the current medical system. Allopathic medicine's refusal to see the consequences of its single most important method of treatment makes it impossible for its practitioners to understand therapies designed to deal with its failures. For the most part allopathic medicine has very little to offer the patient whose immune system has been compromised by constant drug therapy, as well as by other important factors, particularly environmental pollution.

In the final analysis, rebuilding the immune system requires a process of restoration, not intervention, though drugs and surgery may be necessary

stop-gap measures. The amount of time and specialized knowledge it takes to rebuild the immune system, whether we are suffering from candida or other chronic problems, is not available from physicians, given the kind of training doctors get today. This kind of care can be found only through a variety of alternative health services, which are made less, rather than more, accessible by the organized power of the medical doctors' associations.

Health insurance plans rarely, if ever, pay for alternative or complementary health care services, which include naturopathy, homeopathy, acupuncture, chiropractic, nutritional and dietary counselling. Once you've found these practitioners you must purchase their services through a private fee, making them inaccessible to the majority of people.

My exploration of these health disciplines taught me that even at my own advanced state of immune deterioration, meaningful restoration of immune functioning was possible.

Candidiasis

What is Candida?

CANDIDA is a single cell yeast organism which is normally present in human bodies. When it develops into a yeast infection, evidence of local irritation appears in the mouth, throat, gut, and genitals. However, when left undiagnosed or untreated it can become a chronic condition which can seriously undermine the body's immune system.

How do I know what to look for?

1. Chronic vaginitis.
2. Allergy to food and/or environment chemicals.
3. Recurring infections of any kind.
4. Brain Fog.
5. Cold hands and feet.
6. Digestive disturbances.
7. Skin symptoms — rashes, hives, itching . . .
8. Symptoms may mimic such

conditions as multiple sclerosis, arthritis or cystitis and may be implicated in alcoholism and diabetes.

How do I get Candidiasis?

This systemic condition is experienced in three stages: mild, intermediate, and severe. Its presence is ubiquitous to everyone, however overgrowth is frequently the consequence of the recurring, long-term use of broad spectrum antibiotics, or birth control pills, coupled with a high rate of carbohydrate consumption. Silver/mercury fillings and pesticides are also being investigated as contributing factors.

Why hasn't my doctor said anything?

Often, if no specific organ is identified as the culprit in the patient's illness, the patient is left with nowhere to turn. Traditionally,

medicine has viewed candida as a minor local infection. This disabling impact on immunity is not immediately apparent and consequently the gradual deterioration associated with the infection is not recognized. Since 1981, nearly 2,000 research studies have been conducted in North America, 788 of which have been completed in the last 3 years.

How do I get better?

In order to rebuild the immune system, it is the responsibility of each patient to manage a combination of approaches, both traditional and complementary. It has been found that, depending on the severity of the condition, treatments which have proven beneficial to some patients are dangerous to others. Understanding how diet, exercise and lifestyle affect health is the essential prerequisite to rehabilitation.

I discovered that acupuncture is very effective in boosting energy and immunity and in controlling pain. Nutritional supplementation, wisely prescribed, is critical for a system unable to absorb sufficient nutrients from ordinary food. I learned that homeopathy can be miraculous in treating infection and in aiding the immune system, and that food — what you eat, how you eat it, what's in it — can make or break one's mental or physical health. Finally, I discovered that just as other plants and animals living in nature, we live within an environment of air, light and sound to which our minds and bodies react, even though this relationship is mostly unknown to and hidden from us.

Given allopath's limitations, we must have the right to publicly funded, accessible alternative or complementary health care. This will require finding a way to break the medical monopoly of government health funding. This is essential for women, who not only make up the majority of doctors' patients, but also are the primary health care providers in the home, in hospitals,

clinics and communities. We need to find the courage and foresight to confront the limiting ideas and practices of the allopathic system.

Knowledge is power and women as a whole are disempowered within the present medical regime. Women are specifically silenced through the institution of the traditional doctor/patient relationship. It was recognizing and starting to change this destructive relationship that empowered me and helped me to survive.

My situation is no different from thousands of women whose conditions do not fit into pre-existing medical categories. Erudite specialists told me my problems were "in my head," more times than I care to remember. One famous urologist, furious at my insistence in compiling a detailed list of symptoms, told me that one-third of his women patients had the same problems I did, and like them, I had better face the fact that I was "over the hill" and learn to live with my pain and infections.

There was nothing he could do about them. Doctors prescribed antibiotics even after I had told them I was severely allergic to them. Others said, "Don't bother coming to me if you can't take antibiotics. That's the treatment I use." Doctors got angry when, after tackling medical texts in search of answers, I started to come up with hypothetical diagnoses, because they considered such measures an arrogant appropriation of their own role.

Even a strong, determined woman with a deep conviction about her right to understand what is happening to her can be intimidated into silence and self-destructive passivity by such "health" care. I shudder to think what happens to women who have more difficulty speaking up for themselves, or whose first language is not English.

There *are* some wonderful, caring and thoughtful doctors. But most physicians are essentially unprepared to listen to patients. I would even say that the classic doctor/patient relationship is structured to exclude the kind of feedback from patients that would allow a physician

to gather the necessary information for diagnoses and treatment. The kinds of questions that most doctors ask relate to conditions they have learned about or specialized in. If you have a problem which is somehow outside of these categories, you're likely to be written off as a neurotic hypochondriac by most doctors rather than valued as a challenging and potentially educational case.

The problem of patient/physician communication is institutionalized in the schedules the medical associations have developed for our public health insurance plans. It is virtually impossible for a full dialogue about chronic or puzzling conditions to take place in the five or 10 or, maximum, 15 minutes most doctors allot to their patients. Correlation of symptoms, feedback on medication, a full compilation of previous experiences, a discussion of diet and nutrition, presence or history of allergies, are all indispensable to an accurate diagnosis. But it's usually impossible to have a full discussion on any one of these matters, let alone all of them during an office visit. Even doctors with good intentions and a willingness to listen aren't able to provide this kind of care within the schedules that are in place. They are trapped themselves within the dominant practices of their profession.

This has to change, and it must change from both ends. Doctors have to develop some humility and openness in face of their very poor record of health care. And all of us need to approach our health with more responsibility. We can no longer afford to treat our bodies like machines that we take to our doctor to fix. Doctors must begin to listen to patients, to encourage patients to monitor their own bodies in order to enable the patient and doctor to work together in the search for effective diagnosis and treatment.

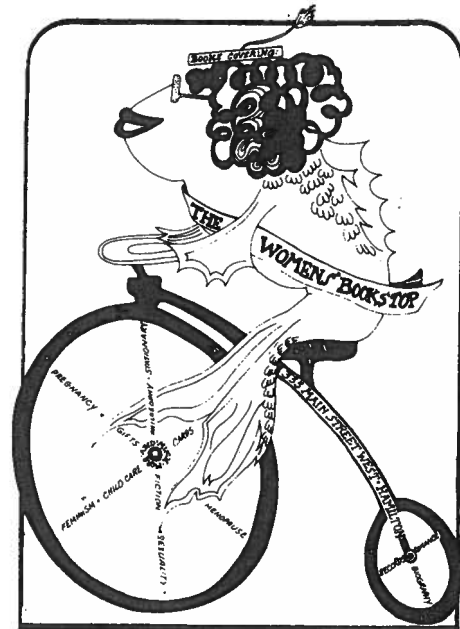
Strong taboos in our society prevent us from being able to discuss and share with friends and family the health problems that plague us. One expects that they are willing to listen and to help strategize about

our illness; that they will try to accommodate special needs (in my case, environmental and nutritional); that they will make special efforts during particularly difficult times. One finds that this expectation is often unrealistic.

Women suffer from candidiasis four times more frequently than men. Relationship and marriage breakdown is extremely common when women have serious candidiasis. Estimates suggest that less than 25 per cent of these relationships survive. It seems that most male partners are not able to provide the nurturing and specialized support necessary. The process by which women come to realize the nature and scope of their health problem, and the inability of their mates to deal with it, is a painful one. And because candidiasis is still not widely understood, other family members can often be unsympathetic in both word and deed. In fact, families often become bitterly divided over diagnosis and treatment. The affected partner may seek help in the alternative health field, while the non-affected partner uses the dismissal of the allopathic doctor to belittle or ignore the real problems candidiasis causes. Then the problem of duelling paradigms, of competing health philosophies becomes acutely painful and destructive.

The effort of taking care of a person with severe chemical and food allergies is simply enormous. Most people are already overburdened by the daily grind of work outside as well as inside the home. This is doubly true for women.

Prepared foods are based on wheat, dairy, sugar, fat, corn, red meat and fermented substances, many of which are bad for all kinds of chronic illnesses, not just candidiasis. Or they are frozen and tinned and have lost a good deal of their nutritional value. Or they are so chemically laden that they are virtually poisonous to ecologically ill people. So just at the time when one really needs to buy food services, one is least able to do so. Shopping, cooking and supplementing food properly for the ill is often a full-time job. If one has financial resources, one can hire someone to help. But that's only an option for a small



333 MAIN STREET WEST,
HAMILTON, ONTARIO
(416) 525-2970
Women's Bookstop

**Candida Research and
Information Foundation
(CRIF)**
presents a

Candida Seminar

with
Dr. Ari Wojdani, PhD.
speaking on
**Chemical Sensitivity,
Candidiasis and the Immune
System**

and
Dr. Marjorie Crandall, PhD.
speaking on

**Candidiasis: An Infection
and an Allergy**

Thursday, April 13, 1989
7:30 pm

OISE Auditorium
252 Bloor St. W., Toronto
Admission \$15.00

Call CRIF at 656-0047, for further
information

minority of the population. And because food needs are specialized, friends often assume they can't help because their own cooking habits would be inappropriate.

For the woman who is sick, the pain of illness is compounded by the knowledge of this burden and by the knowledge that she is responsible for drastic changes in 'normal' family life. It's not a simple matter to refuse to cook the food your partner and children like, or to face the fact that sex is impossible for a period of time, or that you can no longer go out to dinner and the movies with friends because perfume and cigarette smoke make you ill. For women whose identity often depends on their role as social creatures who nurture and bring people together, these decisions are especially tough. Without the ability to assert one's own self-worth, restored health becomes an impossible goal. But these changes are essential for ecologically ill women with candidiasis, if they are to transform the conditions that are assaulting their immune system. The acutely and chronically ill must face the effect these changes will have on their personal relationships, if they want to regain their health.

The feelings of isolation and abandonment that many chronically ill people experience when they realize their loved ones can't identify with their problems are very painful. I now realize that people who have not lived the experience of bodily deterioration and the Kafkaesque trials of the medical system simply can't understand. My experience has shown me that the most valuable resources for sharing and practical support have come through networking with people who are experiencing similar health problems. At the personal level, meeting with people is often the only way to gain enough information and self-respect to act in one's own best interests.

It was because of this realization that I founded the Candida Research and Information Foundation (CRIF). There are now a few dedicated people whose goal it is to serve those who deal with the terrifying problems that I and others had to face alone. Through public education and lobbying, we are attempting to en-

sure that the problem of recurring candidiasis may be prevented altogether.

At CRIF we see single mothers so ecologically ill that they are unable to function physically or mentally. Yet at this very moment they have to make sense of the unfamiliar, complex and difficult procedures they need to follow for recovery. Most women have no one to cook for them or their children. Many are unable to keep their jobs and find themselves on welfare, facing prohibitive costs in services and goods. We see many women who have become suicidal in their poverty and despair. We see

older women, forced to sell or mortgage their homes to finance their health care, losing the only security they have because there is no recognition of the disease and no help for them.

