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Ottawa

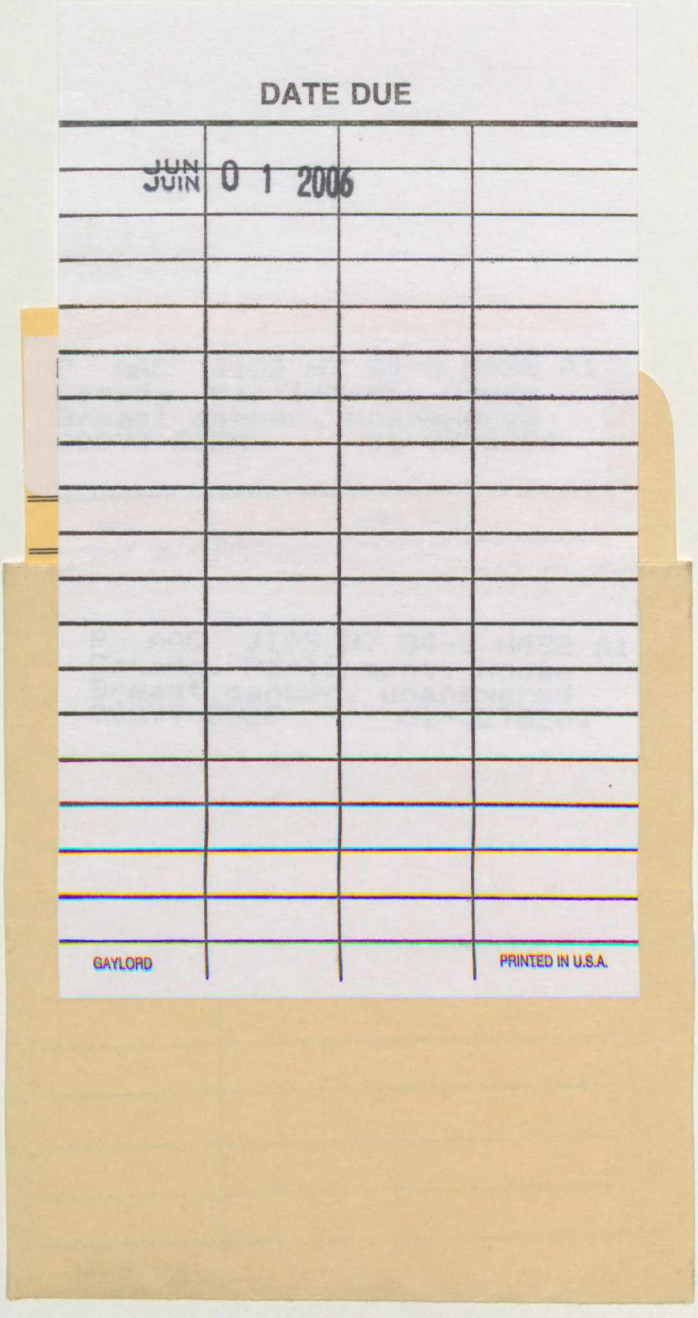
BREAST CANCER: UNANSWERED QUESTIONS

REPORT OF THE STANDING COMMITTEE ON HEALTH AND WELFARE, SOCIAL AFFAIRS, SENIORS AND THE STATUS OF WOMEN

BARBARA GREENE, M.P.
CHAIR

SUB-COMMITTEE ON THE STATUS OF WOMEN

June 1992



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HOUSE OF COMMONS

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Chair: Barbara Greene

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Health and Welfare, Social Affairs, Seniors and the Status of Women

Procès-verbaux et témoignages du Comité permanent de la

Santé et du Bien-être social, des Affaires sociales, du Troisième âge et de la Condition féminine

RESPECTING:

Second Report of the Sub-Committee on the Status of Women on Breast Cancer

INCLUDING:

Fourth Report to the House

Breast Cancer: Unanswered Questions

CONCERNANT:

Deuxième rapport du Sous-comité sur la condition féminine sur le cancer du sein

Y COMPRIS:

Quatrième rapport à la Chambre

Le cancer du sein: des questions sans réponse

Third Session of the Thirty-fourth Parliament, 1991-92

Troisième session de la trente-quatrième législature, 1991-1992

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Rey Pagtakhan

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(Quorum 3)

Researcher

Sandra Harder
Research Branch of the
Library of Parliament

Christine Fisher

Clerk of the Sub–Committee

SOUS-COMITÉ DE LA CONDITION FÉMININE DU COMITÉ PERMANENT DE LA SANTÉ ET DU BIEN-ÊTRE SOCIAL, DES AFFAIRES SOCIALES, DU TROISIÈME ÂGE ET DE LA CONDITION FÉMININE

Présidence: Barbara Greene

Membres

Edna Anderson
Dawn Black
Mary Clancy—(4)

Alan Redway (8 juin 1992 seulement)

(Quorum 3)

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Sandra Harder
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La greffière du Sous–Comité

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The Standing Committee on Health and Welfare, Social Affairs, Seniors and the Status of Women has the honour to present its

FOURTH REPORT

In accordance with its mandate under Standing Order 108(1), your Committee established a Sub-Committee and assigned it the responsibility of examing some aspects of the Status of Women.

The Sub-Committee submitted its Second Report to the Committee.

Your Committee adopted the Report which reads as follows:

Acknowledgements

The members of the Sub-Committee on the Status of Women gratefully acknowledge the contribution of the many distinguished and dedicated members of the medical and research community, of Health and Welfare Canada, and of provincial and national agencies who have given so generously of their time and provided information and opinions so willingly.

The Sub-Committee particularly thanks the many women with breast cancer, and their husbands, relatives and friends, who came forward with valuable advice and many valid recommendations. The Sub-Committee and its staff share your fear, frustrations and your determination to find answers to the many unanswered questions surrounding this disease.

We acknowledge with thanks the competent and concerned contribution of Sandra Harder from the Library of Parliament Research Branch who led the research and the drafting of the report.

We also greatly appreciate the patience and dedication of the Clerk of the Sub-Committee, Christine Fisher, who organized and co-ordinated the hearings and was responsible for the publication of the report.

Thanks also to the staff of the Committees Directorate, the Translation Bureau of the Secretary of State and the Support Services of the House of Commons and the Research Branch of the Library of Parliament for their assistance.

The Chair sincerely thanks the members of the Sub-Committee for their cooperation and their effort to achieve unanimity in the recommendations of this report on behalf of the women of Canada.

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LIST OF RECOMMENDATIONS

1. That Health and Welfare Canada design an extensive and comprehensive media campaign aimed at educating women about the importance of regular breast self-examination. In the design of this campaign, careful attention should be paid to findings of the Canadian Cancer Society's National Needs Study that emphasized the need to develop education and information campaigns that 1) are sensitive to various levels of literacy; 2) reflect the cultural and socio-economic differences among Canadian women; and 3) are aimed at population groups whose use of the health care system is low or below average. (p. 10)

2. That Health and Welfare Canada work with the provinces and territories to establish the most effective mechanism for delivering instruction on the technique of BSE. These mechanisms must consider the importance of guided instruction for women, using appropriate silicone breast models which contain reasonable facsimiles of breast lumps, and/or instruction using women's own breasts. Therefore, the Sub-Committee urges the provinces and territories to evaluate existing facilities and designate appropriate space (such as hospitals, community clinics, breast cancer screening clinics, local halls, schools, workplaces, etc.) for this purpose. Community organizations such as the YWCA, women's organizations, public health nurses, the Victorian Order of Nurses, extramural health nurses, etc. should be involved in the design and delivery of wide-scale instruction in BSE. (p. 10)

3. That the federal government work with the provinces to encourage university medical schools to establish a Review Committee to assess current curriculum on breast cancer. The Committee should direct attention toward the following issues: 1) ensuring that students receive up-to-date training on the identification of breast lumps and on proper methods of distinguishing lumps that require further evaluation from those which do not; 2) ensuring that accurate data on the incidence, risk factors, treatment options for breast cancer, the proper procedure for conducting professional breast examinations as well as the special needs of breast cancer patients are included in the course of training (p. 11)

4. That Review Committees should include in their membership, and work in close consultation with local breast cancer survivor, support and activist groups in assessing and, if necessary, revising their curriculum. (p. 11)

5. That provincial Colleges of Physicians and Surgeons, along with other relevant continuing education bodies, convene a yearly "UpDate" on breast cancer including information on 1) the identification of breast lumps and techniques for distinguishing lumps that require further evaluation from those that do not; 2) risk factors and treatment options for women; as well as 3) an update on the proper method of breast physical examination. All physicians and surgeons whose practice is likely to bring them into contact with breast cancer patients should be required to attend such sessions once every two years. (p. 11)

6. That a National Advisory Panel on Screening Mammography be established, which would include breast cancer activists, survivors, physicians and experts in the field. Upon release of the NBSS results, this panel should convene to consider the results and work toward the development of a national position on breast cancer screening (including the age at which to

begin screening, the recommended frequency, as well as the best method for cost effective and efficient delivery of screening). The National Advisory Panel should then work in consultation with provincial and territorial Ministers of Health and report their findings to the Minister of National Health and Welfare. Recommendations should be periodically reviewed in light of new findings. (p. 14)

7. That the National Cancer Institute of Canada establish a mechanism for tracking research dollars that are allocated to breast cancer as well as to other specific cancer sites. This information should be readily available to the general public and should be published in the Annual Report of the National Cancer Institute of Canada. (p. 19)

8. That 1) the federal government allocate $2 million as seed money for the establishment of the Canadian Breast Cancer Challenge Fund and 2) that the federal government issue a challenge to business and industry to match the contributions of the federal government, dollar for dollar in the space of one year and invite volunteer organizations, support groups and private citizens to do the same and that 3) in consultation with breast cancer survivor groups, the National Cancer Institute of Canada, the Canadian Cancer Society, the Medical Research Council and Health and Welfare Canada, these funds be directed, through existing research granting agencies and breast cancer survivor groups, to new research into the causes of breast cancer. (p. 21)

9. That existing federal cancer funding bodies within Health and Welfare Canada ensure that access to information on funding levels and on the types of research projects that deal with breast cancer is readily available to the public. (p. 21)

10. That the federal government work with the provinces to designate one existing cancer research centre per region in Canada as a "Centre of Excellence" for breast cancer. Such centres should, with the monetary support of the federal government, render state-of-the-art treatment and research on breast cancer and should ensure that their findings are disseminated to all other cancer treatment and research centres in the country on a regular basis. (p. 21)

11. That the NCIC develop ways to address the severity of breast cancer within their organization, including 1) opening up communication lines with breast cancer advocacy and survivor groups, 2) designating special proposal requests that target breast cancer research, 3) inviting breast cancer specialists from both the scientific and the lay community to join their review panels and take an active part in their research funding deliberations, and 4) establishing a mechanism to ensure that accurate and timely information on breast cancer research can be readily obtained. (p. 21)

12. That the PMAC establish mechanisms for tracking the amount of research dollars that are allocated to breast cancer and other diseases and that these figures be made readily and widely available to the general public. (p. 23)

13. That the federal government take a lead role by initiating within the cancer funding bodies of Health and Welfare Canada, a review to determine the extent to which their current structure and methods of funding cancer research allow for the participation of lay persons. This review should lead to the establishment of a committee to put in place mechanisms for: 1) greater public input; 2) greater lay representation on Boards of Directors and review committees; and 3) avenues for greater public dissemination of cancer research funding decisions and results. (p. 25)

14. That the NCIC undertake a similar review and establish parallel committees to work in concert with those established at Health and Welfare Canada's cancer funding bodies, the MRC and NHRDP, to create an environment for greater public input. (p. 25)

15. That the federal government work with the provinces to establish communication links with Provincial Colleges of Physicians and Surgeons and encourage them to advise their constituency of a woman's right to full disclosure of medical and surgical treatment options in the case of breast cancer diagnosis. In addition Provincial Colleges of Physicians and Surgeons should be encouraged to adopt the use of lumpectomies as the surgical treatment of choice for breast cancer patients, unless there are indications otherwise. (p. 27)

16. That cancer research funding bodies within the federal government make the identification of blood and genetic markers of breast cancer a priority research area. (p. 28)

17. That specific commitments regarding the targetting of basic research into the causes of breast cancer be established by the Medical Research Council. (p. 29)

18. That the federal government work with the provinces to encourage provincial cancer research centres to target greater amounts of their research efforts to basic research into the causes of breast cancer. (p. 29)

19. That the NCIC direct greater attention to basic research aimed at identifying the causes of breast cancer and to the development of diagnostic tests that identify early markers of the disease in women. (p. 29)

20. That cancer research institutes, both governmental and non-governmental, make the identification of prognostic indicators for breast cancer patients a research priority. (p. 29)

21. That the federal government take the lead role in ensuring that a share of research funds be reserved for research that explores the links between environmental carcinogens and breast cancer. (p. 29)

22. That government and non-government cancer research funding bodies identify the investigation of possible links between HRT and breast cancer as a research priority. (p. 30)

23. That Health and Welfare Canada, through the Medical Research Council, conduct a long-term epidemiological study of the risks and benefits of hormone replacement therapy for menopausal and post-menopausal women. (p. 30)

24. That Canadian hospitals participating in the tamoxifen trial make public the results of the trial, including accurate information on the side effects encountered by women who were administered tamoxifen. (p. 31)

25. That cancer research funding bodies within the federal government show leadership by undertaking an audit of the extent to which the research they fund identifies the race and gender of subjects as a fundamental variable in the research process, including the use of clinical drug trials. (p. 31)

26. That results of the audit be made public and form the basis for a comprehensive policy on the inclusion of women and various racial groups in all health and clinical trial research. (p. 31)

27. That the proposed Centres of Excellence for breast cancer (see Recommendation 10) also be designated as information centres. Using the model of a "clearing house" these centres would provide comprehensive and easily accessible information on the diagnosis and treatment of breast cancer, primarily to patients, their physicians and care givers. The establishment of 1-800 numbers for access to this information should be considered. (p. 33)

28. That the federal government work with the provinces and existing support groups to develop an information package to be distributed to newly-diagnosed breast cancer patients. The package should outline the risks and benefits of all treatment options and provide answers to the most commonly asked questions about breast cancer. This information should take into consideration a range of literacy levels, and it should be sensitive to the cultural, regional and racial differences in the country. (p. 34)

29. That the federal government take leadership in this area by working with the provinces to assess the access to, and availability of, radiation therapy for breast cancer patients across the country on an ongoing basis. In situations where extensive delays occur, strategies to deal with these delays should be implemented immediately. (p. 34)

30. That special care and attention be taken to monitor the availability of radiation therapists, radiation oncologists and radiologists and when and where necessary, to encourage these professions as career options. (p. 34)

31. That Health and Welfare Canada begin consultations with the Canadian Cancer Society to convene a national workshop on research and treatment issues in breast cancer. Planning and information for the workshop should involve the expertise of representatives from federal and provincial departments of health and leading breast cancer experts working specifically in the fields of treatment, both surgical and medical, and research. The outcome of this workshop should be the publication of "latest findings" in the fields of treatment and research into breast cancer. This publication should be widely available to health care workers and interested members of the public. A similar workshop should be held every two years. (p. 35)

32. That the federal government explore the establishment of an "arm's length" agency, accountable to a Board of Directors and reporting to the Minister of Health and Welfare, to undertake the review and approval of drugs, medical devices and biomedical products and to explore its operation on a cost-recovery basis where possible and desirable. The specific composition of the Board of Directors should be developed in consultation with Health and Welfare Canada and include a balance of scientists, researchers, industry and consumer groups. (p. 36)

33. That the federal government give careful consideration to the development of mechanisms to work toward international harmonization in the review and approval of new drugs, biomedical products and medical devices. (p. 36)

