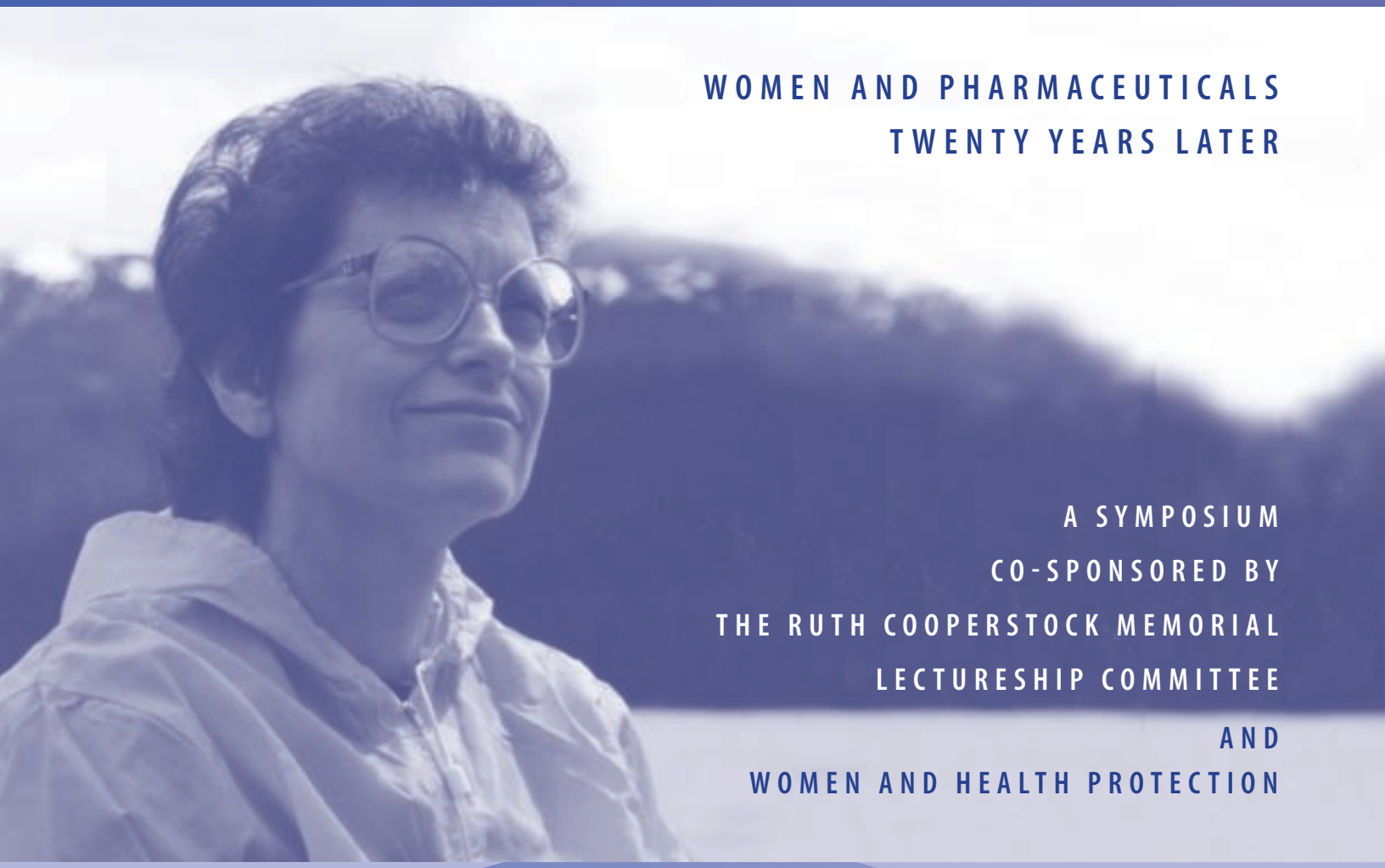
REMEMBERING
RUTH COOPERSTOCK



WOMEN AND PHARMACEUTICALS
TWENTY YEARS LATER

A SYMPOSIUM
CO-SPONSORED BY
THE RUTH COOPERSTOCK MEMORIAL
LECTURESHIP COMMITTEE
AND
WOMEN AND HEALTH PROTECTION

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DEPARTMENT OF PUBLIC HEALTH SCIENCES

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Symposium photos by Tori Foster

RUTH COOPERSTOCK

Ruth Cooperstock, born in 1928, was a medical sociologist as well as a feminist. After an academic life in the US and Canada, she was appointed to the position of Scientist in the Epidemiology and Social Policy Research Department of the Addiction Research Foundation in Toronto in 1966. In 1981, she was cross-appointed to the Department of Behavioural Science, Faculty of Medicine, University of Toronto.

Ruth's pioneering work on psychotropic drug use and the prescribing patterns of physicians earned her an international reputation. Her paper, "Sex Differences in the Use of Mood-Modifying Drugs", became the stimulus for later research on this topic. Because of this work, as well as her broader interests in the study of the health professions, and women and health issues, she was much in demand as a lecturer and panellist in Canada, the United States and abroad. At the University of Toronto, she was actively engaged in research and also taught medical students and graduate students of community health. Her professional papers were widely published.

The Ruth Cooperstock Memorial Lectureship was established after her death in 1985 under the joint sponsorship of the Addiction Research Foundation and the Department of Behavioural Science at the University of Toronto. The theme of the annual lecture is "Social Aspects of Health and Illness."

To celebrate Ruth's work and the 20th anniversary of the founding of the lectureship, a symposium on women and pharmaceuticals was held on November 1st, 2005, in the Department of Public Health Sciences at the University of Toronto, sponsored jointly by the Department, the Ruth Cooperstock Memorial Lectureship Committee, and Women and Health Protection.

The event included three afternoon workshops and an evening panel presentation. The presentations of the three panellists follow, as well as a brief summary of each of the workshops.

PANEL INTRODUCTION

by Anne Rochon Ford

This event has been titled *Remembering Ruth Cooperstock*.

For those of you who did not know Ruth, she was a warm, bright, generous woman who shared freely her knowledge, her passion for social justice, and her wry sense of humour. We lost her far too soon from this world when she died of breast cancer while only in her 50s – twenty years ago this year.

Some of us have no trouble at all Remembering Ruth Cooperstock because her work of several decades ago is still frighteningly relevant today. We see it particularly in the work Ruth did around women and prescription drugs – her razor-sharp analysis of medicalizing women's social problems, of the dangers inherent in the pharmaceutical industry's promotion of drugs to doctors, and of the over-prescription of psychotropic drugs to the elderly. These are all precisely the problems today that Ruth envisioned they would be when she was researching and writing about them in the 1970s and 80s.

As a feminist and a strong advocate for social justice, she came to her work as a sociologist with a conviction that solutions would lie not so often with chemical fixes but with strong support networks, meaningful work lives, freedom from abuse and violence and economic independence.

Personally, I have not only benefited in my own work from the legacy of writing that Ruth left behind, but also knew her as a mentor for a too-brief period before she died. It is an honour to be able to remember Ruth this way, with an event taking place at the university she worked in, surrounded by people who knew and loved her, talking about the issues she cared so passionately about.

Ruth, early in her career

THE PAST

by Connie Clement

I am honoured to be here. I thank the organizers for thinking I might have something of value to say, especially as I look out at a room filled with women and men whom I respect and love, and with whom and from whom I learned much of what I know. Preparing tonight's talk has given me an opportunity to wander down memory lane, to reflect back on the heady days of what I call the "founding fervour" of the Canadian women's health movement.

Let me start by saying that I'm a feminist health activist. No surprise. I bring a feminist perspective to health because:

- I'm female
- Health touches everybody's life, every day of our lives
- It's the most powerful catalyst for personal and social change
- Health is a front door for many people through which to understand and commit to social justice

The challenges we and all women face in terms of pharmaceutical drugs are no less – and, in fact, are more – complex than when feminists and like-minded colleagues began this work decades back.