CRIF offers people information that they simply can't find elsewhere: insight into why they got sick and in which ways they can get better. CRIF has no funds other than a small private grant which covers rent, office supplies and a part-time secretary. Consequently, we are forced to work on a fee for service basis, even though we know how much this limits our accessibility. We

THE CANDIDA RESEARCH AND INFORMATION FOUNDATION

The Candida Research and Information Foundation seeks to research, inform and educate about candida and related immune deficiency illnesses. In addition to candidiasis, we have extended our counselling to include information on hypoglycemia, diabetes, arthritis, Epstein-Barr, lupus and depression. CRIF's basic principles are that each patient has the right to know the success or failure of therapies used by their doctor and that the doctor must recognize the patient's right to information and education.

CRIF gives private consultations during which we look at different therapies to deal with your health problems. Referrals are also given to practitioners from every discipline — naturopaths, homeopaths, allopaths.

CRIF promotes patients' rights to have access to both conventional and alternative treatments. A patient information library contains books on many aspects of health and disease, as well as cookbooks for every gluten free, wheat free, dairy free and sugar free diet. Study groups are offered, which guide people to new ideas and offer support.

Unfortunately, CRIF has no funds and is not recognized by health insurance plans, and is therefore forced to charge fees for its services. CRIF is working towards the establishment of a network of publicly funded patient information centres which would be accessible to all those in need.

The Candida Research and Education Foundation is located at 598 St. Clair Avenue West, Toronto, Ontario M6C 1A6 (416) 656-0047.

HEALTHWISE

dream of seeing these kinds of services available to every person, with patient information centres acting as vehicles for change in these very difficult times. We believe the women's movement needs to fight for the establishment of publicly funded patient information centres of this kind in every community, where access to research, new ideas and information on all therapies would be available.

Patient information centres would meet the needs of those who are seeking new directions in health care. They would educate the patient so that meeting with their doctors would be more meaningful. For the many women who find visits to their doctor difficult and painful, these centres would provide patient advocate services. Through education people would be able to take responsibility for the direction of their health care. Patient information centres could be channels through which feedback on the true health picture of the population could be reported back to doctors and government. They could serve as places in which activists could rally feminist and community support for various issues important in women's health.

It seems natural to end with a call to all women who face illnesses of the immune system to become socially and politically active. It's a way to end isolation — and we must have the voices of women who have experienced these health problems speaking about them. The problem is that when women become so sick, it is extremely difficult to find time, energy and financial resources to fight back. But we also know that every woman is at risk. And healthy women have everything to lose unless they make women's health issues their own. Good health is not only the bedrock of personal well-being. It is also the quality on which we all collectively depend. Love, humour, compassion and achievement. You name it, it depends on health. Isn't it time to learn to nurture and protect our greatest asset!

Maggie Burston was forced to give up writing music because of her illness. She is now well enough to work as a patients' rights advocate, fighting for our right to live in a healthy society.

Where to Go for Info and Support

The following is a list of groups and organizations across Canada which offer information and support to people concerned about immunological problems. It is by no means a complete listing but we offer it as a starting point for people looking at alternative diagnosis and treatment of illnesses which are caused by a weakening of the immune system.

Allergy and Environmental Health Association
(to promote the free exchange of information on prevention and treatment of ecological illnesses)
ES 1
University of Waterloo
Waterloo, Ont.
N2L 3G1
519-885-1211 ext 6576

Allergy Information Association
(re. inhalent and food allergies — publishes *The Allergy Quarterly* — 1 year subscription \$25)
65 Tromley Ave., Suite 10
Islington, Ont.
M9B 5Y7
416-244-8585

Allergy Foundation of Canada
Box 33
Tuxford, Sask.
S0H 4C0

AIDS Education and Awareness Program
(publishes *The New Facts of Life*)
Canadian Public Health Association
1335 Carling Ave., Suite 210
Ottawa, Ont.
K1Z 8N8
613-725-3769

There are AIDS education lines and support groups in most major cities. Consult your phone directory or call your local operator.

Arthritis Society
(Head office, has chapters across the country)
250 Bloor St. East
Toronto, Ont.
M4W 3P2
416 967-1414

Candida Alibicans Support Association
No. 3 — 6344 Kingsway
Burnaby, B.C.
V5E 1C5
604-433-7646

Canadian Chronic Fatigue Association
(\$10 donation for comprehensive information package from medical journals, including a list of support groups)
c/o Tony and Sandy Gray
562 Ashfield Ct.
Pickering, Ont.
L1V 4Y3



Dawna Gallagher

Vicki Waspe Seminars
present

JEAN SHINODA BOLEN, M.D.
psychologist, Jungian analyst and best
selling author of
Goddesses in Everywoman

Lecture:

GODS IN EVERYMAN

A New Psychology of Men's Lives and
Loves

Friday, March 31, 1989
\$15

St. Paul's Trinity
427 Bloor St. W.,
Toronto

Workshop:

**THE HEROINE/HERO IN
EVERYPERSON**

The Mythic Dimension in Times of
Transition

Saturday, April 1, 1989
\$85

St. Michael's College
Toronto

To register: Call (416) 537-6464 or write
707 Markham St., Toronto, M6G 2M2

Canadian Holistic Medical
Association
Box 100-260,
2 Bloor St. West
Toronto, Ont.
M4W 2E2
416-960-4781

Canadian Society for Clinical Ecology
and Environmental Medicine
(re. physicians practising environmental
medicine)
c/o Dr. John G. MacLennan
46 Highway #8
Dundas, Ont.
L9H 4V9
416-628-8241

Candida Research and Information
Foundation
(publishes a quarterly newsletter
— 1 year subscription \$30)
598 St. Clair Ave. West, 3rd Floor
Toronto, Ont.
M6C 1A6
416-656-0047
9:30 — 12:00 Mon — Friday

DAWN (DisAbled Women's Network)
(publishes *Options* — a quarterly
newsletter)
#11 — 3856 Sunset St.
Burnaby, B.C.
V5G 1T3
604-435-0512 (subscriptions and
memberships)

Human Ecology Foundation of
Canada
(re. food, chemical and inhalent
sensitivities)
46 Highway #8
Dundas, Ont.
L9H 4V9
416-431-3227 (Toronto branch) (also
has branches in Waterloo, Quinte, Al-
maguin, London, Hamilton, Halifax-
Dartmouth and New Brunswick)

Lupus Canada
(has chapters across the country)
Box 3302
Station B
Calgary, Alta.
T2M 4L8

Multiple Sclerosis Society of Canada
(100 chapters across Canada)
250 Bloor St. East
Suite 820
Toronto, Ont.
M4W 3P9
416-922-6065

Parents for Education without
Pollution
(re. lowering pollution levels for
children in schools)
c/o Ann Smith
4 Dawlish Ave.
Toronto, Ont.
M4N 1H1
416-488-2600 (Smith's Pharmacy)

Parents of the Environmentally
Sensitive
(re. children with environmental
sensitivities)
P.O. Box 434
Toronto, Ont.
M4G 4C3

Plain Air Environmental Allergy
Society
P.O. Box 46633
Station G
3760 West 10th Ave.
Vancouver, B.C.
V6R 4K8

Prolonged Viral Syndrome
Association
c/o Anne Teehan
154 Timberline Trail
Aurora, Ont.
L4G 5Z5

Sunnyhill Research Centre and
Foundation for Independent
Research on Technology and Health
(re. information on environmental
sensitivity and healthy
environments)
c/o Bruce and Barbara Small
R. R. #1
Goodwood, Ont.
L0C 1A0
416-294-3531 (Toronto line — business
hours)

Healing Insights

with
THE OH CARDS

*Health through self-awareness
and self-empowerment*

Use the OH Cards to:

- practice self-exploration
 - exercise imagination
 - enliven dialogue
 - stretch listening skills
 - express feelings in safety
 - open communication lines
- and... have fun as well!

*The OH Cards are two decks of 88
special playing cards (one of full colour
pictures, one of words) that can be
used to generate insights into one's
life.*

For a free brochure, or a complete set
at \$43 (prepaid), write EOS-hs
Box 6263, Victoria B.C. V8P 5M3
Or call (604) 477-4071



Susan Elliott

A B C S of Immunology

We are all familiar with the symptoms of the 'flu — fever, aches and pains, exhaustion, a general feeling of being 'under the weather.' Most of us don't give the causes of all this misery a second thought. We just want to feel better. What many of us don't know is that these symptoms are the signs of a competently functioning immune system working to rid our body of an infectious agent. The fact that we feel bad now probably means that we will feel better soon.

Our immune system has been getting a lot of press lately. AIDS, increasing numbers of immunological disorders and diseases like 'Total Allergy Syndrome' or 20th Century Disease are all in the news. Other diseases like multiple sclerosis, arthritis and diabetes in which our immune systems attack our own bodies also seem to be more prevalent. And a chronic illness which occurs after infection with the Epstein-Barr virus is so common now that it has been termed the 'Yuppie flu.' To understand what our immune system is and how it functions, we need to become familiar with the language of immunology and the processes that occur when we are exposed to infection.

Our Immune System

Our immune system is a complex organization of cells and organs located throughout our bodies, connected by chemical messengers that travel in our blood and other body fluids. Unlike other body systems,

our immune system does not reside in specific organs. Instead, it is made up of a diffuse network of white blood cells and chemical messengers. In a very general sense, our immune system can be divided into two distinct components — humoral immunity and cellular immunity.

Humoral immunity refers to antibacterial substances known as antibodies in the 'humors' as the ancient Greeks called the bloodstream. Circulating antibodies are our first line of defence against infection. They attach themselves to the infective agent, either killing it outright or making it possible for white blood cells to kill it. However, there are so many different infective agents that we cannot possibly have enough types of antibody to destroy every potential infection. When our bodies identify a new virus or bacteria or a foreign protein, in the case of an organ transplant, other components of the immune system are alerted and kick in to make new antibodies that are specifically directed against this particular threat to our health.

Cellular immunity refers to the different kinds of white blood cells that become involved as the second line of defense against infection. Some of them can destroy the infection immediately, others pass the word on to even more potent cells that rapidly reproduce themselves and flock to the site of the infection.

Communication between defense cells is essential to orchestrate a response to an infection. Our immune cells communicate by means of chemicals called lymphokines that

are produced by some of them and recognized by all the others.

Defense Cells

Our blood is composed of red blood cells or erythrocytes (which carry oxygen to our tissues), platelets (which aid in clotting) and white blood cells or leukocytes (which are our defense cells). Leukocytes include a variety of cells: macrophages, lymphocytes, neutrophils, eosinophils and basophils. One of the symptoms of an infection is often an increase in the total number of white blood cells in the blood or leukocytosis. When there is a reduction in the number, as in AIDS, it is termed leukopenia.

The macrophages or 'cell-eaters' are the largest of the leukocytes. They make up only about eight per cent of the total number of leukocytes but are extremely important nonetheless. Some of them congregate in the liver and the spleen where they eat up old red blood cells, viruses or chemical pollutants. Others remain in the blood ready to engulf any invader. When macrophages spot an infection such as a virus particle, they send out a lymphokine called interleukin-1 which alerts other defense cells to spring into action. Interleukin-1 causes the body temperature to rise giving us a fever. This further stimulates the immune system since all the cells work more effectively at a slightly higher than normal body temperature. Interleukin-1 also breaks down muscle fibres to release needed nutrients,

resulting in aching muscles and fatigue.