34. That the federal government work with the provinces to encourage cancer clinics located across the country to assess their current modes of pre- and post-operative treatment for breast cancer patients and that, where necessary, they upgrade their treatment to take into account: 1) the availability of physiotherapy treatment and 2) access to the various technologies in the treatment of breast cancer. (p. 37)

35. That professional organizations representing health care practitioners identify methods to foster greater cooperation between various sectors of the health care professions and that they work with medical schools to include information on physiotherapeutic techniques as appropriate treatment methods for breast cancer patients in their curriculum. (p. 37)

36. That the proposed national workshop on breast cancer include information on the various methods and advantages of post-operative physiotherapy treatment for breast cancer patients, including consideration that the number of lymph nodes removed in breast cancer surgery be determined on the basis of medical necessity, and that the use of horizontal rather than vertical incisions be considered. (p. 37)

37. That the federal Minister of Health and Welfare encourage provincial and territorial counterparts to review their policy and work toward a compassionate assessment of cancer treatment expense claims, providing such treatment meets the standards of Canadian medical care and is of medical value. (p. 37)

38. That the federal government work with the provinces to assess the quality of support services for breast cancer patients at established breast screening clinics and cancer clinics and, where these services are found to be inadequate, that existing and appropriate staff be designated as "nurse counsellors" and be given the necessary training to act in that capacity. In the course of their assessment, and throughout the development of training programs, medical clinics should ensure that representatives from existing breast cancer support and advocacy groups be actively involved. (p. 40)

39. That the federal government, in cooperation with the provinces, encourage medical schools to pay greater attention to the psycho-social dimension of cancer and other diseases in their curriculum. (p. 40)

40. That the federal government take a lead role in encouraging the provincial cancer clinics across the country to investigate ways in which the delivery of cancer care could be made more caring, humane and sensitive to the emotional and psychological dimension of the disease, including such fundamental things as: 1) ensuring that cancer patients are able to see the same physician during their visits to the cancer centres; 2) that their families have access to information and support, and 3) that details of existing support groups in the area be readily available to all patients. In the course of their investigations, cancer clinics should avail themselves of the experience and expertise of current and former cancer patients and of the Canadian Cancer Society, and include them in their review process. Clinics should build in an evaluation component to facilitate patient input. (p. 40)

41. That Health and Welfare Canada allocate money from the Health Promotion Branch to fund programs aimed at training potential breast cancer survivor group facilitators in group dynamics and counselling. (p. 41)

42. That Health and Welfare Canada assist interested breast cancer survivor groups to develop a framework and an "information kit" to facilitate the establishment of new support groups. Such a "kit" could contain "do's and don'ts", camera ready advertisements for use in local newspapers and magazines, copy for local television advertisements and flyers etc. Once developed, this "kit" should be made readily available to cancer clinics, existing breast cancer screening clinics, and community health centres in order to encourage the establishment of survivor-directed breast cancer support groups across the country. (p. 41)

43. That Health and Welfare Canada, in cooperation with other relevant departments, work with the provinces to provide for the formation of a national network of breast cancer survivor groups. The platform for such a formation should be a national conference of breast cancer patients, survivors, their partners, friends and families and interested persons, planned and coordinated by survivors of breast cancer. This conference should take place not later than June 1993. (p. 42)

44. That the Canadian Society of Plastic Surgeons and the Canadian Society for Aesthetic (Cosmetic) Plastic Surgery withdraw the booklet entitled "Aesthetic Surgery Breast Augmentation" and immediately discontinue its distribution to patients considering breast augmentation. (p. 47)

45. That the Canadian Society of Plastic Surgeons and the Canadian Society for Aesthetic Surgery prepare new information sheets in coordination with Health and Welfare Canada that accurately reflect current knowledge and debate about the risks, complications and possible long-term effects of breast implants, including the debate around the possible effects to *in utero* fetuses and nursing infants, from migrating silicone gel bleed. (p. 47)

46. That the federal government work with the provinces to encourage provincial Colleges of Physicians and Surgeons to ensure that information about post-cancer reconstructive breast surgery accurately inform women of the possibility of delayed detection of recurring cancer. (p. 48)

47. That such reconstructive surgery be undertaken at a time other than the surgery for the treatment of the primary breast tumour. (p. 48)

48. That the federal government work with the provincial and territorial regulatory bodies of physicians, plastic surgeons and oncologists to outline the conditions under which reconstructive surgery and the use of implants should be subject to extreme scrutiny. These may include: 1) women whose breast cancer has a high likelihood of recurrence, 2) women whose breast cancer is newly-treated and 3) women with pre-existing conditions that might exacerbate the possibility of complications such as diabetes and auto-immune diseases. These women should be encouraged to evaluate the possible risks and complications of implants and reconstructive surgery very carefully, in consultation with their physicians, oncologists and plastic surgeons. (p. 48)

49. That the federal government begin consultations with the provinces and territories to establish the parameters for a national registry of drugs, medical devices (implanted in the body for more than one year) and various forms of biotechnologies. Physicians and surgeons, manufacturers or distributors should be required to register the medical procedure, the use of a particular biotechnology, the patient, the date and details of the procedure. Patients should be advised of the existence of this registry and they should be able to notify the registry of any problems, complications or ill-effects they encounter. This information would then be fed to a central registry, housed perhaps within Statistics Canada. (p. 49)

BREAST CANCER
Unanswered Questions

TERMS OF REFERENCE

On September 24, 1991, the Sub-Committee on the Status of Women of the Standing Committee on Health and Welfare, Social Affairs, Seniors and the Status of Women, agreed to undertake a study of breast cancer and the MEME breast implant. As events unfolded over the course of our study, we expanded the terms of reference to include an examination of silicone implants.

On October 22, 1991, the Sub-Committee adopted a plan for the study which included an examination of epidemiological information, an inquiry into research funding and new research directions in breast cancer, issues surrounding treatment of the disease, attention to detection methods, public education and the role of support groups for breast cancer survivors. The study's examination of implants included reference to safety and risk factors, methods of government regulation and approval for implantable devices as well as the range of reconstructive surgical procedures.

Over the course of seven months, the Sub-Committee heard from experts in the fields of epidemiology, treatment, research and detection, and surgical procedures and from survivors of breast cancer.

Testimony is found in Issue Nos. 1-17 of the Sub-Committee on the Status of Women for the Third Session of the Thirty-fourth Parliament.

INTRODUCTION

At the outset of this inquiry, we had what might be considered modest goals in our study of breast cancer. We intended to 1) raise the public's awareness of the serious proportions of the disease in Canada and 2) get an accurate assessment of the amount of research dollars spent on breast cancer in Canada, and the direction of that research.

As a Sub-Committee we feel that we have accomplished the first goal by helping to draw attention to the devastation caused by breast cancer. In that respect, we have also learned a great deal of information, some of it startling, much of it depressing, and some of it hopeful. In short we all know, perhaps, much more about breast cancer than we ever wanted to know.

But what we have also learned is that there are huge voids in the knowledge about breast cancer; there are a myriad of unanswered questions. These gaps are not simply the product of our position as interested investigators. The breach in our knowledge is collective and it occurs at many levels: from patient to physician, to surgeon, to oncologist, to researchers working in

medical laboratories across the globe. We also know that this lack of knowledge exacts a price which is far too great; it costs many women their lives, many husbands and lovers their partners, many children their mothers, and on and on it goes. At some point these human costs have to stop, the questions have to be answered and Canadian women, indeed all women, need to be less vulnerable.

As a Sub-Committee we feel less positive about the accomplishment of our second goal. We still do not know how much money is spent on breast cancer research in this country. As the Report will indicate, pursuing this goal has been one of our most frustrating experiences. Our frustration is reflected in the recommendations we have made in this regard. It is also an issue which this Sub-Committee intends to monitor over time. For those witnesses who were upset by our insistence, we caution you that we will pursue our inquiries. For those witnesses who encouraged us to find the answers, we assure you that this topic will be given priority in our Committee work, in our constituencies, and in our private lives. For we too feel that we have become, in some ways, breast cancer activists. We intend to join in the fight to answer these questions and we hope to bring as many Canadians along with us as possible.

CHAPTER ONE

Epidemiological Overview

Despite the fact that a number of politicians in Canada and the United States have declared "war" on cancer at various points in the recent past, the disease continues to baffle scientists and it continues to rob people of their future. Although a number of witnesses hastened to tell us that many researchers are indeed poised to make major breakthroughs in cancer research, the pace seems all too slow. Dr. Sterns, a professor of Surgery at Queen's University, told the Sub-Committee that he is concerned by inaccurate portrayals of the state of our knowledge about cancer:

> In many ways we've led the public to expect miracles and conveyed the impression that progress and cancer diagnosis and treatment was more advanced than it really is. Some drugs have been developed which allow us to treat previously incurable cancer, but we are still relatively in the dark ages when it comes to understanding the mechanisms by which cancer cells behave . (16:22)

Epidemiology is the study of causation of disease particularly with respect to environmental and lifestyle factors. Epidemiologists, for example, played an important role in establishing the causal link between cancer and smoking. Epidemiological data allows researchers to establish patterns and trends in diseases over time, by age, gender, diet, etc. Three of the primary sources of cancer statistics in Canada are the National Cancer Institute of Canada, Statistics Canada and Health and Welfare Canada. Information on cancer incidence and mortality comes from provincial cancer registries and offices of vital statistics, which send their data to Statistics Canada for compilation at the national level. Epidemiological data on breast cancer is frightening.

INCIDENCE AND SURVIVAL

Epidemiologists estimate that there will be 14,400 new cases of breast cancer diagnosed this year. During the same year, 5,100 women will die from breast cancer; roughly translated that means approximately every two hours, every day of the year another woman will die. Over a woman's lifetime these figures indicate that each woman in Canada has a 10% risk of developing breast cancer (1:12).

Unlike some other cancers, the incidence rates have not declined over the past 20 years. In fact, statistics from Ontario indicate that the incidence of breast cancer has increased at a rate of approximately 1% per year between 1964 and the late 1980's (3:36).

There are variations in the incidence of breast cancer across Canada, with the Atlantic region displaying lower rates on average. British Columbia and Manitoba have the highest rates followed by Saskatchewan, Quebec, Alberta and Ontario (same rates), Nova Scotia, New Brunswick, Prince Edward Island and Newfoundland, whose rate is substantially lower than other provinces (Canadian Cancer Statistics, 1991, Statistics Canada, Health and Welfare Canada, Provincial Cancer Registries and the National Cancer Institute of Canada).

According to the *Mortality Atlas of Canada*, Vol. 4, 1991, the mortality rates for breast cancer show a fairly even spatial distribution in Canada, when compared to other causes of death. However, there are some census divisions in Eastern Canada which show significantly high mortality rates from breast cancer. Based on data compiled between 1980 and 1986, the breast cancer deaths among women ages 35-69 were significantly high in the following census divisions: Montreal, Toronto, Brantford (Ontario) and Sydney (Nova Scotia). These are sometimes referred to as "hot spots".

The Sub-Committee also heard evidence that there are some disturbing trends in the incidence of breast cancer internationally. Between 1975 and 1980, data from Osaka, Japan indicate a 55.1% increase in breast cancer incidence. Less dramatic, although still significant increases are found in Sweden (10%), the former German Democratic Republic (10.7%) and Brazil (16.1%) (1A:4).

According to Dr. Gerry Hill, an epidemiologist, from Health and Welfare Canada, breast cancer is also different from other cancers with respect to statistics on "cures":

> For most cancers a survival rate of five years is a good indicator of cure. Unfortunately, in breast cancer this is not exactly the case, as some women may die as long as 20 years after treatment. (1:12)

The five year crude survival rate for women diagnosed with breast cancer is approximately 66%. Put another way, approximately two-thirds of all women diagnosed with breast cancer survive the first five years. When adjustments are made for death from other causes, the five year survival rate is 73%. That means, of course, that approximately 30% of women who are diagnosed with breast cancer die within the first five years (3:36). Even more disturbing, over a 20 to 25 year period, there has been virtually no change in mortality rates. As Betty Rigbey told the Sub-Committee:

> . . .so little has really changed in the history of treating breast cancer, that 25 years after my mother was diagnosed with cancer I am far more advanced in my disease than she was. Two women, a quarter of a century apart, diagnosed with single tumours the same size, neither of which showed any signs of spread, yet we have very different stories to tell. She is alive and apparently free and clear of disease. I, on the other hand, am literally fighting for my life with metastases in my lungs, bones and liver. This is not right. . . it is wonderful that my mother is doing so well. It is outrageous that I am not. It is outrageous and frightening. (11:20)

THEORIES ON RISK AND RISK FACTORS

Given the very grim statistics on breast cancer, women need to be concerned about their own risk for contracting the disease. Some factors appear to play a significant role in assessing one's level of risk. However, the overwhelming message from experts in the field of breast cancer is that being a woman is the major risk factor. This is evidenced in the fact that between 60 and 70% of women who develop breast cancer have *none* of the suspected risk factors.

Breast cancer accounts for 14% of all deaths in women between the ages of 25 and 49 and the risk of breast cancer definitely increases with age. With respect to this fact, the Committee was warned that the media has done a poor job in addressing the relationship between age and breast cancer risk:

> Inadvertently we frighten a large number of women. When the media deals with breast cancer they almost invariably portray a young woman. Only 25% of breast cancers are diagnosed under the age of 50 and only 7% in women under the age of 40. Yet it's the young women who have been

made most apprehensive about this condition. At the other extreme, older women labour under the misapprehension that breast cancer risks stop at menopause, when the opposite is the case. (16:22)

This is not to say, of course, that younger women are risk free. It is to suggest that the relationship between age and breast cancer risk is important and Canadian women need to know this fact.

The Sub-Committee heard testimony based on Ontario data which clearly demonstrated that the risk of breast cancer increases with age. For example, based on 1989 data from the Ontario Cancer Treatment and Research Foundation, there were 5 cases of breast cancer per 100,000 population among women in the 25-29 year age group. However, the number of cases per 100,000 population increased dramatically to 107 among women in the 40-44 year age group, and to nearly 300 cases per 100,000 population among women in the 60-64 year age group. The incidence peaked at 392 cases per 100,000 in women between 80 and 84 years of age (1A:12).

Although it is difficult to quantify, the Sub-Committee learned that women who have a mother, sister, aunt or grandmother with the disease are at an increased risk for breast cancer. According to the 1992 edition of ™Everyone's Guide to Cancer Therapy:

> The risk factor [for breast cancer] is about six times greater if a mother or sister had breast cancer before menopause, and up to 10 times greater if the cancer was in both breasts.

The span of menarche is also a factor which epidemiologists have examined. Women who begin menstruation early and enter menopause late are thought to be at a higher risk level. Although there is some speculation involved, researchers tend to associate higher risk among this group with higher levels of estrogen production over a longer period of time.

According to some epidemiologists, when all the factors which influence breast cancer are examined together, fertility is likely among the most important. Low fertility and later age at first pregnancy (i.e. after 35 years of age) are associated with higher rates of breast cancer. The Sub-Committee heard evidence that a pre-menopausal woman whose first pregnancy takes place after 35 years of age has three times the risk of contracting breast cancer than a woman who has her first child before the age of 19 (3:37). It is expected that as the women who experienced low fertility since 1960 enter middle age, the incidence of breast cancer is likely to increase (1:12 and 3:37).

We believe the relationship between fertility and breast cancer risk raises some important points. There are no legislative measures that can be put in place to ensure that women who wish to have children undertake their childbearing in their twenties and early thirties. However, as we heard:

> We cannot ignore the fact that women who never become pregnant or those who start childbearing after 30 increase their risk for breast cancer. No legislation can counterbalance this biologic fact, but legislation can make it easier for a woman to have her children in her 20s and still not suffer a career setback. (16:24-25)

This indicates, we feel, the need for programs which facilitate the integration of work and family in such a manner that women who choose to, can have their children without experiencing work-related economic penalties. Further, we are convinced it points to the necessity of greater equality and cooperation between men and women in the provision of child care and the maintenance of household life.