To open, I want to cite Planned Parenthood Federation of America, not always the most radical or women-centred of our colleagues. In the 1950s when Planned Parenthood donated funds to research and develop oral contraceptives, their grant stipulated that the drugs developed be – and I quote – "harmless, entirely reliable, simple, practical, universally applicable and aesthetically satisfactory…"[1] Half a century later, I'd still put forward these standards – along with one about each new drug having added value compared to drugs already marketed. Instead, 50 years later, the world is even more "littered with inappropriate, wasteful and unsafe medical remedies."[2]

I was asked to join this panel to remind those of us who are old enough to remember, and to share with those of us who aren't that old, the immense and widespread impacts that feminists – *especially* feminist health activists – have had in our lifetimes. It is sometimes hard to recognize our successes – real as they are – in the face of the pharmaceutical industry's omnipresent glitz, money and social acceptability. Yet, by celebrating success we are revitalized and can better see the way forward, and it's for this reason that today's event is important.

Pharmaceuticals have always been central to Canada's feminist health movement, more so, I think, than in the US and some other countries. Early movements for women's rights, the vote, working outside the home, have – for far more than one hundred years – included central health components – especially access to birth control and abortion.

In the 1960s, Canadian feminists, working in broad coalitions, fought for access to improved contraception and abortion. A birthplace of our movement was when a group of courageous students at McGill wrote the first issue of the *Birth Control Handbook* in 1968 when providing information about birth

1 From *The Pill: 30 Years of Safety Concerns* (Dec. 1990): www.fda.gov/bbs/topics/CONSUMER/CON00027.html

2 Anwar Fazel, in the preface to *Side Effects*.

control was still illegal. Contraception was decriminalized later that year, as a result of major advocacy to shift social opinion.

Lesson 1: Sustained action – eventually – breaks through to results. Stick with it.

Not surprisingly, feminists' first analysis of prescription drug safety addressed oral contraceptives. Within a few years of the Pill coming on the world market – and being hailed as a saviour – safety concerns emerged. Women without scientific training learned to research, to question their doctors, and stepped into educating other women – all new, exciting and challenging roles.

Although we often think of birth control as the earliest key driver of the feminist health movement, tranquillizers came on the market before oral contraceptives. As early as 1969, Ruth Cooperstock documented differences in male/female use of psychotropic drugs. As the 1970s opened, Ruth began exploring the influence of societally based gender bias (although not yet in that language). Drawing upon research into drug usage patterns, prescribing habits *and* women's experience, Ruth and others were able to build a convincing case that certain drugs were overprescribed for women, and often on the basis of little need. Ruth and her contemporaries helped establish what became a cornerstone of a women's health approach: that individual women's knowledge of their own bodies and their own experiences are vital sources of information and serve as a source of evidence.

Lessons 2 and 3: Lay women and experts together bring a richness of analysis that neither can accomplish alone. Evidence is far richer, more varied and more complex than the double-cohort standard centred within medical and drug research.

It was with the widespread use of oral contraceptives, more so than with the growth of other medical drugs, that feminists came to a tenet we still hold dear. The Pill was the first pharmaceutical product designed especially for healthy people, to be used day in and day out, for years on end. Shouldn't, we asked, the proof of safety be especially vigilant for drugs used by healthy women, bringing us to what we now call the "precautionary principle"? Precaution demands that we don't prohibit action (often of a profit-making nature) only when irrefutable evidence of absolute harm exists; but rather, that we take a cautious stand and hold back in the absence of evidence of absolute safety. As feminists learned more and more about health problems and harm encountered by women on oral contraceptives, psychosocial drugs, and then later as we learned about unnecessary surgeries – C-sections being a good example – this principle could and would be argued over and over and over.

Another lesson: Stay with a good principle, even in the face of no forward movement. Change strategies and tactics, but don't lose sight of underlying values.

By the 1970s, the first community-based, women-specific, feminist-run services were formed. In Toronto, these were the Birth Control and VD Information Centre, the Immigrant Women's Centre, and Hasslefree Clinic. Elsewhere, the Vancouver Women's Health Collective was launched. Ruth was instrumental in helping to start the Women's Counselling, Referral and Education Centre in Toronto.

The mushrooming of local, provincial and national women's groups created what felt to us at the time a groundswell. And, it continued through the 1980s. We grew to many voices, built many networks, learned lots and acquired immense skills. Ontario held its first women's health conference in the early 1980s, bringing women together from all corners of the province including the far North. I'd like to name just a few national actions.

- *Healthsharing* magazine, Canada's first feminist health magazine, in its day published many articles about pharmaceuticals, women's personal stories and broke ground about issues such as toxic shock syndrome and reproductive technologies. It's wonderful to see in one room so many people who wrote, edited or read *Healthsharing*.
- The Side Effects theatre tour, and subsequently the book *Side Effects*. This play went right across Canada, telling real women's stories through theatre with laugher and tears. Local media was garnered everywhere it played and in its path, community women's groups formed all across the country to learn about and do something about women and drugs.
- A national coalition formed to oppose approval of Depo-Provera, an injectable contraceptive, and with no funding or resources, successfully held off Canadian approval for over a decade.
- The DisAbled Women's Network formed in most provinces and nationally. Along with a wealth of other issues, DAWN advocated against the widespread poor and often outright dangerous prescribing of drugs to disabled women.
- DES Action was founded by a mother and daughter. Working out of their home, these two and, increasingly, others spoke to anyone who would listen, testified before government, and created an upsurge of media interest about DES that benefited the rest of the feminist health movement.

All of these groups, networks and events brought a feminist critique to women's use of pharmaceutical drugs and the pharmaceutical industry's use of women.

Government was our ally in those days. The Women's Directorate of the Federal Secretary of State and the Health Promotion Directorate of Health Canada especially were compatriots. Within Ontario we had support from the Women's Bureau and the Premier's Health Council.

In the 1990s, I think the movement – and each of us, individually – grew in sophistication and, at the same time, we lost ground. On the positive side: The movement as a whole reached further beyond our white middle class roots to embrace women from the "world majority." And, skills that had been acquired in movement building, resources,

community and social marketing were put to use in national organizing. The Canadian Women's Health Network finally came into being (after what seemed like a two-decade labour). Combined with the Centres of Excellence in Women's Health, an infrastructure and foundation were finally established to support ongoing work to address the complex relationship between women, their prescription drugs and the pharmaceutical industry, alongside a multitude of other health issues.

Today we can see an immense influence of feminist health activists on the broader women's movements and on progressive health and social justice efforts. Health promotion as we know it wouldn't exist without the foundation of the feminist health movement. Public health, social work, nursing and the mental health professions have all been greatly changed. One measure of success is the extent of mainstream-ification: We have chairs in women's health now at universities! A far cry from when groups of undergraduates set up ad hoc courses any which way they could. Founders of the Radical Nurses Group now hold management positions in public health, government and at community health centres. Canadian media has covered health stories for 20 years now – not always as we'd like them to, but so much so that it's hard to remember when you didn't find health stories in *Chatelaine* and the Toronto newspapers didn't have an assigned health beat.

On the loss side: Our social context became increasingly conservative and policy increasingly supported expanding market economies. Profits within the pharmaceutical sector fuelled the industry as it came of age to generate new, me-too drugs; intensify marketing to doctors; push the boundaries on direct-to-consumer advertising; devise new uses for existing drugs; and seek out ever expanding markets among the young, the old and the healthy. The "movement" component of the feminist health movement has become diminished as women's health has infiltrated the mainstream. A few years ago when Barbara Ehrenreich, a marvellous feminist thinker, writer and activist from the US, had breast cancer, she mused: "Here I was, 59 years old, facing the worst crisis of my life, and there was nothing empowering, no trace of the feminist health movement of the 70s." I think in Canada – at least in its urban centres – we're not that badly off, but we have lost the fervour, the local activity that was so evident 20 years ago.

In closing, I hope that all of us here will recognize a number of gains:

- Our skills, knowledge and tools are all more sophisticated – we're able to build on those who have come before and pave the way for those who come next.
- Our cross-sectoral relationships are rich and robust.
- Our entries into points of influence are numerous.
- Our commitment is great.
- And the need for a movement to fundamentally overhaul the pharmaceutical industry's practices and women's use of drugs has never been greater.

Connie Clement is Executive Director of the Ontario Prevention Clearinghouse, Ontario's leading bilingual health promotion organization. A co-founder/ managing editor of *Healthsharing*, Canada's ground-breaking women's health magazine, Connie's involvement in women's health began as a teenaged volunteer. At Toronto Public Health, Connie worked in sexual health, health promotion and as Director of Public Health Planning and Policy.