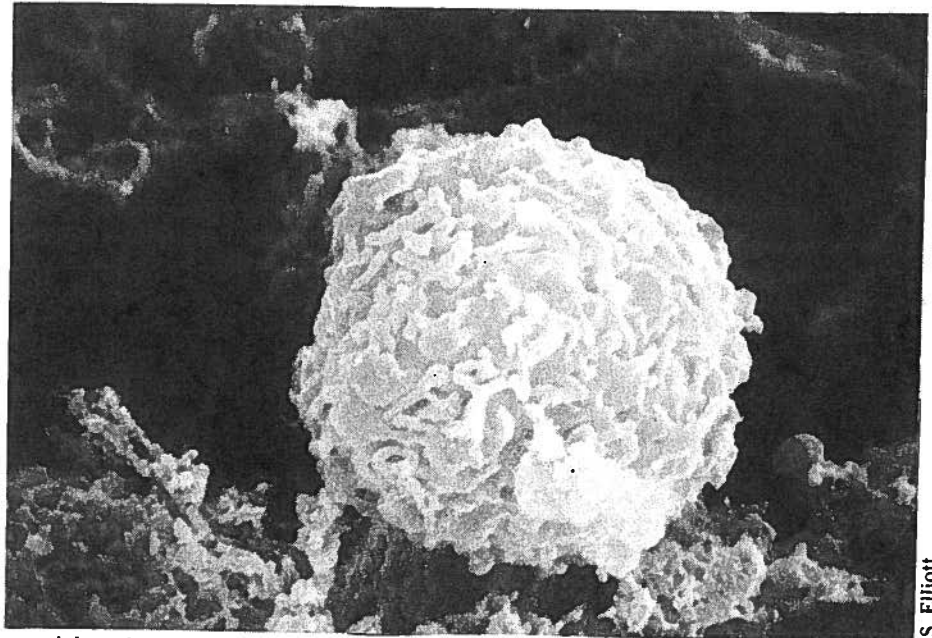
The smallest of the immune cells but the most diversified is the lymphocyte. Lymphocytes comprise about 25 per cent of the total number of leukocytes. There are two types of these cells, B-lymphocytes and T-lymphocytes.

B-lymphocytes (also referred to as B-cells) are formed in the bone marrow. When they have matured, they move out and live in the blood or in one of the areas of lymphatic tissue (like the tonsils) scattered around the body. They produce antibodies 'on demand' against infections. Once a B-cell receives information about what kind of antibody to produce, it churns out quantities of that particular antibody. It is now specialized and cannot make any other kind of antibody. As soon as the infection is destroyed this group of B-cells retires since their special antibody is no longer needed. A few stay on in the body serving as 'memory' cells, ready to reproduce themselves if that same infective agent shows up again. This process is termed 'acquired immunity' and explains why a person who has had the virus causing chicken pox as a child will probably never get it again even if exposed to someone with the infection.

T-lymphocytes (also called T-cells) are named because they migrate from the bone marrow when newly formed to the thymus, an organ located behind the breastbone, above the heart. There they mature and specialize into the more than 10 types now recognized. They are identified by protein markers that appear on their surfaces, and which have been given numbers to distinguish them, hence the name 'T-4 lymphocytes' which have been featured in press reports about AIDS. T-lymphocytes have the ability to recognize hundreds of millions of different invaders, each one identifiable by its characteristic biochemical markers. T-lymphocytes are critical to the immune system because even if there are great numbers of B-lymphocytes around, without properly functioning T-cells our body can't mount an effective immune response and we will catch infections like pneumonia. Three of the more important T-cells are the 'Killer T-cells,'

the 'Helper T-cells' and the 'Suppressor T-cells.'

Killer T-cells are activated by lymphokines to reproduce themselves and rush to the site of the infection. Their methods are different than the macrophages which engulf the invader and 'digest' it. Killer T-cells latch on to the invading cell and kill it by causing it to split open.



A lymphocyte as seen by scanning electron microscopy — 8,000 x actual size.

S. Elliott

Helper T-cells direct other T-cells. When they come into contact with an invader or receive a chemical message from a macrophage, they stimulate other elements of the immune system to gear up. One helper cell can activate hundreds of other cells by releasing a lymphokine called interleukin-2. Interleukin-2 is thought to work by de-activating Suppressor T-cells which normally keep everything on hold and turn off the immune response once the infection is cleared up. By de-activating these cells, our immune process is set in motion and all the elements work together to destroy the infective agent. Helper T-cells of the T-4 category (the ones involved in AIDS) also produce chemicals called interferons which also work to regulate the immune response. Some interferons keep macrophages at the site of infection, others enhance killer cell activity and still others stimulate B-lymphocyte antibody production.

Suppressor T-cells turn off the defense cells as soon as the infection is cleared, to prevent the immune response from getting out of control. These are the cells that are thought to be defective in people with autoimmune disorders such as rheumatoid arthritis where a continuous immune response against the lining of the joints causes pain, swelling

and eventual deformity.

Medium-sized cells called neutrophils make up 50 to 75 per cent of the leukocytes in our blood at any one time. Although capable of traveling throughout the body, neutrophils tend to remain in the blood. They migrate to areas of infection, exude chemicals that attract other cells and cause symptoms of inflammation such as swelling and pus formation. Like macrophages they can also engulf foreign matter but will only destroy it if it is packaged in a particular way. Neutrophils will only accept particles, for example, that have been attacked and surrounded by antibodies.

Cells responsible for allergic reactions normally make up only four per cent or less of the total leukocytes. They are called eosinophils. They secrete chemicals called histamines which cause blood vessels to dilate, allowing other immune cells to get to the area of infection quickly. Excess

histamines are released when a person comes into contact with something she is allergic to. The result is often a runny nose and eyes and a constriction of bronchial smooth muscle in the lungs making breathing difficult. People with allergies have a higher count of eosinophils in their blood.

The least numerous of the leukocytes are the basophils. They make up less than .5 per cent of the total leukocytes. They also produce histamines and are found in increased numbers in certain infections like chicken pox, smallpox and chronic sinus congestion. Although they constitute only .5 per cent of the leukocytes, their total number in an average person with six litres of blood is approximately 200 million.

Antigens and Antibodies

An antigen is any substance either from outside our body ('foreign') or part of our body ('self') that triggers an immune response. Examples of foreign antigens are viruses, bacteria or pollen. Self antigens are portions of our own bodies like the joint lining that is attacked in rheumatoid arthritis.

An antibody is a Y-shaped chain of protein made by B-lymphocytes to match each antigen. B-lymphocyte antibodies are manufactured as a response to an invading organism. For example, when a virus enters the body, B-lymphocytes go into high gear and produce custom-made antibodies which are only able to blend to that particular strain of the virus. Sometimes antibodies can inactivate an infection themselves, but more commonly they attach to the infective agent and make it 'visible' to other cells like macrophages or killer T-cells which then destroy it.

Antibodies travel in the blood and other body fluids when not attaching themselves to antigens. They are transferred to the fetus during gestation giving the baby a temporary 'passive immunity' against diseases the mother has been exposed to in the past. Unfortunately this type of immunity is short-lived and by the time the child is about six months old she must begin to depend on her own developing immune system which produces antibodies as she

is exposed to infections. If a very young or premature infant develops a serious infection, it is sometimes possible to boost the child's immunity by giving an injection of gamma globulin, an antibody which has been separated from the blood and purified.

Organs of the Immune System

Even though there is no one 'immune organ,' a number of organs are important to the immune system. These are the bone marrow, the thymus, the spleen and the lymph nodes.

Blood cells are formed in the bone marrow which is the spongy substance found in the centre of our bones. Leukocytes destined to become T-lymphocytes travel from here to the thymus where they mature and specialize. The thymus also releases hormones into the body which affect the cells of the immune system. The thymus itself is very sensitive to stress hormones released by other organs in our bodies. When we are under a lot of stress our thymus can shrink and thus leave us vulnerable to infections.

The spleen is located behind our lower ribs on the left side of the body. It is normally the size of a fist but in certain immune disorders it enlarges dramatically. Before birth, blood cells are formed in the spleen, but after birth the site of production moves to the bone marrow and the spleen is no longer essential for life. Vast numbers of leukocytes congregate in the millions of tiny blood vessels of the spleen. They are on alert for any infection in the blood that passes by. They also get rid of old unwanted red blood cells and debris. Occasionally they become overzealous and start destroying healthy red blood cells causing anemia. When this happens the spleen is often surgically removed. People who have had a 'splenectomy' for this reason or because their spleen was badly damaged in an accident may be slightly more susceptible to infection, but for the most part they live normal lives since immune cells are found in so many other parts of our bodies.

Lymph nodes are small dense structures up to an inch in length,

found all over our bodies. There are a number of them in the armpit and along the chest, all interconnected. They contain large numbers of lymphocytes which trap infections present in body fluids other than the blood. Because they are interconnected, cancer cells can often spread quickly through them which is why the ones on the chest wall and in the armpit are sometimes removed during a mastectomy. Like the spleen, they are a part of a larger system and are not essential to life.

Even though our understanding of the immune system is rapidly increasing, there is still a great deal that is unknown. As researchers uncover more of the mysteries of the immune system we can only marvel at the design and functioning of one of the most intricate and vital parts of our bodies.

Susan Elliott worked for a number of years in immunology research and is a member of Women Healthsharing.

feminist perspectives

No. 11, Getting Older and Better: Women and Gender Assumptions in Canadian Society, by Susan McDaniel. Explores and questions some assumptions about gender and gender differences which guide much thinking, including supposedly scientific thinking. Some of the challenges and opportunities for women in an aging Canada are highlighted.

No. 13, Some Advice for Overcoming Barriers to Women's Achievement in Non-Traditional Occupations, by Barbara Carroll and Frances Cherry. Provides women contemplating non-traditional careers with information about the types of barriers they may encounter and advice to overcome them. Based on interviews with women already involved in such careers.

Price: \$2.50 + 75c postage each. Order from:

**CANADIAN RESEARCH INSTITUTE
FOR THE ADVANCEMENT OF WOMEN**

151 Slater, Suite 408,
Ottawa, Ontario K1P 5H3

Lorie Rotenberg

Winning the Battle

LIVING WITH EPSTEIN-BARR VIRUS

No longer is the sky the limit nor the world my oyster. Through my experience with chronic Epstein-Barr virus syndrome (CEBV), I have come to learn the meaning of living with limitation. Although I have always been an introspective person, this illness has challenged me to look even deeper within myself to discover how to hear the messages of my body. I am much better now, which tells me that I have gained some understanding of the significance of the Epstein-Barr virus in my life

Links With My Father

On March 30, 1987 I received the diagnosis of Epstein-Barr virus from my physician. I was 37 years old at the time. On March 30, 1955, my father died of chronic nephritis (irreversible kidney malfunction) when he was only 37 years old. This striking coincidence seems an appropriate departure point for my journey into self-knowledge.

My father coped with terminal illness by living each day as if he believed he had many years yet to enjoy. This stance enabled him to survive 13 years after his fateful diagnosis was pronounced. Up until a few months before his death, he functioned normally to all outward appearances, with only two limitations: he had to adhere to a strict diet and avoid stress.

What does my father's illness have to do with me? When I was at my lowest point with Epstein-Barr virus, I often flashed on a mental picture of



Barbara Pasternak

my father lying listlessly in his bed, overcome with fatigue. I sensed a commonality between his experience and the crisis I was grappling with. I feared that, like him, I too would be unable to live my life to its fullest. At that time I did not know that chronic fatigue, the key symptom of CEBV, is, indeed, *not* a symptom of nephritis. Nor was I aware that my father had actually only retired to his bed during the month prior to his death. The memory still so fresh in my mind is the five-year-old child's last image of her father as a sick parent devoid of energy. When I shared this memory with the counsellor whom I was seeing for CEBV-related depression, she urged me to disassociate myself from it. Since my father was wearing

pyjamas while at home sick, she suggested that I wear my street clothes during those days when I was too weak to get out of bed. His illness was not mine.