During our travel to Washington, D.C., where we met with researchers and administrators of the National Cancer Institute, the Sub-Committee learned that a number of additional factors are also being investigated with respect to identifiable risk factors. These include:

1) the use of oral contraceptives over a long period of time;

2) alcohol consumption – moderate consumption appears to be a risk factor;

3) occupational or other exposure to low frequency radiation and electromagnetic fields;

4) exposure to radiation, including the impact of mammograms;

5) environmental toxins and potential carcinogens;

6) the long-term use of hormone replacement therapy in post-menopausal women; and

7) obesity and body shape.

In addition to the studies which identify early fertility as a protective factor, researchers are undertaking work on other possible protective factors including breast feeding, increased exercise and lower levels of fat intake (15A:8).

A great deal of research is currently underway on the impact of diet on the incidence of breast cancer. Such research has gained popularity, partly because diet represents a "modifiable" risk factor. Initial interest in this relationship was sparked by comparative data which examined the rates of breast cancer in women from North America and Eastern Europe with those of women from Asia and so called Third World countries. In Thailand for example, where dietary fat intake is slightly more than 20 grams per day, the age adjusted death rate from breast cancer per 100,000 is approximately 2. By comparison, in Canada where total dietary fat intake is closer to 140 grams per day, there are approximately 24 deaths per 100,000 women (3A:8). In a combined study on the relationship between breast cancer and fat intake, Dr. Geoffrey Howe, from the National Cancer Institute of Canada (NCIC) found that:

> saturated fat intake or animal fat intake in post-menopausal women appears to be associated with increased risk of breast cancer. . . there is a 46% increase in risk between women on the highest intake of saturated fat and on the lowest intake of saturated fat in the North American diet. (3:41)

It should be noted that although Dr. Howe's research does differentiate among various types of fat – saturated (animal fats and dairy products) as well as poly- and mono-unsaturated (vegetable oils) – he stated that it is important to emphasize that a reduction in total fat intake is likely the most prudent move.

None of the witnesses spoke of a definitive causal link between fat intake and breast cancer, and indeed other studies have failed to show any relationship or association. However, given the bulk of evidence which links fat intake to other health problems such as heart disease, obesity and some cancers, it seems important to recommend that women and indeed all Canadians, actively monitor and work toward reducing their fat intake. In view of the fact that a great deal of research demonstrates that a number of health advantages accrue from a low-fat diet, the Sub-Committee would prefer to see attention paid to more sophisticated diet-oriented research, particularly that which examined the possible carcinogenic effect of environmental contaminants, chemicals and additives contained in our food supply.

We feel compelled to underscore the fact that despite the exploration of a large number of risk factors, the very grim fact remains that in 60 to 70% of women diagnosed with breast cancer, *not one* of the risk factors is present. In short, simply being a woman is perhaps the major risk factor for breast cancer. As the Sub-Committee heard:

> Because we are women, we are all at risk for breast cancer. Two thirds of women diagnosed with breast cancer have no known risk factors for the disease. Many of the known risk factors are beyond our ability to control. . . Finding a cure for this disease would be the ideal answer. Continuing and increasing efforts to fund basic research is unquestionably warranted. The problem is, scientific knowledge accrues slowly. Women are still dying fast. (1:39-40)

We would like to echo these words of Pat Kelly, a founder of the Burlington breast cancer support group, and accentuate the fact that our inability to pinpoint certain risk factors and quantify them for women, reflects the need for greater research effort to be directed at the causes of breast cancer. In the face of these unanswered questions, there has been a tendency to focus substantial attention and resources on early detection of the disease. Contained in this approach is the assumption that early detection will contribute to greater long-term survival. For some women, this is true. However, as lofty as this hope is, the Sub-Committee heard of several instances where the disease had already progressed rapidly and of other instances where the cancer had already metastasized (spread to other parts of the body) even with early detection. The following chapter discusses both the methods of detection and some of the difficult issues surrounding detection.

CHAPTER TWO

Detection and Related Issues

In the course of their annual medical checkup it is likely that most women in Canada will receive a breast physical examination from their physician. Some women may also have a mammogram either on the advice of their doctor or of their own volition. Some women may also practice regular breast self-examination (BSE). These are the major tools for detecting breast cancer, but there is evidence that new directions are emerging. Two such innovations, magnetic resonance mammography and the development of a "heat seeking" bra, are discussed at the conclusion of this chapter.

METHODS OF DETECTION

A. Breast Self-Examination (BSE)

BSE is a technique used by women to detect changes in the texture and shape of their breasts and surrounding breast tissue (located in the under arm area). Two different methods of BSE are recognized in Canada. The Canadian Cancer Society (CCS) recommends a circular motion around the breast while the National Breast Screening Study (NBSS) uses a circular motion along radial lines of the breast, similar to the spokes of a bicycle wheel. In both instances, women should keep their fingers together and press firmly on the breast in order to detect any lumps. Similar palpations should be done on the underarm area. BSE should also include a visual examination of the breast noting any changes in the contour and shape of the breasts or nipples. It is recommended that these examinations be conducted every month. In pre-menopausal women the exam should be done after the menstrual cycle is completed. In post-menopausal women the exam should be done at the first of the month or at some other time which women will remember. BSE takes on greater importance when we learn that between 80 and 90% of all cancers are discovered by women themselves either in the course of regular BSE or by accident (1:36).

Despite the fact that BSE is a relatively simple procedure to learn and can be completed rather quickly, a staggering number of women do not perform regular examinations. Based on the 1985 Health Promotion Survey (HPS) conducted by Health and Welfare Canada only 41.4% of the survey population between the ages of 35 and 44 years of age, conducted monthly BSE. Between the ages of 45 and 54, 42.2% of women conducted monthly BSE and 44.9% of women aged 55-64 conducted monthly BSE (HPS as cited in *Women in Canada: A Statistical Report*, Table 16, p. 140, 1990).

It is difficult to guess the factors which may contribute to such low percentages of women performing BSE. However, the Sub-Committee believes that some explanation may lie in the fact that women are rarely taught how to do proper examinations. As we were told:

> BSE is actually a tactile skill. Trying to teach women BSE through shower cards and the provision of pamphlets is not going to be successful. . . The only way women can learn the skill is through guided instruction on their own breasts where they have an opportunity to recognize what is normal for them. (1:36)

The Sub-Committee believes it is essential for women to be taught correct breast self examination techniques as early as possible. We recognize that this is unlikely to happen in the absence of a coordinated national/provincial/territorial effort. Therefore, the Sub-Committee recommends:

1. **That Health and Welfare Canada design an extensive and comprehensive media campaign aimed at educating women about the importance of regular breast self-examination. In the design of this campaign, careful attention should be paid to findings of the Canadian Cancer Society's National Needs Study that emphasized the need to develop education and information campaigns that 1) are sensitive to various levels of literacy; 2) reflect the cultural and socio-economic differences among Canadian women; and 3) are aimed at population groups whose use of the health care system is low or below average.**

Further the Sub-Committee recommends:

2. **That Health and Welfare Canada work with the provinces and territories to establish the most effective mechanism for delivering instruction on the technique of BSE. These mechanisms must consider the importance of guided instruction for women, using appropriate silicone breast models which contain reasonable facsimiles of breast lumps, and/or instruction using women's own breasts. Therefore, the Sub-Committee urges the provinces and territories to evaluate existing facilities and designate appropriate space (such as hospitals, community clinics, breast cancer screening clinics, local halls, schools, workplaces, etc.) for this purpose. Community organizations such as the YWCA, women's organizations, public health nurses, the Victorian Order of Nurses, extramural health nurses, etc. should be involved in the design and delivery of wide-scale instruction in BSE.**

B. Professional Breast Examination

During the course of an annual physical checkup, women should receive a complete physical examination of their breasts by a trained health care professional. According to the HPS, approximately 72% of women between the ages of 25 and 34 had had such an examination within the last 12 months. For other age groups the figures were as follows; 35-44 years of age 70.7%, 45-54 years of age 67.4%, 55-64 years of age 57%, and 65 years and over 54.1%.

The Sub-Committee was told by Dr. Anthony Miller, the Director of the NBSS, that their national study indicated that physicians themselves require instruction on BSE techniques:

> . . .in terms of physical examination of the breasts, I think our study has demonstrated that it is rarely performed well by physicians. The reason is that physicians just do not take the time, they do not actually know what they are looking for. . . I personally believe. . . that we need to set up a professional education program for physicians in this country. (5:10-11)

This position was supported by the testimony of breast cancer survivors who indicated their familiarity with women who had either received inadequate physical examinations or who had received offhand assurances that the lump they felt in their breast was nothing to worry about. Referring to the experiences of women in the Burlington breast cancer support group, the Sub-Committee was told that:

> We estimate that among our group members, approximately 25% were advised upon initially reporting a suspicious breast lump to a physician that it was "probably not serious". . . these women were observed for periods ranging from three months to one year before a pathologic finding confirmed breast cancer in all of them. Some have since died of metastatic cancer. (1:35-36)

We find this information both appalling and frightening. As patients we all need to feel that we can rely on our physicians for the best and most timely advice about our health. At the same time Canadian physicians might take notice of a recent American study by the Physician Insurers of America that determined that delay in diagnosis of breast lumps is one of the leading grounds for malpractice suits. Further, they found that these suits produce among the most expensive settlements. The most frequently cited reasons for delay in diagnosis were failure to be impressed by a patient's own history, a patient's own finding or by the physician's own physical finding. (1:36) Therefore the Sub-Committee recommends:

3. **That the federal government work with the provinces to encourage university medical schools to establish a Review Committee to assess current curriculum on breast cancer. The Committee should direct attention toward the following issues: 1) ensuring that students receive up-to-date training on the identification of breast lumps and on proper methods of distinguishing lumps that require further evaluation from those which do not; 2) ensuring that accurate data on the incidence, risk factors, treatment options for breast cancer, the proper procedure for conducting professional breast examinations as well as the special needs of breast cancer patients are included in the course of training.**

4. **That Review Committees should include in their membership, and work in close consultation with local breast cancer survivor, support and activist groups in assessing and, if necessary, revising their curriculum.**

5. **That provincial Colleges of Physicians and Surgeons, along with other relevant continuing education bodies, convene a yearly "UpDate" on breast cancer including information on 1) the identification of breast lumps and techniques for distinguishing lumps that require further evaluation from those that do not; 2) risk factors and treatment options for women; as well as 3) an update on the proper method of breast physical examination. All physicians and surgeons whose practice is likely to bring them into contact with breast cancer patients should be required to attend such sessions once every two years.**

We are concerned by the information that some physicians may delay in their attention to breast lumps. Of course, we recognize that it is unlikely that all breast lumps require biopsy or further surgical procedures and that their indiscriminate use puts an unnecessary psychological strain on women and a financial strain on the health care system. However, we would like to stress that even one case where such a failure occurs at high cost to one woman is unacceptable. At the present time, we suspect, there is no accurate way to determine the incidence of such delays, and this concerns us. We would urge women to whom this has happened, to report their experiences to

the respective provincial College of Physicians and Surgeons. We would also expect these regulatory bodies to monitor such cases very carefully and to take action which they deem to be appropriate.

C. Mammography

The topic of mammography proved to be one of the most important, yet also one of the most difficult issues for Sub-Committee members to address. We suspect that if we, as a Sub-Committee, heard both confusing and conflicting evidence and discussion on mammography, that many Canadian women may find themselves in a similar position. We feel that, to the extent possible, it is crucial for women to have access to current facts and debates on the efficacy of mammography. However, we realize that facts are always subject to interpretation and this complicates, even further, the task ahead of us.

Mammography is an imaging technique which provides a picture of the internal structures of the breast using X-rays. It is, at the present time, the most widely used technology for detecting breast abnormalities. The sensitivity of mammograms allows them to detect breast tumours long before they would be felt by a woman or a physician using proper physical examination techniques. However, despite the fact that mammograms taken today are superior to those taken in the 1960s, 10 to 15% of cancers are not detected by mammography (5:34).

It is important to make a distinction between diagnostic and screening mammography. Diagnostic mammography is, much as the term implies, used by physicians to further assess physical abnormalities or complaints. Mammography screening, on the other hand, entails performing mammograms on large populations of women with no apparent sign of breast cancer. The process of screening identifies what is normal and what requires further investigation.

At the present time, British Columbia, Ontario, Nova Scotia, Saskatchewan and Alberta have established screening programs, referred to as "dedicated" centres funded by the province to screen women for breast cancer. A number of commonalities among centres exist: they practice two-view mammography, they provide information on BSE, all reports on mammograms are sent to both the woman and her physician, and women may self-refer or be referred by their physician. In British Columbia women 40 years of age and over are actively screened, whereas in the other centres screening does not begin until women are 50 years of age and over. This does not mean that women younger than 50 years cannot have access to mammography. They may get access through their physician. The frequency of screening asymptomatic women 50 years of age and over in the centres is once every two years (5:24-25).

A number of controversies surround the issue of mammography and these, the Sub-Committee learned, contribute to a vast amount of uncertainty in Canadian women. It is, we feel, critical for women to have access to accurate information on mammography so that they can make informed decisions.

1. Age

Another unanswered question facing women is: At what age should mammography begin? Just as Canadian women are apt to receive conflicting information on this issue through the media and from the popular press, the Sub-Committee heard conflicting evidence.

However, based on the evidence that we heard, we learned that the majority of existing studies indicate that mammography provides the greatest benefit in women over 50 years of age. This is due, in part, to the nature of breast tissue in younger women. In pre-menopausal women the breast

tissue is generally more dense and this tends to make detection more difficult. In some cases the density of the tissue may also increase the number of false positive results, which will contribute to great anxiety among women.

In coming to this position the Sub-Committee heard testimony regarding a number of studies that have specifically addressed the efficacy of mammography in women under 50 years of age. In a review of a number of studies whose results were first published approximately seven years after the study was initiated, Dr. Miller told the Sub-Committee that the effect of screening with mammography in women 40-49 years of age illustrated that:

> . . .at least in the early years of the majority of the studies for which we have results, and most presented their results about seven years after they started, there was no reduction in breast cancer mortality. There was, if anything, a suggestion of an increase in breast cancer deaths in the women who were offered screening compared to the control group. (5:5)

However, when the study results are confined to women between 50 and 69 years of age, the results reveal a different picture which indicates:

> that almost without exception, these studies showed benefit (i.e. a reduction in breast cancer mortality), if not early on, then certainly after longer follow-up. There is no controversy over benefit, I believe. (5:6)

As Dr. Miller indicated, the results of the first of these studies, and a desire to establish the effect of screening mammography, led to the development of the National Breast Screening Study, a Canadian study funded primarily by the National Cancer Institute of Canada (NCIC) and Health and Welfare Canada (HWC).

2. *National Breast Screening Study (NBSS)*

The study which began in 1980 had two main objectives, differentiated by age group. In women 40 to 49 years of age, the NBSS was designed to determine whether the combination of annual screening using mammography and physical examination reduced breast cancer mortality. In women over 50 years of age, the study sought to determine whether the inclusion of mammography was essential in screening for breast cancer and to ascertain how much mammography added to screening using physical examination alone.

This means that in women 50-59 years of age, the study was comparing the impact of mammography plus physical examination to physical examination alone. In women 40-49 years of age, the study compared women who had received combined screening (i.e., physical examination and mammography) with women randomly selected to receive one physical examination at the outset of the study and then to be followed by questionnaire only, for a period of years. Over the course of the study, the NBSS recruited just under 90,000 women from 15 centres across the country.