THE PRESENT

by Paula Caplan, Ph.D

I am so thrilled to be back in Toronto and so honoured to have been asked to be on this panel, and I want to thank everybody who has helped to organize it. I loved Ruth Cooperstock, and I bring regards from Boston from Jean Baker Miller, who was Ruth's roommate in college.

I want to talk about women and mental health and how that relates to pharmaceuticals. I know some of you are familiar with what has been called the "Bible" of mental health professionals, the *Diagnostic and Statistical Manual of Mental Disorders (DSM)*, which weighs three pounds (I weighed it) and which contains 374 categories of what the authors, the American Psychiatric Association, claim are mental illnesses. It's published in the United States, but it is used in Canada all the time. It's used globally, it has been translated into dozens of languages, and it's a multi-million dollar business.

The reason I want to talk about diagnosis is that it is the underpinning of everything that happens in the mental health system. You don't have psychotropic drugs prescribed without a psychiatric diagnosis. You don't get psychotherapy paid for unless you have a psychiatric diagnosis. And except for a few feminist health groups in Canada, who have done wonderful things about concerns about the mental health system, a lot of the time we in Canada have uncharacteristically gone along with what Americans are doing with this horrible book.

By definition, everything in the *DSM* is a mental disorder and, therefore, implicitly a medical disorder. Just the title, *Diagnostic and Statistical Manual*, helps create this aura of scientific precision, so the vast majority of psychiatric diagnoses made in Canada are based on the *DSM*. As a result, these days in Canada, although less than in the States, almost the only two things that are ever recommended or studied in well-funded research programs are psychotherapy and drugs. This is not to say that neither therapy nor drugs can ever be helpful, because they can. But the problem is that sometimes each can be harmful, or just not helpful. And certainly the psychiatric labelling itself results in many women going on antidepressants or other drugs, because there's just so much pressure to do so.

There are two criteria that I think should always be met when drugs are recommended, or even when psychotherapy or anything at all (even meditation or exercise) is recommended. One is that all of the known pros and cons of the recommended treatment should be disclosed. And the other is that the whole range of things that have been helpful to at least some people should be mentioned. Sadly, those two criteria are almost never met.

"Mental illness" is a construct. It's like "intelligence" or "love." So, although it's often talked about as though it's scientifically grounded and we know what mental illness is and what it isn't and we know who has one and who doesn't, the fact is that if something is a construct, there is no such real thing out there. Mental illness is not real like a table. Mental illness is what whoever has the most power to create a definition and then get that definition used says it is.

I served on two of the committees that were charged with putting together the current edition of the *DSM*, the *DSM-IV*, before I resigned in horror when I saw what the *DSM* authors did. I learned that the *DSM* includes whatever the people at the top of the *DSM* hierarchy – about a dozen mostly white, mostly male, mostly American, mostly psychiatrists – want to include in the *DSM*. This manual now includes Stuttering, Math Disability, Nicotine Dependence, and Caffeine-induced Sleep Disorder as "mental illnesses". Dr. Leonore Tiefer has done amazing work exposing how ridiculous and how dangerous Female Sexual Dysfunction is as a category of mental illness.

One of the labels that I find most frightening is Major Depressive Disorder. This is not to say that people don't get depressed, but Major Depressive Disorder includes this criterion: if you have lost somebody close to you and you're still grieving two months later, you fit the description of Major Depressive Disorder. Why do we have to medicalize everything? Where is upsetting stuff that happens to people when they go through life? Why do we have to say, "Oh, you're still grieving and it's been two months, so you had better get to a therapist"? And what does that do to the nature of friendship in North America? You hear people say, "My friend was still grieving, but I'm not a therapist so I didn't know what to do, so I sent her to a therapist." People think that therapists have some magic knowledge. I don't know about others, but I know I don't have magic knowledge. And I worry about the fact that everything is being psychiatrized and psychologized.

In addition, much of what is really the consequence of violence and / or various kinds of oppression ends up being diagnosed as mental illness. If I said, "We took a bunch of people and we regularly humiliated them and said vile things to them, how do you think they're going to feel?" you'd say, "depressed, anxious…" Do we want to say that that's a mental illness, or do we want to say, "Be careful, because we are covering up, we are drawing attention away from major social and political ills"? Currently, in preparation for the *DSM-V* that's on the way, a committee has been appointed to discuss whether racism should go in the *DSM* as a mental illness! They've said that it's a way of showing that racism is bad. But there goes hate crime legislation; there goes seeing that racism is a social evil.

In spite of the fact that mental illness itself is a construct and every category in the *DSM* is a construct, some more descriptive of what people really experience than others, the fact that they're in the *DSM* and they're put on OHIP cards means that they become reified. People come to believe that there is such a thing as schizophrenia or there are such things as other categories in there, and we know what they are, and those experts must know how to treat them.

In 1987, when I taught at the University of Toronto and at the Ontario Institute for Studies in Education, I was a member of a committee headed by Janet Stoppard. She had gotten the Canadian Mental Health Association (CMHA) to provide a small amount of funding to the committee to prepare a report on women and mental health in Canada. Jeri Wine was on that committee as well. Instead of looking within the mental health framework, we asked, "What would make women in Canada feel better and function better?" We came up with a huge list of recommendations – some for the CMHA, some for various levels of government, and some for training programs for therapists. The report went out of print almost immediately and, to my knowledge, the CMHA has still not reissued it. And, to my knowledge, few, if any, of the recommendations have been implemented. They included things like making sure that women have enough income, making sure that women

will not be victims of violence… It was the whole feminist social program.

Serious kinds of harm can come to people as a result of getting *any* diagnosis that is in the *DSM*, even one that may sound innocuous, like "Adjustment Disorder." People have lost custody of their children because they're diagnosed with such labels from the *DSM*. People have lost jobs (that's supposed to be illegal, but you have to be able to prove that that's why you got fired). People have lost the right to make decisions about their medical and legal affairs. This is very serious.

As I said, I was on two *DSM* committees. One was about the invented category, which two male psychiatrists are said to have thought up on a fishing trip, called Premenstrual Dysphoric Disorder or PMDD. I want to tell you a little about my experience being on that committee, as a kind of a case study. The PMDD category applied only to women, but similar things are being done with a lot of the categories in the *DSM*. I was appointed to the PMDD committee. The *DSM* people said, "Don't worry. We're not going to diagnose every woman who has just ordinary premenstrual syndrome as having a mental disorder." They said that they were talking about a "tiny number" of women who really get mentally ill just before their period. They said that they were not talking about PMS – bloating, breast tenderness, food cravings – but rather, about a mental illness. They then designed a category whose symptoms went like this: you had to have one mood symptom (e.g., depressed or anxious or irritable or emotionally labile or angry), then you had to have four of the symptoms on a list that included bloating, breast tenderness, food cravings – the very characteristics usually considered part of ordinary PMS. And you have to wonder: What are those physical factors doing in a manual of *mental* disorders?

When I was living in Toronto, I was involved in organizing a protest against the existence of this category and against putting it in the *DSM-III-R*, in 1987. They got so much bad press about it that they didn't end up putting it in the main text of the *DSM-III-R*. They created an appendix for "categories requiring further study," and they put it in there. It had a list of criteria and looked very scientific. However, they did not say, "Don't use this. It hasn't been proven to exist." That's when I got involved, as they were moving toward creating *DSM-IV*. That was the PMDD committee. We were supposed to look at the research and decide whether Premenstrual Dysphoric Disorder was a real entity. But I saw that they ignored the science that didn't fit with what they wanted, or they distorted it, or they lied about it (I know there are lawyers here but I've never been sued and I've said this in print). And that is why I resigned from that committee.

Let me tell you what the good scientific research actually showed about PMDD. A study was done that was the perfect study to find out if there was such a thing as a premenstrual *mental illness*. In this study, they removed breast tenderness in order to keep the terms sex-neutral, and they gave the *DSM* list of PMDD symptoms to three groups of people and asked them to fill out the checklist every day for two months. The groups consisted of women who were diagnosed with PMDD, women who said they had no premenstrual problems, and men. If there were such a thing as a premenstrual mental illness and its criteria had been correctly identified, then of course the three groups would have answered very differently; but there were virtually no differences. And the *DSM* people knew that. In spite of that, they kept PMDD in the next edition of the *DSM*.