Ever since my father's death, I have equated illness with something very grave, portending disastrous consequences. One of my unconsciously held assumptions has been that each time I get sick, I risk never recovering. Flowing from this unacknowledged belief has been my tendency, when first becoming ill, to avoid hearing my body's message that I need to slow down and take time off work. In the past I never went to bed unless I was literally on the verge of collapse — unless my body forced me to. Witness my behaviour in the few weeks leading up to my diagnosis of pleurisy in November 1979. When I finally did get to my doctor's office, she expressed astonishment that I had not reported my symptoms sooner. It was as if I needed her to give me permission to take to my sick bed.

My denial of any illness which has not reached serious proportions, has meant, in fact, that I have failed to hear my body's warning signals and thus been unable to nip minor ailments in the bud. My own actions have made my illnesses more alarming than necessary.

Although I have known for years that I have difficulty ministering to myself at the first signs of sickness, I have not understood until now how this behaviour is linked to my childhood experience of my father's illness. To acknowledge illness in my-

self is to acknowledge the possibility of death. This insight feels both painfully obvious and also quite liberating. The challenge facing me is to come to grips with my fear of mortality.

Coming Out With CEBV

Initially my way of dealing (or not dealing) with the Epstein-Barr virus was similar to the approach adopted by my father towards his disease. Like my father, I sought out alternative healing, although in my case it has been through a naturopath. (I believe the homeopathic remedies which I have taken are, in part, responsible for my improved condition.) Other than homeopathy, my main coping strategy for many months entailed bargaining with the virus through denial. It was as if I were saying to the virus, "If I act like you're not really there and don't give you any attention, then you'll have to go away." I did not want most people to know that I had CEBV. It was a secret only to be disclosed to a chosen few. But even the chosen few, my close friends and family, were spared most of the details. I tended to constantly minimize the level of fatigue I was experiencing, thereby continuing to push myself. I seemed unable or unwilling to accept limitation as an ongoing and integral part of my life.

As was true for my father, most of the time I show little, if any, physical evidence of being afflicted with a disease. None of my most pronounced symptoms, which have included deep and pervasive fatigue (only detectable in my face and eyes by the experienced observer), tingling sensations and occasional numbness in my arms and legs, depression, low-grade fever, enlarged lymph nodes and problems with sleep, is immediately visible. Since what is exposed to others does not accurately reflect the inner reality, I have to constantly make a choice about whether, and to what degree, I wish to be known. Somehow this issue of being known seems central to my experience of this illness. Always the question presents itself: "Do I wish to pretend I am 'normal' or to acknowledge in an open way that I live with Epstein-Barr virus?" For



Barbara Pasternak

The challenge facing me is to come to grips with my fear of mortality

the first five months following my diagnosis I honed my ability to 'pass' for 'normal,' although on a conscious level I did not understand nor would I have described my actions that way.

In September 1987 I read two articles which profoundly affected my interaction with my illness. Through the insights stimulated by these readings I have been able to transform my understanding of my self in illness and thus, over time, transform my experience of illness. "Learning to Live with It," an article by Ray Jobling, presents a detailed account of the author's life with chronic psoriasis. Jobling's description of his "passing," "impression management" and finally his "coming out" as a chronically ill person helped me to

recognize my own cover-up mechanisms.

Shortly after reading Jobling I came across an article in *Healthsharing* by Betty-Ann Lloyd entitled, "No Longer Silently Disabled," which helped me build on my new learnings. Lloyd suffers from multiple sclerosis, but most of the time her disability is not evident. She speaks eloquently of her struggle to accept her difference, to "come out" as a disabled person and to raise consciousness of disability issues within the feminist community in Halifax. She tells of the embarrassment she feels about her actual or potential dependency. For her, "coming out" as a lesbian is usually less difficult than "coming out" as a disabled person.

Her experience resonated with my own. I realized that I was just as afraid of revealing my illness status to people as I am cautious about sharing information about my sexual orientation. Partly it is because of the intimacy and vulnerability which both forms of "coming out" entail. I came to understand how, each time I hid the fact that I have Epstein-Barr virus, I had been disconnecting from a significant part of my being. And I already knew from spending ten years denying my love for women, what psychic damage such repression can cause. I was dumbfounded to discover that I had been expending large amounts of energy in "stage managing" my illness, striving very hard to be accepted as an able-bodied person. But, of course, this often meant that I did not get the support and empathy I felt I needed from my intimates.

By the time I had finished Lloyd's article, I had made an important decision. My days of "passing" in terms of denying illness were over. No longer would I hide my exhaustion or my fear. I would try to redirect the energy formerly drained off into secrecy towards self-healing. If I believed it was psychologically and politically important for me to "come out" as a lesbian, then certainly the same held true for me as an Epstein-Barr virus sufferer. I began to accept the powerful need I have to be known and appreciated just as I am. This virus, like my lesbianism which is also invisible, demands that I reclaim my self not

only in the private arena, but in the public arena as well — that I state explicitly who I am and how I am feeling at any moment in time.

As a result of my new understanding, I began to really let others into my world of illness, a world which had previously been barred to all except my partner. I felt a tremendous sense of relief at no longer having to carry the burden of secrecy. I began to arrange social commitments with the stated agreement that, depending on the severity of my symptoms, I might have to reschedule. My loved ones have certainly offered more support than they possibly could have when I was still "passing."

However, there has been some disappointment as well. In some ways I have found the reaction to "coming out" as an Epstein-Barr sufferer similar to "coming out" as a lesbian. Most of my intimates do not regularly ask me how the virus is behaving. I talk much more than I used to about what it means to live with chronic illness, to wake up most mornings feeling absolutely exhausted no matter how much sleep I have had, to know that, as yet, there is no cure for Epstein-Barr virus and that indeed I may have to live the rest of my life with some degree of limitation. They listen, with interest and concern. But, for the most part, they do not take the initiative in discussing illness with me. Before, I was unknown and invisible. Now, I am known, but in some ways, even more invisible.

It is fear, I think, that prevents them. Fear of acknowledging their fear that they might lose me or that they might develop a chronic illness themselves. Here the parallels with the reactions of heterosexuals to my "coming out" as a lesbian are unmistakably clear. Perhaps it is also discomfort and a sense of impotence that prevents them from talking to me about the virus. My wanting to be fully known and appreciated does not mean that others desire to fully know and appreciate me.

Symptoms of Femininity

Throughout the decade in which I repressed my love for women, I often felt unwell. I knew at some



Barbara Pasternak

Epstein-Barr virus had, indeed forced me to slow down the pace of my life

level, that I was sacrificing an important part of my personhood. However, I did not realize that this would also lead to repressing my Jewish identity, my feminism and my socialism. During this period, I experienced an array of "symptoms of femininity" (to use the phraseology of Miriam Greenspan in her book *A New Approach to Women and Therapy*), ranging from depression and chronic fatigue to claustrophobia and so-called psychosomatic pain (headaches, dizziness, nausea and low-grade fever). After reading Greenspan I began to reinterpret this lengthy period of ill-health, to see for the first time that most of the symptoms which finally drove me to psychotherapy in 1980 were, in reality, passive forms of female resistance to the culturally defined standard of femininity. My body was trying to tell me how unhappy it was to have to hide its sexual passion.

Regrettably, by that point I was so out of touch with my feelings that I was unable to pick up most bodily signals. In order to suppress my deep love for women, I had to suppress other heartfelt sentiments as well. I became emotionally controlled and distant. I threw myself into the world of work and achievement. My workaholicism was fuelled by displaced passion. The real dilemma facing me as I took my first step into the world of therapy was whether I was going to accept the traditional female role with its concomitant heterosexuality.

Letting Go

In May 1987 I embarked on a sabbatical leave from my job as a senior trade union representative. This came none too soon after seven years of intense, emotionally demanding, energy-draining work in an environment where I did not feel that I could be all of myself. My lesbianism was hidden from all but a few of my closest colleagues and my feminism and socialism were often muted to avoid potential conflict. The masculinist world of paid work, with its emphasis on hierarchy, competition and goal orientation at the expense of process and relationship, did not allow for the expression of my "womanly" values. I realized that like my foremothers, Charlotte Perkins Gilman and Jane Addams, who had taken to their sick beds as misfits, I too was unable to make myself fit without incurring psychic injury.

That summer I spent three glorious months camping and hiking with my partner. I was able to slow down and get in touch with the part of me that feels deeply connected to nature. On returning home, I began to seriously contemplate my future working life. It seemed clear that I had but one option — to seek to create a new work situation which would not demand participation on masculinist terms. Eventually I did choose to make a radical career switch involving a return to university. It was while I was struggling with my decision about whether or not to leave my job and the labour movement that I first noted and reported to my naturopath the symp-

tom of overwhelming tiredness.

I remember vividly my complete astonishment and bewilderment at finding myself ill while on sabbatical leave. Hadn't I been doing all the right things to change my life so it was not longer based on self-denial? After "coming out" as a lesbian and entering a committed love relationship, I had moderated my pace of living and working, becoming more rounded by developing new interests and friends, and even begun to let my vulnerability show on occasion. I had started to see a naturopath and, through hiking and swimming, finally felt physically fit. I had begun to work with a feminist counsellor who was teaching me how to value myself. Just prior to the onset of the Epstein-Barr virus, I was someone who had never felt better in her life.

I have come to see that the timing of this virus' arrival in my life is an expression of my letting go after many years of having girded myself. It was only when I was away from my work-place environment, when I was no longer looking over my shoulder all the time to see if someone would discover Lorie the lesbian, that my body could finally succumb to the adrenal exhaustion it was experiencing. At a very basic level, my decision to change career paths has meant that I have been able to relax for the first time in my adult life. This has felt incredibly liberating and exciting. At last my body could yield to its own needs. And insist on making these needs known and felt by the emotional and intellectual components of my self.

Listening to My Body

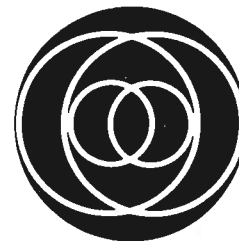
I am convinced that if I had not developed Epstein-Barr virus, I would have approached graduate school in exactly the same way I did undergraduate study and my work in the labour movement — that is obsessively and with definite workaholic tendencies. Somehow I think my body knew that just taking 10 months off work would not, in and of itself, ensure that I would seriously address my drive to perfectionism. Without illness, the most likely scenario is that I would have had a good rest and returned to

work or school with renewed energy, but no fundamental change in my pattern of living and, especially, of working. My body had to find some way to impress upon me the gravity of the situation. In that it certainly succeeded.

I now understand the virus as a self-regulating mechanism which ensures that I avoid overextending myself. When I was first exposed to the idea of illness as a metaphor, my instinctual reaction was to start humming the opening of Paul Simon's tune, *The 59th Street Brigade Song (Feelin' Groovy)*: "Slow down, you move too fast. You got to make the morning last." Through the language of illness comes a message from a deeper part of myself. It is an entreaty to get out of the fast lane, to give up my need to achieve and control, to appreciate life in the present moment, to take time to savour life's gifts.

Epstein-Barr virus has, indeed, forced me to slow down the pace of my life. I found that if I did not get enough sleep or if I had too many social commitments, then my fatigue and general feelings of unwellness increased. Instead of becoming anxious, I listened to my body, pulled on the reins and reduced the tensions in my life. In this way I believe the virus allows the self to disengage from pressure so that it can withdraw and retreat to regain its strength.