This volunteer study has amassed an enormous amount of data and much of the analysis is still not completed. Consequently, the results that Dr. Miller discussed before the Sub-Committee are preliminary and they must be understood in that context.

Dr. Miller explained that in large-scale screening studies, it is possible to get a sense of the long-term outcome by counting the number of women diagnosed with advanced breast cancer. In women aged 40-49 years the objective of the NBSS was to determine whether mammography and

physical examination reduced breast cancer mortality. The incidence of advanced breast cancer is then used as a yardstick to assess the outcome of the study. Preliminary data from the study indicates that in women aged 40-49 years, there were larger cumulative numbers of advanced breast cancer among those women who were receiving annual mammography screening than among the control group who received no mammography (5:9).

The NBSS study has not established the explanatory factors behind this observation and it is now the topic of a great deal of investigation. This fact contributes to the NBSS's inability to report exact mortality figures at this time.

In their examination of preliminary data on women who are between 50 and 59 years of age, the NBSS has, at this point, not found a great deal of added benefit from mammography in women who received mammography and a physical examination. In light of information received from other studies, Dr. Miller explained that analysts would have expected to see a reduction in the number of advanced breast cancers, if the addition of mammography was going to yield substantial benefits over and above those of physical examination (5:9). However, this is not the case. As Dr. Miller discussed:

> What appears initially to be coming from the study is that at least in the short term, mammography is not adding anything very much. It's adding many cancers. We found many small cancers. But because breast cancer has a long natural history (some indications are that it is 20 years in formation) and because we know that mammography can sometimes bring forward the time of diagnosis by about four years, it's quite likely that in order to find a benefit from adding mammography to what we believe are good physical examinations, we will have to continue to follow this group for a very long time. (5:9)

The Sub-Committee feels it is important for this information to be kept in perspective. We would caution women to understand that preliminary data in the 40-49 year age group does not necessarily mean that mammograms contribute to breast cancer. Among women over 50 years of age, neither does the data indicate that abandoning mammography is prudent. Rather, the Sub-Committee would underscore the fact that mammography shows benefit in reducing mortality from breast cancer in women over 50 years of age.

However, what the NBSS may indicate is the absolute necessity and importance of good physical examinations of the breasts by women on a regular basis, as well as the significance of good professional breast examinations. As we heard:

> We are interpreting [the data] as indicating that the physical examinations were very good, as indeed they were. We spent a lot of time. In all provinces outside of Quebec, we used nurse examiners. The physical examinations took an average of about 10 minutes, which is considerably longer than most physicians spend on a physical examination. The nurses were taught to look for signs of early breast cancer, which is essentially what we've been picking up. Indeed, we know that the. . . efficiency of the test in finding cancers was good. (5:9)

Given this statement, and the initial findings of the NBSS, the Sub-Committee would like to reinforce the importance of the recommendations we have made above (1-5). We feel, given the evidence which exists to date, that women under 50 need to carefully weigh their decision to undergo mammography, particularly if they do not fall within a group that has a theoretically higher risk of contracting breast cancer. In consultation with their physicians, they must discuss the relative risks and benefits of mammography and make their decisions based on the most accurate information possible. Therefore, the Sub-Committee recommends:

6. **That a National Advisory Panel on Screening Mammography be established, which would include breast cancer activists, survivors, physicians and experts in the field. Upon release of the NBSS results, this panel should convene to**

consider the results and work toward the development of a national position on breast cancer screening (including the age at which to begin screening, the recommended frequency, as well as the best method for cost effective and efficient delivery of screening). The National Advisory Panel should then work in consultation with provincial and territorial Ministers of Health and report their findings to the Minister of National Health and Welfare. Recommendations should be periodically reviewed in light of new findings.

Diagnostic mammography, as we have outlined earlier in this report, is distinct from screening mammography. This is an important point because there will always be women, of a variety of ages, who will require diagnostic mammography, due perhaps to a higher risk profile, the presence of lumps, etc. These women can access mammography through their physicians.

The Sub-Committee heard from a number of provincial breast cancer screening programs. The benefits of the British Columbia program are evident in its structure and organization, which contributes to a reduction in the cost of mammograms, a centralized system for their interpretation (resulting in fewer misreadings) and a method for tracking women and contacting them for regular mammography screening. At the same time, the program has attempted to deal with the dispersed population of British Columbia by putting in place the operation of mobile mammography units that go to women in less densely populated areas.

The Sub-Committee also heard from The Breast Cancer Screening Working Group, convened in Manitoba in 1991. In light of their consideration of research findings on screening mammography, the working group recommended that the province not initiate mammography screening at this time and that screening be discouraged in asymptomatic women under 50 years of age. Also included in the final report of the working group was a strong indication of the need for women in Manitoba to have access to current information on screening and additional breast health issues, and a recommendation that the province establish an Advisory Group to assess and reevaluate the findings and recommendations of the working group in light of emerging information (15:14-17).

Once the proposed National Advisory Panel is in place, we would encourage the Panel to avail itself of the findings of the Manitoba Working Group and other similar existing groups across the country and to work closely with them in its deliberations.

D. Magnetic Resonance Mammography (MRM)

Although not covered extensively in the Committee's hearings, a relatively new technology, MRM, will likely prove to be an important one for the detection of breast cancer. Researchers who are working in this field have determined that this technology can detect breast cancer with greater accuracy, and it can determine the extent of the disease more meticulously. MRM is able to suppress the signals from the breast's fat tissue during the imaging process. This aids in the identification of lesions that might otherwise be obscured by surrounding fat tissues. In younger women, whose breast tissue is more dense, this technology should be very important.

In a Dallas study, this technique has been tested in 57 women, with highly suspicious lesions, who were scheduled for biopsy. In 47 cases, pathology reports have confirmed 76 lesions. The MRM scans confirmed the results of conventional mammography in 30 of the 47 women. However, the MRM found 100% of the cancers, while mammography gave false negative results by missing cancer in 14 of the 42 patients (*The Medical Post,* January 7, 1992: p. 45).

Unfortunately, the cost of MRM makes it almost inconceivable for use as a general screening tool. However, researchers indicate that the use of MRM may preclude unnecessary surgical biopsies and ensure better treatment procedures in women with breast cancer. We urge hospitals to monitor new technology such as MRM, because over the long term, such technologies will reduce the costs incurred by inappropriate cancer treatment.

E. Heat-Seeking Bra

A recent article in the *Medical Post* indicates that researchers at Glasgow University in Scotland have developed a bra which is able to measure temperature changes in women's breasts over a 28-day period. According to the theory behind the bra, the warmer the breasts, the higher the risk for the development of breast cancer. The development of the bra is based on the assumption that breast cancer will only develop in an "abnormal" breast. Heat profiles, according to the researchers, tend to show significant differences between categories of breasts. Consequently, the bra may be a good indicator of risk for breast cancer. The research team found that there were significant differences between the temperature profiles of women with a low risk of breast cancer and those who had already lost a breast to cancer. The average breast temperature in high-risk women was 1 to 1.5 degrees higher. This bra is about to enter clinical trials.

CHAPTER THREE

Research Funding and Peer Review

As was pointed out in the introduction to this Report, one of the Sub-Committee's goals at the outset of this study was to determine the number of research dollars that are allocated to research on breast cancer. We quickly learned that this goal was, in fact, a very complicated one. While the issue of research dollars is indeed important, it is also significant to understand the manner in which decisions about research are made, who the key "players" in the research process are, what they do, and the extent to which the general public has input into cancer research in this country. The Sub-Committee was also interested to learn the direction and the key issues in breast cancer research. However, despite the fact that we heard from many experts in the field, we recognize that our study cannot explore the full scope of research endeavors in this country.

CANCER RESEARCH IN CANADA

While there are several key players in the field of cancer research in Canada, it is crucial to understand that many Canadian researchers are linked to international research efforts, working with colleagues in the United States, Europe and Australia. Research on cancer takes place in hospitals, universities, independent cancer clinics, government research labs, etc., and research findings are published in medical and scientific journals and disseminated through various research institutes around the world.

THE NATIONAL CANCER INSTITUTE OF CANADA (NCIC)

NCIC is the major player in cancer research in this country. It was established 45 years ago as the result of an agreement between Health and Welfare Canada (HWC) and the Canadian Cancer Society (CCS). In practical terms, the NCIC can be thought of as the "research arm" of the CCS. NCIC has 44 members who review the institute's activities and provide information and advice to the Board of Directors.

Eighteen members of NCIC are appointed by academic and community agencies who have a strong interest in cancer and cancer research. The CCS appoints eight of these 18 members. Twenty-six members are "members at large" and these are "senior scientists, physicians, academics and professionals from universities, cancer centres, and related agencies across Canada" (11:5). The Board of Directors of NCIC is comprised of 14 of these 44 members. Four are selected from the eight CCS representatives. At the present time, the gender balance of the NCIC is disappointing. The Sub-Committee learned that they are attempting to ensure more equal gender distribution on their Board of Directors, their Review Panels and internal committees. At a recent meeting, a motion to this effect was passed. We commend the NCIC for this step and we anticipate their next Annual Report, which should reflect these changes.

Policy of the NCIC is determined by the Board of Directors who are ultimately responsible for all of the programs and decisions of the Institute. In their deliberations, the Board is advised by four "senior committees"; Planning and Priorities, Research, Cancer Control and Finance (11:6). The following quotations explain the mission and the objectives of the NCIC:

> The mission of the National Cancer Institute of Canada is to undertake and support cancer research and related programs in Canada that will lead to the reduction of the incidence, morbidity and mortality from cancer. (11:6)

The Objectives of the NCIC are:

1) to initiate and support cancer research through grants and other mechanisms;

2) to offer a program for the training, development and support of personnel in cancer research;

3) to provide information relating to cancer research and cancer control;

4) to facilitate and actively participate in the coordination of activities sponsored by related agencies, both national and international; and

5) to act in concert with its partner the Canadian Cancer Society (11:6).

The total budget for the NCIC in 1991-92 is $43.4 million. Of that amount, the CCS provides $35.1 million, the Terry Fox Run provides $8.2 million and the balance of the funds ($0.1 million) comes from additional sources (11:6). The Sub-Committee feels it is important for Canadians to understand that the $35.1 million, the largest portion of the NCIC funds, comes from the charitable donations of the general public and is raised through the volunteer labour of millions of Canada's residents.

Following is the breakdown of the total budget of the NCIC as provided by Dr. David Beatty, the Institute's Executive Director:

Research grants to individuals	$25.5 million
Major programs and program projects	9.2 million
Support of individuals in cancer research, students in training and mature scientists	5.0 million
	$39.7 million

The balance ($3.7 million) is allocated to the development of research programs and teams and the expansion and development of regions where less cancer research is undertaken ($1.9 million), workshops ($0.1 million), cancer control, behavioural research and medical affairs (peer review and administration).

The Sub-Committee heard from three representatives of the NCIC; the Director, the Director of Clinical Trials and a member of the Board of Directors, who is a former member of the Advisory Committee on Research. From all three witnesses, we attempted to obtain an accurate figure on the amount of research dollars that are targetted to breast cancer research at the NCIC. In general, we are very dissatisfied with the information we received.

Dr. R. Phillips, a member of the Board of Directors stated of the NCIC that:

> We give about 19 or 20 grants that have breast cancer in their title. This amounts to about $2.5 million of the total. It ignores a lot of very important research. (2:33)

The Director of Clinical Trials, Dr. J. Pater, told the Committee that it:

> . . .is very hard to estimate, at least in the clinical area, and I think it's also true in the basic science area, how much research is going on in breast cancer. . . a lot is happening that is not in public documents, or at least not in easily accessible public documents. (8:6)

The Director of NCIC stated that about 25% of the money directed toward individual research grants ($25.5 million) went to projects that identified a specific cancer site in their title, and 20% of those applications identified breast cancer in their title. Based on these figures, approximately $1.2 million of the $25.5 million went to research that directly targetted breast cancer. However, the NCIC pointed out to the Sub-Committee that 70% of their budget went to basic research, directed at understanding the genetic, cellular and molecular mechanisms involved in cancer. Much of this research, would, according to NCIC, have an impact on the understanding of breast cancer.

However, when asked to produce the exact dollar amount directed toward breast cancer, none of the three representatives from NCIC could provide this information. We find this revelation both surprising and disturbing. We are surprised because the National Cancer Institute in the United States (NCI) has provided information on research funding per specific cancer site for a number of years. In light of the fact that NCIC is the major funder of cancer research in this country, we are disturbed to learn that careful attention to this has not been part of their organizational structure. Therefore, the Sub-Committee recommends:

7. **That the National Cancer Institute of Canada establish a mechanism for tracking research dollars that are allocated to breast cancer as well as to other specific cancer sites. This information should be readily available to the general public and should be published in the Annual Report of the National Cancer Institute of Canada.**

Such a tracking system, we are convinced, will be beneficial for the work of the NCIC by helping them to establish and monitor research priorities. This year, breast cancer will account for the loss of 89,000 women years of life. The tremendous burden and the social, personal and emotional cost of breast cancer make it incumbent upon all research funding bodies to provide the public with information on research efforts that are underway.

GOVERNMENT FUNDING

Cancer research is also funded by other agencies and institutes in Canada. Health and Welfare Canada, under the auspices of the Medical Research Council (MRC) and the National Health Research and Development Program (NHRDP), also fund cancer research. In addition, provincial governments, through local hospitals and provincial agencies (e.g., the Alberta Cancer Board) support cancer research.

In reviewing all health research funding sources in Canada for the 1988-89 period, the total expenditure on cancer research (from all sources) was approximately $52 million. Of that $52 million, over $7.5 million came from federal sources, $4.8 came from provincial sources and $40.2 million came from non-governmental agencies (2:4). Clearly, non-governmental sources such as the NCIC are major players in Canadian cancer research.

FEDERAL FUNDING BODIES

A. The Medical Research Council (MRC)

The MRC is funded by Parliament to:

> promote, assist and undertake basic applied and clinical research in Canada in the health sciences. . . based on decisions taken in the 1970's, MRC handles the basic applied and clinical aspects of the health sciences. . . (2:6)

Because MRC is a multifaceted agency, their total research budget includes funding for a variety of research in addition to cancer research. In 1991, MRC's budget for grants and scholarships totalled $223 million. Of that amount, approximately $6.9 million went to cancer research in general. Of the $6.9 million, less than $1 million ($849,000) went specifically to breast cancer research.

B. National Health Research and Development Program (NHRDP)

The same decision that allocated basic applied and clinical aspects of health research to the MRC, allocated public health care delivery, public health and epidemiology to the NHRDP. According to Dr. May Smith, a representative from NHRDP, their work complements that of MRC but it aims specifically at:

> preventing cancer or improving the quality of care for cancer patients. . . examples of research projects which are funded by this program include; studies which demonstrate and evaluate rehabilitative and invasive support programs for cancer patients, studies that aim at identifying risk factors and the predisposing factors of cancer and studies which are designed to study the early detection of cancer. (2:5)

The total 1990-91 budget for funding public health and health services research at NHRDP is $28.1 million. A reduction in the budget to $26.56 million in 1991-92 reflects the end of certain programs scheduled to conclude in this fiscal year. Over the past 10 years, NHRDP's average, per year, financial support for cancer research was just over $1.5 million. Additional expenditures of $0.5 million per year were directed to training and career fellowship programs and career award programs for persons working in the field of cancer research (2:6-8).

Over a 10-year period, officials from NHRDP estimated that approximately $400,000 per year was spent on projects specific to breast cancer. A major study funded through this program, and directly relevant to the work of this Sub-Committee, is the National Breast Cancer Screening Study, which received $5.5 million of its total cost of $17 million from the NHRDP. In 1991-92, NHRDP estimates identify $32,882.00 for research targetted specifically to breast cancer (Submission from NHRDP, 6 November 1991).