There are a lot of problems with that. One of the most alarming is this: The people at the top of the *DSM* hierarchy and the pharmaceutical companies work hand in glove. And of course the insurance systems, whether government

or private, help that along because they want labels and want things simplified. Because we had demonstrated that there was no proof there was such a thing as PMDD, the *DSM* people held a roundtable discussion after *DSM-IV* was published. The roundtable was funded by Eli Lilly (the makers of Prozac). They got together the *DSM*'s PMDD Committee (needless to say, I wasn't invited) and they published a paper in which they claimed that new evidence had proven that PMDD was a real entity. Well, I read their paper and saw all they did was cite the old evidence that didn't prove that and new evidence that didn't prove it either.

One of the members of this PMDD Committee went to the Food and Drug Administration (FDA) meeting with Eli Lilly when the FDA had to vote on whether to extend the patent on Prozac, which was about to expire. This expiration would have meant the loss of millions of dollars by Eli Lilly. However, if they could prove that Prozac is helpful for another disorder besides depression, for which it had long been approved, they'd get an extension on the patent, which would be worth millions of dollars. So they went to the FDA together and said Prozac helps PMDD. The FDA did not require them to prove that there was such a thing as PMDD. So the next thing you know it's approved, and what happens? They take Prozac and they start manufacturing it in pink and purple and they rename it Sarafem. I believe it's not being sold under that name in Canada, but some of you may have seen the ads on American TV and in magazines.

In one Sarafem commercial, they showed a woman looking enraged and a sweet-looking man who surely never would have provoked that rage. A voice-over said, "You may think you have PMS, but you really have PMDD." Remember how in the beginning the *DSM* people had said, "We're not talking about PMS; we're talking about a tiny number of women"? Well, they did the exact opposite of what they said they were going to do. In the first few months after Sarafem went on the market (usually women are not told that it is Prozac), there were about a quarter of a million prescriptions written. If you type in "Sarafem" and "Canada" on the Internet, you get lots of drug company websites that say "See 'Prozac.'" So lots of women in Canada are taking Prozac for the nonexistent PMDD.

So let me just wrap up. This is dangerous business. Women are still socialized to not want to be angry, not want to be irritable, not want to be depressed, because then we can't meet other people's needs. So when you see a commercial like that, you think, "Look at her. After she took the pill, she's so sweet. I'd like to be like that and I'm so busy. I don't have time for therapy. Just give me the pill." The pressures on women tend to stream us towards asking for this kind of medication. And what the drug companies say is, "Isn't it wonderful that we are teaching women, that we are educating them so they can take control of their mental health care by knowing to ask for Prozac or Sarafem!"

Paula Caplan is a clinical and research psychologist, and was formerly head of the Centre for Women's Studies in Education and Full Professor at OISE and Lecturer in Women's Studies at U of T. She holds academic positions at Harvard University, the Washington College of Law and Brown University. At Harvard, she is teaching Harvard's first Psychology of Sex and Gender course. She is author of 10 books and editor of one. Paula is a highly sought-after speaker and has been awarded many honours for her work in the areas of women and psychology, women and body image, psychiatric diagnoses and their creations, sexual and child abuse, and women and science.

THE FUTURE

by Karen Seabrooke, on behalf of Women and Health Protection

First of all, I'd like to thank the members of the Women and Health Protection steering committee who worked with me on this presentation, and to say that it is an honour to be asked to make a presentation at this Ruth Cooperstock Memorial event.

When first approached to join in a panel on the "past," "present" and "future," I have to say I wanted the "past," and the dynamism and momentum of the past that Connie has described. I'm not too crazy about the "present," as Paula has been speaking about, but lest you think the world is going to hell in a hand-basket…

We in Women and Health Protection have a vision of another world. It's a world where commercial interests no longer dictate how societal problems will be dealt with, and where governments address the root causes of poor health – including poverty, violence against women, racism, and other forms of social injustice. It's a world where our food, air, soil, and water are not contaminated – where everyone has adequate housing, a safe environment, a just income, and quality health care and education. We want a world where women's lives are not medicalized – a world where social and political solutions, rather than technical or pharmaceutical fixes, are the norm.

We envision a world where being a woman does not mean being labelled as having one "disease" or another from puberty to menopause and beyond. However, if we keep going down the road we are on, these are the types of scenarios we'll be dealing with in the future, and don't be surprised if some of these already sound familiar…

We'll live in a world where a ten-year-old girl suffers from an eating disorder, and is dangerously underweight. She is bombarded by ads on TV and in teen magazines telling her she would look better if she was toothpick thin, just like the female supermodels and celebrities are. What will the future offer this child – some new, expensive psychotropic drug that will alter her sense of body size and stimulate her appetite?

Consider what's in store for a 30-year-old woman who isn't getting pregnant just when she wanted to be ... she will likely be placed on a new designer fertility drug that leads to hyper-fertility and causes her to ovulate daily for a month; she may end up with triplets, or even quadruplets ... Then there's the 40-year-old woman who will be encouraged to undergo routine genetic testing to see if she qualifies for one of the new "preventive," biologic drugs to ward off breast cancer, even though the long-term safety and efficacy of these products are unknown.

And what about the future for an 80-year-old widow? Perhaps a long-term stay in a nursing home, where she is lonely, cut off from the world and, quite naturally, feeling unhappy. She may be offered a "choice" of being on psychotherapeutic drugs for the rest of her life, so that she will be less of a "burden" on society – or – because she fears being "warehoused" in an institution for the rest of her life – she

may investigate a new life-extension drug that she has seen advertised daily on television, one that works on telomeres and keeps her cells dividing…

Unless we organize more systematically to bring about change, the future for women is pessimistic, because it's disease-oriented – a situation that suits the pharmaceutical industry just fine, but is not in the best interests of women. Our lives are medicalized, our health and our bodies are commodified and commercialized. **The question is, do we want to live under a paradigm of disease or a paradigm of health?**

I wonder what Ruth Cooperstock would say?

The answer for us in Women and Health Protection is clear. In our vision, a girl is born into a world that cares about her. She will not be objectified, but respected and valued for the unique little person that she is. In our vision, her development would be supported to its fullest, and she would participate in and contribute to society throughout her life. She would know and love her body and how it works and over time she would become the expert of her own health. Programs of early childhood education and care would have helped her form her own positive identity. When she reaches 80, we would still care for and respect her through the development of health programs and communities of support that value her as a person and for what she can still contribute; home care would be the norm and would be adequately funded, with institutions for seniors few and far between.

Our lives would be different if we operated from a more holistic, public health framework, if we had expanded choices and a range of health services and alternatives to choose from, paid for by our health care system. Government decisions and actions would be based on principles of equality, social justice, and the precautionary principle and would "do no harm." Governments would put the public interest, and not private interests, first, because health is a public good, not a private one. Real choices would be expanded if we invested in eradicating the root causes of our problems.

In our vision, our federal and provincial governments would be held accountable by an informed and engaged citizenry who would demand policies that place priority on health for all. Drugs and devices wouldn't be approved if their safety had not been proven unequivocally. There would be stricter limits on patent rights. The influence of industry on the regulatory system, on drug approvals and on advertising would be restricted. Health policy would no longer be industry and market-driven. We've placed limits on other industries, such as banning the tobacco companies from advertising and from sponsoring sporting events; why couldn't we demand similar measures for the pharmaceutical industry?

This is a glimpse of our vision, but how can we achieve it? There are many things we can push for.

- Imagine if Canada adopted a rational drug policy, and provided public health coverage for only *essential* drugs? The World Health Organization has a list we could adapt for Canada.

- How about allocating 100% of the health budget for the public good?

- There are many studies now that draw clear links between our social, political and economic conditions and the state of our health. It's well known that poorer people live shorter lives and are more often ill than

the rich, and it's well known that women bear the brunt of poverty. Perhaps we should look again at the Ottawa Health Charter, agreed to at a meeting sponsored by the World Health Organization, the Canadian Public Health Association, and the Health Protection Branch of Health Canada in 1986. It was an extremely progressive document (which has been updated at international health conferences over the years, most recently in Bangkok), in that it was based on the social determinants of health, and discusses what actions and methodologies are needed to achieve health for all. It's still very relevant today.