Similarly, the virus has confronted my drive to perfectionism which I believe is intimately linked to my tendency towards overextension. I am still in the process of trying to discover the wellsprings of my psychic struggle for self-perfection so that I can change this unsatisfying way of functioning. Again, reading Miriam Greenspan gave me some valuable insights. She views perfectionism as an attempt by the victim of social oppression to gain what appears to be some degree of internal control in a world where external control is denied her. It is a strategy employed by those who are devalued by society. They try to obtain the approval of others through their accomplishments and by striving to be perfect in all that they do. But, since this method of gaining control involves an attempt to measure up to



4th Canadian Congress of Rehabilitation

Toronto, June 21-23, 1989

"Workers & Workplaces Challenges & Innovations"

For more information contact:
CRCD Congress Secretariat,
 One Yonge Street, Suite 2110
 Toronto, Ontario, Canada M5E 1E5
 Tel: (416) 862-0340 Fax: (416) 865-1851

The Woman's Common



A Club for Women

- full bar
- restaurant dining
- weekend brunches
- live entertainment
- lounge & library
- cultural events
- films & speakers
- exhibits by women artists

For more information call 975-9079

Open: Tues. - Fri. 4pm to 1am
 Sat. 11am to 1am
 Sun. 11am to 11pm

Sliding scale membership from \$15.00
 580 Parliament St., Toronto, Ont. M4X 1P8

Allergy

**INFORMATION
ASSOCIATION**

presents

ALLERGY: '89

A one day seminar about allergic disease for allergy sufferers, health care professionals and any person who is either directly or indirectly affected by allergic disease.

Saturday, May 6, 1989
Bristol Place Hotel, Toronto
8:30 am — 4:00 pm
A.I.A. members \$30
non-members \$40

For further information contact:
Allergy Information Association
65 Tromley Drive, Suite 10,
Islington, Ont. M9B 5Y7
(416) 244-8585



standards which are most often defined by the oppressor, it is, at root, externally based. So, in the end, compulsive perfectionism robs the oppressed of any remaining vestiges of self-acceptance or self-worth. It can also, as in my case, hurt the body and make one's life unbalanced by overemphasizing work at the expense of everything else.

As a woman, a Jew and a lesbian, I am an outsider in my own society. I have been, and continue to be, subjected to sexism, anti-semitism, heterosexism and homophobia. To some extent I have internalized the negative messages this society propagates about people like me. However, I have come to learn that I will only feel like a misfit if I allow others to define me in that way. Since "coming out" as a lesbian and getting back in touch with my Judaism, my feminism and my socialism, I have begun to reclaim the locus of control of my self-worth so that more and more I find it residing within me. Through insisting on living my life as the person I am and through engaging in political action aimed at changing the discriminatory conditions under which I am forced to

live, I am beginning to acquire a measure of control that is far healthier physically and psychically than my old "friend" perfectionism.

My difficulty in valuing myself may offer a clue to a deeper insight. The virus allows me to disengage from the prescribed female role of nurturing and taking care of others so that I can turn my attention inward. Perhaps there is another lesson here: the need to develop the capacity for self-nurturing and to accept nurturing from others. The virus provides an opportunity to learn how to use the energy I do have to take care of myself in a loving and appreciative manner. And it challenges me to ask for support from others when it is necessary.

Internal Harmony

My learnings from living with chronic Epstein-Barr virus have led to dramatic changes in my relationship with my body. For most of my life I have subscribed to two common causal explanations of illness. First, I have conceptualized and experienced my body as an object, viewing illness as comparable to machine breakdown. My physician describes how I used to arrive for my appointments demanding that she fix the "problem" immediately so that I could continue to function without interruption. I saw my body as something divorced from the "real me" which prevented me from doing what I wanted. I did not trust it and refused to give its signals anywhere near the weight I allotted to those that emanated from the other parts of myself. I did little to maintain my own body in good shape nor would I allow it to experience much sexual passion. Secondly, since I saw illness as a punishment for failure to take care of my body, whenever I got sick, I would resort to moralistic self-blame, assuming that I had either failed to do something or done something wrong.

Shortly after being diagnosed with Epstein-Barr virus, I watched a television programme featuring Dr. Carl Simonton, the renowned cancer specialist. His discussion of the benefits of imagery and visualization as self-healing techniques for cancer pa-

tients inspired me. I realized that I had been fighting my body, seeing it as an enemy, rather than cooperating with it in its struggle to strengthen my immune system. I began to visualize my white blood cells as an army of Amazon warriors with thousands of spray cans full of antibodies designed especially to kill the Epstein-Barr virus. Visualization did not

Chronic Fatigue Syndrome

Chronic fatigue syndrome is also known as post-viral neuro-myasthenia or chronic Epstein-Barr-virus syndrome (CEBV). Although the cause is not exactly known, there may be a connection with a virus (possibly the Epstein-Barr virus) plus some other attack on the immune system.

Epstein-Barr is a member of the herpes family of viruses which include herpes simplex, chicken pox and human B lymphotropic virus (HBLV). What these viruses have in common is that they infect B-lymphocytes and are with us for life. After their initial attack they remain dormant in our bodies and may erupt at any time under conditions of stress or immune system upset. The Epstein-Barr virus is everywhere, and is thought to be present in 90 per cent of the world's population. The initial attack may come in childhood when it is very mild, or in adolescence when it causes infectious mononucleosis or 'kissing disease.'

Many patients with chronic fatigue syndrome have elevated levels of antibodies against the Epstein-Barr virus which led researchers to think the virus was the cause of the syndrome. However, the number of patients who have normal antibody levels has led to the controversy about whether the Epstein-Barr virus is the only cause. At present there is speculation about other co-factors including a depressed immune system or another virus being involved.

WHS

MY STORY, OUR STORY

come easily to me. What worked best for me were brief flashes on the battle scene twenty times a day.

Too often in the early days virus-induced depression would overwhelm me and I would lapse into feeling wounded and sorry for myself. My attempts to normalize myself through "passing" only intensified my sense of isolation and despair. As I have gradually learned to hear and honour my body's messages I have begun to experience myself as less driven and more at peace with my body and, hence, my self. My body no longer appears to my emotional, intellectual and spiritual selves as the great controller. Internal harmony among my selves is becoming a reality.

On some very fundamental level, I see my prolonged involvement with illness as mirroring my struggle for authenticity. If I can reject external definitions of myself, and instead accept who I am and act on my need to be known as I am, then I believe full health will be mine again. This journey inward has increased my desire to savour the joys of the present, whatever my physical limitations, and given me courage to face the future.

Further Reading

Jobling, R., "Learning to Live With It." In A. Davis & G. Horobin (Eds.), *Medical Encounters: The Experience of Illness and Treatment*, Croom Helm, London, 1977.

Lloyd, B., "No Longer Silently Disabled." *Healthsharing* (Fall 1987), 8(4), 26-28.

Greenspan, M., *A New Approach to Women and Therapy*, McGraw-Hill, New York, 1983.

Simonton, O.C., Matthews-Simonton, S., & Creighton, J.L., *Getting Well Again*, Bantam Books, New York, 1970.

A longer version of this article was first written in December 1987 for a course taught by Ron Silvers at the Ontario Institute for Studies in Education.

Lorie Rotenberg is very much alive and well and living in Toronto. She will soon be starting work as a feminist therapist.

Making My Operation Operate For Me

Wendy Annand

When I received the unwelcome news that I needed a hysterectomy I was being treated for environmental hypersensitivity. Because of all the special care I had taken to deal with the condition since my diagnosis two years earlier, I was very concerned about the surgery. I was terrified the stress of the operation, the drugs I would need to take for it and the hospital environment itself would trigger my sensitivities and send me back into the physical condition I had been struggling so hard to escape. I was determined to make sure that wouldn't happen.

For the two years prior to my diagnosis of environmental hypersensitivity I had been unable to work and was in extreme pain, suffering from headaches, insomnia, fatigue and kidney, muscle, breathing and ear problems. Quite naturally I was also depressed, particularly because of my inability to obtain a medical explanation for all these symptoms.

After I discovered what was wrong with me, I learned that people who suffer from this illness, also known as "20th century disease," are extremely sensitive to a wide variety of substances and often will become ill after only minor exposures. Environmentally hypersensitive people react to things like petroleum-derivative products such as plastics and hair conditioners and to cigarette smoke, fungi and pollens to name only a few.

Although in the two years following my diagnosis I had made the necessary changes in my life to reduce my exposures to things affecting me, I was still a long way from well. I could work full time under controlled conditions and participate in many social activities. Spending as much time as possible in environments I could control (my

home, car and office) allowed me to cope better with exposures to those things which I could not avoid and which caused symptoms. A very strict diet, special serums and drops to help "desensitize" me and the use of certain substances to reduce reactions were all helping my body slowly recover.

I vividly remember the day in mid-February of 1985 when, during a routine examination, my doctor discovered what he presumed to be a large fibroid growth in my uterus. I was terrified. My immediate thought was that it would be just my luck to die during an operation after everything I had already endured with the environmental sensitivity. But the "poor me's" soon passed and I started to plot my course of action to make the operation as safe for me as I could.

A gynecologist confirmed the diagnosis and laid out the options.



Since the tumour had reached the size of a 16-week-old fetus in the year-and-a-half since my last examination, my choices were either to proceed immediately with surgery or wait and watch the tumour's rate of growth. The second choice involved the risk of hemorrhaging or having the increased size of my uterus interfere with my bladder or other organs. I was told that removing the growth alone might result in regrowth and the necessity of another operation, so I chose to have a partial hysterectomy (my ovaries were not involved).

As for how the operation would affect my environmental hypersensitivity, time was running against me. I did not want to add to the frightening event the additional physical stresses of summer, caused by the increase of inhalant allergens during that season. I therefore asked my gynecologist to arrange for me to see an anesthetist before my upcoming trip to Toronto to see my clinical ecologist who was treating me for the hypersensitivity. (Clinical ecologists are medical doctors who have received special training for diagnosing and treating environmental illnesses.) I reasoned that if I found out in advance what drugs the anesthetist would use during the surgery, and if I could obtain samples of them, the clinical ecologist and I could determine whether I was sensitive to them and could then take precautions.

Unfortunately, I encountered the same kind of attitude from the gynecologist which had so frustrated me during my long and near-futile search for an explanation of my environmental illness. The gynecologist and surgical team were unable or unwilling to understand my needs and I was refused access to the anesthetist prior to my departure for Toronto. Needless to say, I would have no further dealings with that gynecologist and wrote to my general practitioner saying that I would find a more appropriate surgeon on my return from Toronto.

By the time I returned to Halifax, I had a list of suggestions as to how I should be treated during the operation, should I have a drug reaction. I had some neutralizing drops (a dilution of a substance that will stop a

reaction to a normal dose or exposure to that substance) which would help me overcome the reaction. Some of this was guess work as we did not know the specific drugs which an anesthetist would be using.

However, since antibiotics and morphine are drugs commonly used during surgery, I brought back Amoxicillin and morphine drops. I also got a prescription for Mycostatin to protect myself from antibiotics that would trigger my candidiasis (an over growth of the yeast organism *candida albicans* in the body). Having already been tested for sensitivity to a couple of anesthetics and



anti-nausea drugs, it appeared that a combination of my regular synthetic ethyl alcohol drops and formalin drops would counteract most reactions. Oxygen and Alka Seltzer Gold (an alkaline to neutralize the acidic response of an allergic reaction) are always helpful to me when my body is over-exposed to harmful substances. But ultimately, my goal was to use as few drugs for as short a time as possible during and after the operation.