In the case of both federal funding bodies, the Sub-Committee was told by Dr. F.S. Rolleston, Director of Scientific Evaluation at the MRC, that the estimates of funds directed to breast cancer:

> . . .must all be regarded as underestimates as this classification also shows that large amounts are spent on basic science areas that impinge on many specific diseases. For example, endocrinology ($7.4 million), immunology ($8.1 million), metabolism ($6.6 million) and biochemistry and molecular biology ($22.6 million) are all relevant to breast cancer. (Submission from MRC, 6 November 1991)

While we clearly understand that a great deal of "crossover" does exist in cancer research, we feel compelled to reiterate that given that approximately 14,000 new cases of breast cancer will be diagnosed this year and that approximately 5,000 women will die of this disease, there is a need for greater targetted research on breast cancer. The comments of the Director of the Division of Epidemiology and Statistics at the Ontario Cancer Treatment and Research Foundation are telling:

> My priority would be to put breast cancer into perspective. I don't think governments appreciate that it is the leading cause of premature lives lost among women in Ontario. The magnitude of the problem dwarfs AIDS. In 1989, 4,000 women were diagnosed as developing breast cancer in Ontario and 304 individuals developed AIDS. The amount of publicity you see for AIDS versus the amount of publicity you see with regard to just this one form of cancer does tend to concern me. (1:31)

At the same time that the individual tragedy of breast cancer costs many women their lives, we also recognize that this disease contributes to a fundamental loss of human potential. We would like to see the federal government, business, industry and indeed all Canadians, take this loss both as a challenge, and as an opportunity to illustrate their support for the courage demonstrated by women who have breast cancer – particularly those who are battling for their lives at this very minute. The time has come to establish a national focus. Therefore, the Sub-Committee recommends:

8. **That 1) the federal government allocate $2 million as seed money for the establishment of the Canadian Breast Cancer Challenge Fund and 2) that the federal government issue a challenge to business and industry to match the contributions of the federal government, dollar for dollar in the space of one year and invite volunteer organizations, support groups and private citizens to do the same and that 3) in consultation with breast cancer survivor groups, the National Cancer Institute of Canada, the Canadian Cancer Society, the Medical Research Council and Health and Welfare Canada, these funds be directed, through existing research granting agencies and breast cancer survivor groups, to new research into the causes of breast cancer.**

Further the Sub-Committee recommends:

9. **That existing federal cancer funding bodies within Health and Welfare Canada ensure that access to information on funding levels and on the types of research projects that deal with breast cancer is readily available to the public.**

10. **That the federal government work with the provinces to designate one existing cancer research centre per region in Canada as a "Centre of Excellence" for breast cancer. Such centres should, with the monetary support of the federal government, render state-of-the-art treatment and research on breast cancer and should ensure that their findings are disseminated to all other cancer treatment and research centres in the country on a regular basis.**

The Sub-Committee also recommends:

11. **That the NCIC develop ways to address the severity of breast cancer within their organization, including 1) opening up communication lines with breast cancer advocacy and survivor groups, 2) designating special proposal requests that target breast cancer research, 3) inviting breast cancer specialists from both the scientific and the lay community to join their review**

panels and take an active part in their research funding deliberations, and 4) establishing a mechanism to ensure that accurate and timely information on breast cancer research can be readily obtained.

While our study has focused specifically on breast cancer, we have also obtained general information on the funding of cancer research in Canada. Figures provided by the NCIC indicate that of the approximately $2.60 spent per Canadian on cancer research, over 60% comes from the NCIC, a non-governmental agency, through the charitable donations of Canadians. The NCIC estimates that the federal government, through the MRC and other various Health and Welfare Canada programs, allocates $10 per Canadian to support biomedical research. Of that $10, at the most $1 per Canadian goes to support cancer research and cancer control. The situation in Canada is in stark contrast to that of the United States, where the federal government funds the National Institutes of Health (NIH) for biomedical research in the amount of $75 per person. The National Cancer Institute, one of the NIH institutes, distributes $8 per person to support cancer research and cancer control activities. The American Cancer Society, which raises approximately $1.50 per person, allocates $0.50 per person to cancer research. Thus, of the $8.50 per person spent on cancer research in the United States, over 90% comes from federal government funds (Submission of the NCIC, 6 April 1992).

We recognize the fundamental differences between the structure and organization of health care and health care spending in the United States and Canada, but we are struck by the fact that the onus for raising cancer research funds in this country falls disproportionately on the shoulders of Canadian citizens. The NCIC urged the Sub-Committee to recommend that the federal government increase the resources they currently allocate to cancer research in this country. We see this recommendation as an important consideration and we encourage the federal government to reassess its current commitment to cancer research.

In addition to federal government funding for cancer research and that of the NCIC, the Committee learned of one organization that raises funds specifically for breast cancer research, the Canadian Breast Cancer Foundation.

CANADIAN BREAST CANCER FOUNDATION (CBCF)

The CBCF was established in 1986 through the volunteer efforts of several Canadian women who wanted to be able to raise money and ensure that it was targetted to breast cancer research. The headquarters are located in Toronto and although only one other province in Canada has recently established a branch of the CBCF, it is a national non-profit organization that receives funding from corporations and is actively involved in a number of efforts aimed at raising dollars for breast cancer research and education. According to Bette Johnson, national expansion is a top priority on the CBCF's 1992 agenda (2:19).

The Committee was impressed by the creativity and ingenuity of the CBCF members. In their fund raising efforts they have joined forces with a number of corporations and are working in partnerships through the promotion of certain products to generate funds for research and education. A number of their current projects should raise over $1 million for breast cancer in 1992 and past efforts have seen approximately $500,000 distributed to various researchers across the country.

Research on breast disease and breast cancer is also being carried out at a private research company located in Kentville, Nova Scotia and at a private oncology clinic in Toronto. Witnesses from both of these locations provided the Committee with some interesting new directions in cancer research.

THE PHARMACEUTICAL MANUFACTURERS ASSOCIATION OF CANADA (PMAC)

The PMAC is an umbrella association which represents the interests of 64 member companies operating in the research-based sector of Canada's pharmaceutical industry. The PMAC is currently involved in an extensive "public education" effort aimed at informing Canadians of the research and development work they are undertaking. Given this effort, the Sub-Committee was interested to learn how much of their research efforts were directly targetted at breast cancer. Like other funding and research bodies, the PMAC was unable to provide us with these figures. They did, however, make a commitment to survey their member companies and attempt to come up with these figures. The Sub-Committee looks forward to receiving this information.

We did learn that the industry is indeed involved in a variety of research endeavours. A recent survey indicated that between 1986-87 and 1989-90, private industry funding of research and development (biomedical research) at medical faculties had more than tripled (17:4). The three-year average growth rate of private industry funding to medical faculties was 38.3 % compared to the average of 9% for all other sources combined (such as the Medical Research Council, provincial sources, and voluntary non-profit sources such as the National Cancer Institute of Canada).

According to the PMAC, their commitment to basic research showed the largest gain over the 1989-91 period, moving from $53.5 million to $70.1 million, accounting for 26.3% of their total research and development expenditures (Third Annual Report, Patented Medicine Prices Review Board, 1990).

It is important to bear in mind that these research figures cover all forms of biomedical research including but not specific to cancer research. Given the scope of their research and given the fact that the PMAC represents 64 companies, the Sub-Committee feels it is important that the PMAC be able to track the number of research dollars that are directed to specific drugs and diseases. Therefore, the Sub-Committee recommends:

12. That the PMAC establish mechanisms for tracking the amount of research dollars that are allocated to breast cancer and other diseases and that these figures be made readily and widely available to the general public.

Keeping in mind that research funds spent on other forms of cancer are relevant to breast cancer, but also in an effort to accomplish our goal of identifying the number of research dollars that are spent *directly* on breast cancer, we estimate that among the NCIC, MRC, NHRDP and the Canadian Breast Cancer Foundation, approximately $3.1 million can be identified as money *targetted specifically to breast cancer research*. Because the PMAC was not able to provide similar information, this figure excludes any money spent by them on breast cancer research. We feel that in light of these figures, our recommendation to establish the Canadian Breast Cancer Challenge Fund (Recommendation 8) will make an important contribution to the future of breast cancer research.

HOW RESEARCH DOLLARS ARE ALLOCATED – PEER REVIEW

As the Committee learned from Dr. Beatty and from the directors of other funding agencies, cancer research in Canada is basically a "researcher-driven" system:

> The basic process (of allocating funds) involves an investigator action and an institute response. The investigator submits a request for funds to undertake a specific research project; the institute asks experts in the area of the specific research project to review the request and decide upon the merit of the request. There are (at the NCIC) four basic steps in the peer review process: application, peer review, advisory committee review and board of directors decision. (11:6)

The direction of research efforts or the overall policy decisions about the research process at the NCIC are, to some extent, incorporated into the various different peer review panels. In addition to the ten panels, there are two additional panels, one of which is focused on selecting the best personnel for biomedical cancer research and control, and the other is a newly created panel on behavioural research. However, according to the testimony the Sub-Committee heard from various agencies, the nature and direction of cancer research in this country is determined, for the most part, by the nature and direction of applications received at research facilities. Final funding decisions are made based on "peer review."

PEER REVIEW PROCESS

Almost as important as the amount of money that is spent on breast cancer research in this country, is the manner in which research bodies, including government, determine the allocation of research funding. These decisions are made, by and large, on the basis of a process known as "peer review." Applicants submit research proposals; these are then anonymously reviewed by an applicant's peers (other physicians, scientists, researchers in the field, etc.); applications receive scores, and those with the highest scores are then reviewed by various panels or committees within research organizations where final decisions are made.

The Committee has asked itself, then, in practical terms, what does this mean? We believe the following observations are important:

- Research on cancer in Canada is likely carried out by a relatively small number of researchers, physicians and scientists who review each others work.
- This process may create a type of "closed" circle, where new researchers with innovative proposals may be excluded.
- Few specific directions or policies on cancer research guide the process. Rather, the funding of cancer research depends upon the nature of applications received. If researchers do not perceive that a scientific "problem" can be solved, they may be less likely to even propose research projects. If projects on difficult problems are not even proposed, these problems will never be solved.
- The avenues for input from the general public, often those who raise the research funds, are limited, if they exist at all. Since they are not among the relatively small number of scientists and researchers active in the community, their ability to assess research applications may be judged, by researchers, to be inferior, thereby "justifying" their exclusion.
- The apparent stronghold which the "peer review" process currently has in the research community, is unlikely to be challenged by the community itself because it benefits directly from the current process.

Similar points were raised before the Sub-Committee. When we consider that 20-30 years of intensive research on breast cancer, and cancer in general, has failed to reduce the mortality rate of breast cancer, this may be a signal that changes to the research process are in order. Speaking on this issue, we heard, from Dr. David Horrobin:

> . . .[We should] support as much diversity as possible. . . avoid allowing single groups to collar huge amounts of research funding. . . I would argue that what we must do is hand over substantial control of research funds to lay people. . . lay people do not have a vested interest in the outcome of research, other than in seeing practical results. . . lay people should have a very substantial part in controlling how research money is spent. . . (9:6-7)

As a Sub-Committee, we believe it is outdated, in 1992, to adopt an approach that suggests that only physicians and scientists are equipped and qualified to evaluate the efficacy of research proposals and to make policy decisions on the nature and direction of cancer research. Given our observations and the evidence we heard, the Sub-Committee recommends:

13. **That the federal government take a lead role by initiating within the cancer funding bodies of Health and Welfare Canada, a review to determine the extent to which their current structure and methods of funding cancer research allow for the participation of lay persons. This review should lead to the establishment of a committee to put in place mechanisms for: 1) greater public input; 2) greater lay representation on Boards of Directors and review committees; and 3) avenues for greater public dissemination of cancer research funding decisions and results.**

The Sub-Committee further recommends:

14. **That the NCIC undertake a similar review and establish parallel committees to work in concert with those established at Health and Welfare Canada's cancer funding bodies, the MRC and NHRDP, to create an environment for greater public input.**

Public accountability for cancer research funding decisions is something that funding bodies and institutes ignore at their peril. The formation of lobby and advocacy groups around the issue of breast cancer will, in our opinion, likely create an environment where accountability becomes an increasingly important issue. Research institutes have the opportunity to demonstrate their good will. The Sub-Committee believes they should avail themselves of this opportunity now.

CHAPTER FOUR

Research Directions

The first chapter of this Report indicated that research into the relationship between fat consumption and breast cancer was one area that was under investigation by medical and scientific researchers in Canada. The Sub-Committee learned that there are a number of important research directions currently being pursued. We also learned that there are a number of areas that are drastically under-funded and under-researched. The following discussion provides a sample of some research directions and indicates those areas and priorities that, as the Sub-Committee learned, will need to be pursued with greater vigour if we are to win the battle against breast cancer.

A. Methods of Surgical Treatment

Early surgical treatment for breast cancer generally employed the use of a radical mastectomy. In this procedure the breast, underarm lymph nodes and muscle tissue were removed. This surgery began in the 1900s and was popular until the mid1970s (3:5). The alternative to radical mastectomy is what is known as the lumpectomy, in which the cancerous lesion, some surrounding tissue and usually several lymph nodes are removed.

One of the messages that came across loud and clear to the Sub-Committee was that there is ample evidence to support the position that lumpectomies (sometimes referred to as breast conservation or partial mastectomy) followed by radiation can not only improve the cosmetic outcome of breast surgery, but can be substituted for mastectomy, particularly in early stage breast cancer (4:33). Early work in breast cancer was based on the belief that the disease spread in a local fashion through the lymph nodes and that removal of the breast and lymph nodes would remove the cancer. However, Canadian researchers subsequently found that breast cancer cells were present in the blood of breast cancer patients, and this discovery led surgeons and oncologists to the realization that the method of spread was in fact through the blood. In light of these findings, supported in controlled clinical trials, surgical procedure was altered (4:36).

This message, we believe, is an important one for Canadian women and physicians alike. Medically inappropriate mastectomies continue to be performed in Canada, and although the figures are not readily available, the treatment continues to be the standard treatment for some Canadian surgeons. While we recognize that there may be circumstances where mastectomy will provide the best prognosis for women (i.e. instances where the cancer is located in several spots in the breast) we believe that women across the country deserve to know, and have a right to know, the full range of surgical and treatment options that are available. Therefore, the Sub-Committee recommends:

15. That the federal government work with the provinces to establish communication links with Provincial Colleges of Physicians and Surgeons and encourage them to advise their constituency of a woman's right to full disclosure of medical and surgical treatment options in the case of breast

cancer diagnosis. In addition Provincial Colleges of Physicians and Surgeons should be encouraged to adopt the use of lumpectomies as the surgical treatment of choice for breast cancer patients, unless there are indications otherwise.

B. Genetic Research

Through the testimony, the Sub-Committee quickly learned that much of the promise of cancer research in general, and breast cancer in particular, lies in the vast field of genetic research. The Sub-Committee was told by a former President of the National Cancer Institute of Canada that there have been momentous changes in the way in which cancer is understood. Until the discovery of recombinant DNA in 1978, scientists were only able to examine cancer as it appeared. They were, by and large, unable to look at what actually started the cancer. The 1978 discovery gave scientists the ability to manipulate genetic material, and through this work investigators were able to identify actual cancer genes that predispose cells to become cancerous (4:45).

Subsequent research has now found that there are likely more than 100 cancer genes and that all of us have these genes in our genetic profiles. The cancer genes control important processes in our development, but in the cases of cancer, something in these genes has "gone wrong", causing the abnormal genes to proliferate and form cancerous lesions, or to produce other forms of cancer, such as leukemia.