- Our solutions must transcend the health sector and engage beyond national boundaries. We must make the promotion of health central to the global development agenda. In both north and south, we need public health approaches that enable people to increase control over and improve their health. Policies must go beyond the social determinants of health, to address the structural determinants of health, and we must move beyond a focus on individual risk behaviour towards making healthy choice an easier choice through a wide range of environmental and social interventions. We need to tackle the continued commercialisation and privatization of global health and the biomedical and technological biases that are taking us down some new and scary roads.

- Even beyond the privatization of health care, we need to be concerned about a much bigger problem – the commodification of Planet Earth, which can only be remedied by much broader actions. Addressing these problems will require a vigorous advancement of preventive approaches, redirecting taxes to enable healthy behaviours and make non-toxic remedies more accessible, incentives to organic growing, and big changes in approaches to care-giving, involving a much

larger range of services and options. It will require reforms in international trade, and the general implementation of sustainability and precautionary principles on a global scale.

There are many steps and interesting initiatives and strategies happening in the world that we could learn from and and / or build on in the future.

- Maybe we could take a page from the "green prescription movement," which has come about as an antidote to the increased medicalization of our lives. Originating in New Zealand, this model encourages doctors, rather than issuing a prescription for a drug, to write a specific "green prescription" for anything from exercise and nutritional changes for diabetes and cardiovascular disease, to yoga and support groups for depression.

- We can envision, for example, calling for a fundamental, Canada-wide environmental audit that establishes a baseline for the future by testing water, food (milk, meat), soil, and air for the presence of pharmaceuticals and toxins. Such an audit would require an approach that would involve all the relevant sectors – health, housing, labour, environment, education, among others. It would set targets and establish a baseline for follow-up against which to measure reductions in the future. It's being done in other countries.

- What about calling for a national enquiry into the over-prescription of psycho-therapeutic drugs to elderly women?

- We could even generate debate on why Canada doesn't nationalize drug production and drug companies. Are there benefits to the private corporate control of pharmaceuticals for anyone other than the corporate stakeholders? What would be the benefits of national control of pharmaceuticals? Let's face it, the pharmaceutical industry needs more control than most others.

It's important to keep in mind that our vision will remain just that – a vision, a nice dream – unless we become more strategic in our thinking and our actions. What have we learned from the past that can guide us into the future? Twenty years ago, women's health advocates raised concerns about the dangers of New Reproductive Technologies. We discussed and questioned the science of the hormonal contraceptive Depo-Provera, and its potential for abuse among disadvantaged women with no access to follow-up care. Twenty years later we have been proven right in our concerns. We've had Norplant, we've had DES, and we've had the Meme breast implant. If you were at Barbara Mintzes' workshop this afternoon, you heard about the drugs Jasmine, Diane, and Julie (Xenical), and maybe even Anya. Most likely, an oral contraceptive named Seasonale®, which will suppress menstruation, will be approved for use soon in Canada. Do we want an oral contraceptive that will not only prevent pregnancy, but suppress women's periods? Because that's what this drug will do.

More than ever – especially with some of the new genetic and nano-technologies that are being researched and introduced today, we need to work together. We need to articulate a common political agenda, and a set of long-term strategies to make our vision a reality. We need multi-disciplinary approaches, involving many sectors and communities. We'll need new tools and new skills and the expertise of many to challenge the science. We need to work at the community level, listen to women's

lived experiences and engage people as agents of change. We need to identify and work with allies in many fields in society to bring about a new reality – including allies in various departments of government and politicians. We have to build for the future – build stable institutions, and promote sensible and workable health policies. We already have friends and allies in many places and a lot of contacts across the country and throughout the world. We have to build and deepen our relationships – among those of us in the women's health movement and beyond. It always comes down to relationships.

Paula's presentation provided us with an excellent sense of the challenges we face, and Connie reminded me of the excitement, dynamism, momentum and influence of the women's movement and citizens groups in Canada in the past. She reminded us of our global connectedness and solidarity with women around the world. We need to deepen our efforts, build this momentum again, and strengthen and build citizen's movements, across sectors, across boundaries and across borders.

And we in Women and Health Protection will bring to this effort our feminist approach to politics, our wisdom and lived experiences, our qualitative research and our movement-building processes. Just as Ruth Cooperstock would have us do.

Thank you.

Karen Seabrooke is a member of the steering committee of Women & Health Protection. She works as Canadian program coordinator for Inter Pares, an international social justice organization based in Ottawa. Karen worked for many years with women's organizations in Canada and the south on issues relating to women's health and reproductive rights, facilitating networking, exchanges, and joint research and policy initiatives among groups. She is a member and co-founder of the Women's Health Interaction collective, and has been a board member of local women's addiction centres and women's shelters.

Why just drugs, for heaven's sake? Broadening the scope of 'therapy' to include the real world

a workshop led by Warren Bell, M.D.

This session took a hard look at the historical roots of our reliance on patent medicines and offered some antidotes to this addiction, emphasizing the importance of history as a critical teacher. What follows summarizes the information presented by Dr. Bell as well as capturing some of the group discussion that ensued.

The historical roots of therapeutic drugs

An inquisitive, analytical European noticed that Nature, whom he feared and mistrusted, was nevertheless working wonders; so he used clever tools to extract, imitate and control one small facet of Nature's rich abundance, and then established rules to allow him and those close to him to gain almost limitless financial gain from this venture.

The development and use of therapeutic drugs has its roots in the culture of 15th-century Europe. This was a Eurocentric, Christian culture, characterized by a general antipathy to natural processes and the world of nature. It was an era when the developing ethic was science versus everything else, a time that was intensely coloured by Christian mythology (wild animals were fearsome, mountains were insurmountable forces) and when the prevailing notion was that man had, and needed to have, dominion over animals and nature.

Scientists of that era took a reductionist approach and were preoccupied with dissection and taking the things of nature apart as a way of understanding, taming and controlling them.

Medieval culture was built on a cultural bias that did not trust the world of nature and all things natural (one example being the desire to "tame" childbirth).

The ultimate expression of this rebellion against nature, in the mid-19th century, was the establishment of intellectual property rights, allowing man to "tame the world with his mind." What man could create with his mind and have patented was seen as an improvement on nature.

The corporation – the newly developed socio-cultural form that also reached its completed form in the mid 19th century – was a tool that facilitated this way of thinking. It was designed to pragmatically exploit the world and facilitate western European expansion. Rooted in an attitude of "everything belongs to us," corporations were allowed to exploit at will and were held only minimally liable. (The acronym "ltd" after the name of many corporations means "limited liability.") The creation of the corporation as a player in society gave us the licence to do unconscionable things in the name of corporate profitability – and the notion of "limited liability" made the investor invulnerable.

It was this Eurocentric culture that led to the Industrial Revolution and set the stage for humans, believing wilful (same root as wilderness) nature to be inherently bad and out-of-control, to dedicate themselves to controlling and improving on nature.

The therapeutic realm outside of the world of drugs

Outside the world of drugs is where we find all that cannot be patented. Complementary and alternative medicine includes physical therapies, as well as natural and biological therapies – all of those things that are not human creations. This non-drug realm includes practitioners who operate outside of the dominant paradigm: midwives, community healers, witches, sage-femmes, herbalists and many others.

Eurocentric culture and the Industrial Revolution led us to condemn indigenous cultures and those who live in harmony with nature. This same worldview today is leading us to attempt to control natural functions (for example, menses suppressed with drugs, childbirth managed through foetal monitors and Caesarean sections).

But all that has been neglected, maligned and suppressed is now resurfacing. We are witnessing more concern with and attention to basic lifestyle choices around nutrition, exercise, and psychological and spiritual practices. There is a renewed embracing of physical therapies: massage, chiropractic, and mind-body therapies. There is also an upsurge in community-embedded activities, behaviours and agreements, such as anti-smoking by-laws and seat belt legislation.

Ecosystem-based interventions will be the wave of the future, that is, interventions that will restore and clean up our ecosystems, and that are designed with sustaining the ecosystem in mind. We are increasingly being called on to pay attention to the ecological impact of our actions (for example, to be conscious of the extent to which the drugs we take and the cosmetic products we use end up in our water systems).