While I knew what had to be done to get through the operation, I was not convinced that I could organize the operation to my satisfaction in

Nova Scotia. My clinical ecologist in Toronto referred me to a gynecologist in Toronto who had experience in dealing with my condition and who had access to a special "allergy room" in a local hospital. The operation could have gone ahead there in April. However, Toronto was certainly not my preference because of the expense and all the hassles involved with travel, food and accommodation.

Meanwhile, back in Nova Scotia, a friend was busily gathering the names of potentially sympathetic gynecologists and anesthetists from her network of friends. On my return, my general practitioner and I reviewed the names and contacted our mutual first choice. After listening to my general practitioner explain the problem, this doctor was willing to accept me as a patient. In fact, after talking with me, he indicated that he considered me something of a challenge.

While he was booked for surgery until mid-July, after I explained the problems associated with that season, he agreed to come back from his vacation to operate on May 31. The operation would take place in the largest and busiest hospital in the Maritimes. Arrangements were made for me to meet with the anesthetist and the head nurse of the floor I would be on. I appreciated the anesthetist's candid admission that he was also deciding, during our interview, whether or not he wanted to take me on as a patient. He decided to go ahead with it. The head nurse was wonderfully helpful. It probably did not hurt my cause that she and my father came from the same small rural community!

As I was making these contacts, the gynecologist was enlisting the cooperation and understanding of the operating room and recovery staff. The dietician promised cooperation with meeting the requirements of my special diet and I provided copies of my menu for a week, even though I arranged to bring in most of my own food and water. Cleaning staff agreed to allow my mother to look after my room during my stay as a way to eliminate major exposure to their cleaning substances.

To best control my exposures, it was obvious that I would need a pri-

vate room. Hospital staff aired our a room before my arrival and had a sign preventing anyone from entering without first checking at the desk. Even staff who wore perfume or who smoked were kept away as much as possible. I was admitted a day early to ensure I wasn't "bumped" from the private reservation. My mother cleaned the room with my safe supplies — Borax, baking soda and Bon Ami powder. My portable air purifier ran all day — its charcoal filters absorbing unwanted chemicals and odors. We covered the mattress with an emergency blanket — this cuts down on the amount of off-gassing from the chemicals used in the production and fire-proofing of regular mattresses. I brought in my own sheets, blankets and towels, as regular detergents, starches and laundry additives can cause problems.

During my stay, the dietary department did a remarkable job of accommodating my diet. They tried to prepare my organic foods as I requested or occasionally substituted items from the same food family on the regular menu. Mineral water supplemented the well water my parents brought in daily. The nursing staff were very kind and competent. I had left a copy of the story of my illness with the head nurse. Most of the nurses read the story and asked pertinent questions about my condition.

Just prior to the operation, the recovery room and operating staff came to my room to ask last-minute questions. Recovery-room staff agreed to administer oxygen with my porcelain mask (regular masks are made from petroleum derivatives) and to give me my neutralizing drops until I was conscious enough to administer them myself. Because of suggestions the anesthetists had made, the operating room hazards were lessened considerably. Rather than use a jelly on the tube inserted in my throat, they used a saline solution. A new bag and tubing were used to supply oxygen as they were treated only with gamma rays rather than chemicals. Two drugs in combination provided the anesthetic effect. As well, a muscle relaxant, an anti-nausea drug, an antibiotic and a pain killer were administered. The operation went entirely as planned

— the growth was a single non-malignant fast-growing fibroid tumour. The only surprise was some endometriosis which was cauterized at the same time.

By early afternoon, I was back in my room and by late afternoon, able to talk coherently to visitors. I had brought in my TENS machine (transcutaneous electrical nerve stimulator) and a physiotherapist explained the necessary positioning for the abdominal incision. I had originally obtained this machine when no other form of pain control would relieve the symptoms of my long illness. With the TENS, I was able to stop using pain killers the day after the operation.

I required no drugs after the first day. I continued my neutralizing drops and Mycostatin as well as large quantities of Vitamin C to speed healing. A week after the operation I was released from hospital — already able to take fairly long walks and look after myself. The clinical ecologist in Toronto felt I would need extra time off work to rest up from the stress to my body, so I took nine weeks instead of the seven normally recommended.

Of course, everything I did involved time, work, and great financial cost. There is no doubt that environmental sensitivity is an expensive disease. A poor woman could remain incapacitated or even die from it because she could not afford the costs associated with getting both the right diagnosis and then the treatment. I was fortunate that I could cover both because I received disability insurance and because I had personal savings to fall back on. If it wasn't for both of these, my money would have dried up before I was ever diagnosed.

While the hysterectomy naturally set back my overall recovery, I actually did quite well, all things considered. I shudder to think what might have happened had I either become discouraged and put off the operation or gone ahead with a surgical team who made no allowances for my condition. Whenever I became overwhelmed at everything that had to be done for the operation, a friend or family member was always there to prod me along and support me. While many people with



all under one roof

Parentbooks

201 Harbord St. Toronto, Ont. M5S 1H6

Mon. — Sat. 10:30 — 6:00

Phone (416) 537-8334

my condition are not as fortunate to have such support, there are always other hypersensitive people who can provide suggestions and encouragement, if needed.

My hospital experience was a valuable lesson to me. There are medical people who are open-minded enough to listen to patients who have controversial problems like mine. (Many doctors don't believe there is such a thing as environmental hypersensitivity or that the treatments we use can bring about the relief we actually experience.) If your doctor does not listen to you, find one who will. It may not be easy, but it can be done, and you will reap the rewards. You can obtain appropriate and sensitive medical help if you take charge, ask questions and make your needs abundantly clear. I did and I'm still here to tell the tale.

Wendy Annand works as a parole officer and is active around women's health and family violence issues in Nova Scotia. In her spare time she offers advice on environmental sensitivity.

Anna Kohn

Shots in the Dark

The Risk of Infant Vaccination

Every window in the house was pushed wide open. It was 2 a.m. on a stifling July night. Katie Kortekaas wondered what her neighbours were thinking. For hours her three-month-old baby Maureen had been shrieking for 20-minute stretches, then falling asleep exhausted. Moments later she'd wake up screaming again, throwing her head back and forth. Her fever was peaking at 102 degrees.

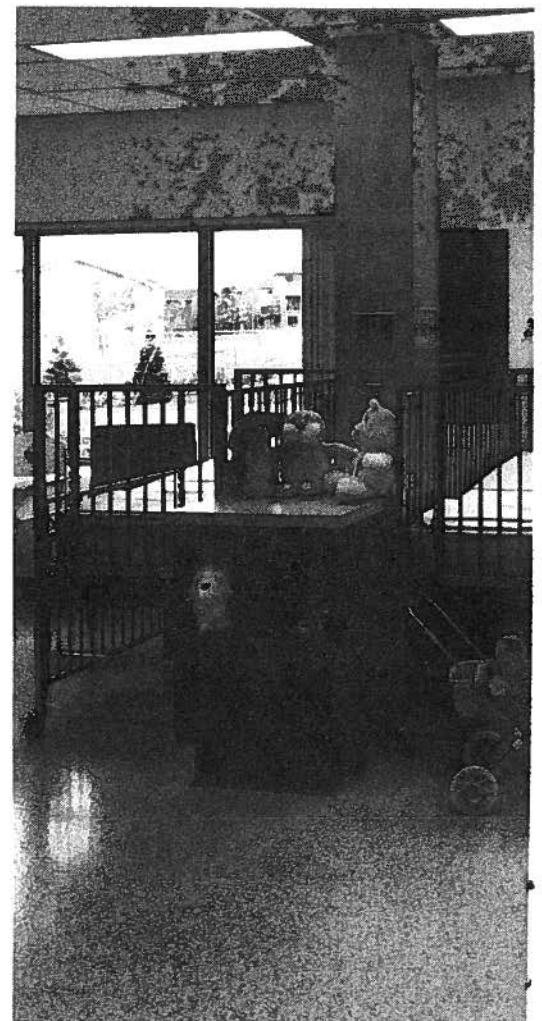
Earlier that day Maureen had had her first well-baby checkup. While the doctor weighed her, Katie took her two-year-old son, Kevin, to the bathroom. When they returned Maureen was crying. An empty vaccine vial and syringe lay next to her on the examination table. "Oh — you gave her the needle! Why did you do that? I didn't even have a chance to tell you that Kevin had a really bad reaction. The poor kid screamed for 13 hours," Katie told her doctor. She recalls his answer, "When she develops a temperature, give her some Tylenol or Tempra. There's nothing to worry about."

But there was plenty to worry about. Maureen is five years old now and, at an age when most children have long since mastered walking and running, she's just learning to sit up. Mentally, her development is about that of a six month old. She suffers from frequent, severe seizures and the medication she must take costs up to \$250 a month. Two North American doctors have diagnosed her as brain damaged. The cause they name: an adverse reaction to pertussis (whooping cough) vaccine.

Almost every Canadian baby is injected with pertussis vaccine five times: at two months, four months, six months, 18 months and when the child is between four and six years old. Each injection commonly combines four different vaccines: diphtheria, pertussis, tetanus and polio. Hence the shot's name DPT-P. (some provinces don't include polio in what they call a DPT vaccine.) It is the pertussis component that is highly problematic, frequently causing minor responses such as low fever and crankiness and, more rarely, severe reactions such as brain damage and blindness.

Despite these side effects, much of the North American medical profession says that the benefits of whooping cough vaccine far outweigh its risks — that it does protect children from a nasty disease. While parents of vaccine damaged children are not necessarily against inoculation in principle, they are uneasy about the way vaccines are commonly administered. Doctors who don't warn parents about risks, and don't ask thorough questions that could reveal whether a child will be at risk if vaccinated, worry these parents. They are also troubled that Connaught Laboratories Ltd., Canada's sole manufacturer of pertussis vaccine, has yet to market a safer, purer version of the shot. And they are not convinced that whooping cough vaccine is more of a boon than a detriment to society.

Pertussis is not a pleasant disease. Those infected develop a cough so harsh and drawn out that each bout often induces vomiting. Even in nor-



mal healthy children it is a two-to-three-week illness. The cough is so severe that infected children must gasp frantically to catch their breath. "They make a terrible, terrible sound, this whoop. It really is a whooping cough," says Dr. Catherine

Oliver, a family physician in Toronto. Still, in developed countries pertussis is not the life threatening disease it used to be.

Many North American doctors and Health and Welfare Canada argue that without vaccines whooping cough would quickly reach epidemic proportions. As evidence they cite statistics from Britain where the vaccination rate fell from 80 per cent to 30 per cent (and down to 10 per cent in some areas) over four years, following adverse publicity in 1974. By the end of 1978, clinically reported cases of pertussis numbered 66,000, up from 9,000 in 1975. But those numbers may be misleading. Even

medical advocates of the vaccine admit that doctors underreport the disease except when vaccination rates drop. Then, "Physicians tend to diagnose pertussis 'every time a baby clears his throat.'" That's what Robert Mendelson, M.D. is quoted as saying in the book *DPT: A Shot in the Dark*, published by Harcourt Brace Jovanovich in 1985. Even if Britain's epidemic statistics weren't overreported, they still don't reveal that while the disease increased, the number of claims for compensation from the government fell to zero. Thus, when innoculation rates fell, so too did instances of brain damage linked to the vaccine.

In the weeks following her first shot, Maureen's personality changed. Before, Katie would sit her in her baby bucket seat on the kitchen counter, at the hub of the household's activity. Maureen would play with her hands and feet and gurgle excitedly. Now she was uninterested, cranky, not herself. On August 8, a worried Katie took her daughter back to the doctor. "He said, 'There's nothing wrong, it's just a stage she's going through. All you mothers are the same — calm down. Enjoy it. She's a fine baby,'" Katie recalls. Then he gave Maureen her second DPT-P shot. "I stood there and let him. I believed him. He had convinced me. Again, there had been no real discussion."