What scientists working in this field have also discovered, is that cancer does not occur overnight, as it were, or through a single change in a single cell. Cancers tend to grow and develop over a period of time, and this process is evidenced through a series of cellular changes:

> A lot of people thought that what happened [in the development of cancer] was that you got a single change in a single cell and it became a cancer cell. In general that does not happen. Sometimes it may happen, but in general it does not. You have to have a successive series of changes. One change won't produce a cancer cell. You need a second, a third or a fourth change in these cancer genes in order to produce the cancer. . . these hundreds of cancer genes are involved [in] these successive series of changes. (4:7)

Through the use of molecular pathology, scientists are working at identifying these series of changes in cells. If they are able, for example, to identify the first step in a series of cell changes that result in breast cancer, then they will be able to identify populations at higher risk for developing the disease (4:7-8). In light of difficulties that are part of the existing methods of early detection (BSE, professional breast examination and mammography), the Sub-Committee recommends:

16. That cancer research funding bodies within the federal government make the identification of blood and genetic markers of breast cancer a priority research area.

The Sub-Committee was told that much of the research that led to the discovery of the cancer genes was based on research done 20 to 30 years earlier. These earlier scientists were doing what is generally referred to as "basic research" or "basic science", which often addresses issues such as genetic makeup, molecular structure, cell structure, etc. Such research is, ultimately, very important to medical research, including gene therapy on specific diseases such as breast cancer. Basic research may very well produce the information that will help uncover the causes of breast

cancer. As the Sub-Committee was told by many survivors of the disease, identifying risk factors, as important as that may be, does not tell us the cause of breast cancer. This must be the ultimate goal. Therefore, the Sub-Committee recommends:

17. **That specific commitments regarding the targetting of basic research into the causes of breast cancer be established by the Medical Research Council.**

18. **That the federal government work with the provinces to encourage provincial cancer research centres to target greater amounts of their research efforts to basic research into the causes of breast cancer.**

The Sub-Committee recognizes that, given the present structure and organization of cancer research in Canada, the work of the NCIC is by far the most important in the battle against cancer. In light of this, we recommend:

19. **That the NCIC direct greater attention to basic research aimed at identifying the causes of breast cancer and to the development of diagnostic tests that identify early markers of the disease in women.**

C. Prognostic Indicators

Apart from the fact that the causes of breast cancer are unknown, there is also concern regarding the sophistication of tests to determine the likelihood of the cancer recurring, spreading or metasticizing to other parts of the body. The fear of recurrance or metasteses is likely the greatest fear breast cancer patients face. If physicians could determine the likelihood of recurrance or metasteses they would be in a better position to determine the aggressiveness of the treatment required. Therefore, the Sub-Committee recommends:

20. **That cancer research institutes, both governmental and non-governmental, make the identification of prognostic indicators for breast cancer patients a research priority.**

D. Environmental Carcinogens

The Sub-Committee was disappointed to learn that the impact of environmental carcinogens did not appear to be receiving a great deal of attention among breast cancer researchers. Indeed, the major sub-category of environmental research appeared to be geared toward research into the relationship between diet and breast cancer. We would prefer to see the concept of environmental factors more broadly defined, so that it includes such things as the impact of low frequency radiation, and exposure to air, water and food related carcinogens, such as pesticides. We recognize that there is a danger for such research directions to be dismissed as "far-fetched" and "marginal". Therefore the Committee recommends:

21. **That the federal government take the lead role in ensuring that a share of research funds be reserved for research that explores the links between environmental carcinogens and breast cancer.**

E. Hormone Replacement Therapy

It is not uncommon for women who have reached menopause, or for women who are going through menopause, to be prescribed estrogen, or a combination of estrogen and progesterone, as a method of replacing gradual loss in the body's production of estrogen. The Sub-Committee

was told that this treatment, referred to as hormone replacement therapy (HRT), protects women against osteoporosis (a condition resulting from low levels of calcium in the bone), and various forms of heart disease.

However, we also learned that some breast tumours are "estrogen receptive", indicating that they might flourish in an environment where estrogen is present. This fact, along with the recognition that HRT is generally prescribed at a time when, statistically, a woman's chance of contracting breast cancer is increasing, causes us a great deal of concern. We heard evidence of some studies that indicate that the combination of estrogen and progesterone guard against any increased risk of breast cancer as a result of HRT. However, researchers at the U.S. National Cancer Institute told us of conflicting evidence that tends to discount the protective factor of progesterone (15A:8).

What has quickly become apparent to us, and this is supported by the testimony of witnesses, is that very little is known about the long-term effects of HRT on post-menopausal women. As we heard from Dr. Sterns, of Queen's University:

> We also need to know about the effect of the use of estrogens in post-menopausal women on the breast and on breast cancer. With thousands of women being placed on hormone replacement therapy we need to have epidemiologic surveillance. . .The thing that concerns me is that while estrogen may be extremely helpful for the majority of women, there's going to be a sub-group that is very susceptible. In that group we're going to see problems with malignancy developing, but we don't know what that sub-group is . (16:24,27)

The Sub-Committee recommends:

22. **That government and non-government cancer research funding bodies identify the investigation of possible links between HRT and breast cancer as a research priority.**

23. **That Health and Welfare Canada, through the Medical Research Council, conduct a long-term epidemiological study of the risks and benefits of hormone replacement therapy for menopausal and post-menopausal women.**

F. Tamoxifen and the Breast Cancer Prevention Trial

Tamoxifen is a drug that began to be fairly widely used in the treatment of breast cancer some 15 years ago. For the most part, it was used to shrink cancers in some women and, in cases of women with advanced breast cancer, to prevent recurrance and metasteses. Subsequently, the drug began to be used as an "adjuvant" therapy (an additional therapy) in women whose disease did not show signs of spread, in order to provide additional protection. The Sub-Committee also learned of a massive clinical trial now underway in both Canada and the United States.

This trial will attempt to establish the efficacy of tamoxifen in the prevention of breast cancer. The trial will recruit 16,000 women in Canada and the United States who fall within a slightly higher risk category for breast cancer. The study, estimated to cost $68 million, will carry on for five years. Participants will be randomly allocated into two groups; one group will take tamoxifen every day for five years, while the other group will take a placebo. At the conclusion of the study, researchers will assess the extent to which tamoxifen can be seen as contributing to the prevention of breast cancer.

Throughout our hearings we learned that there are also some concerns about the safety of tamoxifen when it is distributed to a population of "well women" who show no signs of breast cancer. The National Women's Health Network, located in Washington, D.C. told the

Sub-Committee that they have grave concerns about the wide-scale use of a toxic anti-cancer drug in a large population of well women. Among their concerns are: 1) that use of the drug among pre-menopausal women gives them a longer life span in which to develop long-term problems, 2) that pre-menopausal women's hormone system is substantially different from that of post-menopausal women and not enough research has been directed to the long-term impact of this drug on either pre- or post-menopausal women, 3) users of tamoxifen have reported endometrial cancers, 4) in animals, liver cancer has developed after lengthy use of the drug, 5) fewer than 4,000 women in the United States have been on tamoxifen for a period of five years (*The Network News*, National Women's Health Network, Fall 1991).

As a Sub-Committee we share the concerns expressed about the wide scale use of an anti-cancer drug in well women. We urge women considering participation in this trial to ensure that they feel they have been given adequate information about the risks entailed in this trial. At the completion of this trial we recommend:

24. That Canadian hospitals participating in the tamoxifen trial make public the results of the trial, including accurate information on the side effects encountered by women who were administered tamoxifen.

G. Gender Parity in Health Research

One of the concerns expressed by witnesses who appeared before our Sub-Committee was the necessity of ensuring that gender is included as a fundamental variable in all health research undertaken in Canada, including the use of clinical trials. The Sub-Committee learned from their counterparts in the United States that the Congressional Caucus on Women's Issues (CCWI) called, in 1989, for a study of the extent to which women have been excluded from research funded by the American National Institutes of Health (NIH). The CCWI found that the NIH had not made a great deal of progress towards including women in clinical trials. Through the efforts of the CCWI, the NIH is now in the process of strengthening its policy requiring the inclusion of women and minorities in clinical trials and health research. We feel that similar efforts must be undertaken in Canada if we are to produce research information that is relevant to women and members of minority groups. Therefore, the Sub-Committee recommends:

25. That cancer research funding bodies within the federal government show leadership by undertaking an audit of the extent to which the research they fund identifies the race and gender of subjects as a fundamental variable in the research process, including the use of clinical drug trials.

26. That results of the audit be made public and form the basis for a comprehensive policy on the inclusion of women and various racial groups in all health and clinical trial research.

The Sub-Committee expects that such an undertaking at the federal level will establish this practice as a necessity in other non-government cancer research institutes, particularly the NCIC.

CHAPTER FIVE

Treatment Issues

As we pointed out earlier in this report, up until the 1970's the standard treatment for breast cancer was a mastectomy. It was not until the mid to late 1980's that surgeons began to adopt the lumpectomy as a viable surgical procedure. We learned that much of the credit for this change in direction goes to a Canadian radiation oncologist, Dr. Vera Peters, who did one of the first case control studies that showed little difference when one compared the outcome of women who had undergone radical mastectomy with women who had undergone lumpectomy plus additional radiation. Subsequent clinical trials confirmed the findings of Dr. Peters, and by the mid 1980s the percentage of surgeons doing lumpectomies had increased rather dramatically (4:35, 37).

However, the Sub-Committee did hear that there continue to be pockets where mastectomies are performed with alarming regularity. A recent study undertaken in Toronto confirms the fact that in the United States, for example, the percentage of mastectomies continues to be high. Dr. Roy Clark found that, in some areas of the United States, up to 75% of women still undergo radical breast surgery. In Canada, he estimates that approximately 20-35% of women with breast cancer undergo mastectomy. With respect to the treatment of breast cancer in patients whose cancer has not spread, the Sub-Committee feels it is important for Canadian women to know that lumpectomy is an appropriate treatment.

ACCURATE INFORMATION

We believe that the general area of treatment of breast cancer raises some important issues for women. One of the recurring themes in our hearings was the desire of women to know as much as possible about the various treatment options, both surgical and medical, that are open to them. We also learned that the field of breast cancer treatment, indeed the whole area of medical treatment in general, is changing so rapidly that greater attention needs to be paid to the issue of access to information. In light of this, the Sub-Committee recommends:

27. That the proposed Centres of Excellence for breast cancer (see Recommendation 10) also be designated as information centres. Using the model of a "clearing house" these centres would provide comprehensive and easily accessible information on the diagnosis and treatment of breast cancer, primarily to patients, their physicians and care givers. The establishment of 1-800 numbers for access to this information should be considered.

The Sub-Committee saw excellent examples of information pamphlets developed by breast cancer survivor groups. While the information we saw was developed to address the needs of women in specific areas, we found the model most comprehensive. Using the information format developed by the Burlington Breast Cancer Support Services Inc., the Sub-Committee recommends:

28. **That the federal government work with the provinces and existing support groups to develop an information package to be distributed to newly-diagnosed breast cancer patients. The package should outline the risks and benefits of all treatment options and provide answers to the most commonly asked questions about breast cancer. This information should take into consideration a range of literacy levels, and it should be sensitive to the cultural, regional and racial differences in the country.**

ACCESS TO RADIATION THERAPY

Given the rise in the number of lumpectomies being routinely performed across the country, more and more women will require timely access to radiation facilities in their local hospitals and cancer centres. The Sub-Committee heard from Dr. Aileen Clarke, Director of the Division of Epidemiology and Statistics at the Ontario Cancer Treatment and Research Foundation, that:

> . . .getting into the hospital [for treatment] is not a problem. What is a definite problem in Ontario is a scarcity of radiation therapy resources. . . . 25% of the patients who are waiting for radiotherapy in the province of Ontario are breast cancer patients. (1:28)

The Sub-Committee also learned that similar problems exist in other provinces, and that access to radiation therapy is a national health issue in this country. Therefore, we recommend:

29. **That the federal government take leadership in this area by working with the provinces to assess the access to, and availability of, radiation therapy for breast cancer patients across the country on an ongoing basis. In situations where extensive delays occur, strategies to deal with these delays should be implemented immediately.**

30. **That special care and attention be taken to monitor the availability of radiation therapists, radiation oncologists and radiologists and when and where necessary, to encourage these professions as career options.**

TREATMENT PROTOCOLS

There was conflicting evidence regarding the need to develop standardized treatment protocols for breast cancer patients. For example, concern was expressed over companion treatment in the case of lumpectomies:

> Not all women with lumpectomy are given the choice of radiation or chemotherapy. Some women who have surgery will automatically go on to having aggressive chemotherapy. I would like to see some standardized protocols for the treatment of breast cancer. (1:26)

Pat Kelly, the founder of the Burlington breast cancer survivor group, also elucidated the frustration women feel with respect to breast cancer treatment procedures. Some women who seek second and third opinions receive conflicting advice:

> Frequently they are told by one oncologist that their approach might be chemotherapy prior to surgery with a subsequent investigation of the need for either adjuvant therapy or radiation. In consulting a surgeon, they will be told immediately, we will do surgery and there may or may not be radiation and there may or may not be chemotherapy. There is no systematic approach to getting standardization of treatment. It is most necessary. (1:41)

On the other hand, the Sub-Committee also heard that there are some important risks in the establishment of treatment protocols:

> The problem [with standardized protocols] is that it gets into value judgements. Someone has to say what that treatment is. You are no longer looking at scientific questions and moving ahead, you are trying to freeze frame something and say what it is. . . The radical mastectomy [for example] was the wrong operation but everybody had a consensus that it was the right operation. It wasn't until we did scientific trials that we came to understand that it was the incorrect operation. (3:5)

In response to the same issues we also heard:

> If we have national standards, a prescription laid down by a legislating body, we would end up with a group of physicians who work by a cookbook method, who abrogate thinking and clinical innovativeness to a prescribed protocol. Nothing could be worse in these times when the scientific information is changing so rapidly. . . (16:36)

As a Sub-Committee, we can appreciate the concerns expressed by both constituencies in the debate on standardized protocols for breast cancer treatment, but we strongly feel that a "middle ground" needs to be established. We would like to be assured, as would all women in this country, that a diagnosis of breast cancer, whether it be in Newfoundland or Manitoba, would receive treatment that is appropriate, up to date, and relevant for the specific diagnosis and for the patient. While we do not recommend the institution of strict national protocols, we feel that the achievement of cross-national standards in treatment of breast cancer is dependent upon on-going cross-national dialogue and information exchange.

In 1988, '89 and '90, Health and Welfare Canada and the Canadian Cancer Society jointly sponsored national forums to collaborate on breast cancer screening. These forums provided for provincial and federal government representation as well as the representation of certain specific non-governmental organizations. The Sub-Committee feels that the convening of a similar event would be beneficial at this time. Therefore we recommend:

31. **That Health and Welfare Canada begin consultations with the Canadian Cancer Society to convene a national workshop on research and treatment issues in breast cancer. Planning and information for the workshop should involve the expertise of representatives from federal and provincial departments of health and leading breast cancer experts working specifically in the fields of treatment, both surgical and medical, and research. The outcome of this workshop should be the publication of "latest findings" in the fields of treatment and research into breast cancer. This publication should be widely available to health care workers and interested members of the public. A similar workshop should be held every two years.**

ACCESS TO DRUGS AND THE DRUG APPROVAL PROCESS

We did hear of one case where a breast cancer patient had difficulty in accessing certain cancer treatment. As Sylvia Morrison told us:

> . . .conventional low-dose chemotherapy would have very poor prognosis due to the size and the very aggressive nature of the tumour. This was all I could be offered at the regional cancer centre. . . I was well advised to seek a second opinion, preferably in the United States, where bone marrow transplantation was being used as a treatment for advanced breast cancer. (1:45)

As the Sub-Committee learned, this woman was lucky to have two of her children in medical school; one of them was affiliated with the Sloan-Kettering Cancer Institute in New York City and this served to hasten her access to treatment. We recognize that this is not the case for all women and that access to "cutting edge" treatment options and drugs can be very uneven across the country. As we came to understand, there are some significant problems in the structure and organization of current methods for reviewing and approving drugs in Canada.