Obstacles to change

Although many recognize the need for change, we face many obstacles, including:

- a societal infrastructure that celebrates intellectual displacement of natural processes;
- a reductionist approach, with the corporation as key;
- the corporation, in its current form, as the dominant social institution in our world; (The number of multinational corporations went from 500 in the year 1600, to 7,200 in the year 1969, to 63,000 in 2004.)[3]

3 Taken from Medard Gabel and Henry Bruner, Global Inc.: *An atlas of the multinational corporation*, The New Press, New York, 2003.

- the dominance of the medical profession: when doctors and surgeons united at the turn of the last century to do away with all natural-based practitioners, it was the triumph of intellectualism over intuitive and naturalistic health care. We are still fighting with that legacy today as natural-based health care providers make their way back into the arena;
- intellectual property rights, which dominate the world of science and economics;
- a mindset that still fosters the illusion of localism, that is, the belief that what we do locally has no effect on anyone else;
- the myth of personal impotence – left-over chains from our hierarchical past ("the divine right of kings") – which has vestiges in contemporary behaviour where many feel they have no power and are impotent in the face of a grander social scheme.

A look toward the future

Notwithstanding the obstacles mentioned above, in looking toward the future we can expect:

- ever-widening circles of choice. Moving beyond a dogma of dominance over nature, we have many more choices (for example, midwives are coming back into their own);
- ever-broader diffusion of power and hence empowerment – embracing the notion that we can DO things in the world; our options are no longer as strictly prescribed – much more is allowed now;
- progressively reduced material consumption and energy inefficiency. It is recognized that we are going to have to change our ways and that we have to think about this in every realm. Note, however, that propelled by a powerful drug industry, modern medicine is still moving in the exact opposite direction with the huge over-consumption of drugs leaving a massive ecological footprint;
- greater emphasis on internal standards and personal development – "social creatives" are coming into their own in this era; this is a big and important trend driven by an inner set of principles: spirituality, tolerance, strength to stand up for what you believe;
- a flowering of creativity and sharing: thinking like an ecosystem – that is to say, conceiving of relationships in webs, rather than in linear patterns.

During the course of the workshop, several participants expressed the feeling that, in the paradigm being presented, health was individualized rather than seen in its political context. Basic lifestyle choices were emphasized; but the social determinants of health – gender, income, social class, ethnicity – were not included. These social determinants of health affect information about choices and the time and money to access alternatives. While the lifestyle model of health presented was seen as broader than the bio-medical model, some participants felt that it leaves out a fundamental part of the picture.

The discussion identified three models of health: 1) biomedical, 2) lifestyle, and 3) one based on the political economy of health. The material presented in the workshop moved from the first model to the second. Participants argued that there was a need to not only consider the third model, but also to engage in social action to address the social and political aspects of health.

Warren Bell is a practising family physician in a rural community in BC and a long-time proponent of integrated medicine. He's past president of the Canadian Association of Physicians for the Environment, and of Physicians for Global Survival, and the newly elected president of the Association of Complementary and Integrative Physicians of B.C.

Diane, Julie, Yasmin . . . who are these women and what are they doing in your medicine cabinet?

a workshop led by Barbara Mintzes, Ph.D.

This session discussed the marketing of pharmaceuticals to women, with special attention to the role of direct-to-consumer advertising. The following is a summary of the material presented by Dr. Mintzes.

There is a gulf between fantasy and reality in what drugs actually do and how they are marketed. The main change in the promotion of drugs to women over the last 20 years has been the increase in direct-to-consumer advertising (DTCA). In many ways, however, the promotion of drugs raises the same issues for women today as it did twenty years ago. Some of these issues are:

- Anti-anxiety and sleeping pills have been over-prescribed, as have anti-depressants since the 1990s. Women are the main targets of these promotions.
- Whether for anxiety or depression, if a drug is the solution, the implication is that the problem is the woman, not the society she lives in.
- Many aspects of womanhood are presented as diseases (menopause, osteoporosis, overactive bladder, etc.).
- Unsafe and ineffective drugs are promoted; some of the largest drug disasters have affected women in particular (DES, etc.).
- Vulnerable groups of women have been targeted: teenagers, the elderly, pregnant women.

Since the 1990s there has been a rapid growth in DTCA of prescription drugs. DTCA is legal in only 2 countries: the US and New Zealand. Spending on DTCA has gone from less than US $100 million per year in 1990 to $2.5 billion in 2000 and $4.1 billion in 2004. US television advertising has boomed since 1997. This affects Canada due to cross-border media availability. There is also more and more "made-in-Canada" DTCA and increasing pressure for DTCA to be legalized in Canada.

DTCA of prescription drugs is illegal in all but 2 countries because:

- when a drug is available only by prescription, it normally means that it is more toxic than non-prescription drugs, or less well-understood, or that it is intended to treat a condition that is not easily self-managed;
- those needing prescription medications may be seriously ill and are more vulnerable;
- ultimately, it is a matter of public safety.

One of the concerns raised by DTCA is that these marketing campaigns focus on new drugs. This stimulates widespread use when knowledge of the harms they can cause is inadequate. In addition, marketing of drugs for depression and anxiety promotes individual drug solutions for problems that are largely a result of social conditions and women's role in society makes it seem that these problems are individual rather than collective responsibilities.

A recent US study looked at the relationship between DTCA and medicalization of normal life problems. Kravitz and colleagues used hundreds of unannounced visits of "standardized patients." These were women actors in their 40s pretending to be patients. They were randomly allocated to either have symptoms of clinical depression or "adjustment disorder" (normal life problems that did not need drug treatment). If a patient asked for

Paxil (paroxetine), she was prescribed an antidepressant more than half the time, whether she had "adjustment disorder" or depression. If she did not request a drug, doctors were much more likely to prescribe antidepressants for depression than for "adjustment disorder." (*Journal of the American Medical Association 2005*; 293(10):1995-2002)

Under US regulations, there are 3 categories of drug ads:

- Reminder ads: which state brand name only.
- "Help-seeking" ads: which state a health condition only, with no brand name, but a suggestion to "ask your doctor" about a treatment.
- Full product ads: which include a brand name and health claims; risk information is required in these ads.

Although DTCA is illegal in Canada, Health Canada began allowing "help-seeking" ads in 1996 and reminder ads in 2000. This was done without any discussion in Parliament or vote on a change in law; existing laws were simply reinterpreted.

What is advertising?

- The Canadian Food & Drugs Act defines advertising as "any representation by any means whatever for the purpose of promoting directly or indirectly the sale or disposal of any food, drug, cosmetic or device."
- In 1996, a Health Canada policy paper put forward a new interpretation that set limits on this definition. It stated that, for a message to be classified as advertising, its primary purpose must be to stimulate sales. It clouds the issue by stating "No one factor in itself will determine whether or not a particular message is advertising."

This revised interpretation was used in responding to a letter of complaint sent to Health Canada by Women and Health Protection about an advertising campaign for Xenical (the "Julie" ads), a weight loss drug. The response stated that

> *"These types of messages are considered non-promotional when there is no specific drug mentioned, no drug manufacturer named… From a regulatory perspective, a violation of the Food & Drugs Act has not occurred."*
> – Khunder, Health Canada, July 2005

In November 2000, a Health Canada policy statement about reminder advertising stated that

- a manufacturer may say a drug name, but not its indication (that is, its approved use),
- or it may name a disease (or condition), without naming a drug.

This interpretation has been justified because of a clause added to the law that allowed price advertising. However, it is in keeping with neither the spirit nor the wording of the law. The clause, added to the Food & Drugs Act in 1978, states that

> *Where a person advertises to the general public a Schedule F Drug [prescription-only], the person shall not make any representation other than with respect to the brand name, proper name, common name, price and quantity of the drug. (C.01.044)*

There is a false belief that we would never have extreme US-style DTCA in Canada and that the type of reminder ads that we see, such as those for Accutane and Diane-35, would be allowed in the US. However, US FDA rules on reminder advertising specify that

- no medical specialty may be mentioned
- no reminder ads are allowed for drugs with serious safety warnings ("black box").