That evening and night were similar to those following Maureen's first vaccine. Each time the crying began, Katie rushed into the baby's room to find Maureen lying on her stomach, hands over her head, pulling her head down to one side toward her chest, drawing her knees up to her chin. Her arms trembled. Her body seemed stiff.

At subsequent checkups Katie told her doctor about those reactions and that Maureen, by then nine months old, was not developing at a normal rate. "By nine months you should have Godzilla on your hands. You should have a child that's climbing up the piano. And we just didn't have it. We were still back at the three-month level," says Katie. Her doctor continued to reassure her.

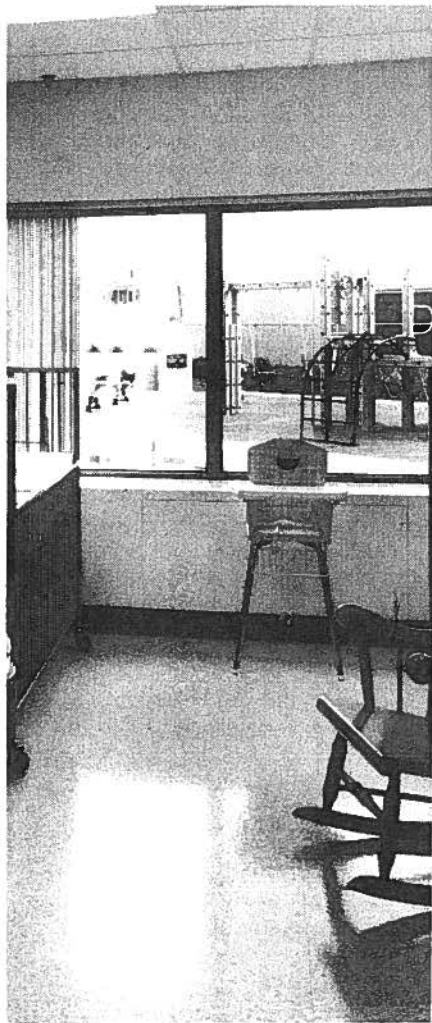
After Christmas, Maureen's father, Henry, took her for her third shot. He reminded the doctor that their son Kevin had screamed for 13 hours after his DPT-P vaccination. Henry remembers the doctor saying, "No problem. That's to be expected. He's okay. Look at him." And Kevin was okay. He had recovered. But Maureen hadn't.

Henry, unlike his wife, was not reassured. "There something *wrong* here," he told the doctor. "You keep ignoring the fact that we're saying something is *wrong*." The urgency in Henry's voice had an effect: within five weeks, the Kortekaas family met with a neurologist. He diagnosed "developmental delay," and told them Maureen might still catch up.

But when she was about a year old, Maureen began to have more problems. Periodically she would develop pneumonia so severe it required hospitalization. And she would utter a strange little cry from time to time. Katie never seemed to be in the same room as Maureen when it happened. Then one evening while Maureen was in her high chair, strapped in because she couldn't sit up, Katie was poised to feed her first mouthful of dinner when Maureen's eyes glazed over and went vacant. "I was staring right at her. She went to open her mouth and she was gone. I was trying to feed a statue for four or five seconds." When Maureen regained consciousness, she made that same odd cry. Her face registered terror. "She just came back and everything around her must have come crashing in." Katie, who grew up with friends with an epileptic child, knew she had just witnessed a seizure. It is known as a petit mal seizure, and it is caused by erratic brain activity.

Next, Maureen embarked on a series of medical tests. Diagnosis: retardation. "The doctor said, 'Mrs. Kortekaas, I would suggest you just take your child home and give her all the love and attention you can, because there's nothing we can do.' I said, 'Well, what's caused it?' He said, 'We don't know. An act of God.'"

Medical knowledge of extreme adverse reactions to pertussis vaccine dates back to the early 1930s. But the most widely read study came in 1948 from Randolph K. Byers and



"There's nothing wrong. It's just a stage she's going through."

Frederick C. Moll of the Harvard Medical School. They studied 15 children, who, prior to pertussis vaccinations, were normal with no history of convulsions. Each child reacted violently within 72 hours of the shot. Of the 15, only one recovered completely. Three were observed too briefly to draw final conclusions, two died, and nine "suffered from damage to their nervous system, which in most instances promised to interfere with complete living."

Similar reports were published in the decades following. Then in 1972, a two-year UCLA study funded by the United States Food and Drug Administration was released, detailing reactions that occurred strictly within 48 hours of the vaccinations. Thus when two infants died four days after their DPT shots, this was not included in the study's published results. The British National Childhood Encephalopathy (brain damage) study, published in 1981, found significant reactions occur up to seven days after vaccinations. Statistics from the UCLA study, therefore, are likely misleadingly low.

More than 16,000 DPT and DT

vaccinations were monitored in the UCLA analysis, which found that adverse reactions happened far more frequently from shots containing pertussis vaccine. Further, it found that instances of shock, convulsions, high pitched screaming, fever and vomiting were far greater than ever reported. Its results showed that an estimated one in 778 children had convulsions, one in 778 had collapse or shock symptoms and one in 318 developed high-pitched encephalopathic screaming.

For several reasons, those estimates — high as they may be — are conservative. High-pitched screaming was not considered a serious reaction. Further, those considered high risk were screened out and excluded from the study. What's more, while the report said there was no permanent brain damage among those studied, it never made a follow-up investigation of the affected children.

Dr. Ron Gold, chief of infectious diseases at Toronto's Hospital for Sick Children and one of Canada's main advocates of pertussis vaccine, says the British NCES study proved that whooping cough breaks out in large numbers when immuniz-

ation drops off, that areas where the biggest decline in vaccinations occurred had the biggest increase of pertussis. He points out that 20 per cent of the infected children were sick enough to be hospitalized. While he concedes some of the increase was due to doctors reporting cases more often, Gold maintains that even in healthy well-nourished children, pertussis in the first six months of life is potentially fatal or very severe, causing secondary illnesses such as pneumonia and bronchitis. But in a critical TV documentary, *DPT: Vaccine Roulette*, microbiologist Dr. Bobby Young said, "These days when we have bacterial antibiotics, when we have chemotherapy, death from pertussis is a relatively rare event."

In Canada, whooping cough is almost gone. About 2,000 cases are reported each year, a drastic drop from the epidemics before 1945. The largest outbreak, in 1934, peaked at 19,484 cases. In an article Gold wrote for the *Canadian Family Physician* in January 1986, he says, "Following the introduction of a combined diphtheria toxoid-pertussis vaccine in 1943, the incidence of pertussis declined significantly." But when questioned, he acknowledges that with improved sanitation and nutrition, outbreaks were diminishing before inoculation became widespread. Deaths from whooping cough in the developed world occur in about one of every several thousand cases, according to Gold. (In order to arrive at a more accurate number, studies would need to examine several million cases, which has never been done.) But, given that doctors underreport the illness, that fatality estimate is likely exaggerated.

Roughly two per cent of all children under six get a fever and have a seizure — which could lead to brain damage, says Gold. "All I'm saying is it's very difficult to put a cause and effect relationship [between the DPT-P shot and the seizure] . . . All we have is this time relationship which seems real but is occurring at an uncommonly low rate . . . It's very easy to have a coincidence." Nevertheless, Gold believes that a cause and effect relationship could exist: "Is it biologically plaus-



Pamela Harris

ible that the vaccine could do something? I think the answer is yes."

A few years ago Gold denied that such a relationship was possible, says Bill Dunlop, the Kortekaas' lawyer. "The doctors are strange," he says. "When the cases [law suits] were first started, doctors took the position that the vaccine didn't cause brain damage. Now they say it causes brain damage but it's not their fault. Or if it's their fault, the children should be compensated by the government."

One doctor who would like to see the federal government set up a compensation plan is Catherine Oliver. After working in East Africa with CUSO (Canadian University Services Overseas) for two years, she is a firm advocate of the vaccine despite its complications. In undernourished children, whooping cough has a devastating effect: an estimated 10 to 20 per cent of those infected die from the disease. Although it is true that well-nourished children can almost always withstand the illness, Oliver says: "I don't know if that's any argument for putting your child through that. I don't go along with the mainstream medical views on a lot of things, but you have to go pretty far to find somebody who doesn't feel childhood immunizations are worthwhile." Oliver says that physicians are obligated to warn parents about risks, yet she can't recall ever hearing that at medical school.

Maureen Kortekaas' continued medical tests were producing strange results. Though doctors were fairly certain her problem was genetic, test results weren't consistent with that diagnosis. Most genetic brain defects affect fine motor skills, but it was Maureen's gross motor skills that were problematic. For example, she had no trouble picking up a specific tiny object that was surrounded by similar ones, yet she couldn't judge distances between her hand and large objects. Doctors were unable to find evidence of genetic birth defects after testing both Maureen and her parents. The Kortekaas were getting nowhere.

Warning Signs of High-Risk Children

The Ontario Ministry of Health warns that these children should definitely not receive DPT-P shots without checking with a doctor:

- Any child sick with something more serious than a cold;
- Some children who have had convulsions or other problems of the nervous system;
- Any child who's had serious reactions to DPT-P shots before, including high fever, shock, seizures and persistent screaming;
- Any child with allergies to antibiotics called neomycin or streptomycin.

The Federal Health Department warns further that the vaccine should not be administered to children who:

- Suffer from an evolving neurological disorder;
- Have a history of seizures before receiving the DPT-P shot;
- Develop seizures during the shots.

The Association for Vaccine Damaged children offers further suggestions for parents to discuss with their doctor:

- A child who has a personal or family history of neurological disorders or drug and food allergies;
- A child whose sibling developed a bad reaction to DPT-P vaccine;
- A child who is recently recovering from an illness that includes a cold or fever;
- A child who, after being vaccinated, becomes: pale or unresponsive, jumpy or excessively irritated, suffered vomiting and diarrhea;
- A child who, after being vaccinated, develops: high fever, a hard or bulging soft spot at injection site, rigidity or spastic movements, convulsions, screaming or crying for long periods, a complete change in behaviour, sleep patterns or personality.

Katie had always confided details of Maureen's problems to her former secretary, who one day pulled out a newspaper clipping from her drawer and handed it anxiously to Katie. "Maybe you really don't want to see this, but — have you seen this article? This really sounds like everything you've told me about Maureen and the way she acts." The story was about the Ventress family of Oshawa whose child had been brain damaged from pertussis vaccine. Katie raced through the article and sat down, faint, feeling she could throw up.

A few hours later, she and Henry were en route to the Ventress' home, nervously excited. "We walked in and this little boy — just a whisper of a child, a frail, sickly little kid was lying on the carpet rolling his head back and forth, his tongue kind of drooling. He had that same roly, lifeless stupor. It was frightening. The children were so much the same. It

was like seeing a ghost."

The Association of Vaccine Damaged Children (ADVC) is made up of 160 Canadian families. It describes itself as an association for people concerned about the extent and frequency of such damage. It is an offshoot of the Committee Against Compulsory Vaccination (CAVC), a civil rights group formed in November 1983. CAVC successfully lobbied the Ontario government to amend the Compulsory Immunization of School Pupils Act to allow exemption based on conscience and sincerely held convictions. Its goals are similar to those of AVDC: to inform the public of the dangers of whooping cough vaccine; to press governments, the medical community and drug companies to warn the public about danger signs for adverse reactions; to see that a Canadian study of pertussis vaccine's side effects is done; to have initial DPT-P shots delayed until infants are older

with better developed neurological systems; to urge that a safer, less toxic vaccine be marketed; and to have the federal government provide compensation packages for victims.