In our discussions with the Pharmaceutical Manufacturers Association of Canada (PMAC), we learned that the length of time for drug approval in Canada has continued to increase. In 1986, an average of 702 days was required for the approval process. In 1991, this time period had expanded to 1,163 days (17:18). The Sub-Committee also heard from a representative of the Canadian Society for Clinical Investigation (SCI), a national body representing Canadian physician researchers. This organization expressed a number of concerns regarding the process for drug approval.

Among their concerns were: lengthy approval times, the continued "backlog" of drugs awaiting review, the lack of a use of outside reviewers at the Bureau of Human Prescription Drugs within the Health Protection Branch at Health and Welfare Canada, and a weak system of surveillance of drugs once they have been on the market for a period of time (17:18).

In light of these concerns and in the interest of producing maximum efficiency without sacrificing safety, the Sub-Committee recommends:

32. **That the federal government explore the establishment of an "arm's length" agency, accountable to a Board of Directors and reporting to the Minister of Health and Welfare, to undertake the review and approval of drugs, medical devices and biomedical products, and to explore its operation on a cost-recovery basis where possible and desirable. The specific composition of the Board of Directors should be developed in consultation with Health and Welfare Canada and include a balance of scientists, researchers, industry and consumer groups.**

33. **That the federal government give careful consideration to the development of mechanisms to work toward international harmonization in the review and approval of new drugs, biomedical products and medical devices.**

POST-OPERATIVE CARE

The Sub-Committee learned that many women have no access to any substantial post-operative or pre-operative consultation and care for the treatment of breast cancer. A number of long term complications can arise from the type and methods of surgery used in the treatment of breast cancer. These include; lymphedema (swelling of the arm due to the loss of lymph nodes in surgery), nerve pain and damage due to the unnatural position of the body during surgery, tissue damage during radiation and delayed healing of the surgical wound. These complications can make it painful and practically impossible for women to carry out even the most routine activities after surgery.

Some breast cancer patients are provided with exercises to do in order to help restore muscle strength and mobility. However, according to Cynthia Webster, a physiotherapist who treats breast cancer patients, greater care and increased access to appropriate pre-and post-operative

treatments would greatly enhance women's recovery time and their quality of life (14:8). The Sub-Committee believes that greater attention should be paid to a range of physiotherapy techniques and modes of treatment. Therefore we recommend:

34. That the federal government work with the provinces to encourage cancer clinics located across the country to assess their current modes of pre- and post-operative treatment for breast cancer patients and that, where necessary, they upgrade their treatment to take into account: 1) the availability of physiotherapy treatment and 2) access to the various technologies in the treatment of breast cancer.

The Sub-Committee was disturbed to learn that power struggles between various health care practitioners may help to account for the lack of cooperation between physicians and physiotherapists. Speaking of the situation in British Columbia, Cynthia Webster stated that:

> I feel there is a political pull. . . physiotherapists in the province of B.C. are now licensed to be primary care givers (which means) we do not need a physician's referral. So what happens is that they (physicians) say, fine, you don't need us, then we won't refer (patients) to you. (14:13-14)

Therefore, the Sub-Committee recommends:

35. That professional organizations representing health care practitioners identify methods to foster greater cooperation between various sectors of the health care professions and that they work with medical schools to include information on physiotherapeutic techniques as appropriate treatment methods for breast cancer patients in their curriculum.

36. That the proposed national workshop on breast cancer include information on the various methods and advantages of post-operative physiotherapy treatment for breast cancer patients, including consideration that the number of lymph nodes removed in breast cancer surgery be determined on the basis of medical necessity, and that the use of horizontal rather than vertical incisions be considered.

COMPASSIONATE ASSESSMENT OF CANCER TREATMENT EXPENSE CLAIMS

The Sub-Committee learned that, in some situations, treatment for breast cancer has been pursued outside of the country, specifically in the United States. We would like to think that these situations are rare, and indeed the vast majority of breast cancer survivors who appeared before us have been treated in Canada. However, there are situations where other avenues may need to be pursued, and we strongly feel that greater flexibility may be required. We would urge provincial medical plans to be less rigid in the assessment of such claims. In extreme circumstances, patients may need to receive treatment as quickly as possible. Such situations may preclude their applying for coverage for out-of-country procedures prior to receiving the treatment. We would hope that reimbursement for such patients would be forthcoming without punitive consequences. Therefore, we recommend:

37. That the federal Minister of Health and Welfare encourage provincial and territorial counterparts to review their policy and work toward a compassionate assessment of cancer treatment expense claims, providing such treatment meets the standards of Canadian medical care and is of medical value.

CHAPTER SIX

Support, Advocacy and Activism

If the Sub-Committee learned one thing from the hours of difficult and emotional testimony of breast cancer survivors, it was that women are taking, as indeed they must, an active role in their own medical treatment. Where some women may have once passively accepted the advice of their physicians, a new group of women is emerging. These women want, indeed they demand answers to difficult questions. And, make no mistake, these women are well informed about the disease and they intend to stay so. Their input into the Sub-Committee's hearings provided perhaps some of the most valuable and profound testimony many of us have ever heard. As a Sub-Committee we would like to tell them that we are awed by their courage, inspired by their strength and motivated by their social and political involvement. Apart from the many useful and specific recommendations they made, they emphasized the importance of support, advocacy and activism.

SUPPORT

The diagnosis of breast cancer, in fact of any cancer, has been identified by many witnesses as a "turning point" in their lives. Often patients are expected to make major decisions about their treatment and care in short periods of time. This fact places the women under additional stress and complicates the situation they are already facing. As Paula McPherson, a breast cancer survivor, told the Committee:

> I was stunned to learn that I was the one who would make the final choice about what chemotherapy drugs I was to be given. Here I was trying to absorb a lot of very complicated medical information and to make decisions at a time when I was intellectually and emotionally incapable of making those decisions. (11:19)

Such experiences point to the importance of women having a friend or partner with them throughout the course of their interaction with the medical system and to the importance of being well informed. While the nature of the support required may differ over the course of their treatment, all women require access to information and support.

The Committee learned of an experimental program for cancer patients that is now in clinical trials in Winnipeg:

> We have a nursing intervention where we meet for about 20 minutes with newly diagnosed, newly referred patients before they're seen by the physician. . . we explain that we're nurses working in collaboration with a physician and that we will be following them along through their care. . . Then we help them clarify a question list for the physician, and we actually write down the questions with the woman. (7:42)

Similar programs, using "nurse counsellors" are also in place in Britain. These counsellors are senior oncology nurses who are also trained as counsellors. Their role is to provide information on an ongoing basis, to explain procedures, and to assist the patient in making informed decisions and asking the questions they have regarding their care.

Therefore, the Sub-Committee recommends:

38. **That the federal government work with the provinces to assess the quality of support services for breast cancer patients at established breast screening clinics and cancer clinics and, where these services are found to be inadequate, that existing and appropriate staff be designated as "nurse counsellors" and be given the necessary training to act in that capacity. In the course of their assessment, and throughout the development of training programs, medical clinics should ensure that representatives from existing breast cancer support and advocacy groups be actively involved.**

PSYCHO-SOCIAL ASPECTS OF CANCER

For quite some time social scientists, health care providers and patients have been interested in the relationship between the mind and the body as it relates to both wellness and illness. While this area of investigation is likely underdeveloped, it is receiving increasing attention. As the Sub-Committee heard from Dr. Alastair Cunningham, who is looking into this relationship:

> . . .cancer is often viewed as a purely biological problem with biological causes, so it's treated by biological and materialistic means – surgery, radiotherapy and chemotherapy. Of course these are very useful means, but that is all that is countenanced. I think this view of cancer is a misconception. Cancer has much to do with the mind or the mental emotional state of a person. . . and it needs to be responded to accordingly. I think we need to take the emotional aspects, the emotional pain of cancer and of a lot of other diseases, seriously in a way we really don't do now because our health care system, by and large, doesn't treat it. (3:25, 28)

The importance of support, particularly in the context of organized support groups for breast cancer patients, has been explored in an American study. This study showed that women with metastatic cancer, who participated in a support group once a week for a year, lived 18 months longer – twice as long – than women who were not in a support group. While this study has not been replicated in Canada, there is an effort underway to obtain research funds to do so (3:30).

The Sub-Committee was encouraged to hear that in the bodies where decisions are made on the allocation of research funds, specifically the NCIC, more attention is now being paid to the psychosocial dimensions of cancer. In a National Needs Study funded by the CCS, investigators found that women with breast cancer were among the most frequent users of public meetings, community groups and hospital groups. However, the Study also found that breast cancer patients want access to more services to help them understand their disease and its treatment than they have been able to get. According to Dr. Mary Vachon, the principal investigator on the National Needs Study, breast cancer patients have no intention of settling for less than they want, indeed for less than they deserve (7:31).

Based on the testimony of both survivors and researchers working in this area we feel there are major gaps which need to be addressed. Therefore, the Sub-Committee recommends:

39. **That the federal government, in cooperation with the provinces, encourage medical schools to pay greater attention to the psycho-social dimension of cancer and other diseases in their curriculum.**

40. **That the federal government take a lead role in encouraging the provincial cancer clinics across the country to investigate ways in which the delivery of cancer care could be made more caring, humane and sensitive to the**

emotional and psychological dimension of the disease, including such fundamental things as: 1) ensuring that cancer patients are able to see the same physician during their visits to the cancer centres; 2) that their families have access to information and support, and 3) that details of existing support groups in the area be readily available to all patients. In the course of their investigations, cancer clinics should avail themselves of the experience and expertise of current and former cancer patients and of the Canadian Cancer Society, and include them in their review process. Clinics should build in an evaluation component to facilitate patient input.

The provision of both information and support services must be sensitive to the divergence of the breast cancer population. Such services must take into account the literacy level, specific language requirements and cultural background of its users (7:28-30).

In light of the striking evidence that support groups can extend and enhance the quality of life for breast cancer patients, the Sub-Committee urges physicians to apprise themselves of, and be receptive to, information on existing support groups in their area, such as those sponsored by breast cancer survivor groups and the Canadian Cancer Society. This information should be readily available in physicians' offices, medical clinics and existing breast cancer screening clinics.

Further, the Sub-Committee recommends:

41. **That Health and Welfare Canada allocate money from the Health Promotion Branch to fund programs aimed at training potential breast cancer survivor group facilitators in group dynamics and counselling.**

42. **That Health and Welfare Canada assist interested breast cancer survivor groups to develop a framework and an "information kit" to facilitate the establishment of new support groups. Such a "kit" could contain "do's and don'ts", camera ready advertisements for use in local newspapers and magazines, copy for local television advertisements and flyers etc. Once developed, this "kit" should be made readily available to cancer clinics, existing breast cancer screening clinics, and community health centres in order to encourage the establishment of survivor-directed breast cancer support groups across the country.**

ADVOCACY AND ACTIVISM

There is often a tendency to equate activism and advocacy with large scale "disruptive" behaviour. The Sub-Committee received an overwhelming message from the breast cancer survivors and activists who appeared before us that this is not their intention. Rather, their goal is to raise the profile of breast cancer as a major national health issue, to support appropriate research on breast cancer, to encourage an increase in research funding, particularly with respect to research into the causes of breast cancer, to ensure that women and their families have access to up-to-date information on the disease, and to offer emotional support to women who are living and dying with the disease.

As a Sub-Committee we are supportive of the actions of the survivor groups from whom we have heard. We predict that the formation of similar groups across Canada will make important contributions to the direction of breast cancer research and treatment, to the quality of life for breast

cancer patients and to the level of public knowledge of this disease. While it is likely that there are a number of similar groups operating across the country already, there is no existing mechanism for such groups to communicate effectively. Therefore we recommend:

43. That Health and Welfare Canada, in cooperation with other relevant departments, work with the provinces to provide for the formation of a national network of breast cancer survivor groups. The platform for such a formation should be a national conference of breast cancer patients, survivors, their partners, friends and families and interested persons, planned and coordinated by survivors of breast cancer. This conference should take place not later than June 1993.

CHAPTER SEVEN

Breast Implants and Reconstructive Surgery

Although our original Terms of Reference for this study indicated that the Sub-Committee would examine breast cancer and the MEME implant, as events unfolded around the issue of silicone implants our study expanded to include these concerns. Given the complexity of the topic, we recognize that it likely deserves even greater attention than we have been able to devote to it in the course of our examination of breast cancer. Nonetheless, we do feel compelled to address the issue and make several recommendations that we believe to be important.

BACKGROUND

By now, there are likely few Canadians who are not familiar with the controversy surrounding breast implants. Initial concern over these devices was focused, almost entirely, on the MEME implant. It was not long, however, until the debate widened to include all breast implants containing silicone gel. The MEME implant, which was withdrawn from the world market by its manufacturer (Surgitek a division of Bristol Myers) on April 18, 1991, was distinguished from other implants by its particular construction. Like other breast implants, the MEME was composed of silicone gel. However, in the construction of the MEME, this gel was enclosed in a sleeve made of polyurethane foam. Most of the controversy and concern over the MEME implant was focused on this sleeve.

A certain amount of Canadian and American research had determined that the chemical 2-4 toulene diamine, (TDA), was produced when the polyurethane sleeve broke down. This chemical had been found to produce liver cancer in laboratory rats. Dr. Robert Guidon of Laval University had further claimed that relatively mild laboratory conditions could produce a decomposition of the polyurethane foam. In the event that this happens, there is additional concern over the contents of the silicone, which could potentially leak into the breast tissue. Although the Sub-Committee heard that Health and Welfare Canada has been unable to corroborate this claim, we learned from Dr. Pierre Blais, who has examined many implants that have been removed, that the contents are:

> . . .a mixture of oil of the same type that was injected in breasts in the 1950's and 1960's. . . when we take those [the contents] apart, we never recover fewer than five or six different compounds, and, in several cases, we've recovered as many as 60 to 70 chemical entities in there, some of which we cannot even identify. (12:12-13)

In responding to the allegation that more than 60 or 70 chemical compounds could be present, Dr. E.G. Létourneau, the Director of the Bureau of Radiation and Medical Devices, stated that:

> . . .we could not find any evidence there was anything else but silicone in the breast implants that went through our system and were sold in Canada. The chemists tell me that it is essentially silicone. . . I consulted with our materials expert [on this question]. The submissions that we've received and the tests that we've seen do not support the claim that there is anything else but silicone gel in [the implants]. (13:14)

After the MEME was removed from the market, Health and Welfare Canada issued a warning to physicians not to use the implant. However, the Sub-Committee did learn of one case where a Quebec woman received the MEME implant after the voluntary moratorium. This case is now the subject of legal action (9:44).

In Canada, apart from the controversy over the actual composition of the MEME implant, an enormous amount of attention was focused on the manner in which Health and Welfare Canada (HWC) had handled the contentions that the implant was unsafe and that it should be removed from the market. Allegations that the department ignored the early warnings of Dr. Blais, then employed by the Bureau of Radiation and Medical Devices within HWC, have raised concerns regarding the very structure and organization of monitoring drugs and medical devices in Canada. An internal review of the relevant regulatory and administrative issues was conducted by the Department of Health and Welfare in October of 1991.