As well, US industry self-regulatory guidelines, adopted in 2005, specify that there may be no reminder ads on television, something seen frequently in Canada. Although Canada's laws

are more restrictive than those in the US, no company has been fined or had any other sanctions imposed for any promotional violation, including DTCA, in Canada since 1978. This is because there are serious problems with enforcement of the laws governing drug promotion. Ultimately Health Canada is responsible for enforcement of the law but in practice it has delegated much of this work to two self-regulatory bodies:

- the Pharmaceutical Advertising Advisory Board (PAAB) runs a voluntary pre-screening service for ads targeting health professionals, for example in medical journals or in the materials accompanying drug detailers who visit doctors;
- Advertising Standards Canada (ASC) is responsible for regulating the content of advertising for non-prescription drugs.

Recently, both agencies have begun to provide advice to companies about whether campaigns for prescription drugs (DTCA) would be considered "advertising" under the current interpretation of the law. This is a voluntary service that companies can request.

These organizations have published procedures to respond to complaints about advertising that is inaccurate or misleading or in another way violates the law. However, complaints about DTCA largely fall between the cracks. Any complaints about DTCA sent to PAAB or ASC are passed on to Health Canada. However, this remains problematic for the following reasons:

- Health Canada does not use its resources to monitor or enforce DTCA legality;
- There is nothing published that tells the public how to make complaints about DTCA to Health Canada;
- There is nothing published explaining how complaints are investigated;
- Health Canada does not involve the complainant in the investigation or even inform them of what was decided; Women and Health Protection had to use an Access to Information request to find out how their complaint was received.

One example of a drug that has been advertised in Canada is Diane-35 (cyproterone and estradiol).

- Diane-35 is associated with a greater risk of potentially fatal blood clots than other estrogen-progestin drugs and has also been associated with liver cancer.
- It has not been approved in Canada for birth control.
- It has only been approved for use in women with severe acne that has been unresponsive to other treatments.
- It has been heavily advertised to teenaged girls for off-label use (the girls pictured in the Diane 35 ads clearly do not have severe acne).
- This is blatantly illegal advertising.

Canada compared to the US – myth versus reality:

- The US has clear rules about reminder ads: you can't hint at how a drug is used and you can't have reminder ads for dangerous (black box) drugs.
- The US has a government branch, the Division of Drug Marketing Advertising and Communication at the Food & Drug Administration, that regulates advertising.
- Health Canada employs less than one full-time person on regulation of drug promotion of all forms, including DTCA.
- Canada relies largely on industry self-regulation, or on a "multi-stakeholder approach" (PAAB) with heavy industry presence. This makes sense if regulation is understood to be about creating fairness for the industry, not if it is a public health issue.

Although the US regulates DTCA, there are problems with the process. For example, although the US requires risk information in full product ads, these are usually stated with a background of visuals that are distracting – happy, smiling people running through fields holding hands, for example. There are no regulations requiring honesty about benefits, and ads often exaggerate the likelihood of treatment success. Additionally, the US FDA does not require pre-screening. Companies must submit ads when a campaign is launched. By the time the FDA judges an ad to be illegal, millions of people may have seen it on TV.

Advertising of new drugs tries to convince us that the newer drugs are always better. This is not the case. *La Revue Prescrire*, a French independent drug bulletin, has evaluated all new drugs for French doctors and pharmacists since 1981. This is what they found from 1981 to 2004:

from *La Revue Prescrire*

New drugs that were a major therapeutic advance	7 (0.2%)
New drugs that were interesting, representing an important advance, but with some limitations	77 (2.5%)
New drugs that were of some value	223 (7.2%)
New drugs that had minimal to no additional value	2576 (83.2%)
New drugs that were worse than existing therapies	87 (2.8%)
New drugs where there was insufficient evidence – judgment reserved	126 (4.1%)
Total	3096 (100%)

There is a disconnect between the shiny drug ads promising happiness and health if you just take this pill and the fact that to get a new drug to market, companies do not have to provide any evidence that it is better than existing treatments. As the table above shows, very few drugs are real "breakthroughs." Beneath the message about each individual drug, DTCA presents the fantasy that "newer is better" and that medicines provide a magic solution to unhappiness, ageing and other life problems.

For women, the strongest example of this was in the selling of hormone replacement therapy (HRT). Heavy marketing of HRT succeeded in shifting the meaning of menopause; many women were convinced that they should take hormones to preserve their health and youth. The Women's Health Initiative was the first study to examine the effects of long-term use of hormones by healthy women. The study found that HRT caused more harm than it prevented, including blood clots, heart attacks, strokes, and breast cancer. One in 100 more women were seriously harmed over a 3-4 year period. This translates into many thousands in the general population. Meanwhile, the effects on quality of life were found to be transient, small, and symptom-dependent.

The experience with HRT is a lesson for the future. Women were told that menopause caused health risks they needed drugs to cure. The cure in this case was much worse than the "disease": being a woman who happens to reach a certain age. The lesson for Canada's government is that enforcement of our laws governing drug promotion is a public health concern, including the law prohibiting DTCA.

Barbara Mintzes is a member of the Women and Health Protection Steering Committee and Vice-President of DES Action Canada. She has a Ph.D. in epidemiology from the University of British Columbia. Her doctoral research examined the effects of direct-to-consumer advertising of prescription drugs. Barbara currently works with UBC's Therapeutics Initiative, carrying out evaluations of drug safety and effectiveness.

Is sex more like dancing or digestion? The medicalization of women's sexuality

a workshop led by Leonore Tiefer, Ph.D.

The objective of this workshop was to debunk the developing mythology about female sexual dysfunction and to demonstrate the role the pharmaceutical industry has played in fuelling this mythology. What follows is some of the material presented by Dr. Tiefer.

Let's contrast two models of sexuality.

The medical model of sexuality is characterized by:

- mind-body dualism
- biological reductionism (moving towards the smallest element)
- universal sexual function (my pancreas functions like yours and everyone else's, is this true for sexuality?)
- individualism (medical problems occur in one person's body. Is sex the same sort of thing?)
- reified disorders (it is part of the medical model because it is "real." Diabetes is real. Is a sexual disorder real in the same way?)

The socio-cultural model of sexuality is characterized by:

- diversity (sexuality is expressed in many different ways; there are no pan-historical, trans-cultural or mammalian universals.)
- meanings and motives are paramount (context is key)
- co-creation (as with friendship, it happens when there's more than one person and each combination is different)
- primary processes are learning and socialization
- different expressions, depending on goals, training, coaching, talent, priority and life phases.

Medicalization can be defined as "a *social process* whereby behaviours, conditions, or habits are framed as *matters of health and disorder* to be governed by medical language, authorities and institutions." The stages of medicalization outlined were:

1. an initial contest over the "nature" of a behaviour or condition;
2. a publicity buzz about "new" biological research, including the celebration of medical treatments and the marginalization/trivialization of the non-medical;
3. the growing authority of medical experts, accompanied by a growing hegemony of medical meaning ("health" problem); and
4. institutionalization within medicine (organizations, journals, classification systems, training, research), accompanied by the underdevelopment of alternative models.

The direct promoters of medicalization include doctors and other health care professionals, the pharmaceutical industry, biotech, medical device and research equipment industries, medical researchers, public relations and advertising companies, health and science journalists, conference organizers, contract research organizations, medical publishers and the clinical trials industry. Additional indirect promoters are political and industry groups opposing non-medical approaches to health such as workplace and family policy reform, direct-to-consumer advertising reform and environmental reform.

BUT, it takes more than just promoters of medicalization for it to succeed. It takes people who have learned to look to biomedi-

cal science and experts for explanations and help. People find medicalization of sexuality attractive because:

- it appeals to a general cultural biomania;
- it offers an optimistic halo of scientific progress;
- it promises simple, quick, expert solutions;
- it removes blame, guilt, or shame for a "problem" (in a culture of individual responsibility);
- it reduces embarrassment (of the doctor, the patient, the media); and
- it allows couples to avoid interpersonal conflict.

From an historical perspective, there have been five phases in the current medicalization of sexuality.