The two groups have managed to push the Ontario government to make it mandatory for doctors to report cases of adverse vaccine reactions. AVDC hopes this will create the data necessary to prove to the government that compensation plans are needed. But perhaps almost as important as its political activities, is the emotional support AVDC offers its members.

Katie and Henry Kortekaas have managed to find some ways to deal with their rage and frustration. Both are active in the AVDC. "We owe it to Maureen, so her life has some meaning. If in an alternate universe we said to her, 'What would you have us do?', I'm sure she would say, 'Fight for it. Fight for it, fight so it doesn't happen again to some other child,'" says her father. Henry is chairman of the Easter Seal Society for the Whitby Rotary Club, and Chairman of a branch of the Crippled Children's Committee. "You can't just be angry," he says. "It's not socially acceptable to vent it in a destructive way."

The Kortekaass now have another child: Julie, a lively four year old. But it is Kevin, now eight, whom Katie feels has been psychologically damaged by Maureen's condition. To prepare him for Maureen's arrival, his parents spent months telling him he was lucky to have a brother or sister on the way. "He was so excited," recalls Katie. "And he's never had the sister we promised him. Thank God we have Julie."

Though Katie has come to terms with Maureen's condition, she doesn't hide her anger: "I never thought this was in my life. I'm pissed off, I'm telling you. I thought motherhood would be a lot different than what I've ended up with."

Exactly two years after Maureen's first DPT-P shot, Katie and Henry decided to sue for damages. They were angered by doctors who treated Maureen's symptoms but didn't investigate the cause of her condition.

The couple is not optimistic about how long litigation may take. A similar court case with the Rothwell family in Burlington began nine years ago. Patrick Rothwell's parents claimed that a severe reaction to pertussis vaccine left their son blind, retarded and unable to speak. The examinations for discovery alone lasted a year, and the 74 day trial in the Ontario Supreme Court resulted in a 387 page judgement that found that the Rothwells weren't able to prove beyond a doubt that a component of the vaccine caused the damage. The Rothwells are appealing the decision.

Some countries such as Japan, West Germany, Sweden, Denmark and Britain, have public compensation plans for vaccine damaged children, but Canada does not. At present, however, both the Canadian Pediatric Society (a national child advocacy association of about 1,500 pediatricians) and the National Advisory Committee on Immunization

Some countries have compensation plans. But Canada does not.

are calling for the creation of a national compensation plan. Everyone, according to Bill Dunlop, lawyer for both the Rothwells and the Kortekaass, would welcome such a plan: doctors, because law suits are costly and can damage reputations; families, because litigation is a lengthy and expensive process; and the manufacturers, who currently pay damages themselves. Insurance companies will no longer provide coverage; they've been scared off by successful damage suits against producers of pertussis.

Connaught Laboratories Ltd. is the sole manufacturer of Canadian pertussis vaccine. Given the huge rise in U.S. law suits recently, the U.S. Connaught Laboratories Inc. has recently raised the price of whooping cough vaccine. In Canada in the last four years, Connaught has also raised the price from \$5.85 per dose up to \$10.00, in an attempt to insure itself

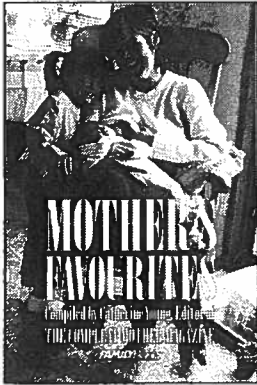
against possible legal damages. It has also spent the past few years developing a safer, less toxic form of pertussis vaccine — known as A-celular — which it hopes to market within a year. Dunlop is glad the purer vaccine is in the works, but is unimpressed with Connaught's efforts: "The technology was available in 1974. Of course they're working on it now. A few years have passed."

These days, life at the Kortekaas household is hectic. Both parents have demanding, full-time jobs. A specially trained live-in nanny looks after Maureen, whose needs dictate the family's schedule. After work, association meetings and paperwork for litigation, domestic chores and spending time with Kevin and Julie consume all of Katie and Henry's time. They have little time together and less time alone.

Their expenses are high. In 1986, \$2,300 went to Maureen's medication bills. The nanny — without whom Maureen would likely be institutionalized — is paid \$900 a month. Specially made shin splints to stop Maureen's feet from hanging limp, cost \$930. Diapers alone cost about \$100 a month. A wheelchair-type high chair frame with a seat molded for Maureen's body cost almost \$1,000. Although they recover some of those expenses from tax rebates and their insurance company, the money must be spent before they can claim it. And when Maureen gets older, the Kortekaass will need to construct a wheelchair ramp and make extensive bathroom renovations.

If the federal government does come through with a compensation plan for vaccine damaged children, life, at least financially, will ease up for Henry and Katie Kortekaas. "People ask what's going to happen in twenty years," says Henry. "I don't want to think about it. We have to think about what's going to happen next year." Katie interrupts: "Next week, maybe."

Anna Kohn works as a magazine editor and writes freelance articles when she has the time.



MOTHER'S FAVOURITES

compiled by
Catherine Young

from the *Complete Mother Magazine*

The perfect gift for
every new mother

"Just off the wall enough . . . Plenty of my colleagues would be horrified. I like it."

Allan Cunningham, MD, College of Physicians and Surgeons, Columbia University

A treasure trove of motherhood lore sharing the joy, the pain, the wisdom and laughter, mother to mother. From pregnancy and childbirth to breastfeeding and disposable diapers.

\$12.95/paper/55021-019-X

NC PRESS LIMITED *The Health Book Specialists*
Order Department: 260 Richmond St. W. Ste 401
Toronto ON M5V 1W5 (416) 593-6284

A Guide to Feminist Expertise

The CRIAW Bank of Researchers

A computerized database of feminist researchers working in various fields and committed to the advancement of women.

The Bank allows you to identify researchers with whom you may wish to network or who are working in fields in which you may be seeking expertise.

An indispensable tool for journalists, professors, action or community researchers, policy makers and conference organizers.

MAKE IT WORK FOR YOU!

CRIAW

Canadian Research Institute for the Advancement of Women

151 Slater, Suite 408
Ottawa, Ontario K1P 5H3
(613) 563-0681

N.B. We encourage all feminist researchers to register in the bank. Application forms available from CRIAW.



Coming soon...

in *Healthsharing's* Summer issue

Overcoming weight prejudice
Surviving incest
Breastfeeding
Cervical caps
Coping with migraines

plus reviews, updates, resources and much more!

Canada's Only Women's Health Quarterly

UPCOMING CONFERENCE BEYOND SURVIVAL: WOMEN, ADDICTION AND IDENTITY

This four-day national conference will explore different forms of addiction (eating disorders, drugs, alcohol), as well as theoretical concepts and clinical practices from a feminist perspective. There will be over 40 workshops and panels, intended to provide forums for discussing the intersecting dimensions of early childhood trauma, violence against women and addictive coping mechanisms.

Conference presenters include dynamic therapists, researchers and community organizers such as:

Susan Aaron

••••

Ellen Bass

••••

Sandra Butler

••••

Connie Coniglio

A conference for professionals who work with addicted women

Mar 31 • Apr 1 • 2 • 3
1989

For additional information you may contact Ani Arnott,
Community Resources and Initiatives,
150A Winona Drive,
Toronto, Ontario M5G 3S9,
(416) 658-1752.

RESOURCES & EVENTS

International Day of Action

The Women's Global Network On Reproductive Rights is planning the second International Day for Women's Health to focus on issues of maternal mortality and morbidity on May 29, 1989. Last year over 100 women's groups and organizations from over 45 countries participated in a variety of ways to raise public consciousness about maternal mortality.

Groups interested in participating this year please contact Women's Global Network On Reproductive Rights, Nieuwe Zijds Voorburgwal 32, 1012 RZ Amsterdam, Netherlands. (30-20) 20 96 72.

Women and Mental Health

The Alberta North Central Region of the Canadian Mental Health Association is hosting a conference, *Women and Mental Health: Social, Economic and Political Perspectives*, May 11-14, 1989 at the Banff Springs Hotel, Banff, Alberta. Keynote speakers include: Phyllis Chesler, Paula Caplan, Freda Paltiel, Susan Penfold and Jeffrey Masson. Covering all aspects of women's mental health, the conference will be of interest to all mental health professionals, social workers, health educators and lay persons.

Contact Karen McFarlane, Conference Coordinator, 9th floor, 10050 — 112 St., Edmonton, Alta. T5K 2J1.

Allergic Mothers-To-Be

Baby Beware!!! Notes on the Care and Feeding of the Allergic Mother-To-Be has been published by the Alberta Children's Hospital. This practical guide to what you can and should eat includes sample menus (with recipes), general information on food additives, a recommended reading list and a list of allergy

associations. It is based on the experiences of 18 allergic pregnant women, counselled by the author, Jane McNicol R.D., who were concerned about how their diet might affect their unborn child. To order send \$6.95 plus \$1 handling and postage to Alberta Children's Hospital, Health Promotion Resource Centre, 1820 Richmond Rd. S.W., Calgary, Alta. T2T 5C7.

Breast Cancer Series

The YM-YWCA of Winnipeg has recently published a set of five books written for people who want information about breast cancer. The books in the series are: *Understanding Breast Cancer, Diagnosis and Treatment, After Breast Cancer, A Time for Sharing, Glossary and Resources*. Available for \$5 per book or \$15 for the set from: YM-YWCA of Winnipeg, Women's Resource Centre, 100 — 290 Vaughan St., Winnipeg, Man. R3B 2N8.

Sexuality and Values

Sexuality and Values, the University of Guelph's 11th annual sexuality conference, June 19-21, 1989, will examine current issues in human sexuality, sex education, and counselling for sexual problems.

For further information, write Continuing Education Division, University of Guelph, Guelph, Ont. N1G 2W1. (519) 824-4120, Ext. 3956.

Women and Health

The Ontario Advisory Council on Women's Issues has published the first booklet in its Action On Issues series. Called *Women and Health*, this 50-page booklet grew out of the Council's 1985 Women and Health

Conference and looks at some of the major themes regarding women's health. It provides information on how women can best use the health care system and offers advice on how to more actively take care of their own health. Available free from: Ontario Advisory Council on Women's Issues, 880 Bay St., 5th floor, Toronto, Ont. M7A 1N3 or call collect (416) 965-5824.

AIDS Video

AIDS — A Worldwide Effort Will Stop It provides a clear and concise explanation of how the AIDS virus works, how it is transmitted, and how it is NOT transmitted. This 15 minute video, available in French or English, examines successful AIDS prevention programs around the world while providing a comprehensive review of the AIDS situation worldwide.

Available in VHS for \$16 U.S. per copy plus \$2 U.S. postage and handling from WHO, CH-1211, Geneva 27, Suisse. While not available yet for purchase in Canada, it can be loaned from The AIDS Education and Awareness Program, Canadian Public Health Association, Suite 400, 1565 Carling Ave., Ottawa, Ont. K1Z 8R1. (613) 726-3769.

PMS Newsletter

In Control is a support newsletter for women living with stressful premenstrual changes. Encouraging women to take control of their bodies and their lives, it offers clear, critical and easy to read reviews, the latest information, pros and cons of existing treatment and a forum for Canadian women to write about their experiences.

One year subscription \$20 (6 issues) from: Canadian Association of Premenstrual Changes, 4815 Bessborough, #4, Montreal, P.Q. H4V 2S2.