Phase I: pre 1984

- 1966 Masters and Johnson publish *Human Sexual Response*
- development of sex therapy clinics from 1970 on
- 1980 *Diagnostic and Statistical Manual of Mental Disorders* adopts "human sexual response cycle"
- 1980 Spark, et al, "Impotence is not always psychogenic" published in the *Journal of the American Medical Association (JAMA)*
- Urologists begin work with implants, hormones, surgical experiments, herbs, vacuum devices; first conferences held

Phase II: 1984-92

- 1984, experimental intracavernosal injections (not approved by the Food and Drug Administration (FDA) until 1995)
- Urology sexuality clinics, newsletters
- Impotents Anonymous chapters launched
- Publicity – "new hope"
- 1990 – American Urological Association declares sexual dysfunction "a disease entity"
- 1992 – National Institutes of Health Consensus Conference on Impotence (renamed erectile dysfunction - ED)

Phase III: 1992-98

- Increasing pharmaceutical industry/urologist/sexologist collaboration
- Clinical trials on Viagra begin in 1993
- ED "disease awareness" (intracavernosal injections approved 1995; intra-urethral treatment approved 1996)
- Urologists organize ED research organizations, conferences, journals
- Urologists start talking about Female Sexual Dysfunction (FSD)
- Prescription Drug Users Fee Act (PDUFA) (1992) and Food and Drug Administration Modernization Act (FDAMA)(1997)
- Viagra approved March 1998

Phase IV: 1998-2000

- Viagra morphs from a medicine to an enhancement drug; becomes a cultural icon
- Pharmaceutical industry-sponsored meetings create FSD as a condition and a cohort of FSD experts
- data published in *JAMA*, 1999, claim a "43%" FSD prevalence rate; this becomes the lynchpin in the FSD disease awareness campaign
- FDA offers FSD clinical trials' guidance in 2000

Phase V: 2000-present

- "New View" Campaign launches anti-FSD website in 2000; conferences, books, press
- 2 additional ED drugs approved in 2003
- FSD drugs fail (2004: Pfizer withdraws Viagra; Procter & Gamble testosterone patch "Intrinsa" rejected)
- FSD continuing medical education and drug promotion unabated
- premature ejaculation (PE) disease awareness campaign begins

March 1998, when Viagra was released as a medication, was a watershed moment in the history of human sexuality. One month later, *Business Week* referred to it as being in the vanguard of

the transformation of the drug industry: this was the advent of "lifestyle drugs." These drugs would treat conditions rather than diseases; they would "enhance the quality of life for healthy people." In a music textbook, there is no discussion of the anatomy, yet various parts of the body are involved in making music. What you do see are expressions of music, its components, instruction on its creation and the importance of practice. Books on sexuality start with anatomy, especially the genitalia, and talk a lot about hormones. There is little or nothing on talent, training and practice, cultural variations, power, etc.

In thinking about sexuality, we need to think about the concepts and model we are using. The body doesn't determine the conceptual frame, nor does it dominate. It is the mind that starts the process of arousal. Textbooks on human sexuality talk more about drive than experience. We need to ask – is Viagra stimulating a desire for sex or sex with a certain person? ("Was that you or the Viagra?")

The 1997 conference in Cope Cod was a *closed* scientific meeting. Participants included about 50% doctors and 50% pharmaceutical company representatives. It was a conference about clinical trials sponsored by the pharmaceutical industry and attendance was by invitation only. This was a shift for sexology.

As public money is withdrawn from the universities, the pharmaceutical industry takes its place. And the pharmaceutical industry's approach is a marketing approach. A key phase in the marketing is the involvement of both the media and scientists *long before* a product is developed. Having experts on side is crucial to marketing and branding. So the scientists end up in bed with the pharmaceutical industry.

At the closed door "consensus conference" in 1998, a new FSD classification system was developed.

- 18 of the 19 experts present had a history with the pharmaceutical industry.
- Only half were sexologists.

In 1999, pharmaceutical industry consultants re-analyzed 1994 survey data to produce a global score, stating that 43% of American women "suffer from sexual dysfunction." A public relations disease awareness campaign was launched in which the 43% figure was widely promoted. The result was an increase of almost 100% over four years in off-label prescribing of drugs to treat FSD. Women were getting a product that was inadequately tested because their doctors thought the product was appropriate, even though the use was not sanctioned by the FDA. But, the doctors were getting their information from conferences and materials sponsored by the pharmaceutical companies.

Feminism was translated as product equality – if men have Viagra, women should have a drug too. Freedom, in this context, becomes freedom to choose a product. Viagra was not approved for use with women, but it didn't matter, because the message was already in the public domain and had taken hold.

In 2004, the message shifted and the focus was no longer the "arousal" problem, but rather the "desire" problem. Proctor & Gamble had begun to publicize the prevalence of "hypoactive sexual desire disorder" in postmenopausal women. Promotion of testosterone and the Intrinsa patch began.

In 2004, the regulatory atmosphere in the US changed with the Vioxx scandal and publicity about anti-depressants leading to suicide in teens. In this atmosphere, despite everything the drug company had done, Intrinsa was rejected. In fact, their lukewarm data were no better or worse than what had been presented for other drugs that were approved.

But the public relations machine didn't stop. A *JAMA* paper correlating sexual desire and free testosterone levels stated that there was no evidence of a correlation. But the summary stated, "our results are not in conflict with testosterone being used pharmacologically to treat hypoactive sexual desire disorder." (*JAMA,* July 6, 2005)

The harms of sexuo-medicalization include:

- unintended consequences for sexuality
  - genitalization of sexual experience / satisfaction
  - performance insecurity
  - McDonaldization of sex (standardized, quantified)
- diagnostic and treatment mismanagement and harm (over-medicalization)
- social harms
  - neglect of sex education, media literacy, consumer literacy and other forms of preparation for sexual life and PREVENTION of sexual problems
  - neglect of complex psychological and interpersonal factors in sex
  - corruption of sex research with pseudo-science, pseudo-education, disinformation and conflicts of interest.

The New View Campaign is a feminist conceptual challenge to the medical model of sexual problems, which includes:

- The Manifesto
- New View book and teaching manual
- lectures, publications, presentations, etc.
- a 5-year grassroots pharmaceutical industry-watchdog campaign, which has included
- a website: www.fsd-alert.org
- lectures, publications and two New View conferences
- FDA presentations and media interviews

The Manifesto is the intellectual backbone of the Campaign. It is a critique of the medical model of sexual problems.

- it uses a human rights discourse instead of medical disorders as the framing device
- it provides a non-normative definition of sexual problems

- whatever women say is a problem IS!
- it provides a classification of *causes*, not disorders
- causes are: socio-cultural / political / economic, relationship, psychological and medical

There are some benefits of sexuo-medicalization, including

- the legitimization of women's sexual pleasure for women, men, professionals; opens dialogue
- the promotion of physician education and comfort
- the fostering of physiological sex research and better medical care (e.g., careful surgeries)

Challenging medicalization:

- requires reviewing the entire medical model of sex – is sex more like dancing or digestion?
- requires more than just saying men and women are different
- requires regulating the role of the pharmaceutical industry in medical research and education and in consumer advertising

Challenging sexuo-medicalization means emphasizing problem prevention through:

- comprehensive sex and relationship education for parents, children and adults
- accessible sexuality and reproductive services
- media literacy
- consumer literacy
- educating health / science journalists about sexuality.

Leonore Tiefer is a Clinical Psychologist with an appointment at the NYU School of Medicine. She is a prolific author and has been an officer of US and international sexology organizations. In 1999 she convened an educational campaign to challenge the pharmaceuticalization of women's sexuality.

from Jessica Hill

Ruth would have loved this day: the ideas,

the discussion and the inherent tension between science and the individual experience.

Ruth had huge integrity as a woman and as a professional. She was a role model for me as a budding public servant. She provided a foundation from which I developed my own values. She questioned ideas and was not afraid to challenge institutions, such as the pharmaceutical industry. However, she did this by capturing the human experience and validating it scientifically.

Ruth had a generosity of heart and spirit and was able to truly listen to others and to share her insights in a way that help inform new directions for public policy and academia. It is very important that we sustain this annual memorial event so that Ruth's values and talent can be reinforced in others.

Jessica Hill co-authored Ruth Cooperstock's seminal book, *The Effects of Tranquillization: Benzodiazepine Use in Canada*. She has recently retired from her position as Deputy Minister in the Ministry of Children and Youth Services in the Government of Ontario, after a long and successful career in the public service.

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