The focus of this internal review responded to the charge that the MEME should have been subject to "pre-market" submission of evidence from the manufacturer in order to establish its safety and effectiveness before it was made available for use by plastic surgeons. The contention is that this route might have helped to avoid the widespread use of the MEME. However, HWC determined that the MEME was not subject to such a condition, because it had been on the market prior to the timing of an amendment that added breast implants to the list of devices subject to a "pre-market" submissions. Breast implants that were sold, or offered for sale, for the first time on or after October 8, 1982, or those that underwent a change in character, would be subject to the pre-market review. All others would be exempt from the requirement. Because the MEME was available to physicians before the amendment came into force, the pre-market submissions surrounding its safety and effectiveness were not required.

Following the publication of the Internal Review by the Department of Health and Welfare in late October 1991, the Minister of Health and Welfare commissioned an external audit to review, assess and report upon the extent to which the Health Protection Branch:

1) administered the Food and Drugs Act and its Regulations in regard to the MEME implant; and

2) followed established Branch administrative and regulatory processes and procedures for medical devices in regard to the MEME implant.

The audit of the internal review, undertaken by an independent research firm, is not yet available. As a Sub-Committee, we anticipate this report and intend to review it when it becomes available.

SILICONE IMPLANTS

In the wake of the MEME implant controversy, attention also began to be directed at all breast implants containing silicone gel. Scientists and researchers working in both independent laboratories and within Dow Corning, one of the largest manufacturers of silicone implants, had expressed concerns regarding the possibility of "gel bleed", a condition where the gel escapes from the implant and travels throughout the system, or becomes locally concentrated in the breast tissue. Some allegations regarding the link between silicone gel bleed and auto-immune diseases (such as lupus or scleroderma) or immune problems in general, have been made.

A situation that outraged the public, and brought action by the Food and Drug Administration (FDA) in the United States, and subsequently in Canada, was the revelation that Dow Corning, a key manufacturer, had known of a variety of safety problems with silicone gel filled implants for a

number of years. Documents released by Dow Corning to the American Food and Drug Administration (FDA) indicated that the company was aware of silicone gel leakage for at least 30 years. Internal documents contained doubts and questions about the safety and reliability of the silicone implants.

When the Sub-Committee travelled to Washington D.C. in early March 1992, we learned that former employees of Dow Corning are now coming forward with information that the industry was aware of a range of health risks with silicone implants, including studies which linked the implants with cancer and other diseases in laboratory animals. Companies were able to withhold such information for years based on their claim that studies contained "proprietary" information such as trade secrets on the composition of the implants. Dow Corning has now ceased production of silicone implants.

On February 20, 1992, an American Expert Panel recommended that the U.S. government place certain restrictions on the use of silicone implants. Basically, these recommendations indicated that implants used for augmentation should only be used under research situations where patients had informed consent. Theoretically, this means that the number of implants for augmentation would be restricted to the number required to conduct methodologically sound studies at accredited university hospitals. The Panel had less strict requirements for breast cancer patients. However, the need for silicone implants in these patients would have to be medically determined and their use would be restricted to locations that monitored and followed these patients over a period of time (15A:15).

On April 20, the FDA supported the recommendations of the Expert Panel and upheld the use of implants in the limited circumstances discussed above. In Canada, an independent advisory committee headed by Dr. Cornelia Baines, made a similar recommendation to the Minister of Health and Welfare. In their report, the advisory body recommended the use of silicone implants in women over 40 years of age and in women who required reconstructive surgery. However, the Minister decided that such a recommendation tended to discriminate among women and might be subject to challenges under the *Charter of Rights*. Consequently, the moratorium on silicone implants was extended for an additional six months.

During the six-month extension of the moratorium, the federal Laboratory Centre for Disease Control will conduct additional studies on the implants focusing on their possible health risks. The advisory committee made additional recommendations, including: the establishment of a 1-800 number for information on implants, the development of a national implant registry, additional medical education for physicians and workshops to develop guidelines for implant surgery as well as for improved methods of screening for any health problems linked to the implants. The toll free number has been established. The decision to extend the moratorium will be reviewed in early fall of 1992.

ISSUES RAISED IN OUR STUDY

Access to Accurate Information

As a Sub-Committee we feel the issue of access to safe implants is of utmost importance to women who either require or request implants. Given the questions surrounding such devices, we insist that women have a fundamental right to accurate information regarding the risks and

possible complications associated with the use of implants. During our hearings we received testimony from women who provided us with the most painful of details regarding their experiences with implants:

> Not more than four days after I had the implants the secretions, the swelling, the deforming of my face, the deforming of my breast. . . I couldn't believe this was me. . . I woke up one morning with the prosthesis up against my throat. It took me eight hours to bring it down with heating pads and whatever else we could do. The pain was excruciating. Three days later, it was under my arm when I woke up. There was nothing in my breast tissue. (9:34, 36)

From another woman speaking about her experiences we learned:

> "These implants [the MEME], in less than three weeks, eroded through my skin, causing unresolved infection, tissue death and leaving big holes. The infection continued to run rampant even after I had had the implants removed. . . I lived almost one month in and out of one type of intravenous or antibiotic. . . I had nine operations and five lengthy hospitalizations for chronic infections, resulting in approximately 180 days spent in one hospital or another. (6:5-6)

In our discussion with both of these women, who are founding members of an organization called Je Sais/I Know, a network of women who are concerned about breast implants, we learned that many of their members did not have access to information on the risks and possible complications. Manufacturers of implants provide information sheets with the devices, which list the range of problems that may occur. One witness, who was able to supply samples of these documents, told us:

> When I went to see the plastic surgeon who had implanted these products in me, I had no idea what I had. I had absolutely no idea about the product and what it was made out of. He showed me no documents, no product, nothing. (9:34)

The other witness told us:

> . . .the doctor did not even tell me that he was going to use MEME implants. I never questioned him because, first, I trusted him and believed that no doctor would use anything before it had been proven safe. . . (6:6)

As a Sub-Committee we would like to emphasize that women should be adequately informed of all the complications, risk factors and possible side effects that are associated with this, and other medical procedures. In the course of our study, we heard from Dr. Raouf Ismail, a Quebec plastic surgeon, who spoke as a representative of the National Capital Society of Plastic Surgeons. He provided us with a sample pamphlet, which is given to patients who make inquiries about breast implant surgery. This pamphlet gives unequivocal answers to the following questions:

1. Is there an increased danger of breast cancer after implantation of a breast prosthesis? Answer: NO

2. Can you examine your breasts yourself after having undergone the operation? Answer: YES

3. Can you still have mammograms? Answer: YES

4. Can you breast-feed? Answer: YES

In light of the uncertainty surrounding these questions we judge this pamphlet to be, in the current context, misleading. For example, the pamphlet does not inform women that mammography after a breast implant needs to be done by a radiologist who is experienced in the exact views required to detect abnormal lesions. As we heard:

> We advise all patients who have silicone prosthesis to mention this to their radiologists and make sure they have the special views recommended; otherwise, the prosthesis can hide cancer for a period of time. We don't want to hide it for any period of time. (16:11)

With respect to complications, the pamphlet indicates the possibility of hardening of the breasts due to the formation of scar tissue. However, the document continues to indicate that the use of external pressure to relieve this hardening may be indicated. This information is at odds with the recommendations made by the Expert Panel in the United States and by companies that manufactured the implants, who now advise against this treatment due to the possibility of implant rupture and extensive silicone bleed. The Sub-Committee was also told that one plastic surgeon who conducted a study on the safety of the MEME implant and who had used the implant in surgical procedures would not, herself, have an implant, due to the fact that she was of childbearing age and she might want to breast feed. Providing simplistic answers to complex questions is, in our view, not adequate.

In light of these issues and in view of the current controversy that continues to exist around implants the Sub-Committee recommends:

44. That the Canadian Society of Plastic Surgeons and the Canadian Society for Aesthetic (Cosmetic) Plastic Surgery withdraw the booklet entitled "Aesthetic Surgery Breast Augmentation" and immediately discontinue its distribution to patients considering breast augmentation.

45. That the Canadian Society of Plastic Surgeons and the Canadian Society for Aesthetic Surgery prepare new information sheets in coordination with Health and Welfare Canada that accurately reflect current knowledge and debate about the risks, complications and possible long-term effects of breast implants, including the debate around the possible effects to *in utero* fetuses and nursing infants, from migrating silicone gel bleed.

ALTERNATIVES TO BREAST IMPLANTS

The Committee discovered that there is, in addition to breast implants, a range of surgical procedures that may be used in the case of mastectomy for breast cancer. These procedures may also be used for the purposes of augmentation. We were concerned to understand the context for the use of this range of surgical procedures. In other words, we wanted to understand the advisability of surgical breast reconstruction for mastectomy patients and to determine the extent to which women are informed of any risks or complications that might be attached to these options, especially if they are undertaken as a result of mastectomy.

We learned that there are several techniques employed by plastic surgeons. One procedure involves the use of the local tissues that can be rotated upwards to reconstruct the breast. One of these procedures involves extensive use of tissue that is pulled up internally from the abdomen and used to form a new breast. Another operation involves the use of the dorsal muscle (located in the back and sometimes referred to as the "hugging" muscle), which is rotated toward the chest and,

together with additional tissue, is used in reconstruction (16:7). These procedures are extremely complex and require lengthy surgery and, as the Sub-Committee learned, there are certain patients who are poor candidates for these procedures.

We were advised that women should be made completely aware of the risks entailed in these procedures and that the decision to undergo them should, ideally, be made apart from any surgery whose primary goal is to deal with breast cancer. In other words, women should not, according to Dr. Sterns, be expected to make decisions about reconstructive surgery at the time they are making decisions about cancer:

> I believe reconstruction should be done at a time other than the time that the primary tumour is treated. It's too complex an emotional environment for the patient to sit down and look at all the problems rationally. . . its overwhelming. (16:31)

At the same time we were informed that there are some risks entailed in cases where reconstructive surgery is undertaken for patients who have had cancer surgery:

> Because cancers requiring mastectomy are often more advanced or aggressive, recurrence of disease at the mastectomy site and elsewhere is possible. Undertaking reconstruction can jeopardize early discovery of such local recurrence. . . Post-operative scarring and nodularity complicates surveillance for new cancers. (16:32)

Given these findings, we recommend:

46. That the federal government work with the provinces to encourage provincial Colleges of Physicians and Surgeons to ensure that information about post-cancer reconstructive breast surgery accurately inform women of the possibility of delayed detection of recurring cancer.

47. That such reconstructive surgery be undertaken at a time other than the surgery for the treatment of the primary breast tumour.

The Sub-Committee recognizes that the use of breast implants and reconstructive surgery poses a very real dilemma for breast cancer patients. We are sensitive to the fact that many women will want to undergo reconstructive surgery or have breast implants, and that such undertakings may indeed be important for their emotional recovery from breast cancer. However, we feel that evidence suggests that such procedures must be undertaken with extreme caution, and that there are likely some women for whom these procedures are not indicated. Therefore, the Sub-Committee recommends:

48. That the federal government work with the provincial and territorial regulatory bodies of physicians, plastic surgeons and oncologists to outline the conditions under which reconstructive surgery and the use of implants should be subject to extreme scrutiny. These may include: 1) women whose breast cancer has a high likelihood of recurrence, 2) women whose breast cancer is newly-treated and 3) women with pre-existing conditions that might exacerbate the possibility of complications such as diabetes and auto-immune diseases. These women should be encouraged to evaluate the possible risks and complications of implants and reconstructive surgery very carefully, in consultation with their physicians, oncologists and plastic surgeons.

The Sub-Committee believes that there are clearly some cases where the use of breast implants and the practice of surgical reconstruction are inappropriate, and we feel strongly that women should be fully apprised of this fact. In certain instances, as the evidence suggests, these procedures should be denied.

NATIONAL REGISTRY

The Sub-Committee recognizes that certain facts compound existing questions related to breast implants, in particular, and medical devices more generally. One of these problems is that adequate mechanisms are not in place to monitor the complications and long-term effects of implanted devices. Consequently, there is no way to estimate the number of breast implants that are in use at the present time, the possible range of problems, or the levels of satisfaction associated with these devices.

We see the lack of such a registry as a major inadequacy in our current medical system. In the absence of such a mechanism, physicians and surgeons can easily lose track of the persons who have breast or other implants. This possibility complicates their ability to pass on new or emerging information on possible problems with implants to patients, and it closes off the opportunity to track patients over a long period of time in order to produce longitudinal data bases for methodologically sound research.

From the consumer's perspective, such a registry would provide an opportunity to report problems or complications with implants and to make inquires with respect to complication rates of implants or other substantial medical devices, in order to make informed decisions about medical treatment. We cannot help but be struck by the fact that consumers can register complaints about business transactions, automobiles and services, and yet there is no counterpart for such things as breast implants, heart valves, hip joints, pace-makers, etc.

Therefore, the Sub-Committee recommends:

49. That the federal government begin consultations with the provinces and territories to establish the parameters for a national registry of drugs, medical devices (implanted in the body for more than one year) and various forms of biotechnologies. Physicians and surgeons, manufacturers or distributors should be required to register the medical procedure, the use of a particular biotechnology, the patient, the date and details of the procedure. Patients should be advised of the existence of this registry and they should be able to notify the registry of any problems, complications or ill-effects they encounter. This information would then be fed to a central registry, housed perhaps within Statistics Canada.

REVIEW OF MEDICAL DEVICES

One of the issues that the controversy over implants has raised for this Sub-Committee, and for the general public, is the fact that the current structure and organization for governing and monitoring the sale of medical devices in this country is based on the notion of "voluntary compliance" on the part of manufacturers. Ultimately, responsibility for the safety and efficacy of medical devices rests on the assurances that manufacturers provide to HWC. In the present system, there are no labs within HWC undertaking tests on new devices in order to ensure their safety, nor does HWC have the capacity to conduct pathologic tests on explanted implants, at this time. The role for HWC, within this framework, is largely an auditing role to ensure that where required, pre-market testing and studies have been carried out by the manufacturer. As a Sub-Committee, we must ask how adequately such policy serves the interests of Canadian women.

As we have indicated earlier in this Report, the Sub-Committee learned that there are some significant concerns regarding the approval process for drugs in Canada. Similar concerns exist for medical devices. In March 1991, Health and Welfare Canada established a committee to review the entire process by which medical devices are regulated, and we see this as a very positive step. We anticipate the report of the Medical Devices Review Committee, and we hope that their findings will support our call for a restructuring of the process of approving drugs and medical devices.

CONCLUSIONS

The title of this report, *Unanswered Questions*, we feel, epitomizes the situation surrounding breast cancer. And while we know that the answers to questions about this disease will eventually be found, we feel that this can only be accomplished with the requisite amount of money for research and a commitment to address the profound devastation caused by breast cancer. In our deliberations, we heard that although breast cancer is a disease that strikes women, we must begin to see it as a disease affecting families, communities and indeed the country. We heard very compelling and moving testimony from Barry Toghill, who lost his 45-year old wife to breast cancer:

> I believe the cancer treatment treats the disease but not the patient. It comes across as a not-caring system, right to the last day of life, and I saw this firsthand. Cancer is a traumatic, mental, physical and emotional problem for the patient and her family. . . there is a need for the family to be involved. When the wife dies – and as we know, many do – it's the husband who has to pick up these pieces. The men have to be helped here, and the men have to help as well. . .Their wife's problem is their problem as well as the problem of their children. (14:26)

We feel that breast cancer needs to be understood as a social problem of near epidemic proportion. We believe this kind of understanding, this type of analysis, is necessary to develop a national focus around finding the answers to breast cancer. As a country, we have seen the attention that can, and has been, directed to finding answers with regard to AIDS. Research on AIDS has made great strides in the recent past, and this is directly related to the level of financial commitment attached to finding a cure for the disease.

However, AIDS research has also benefited from the high level of social and political commitment of AIDS awareness and activist groups. As a Sub-Committee, we are inspired by the formation of Breast Cancer Action, a grass roots organization that evolved as a result of our study and mirrors, in some ways, the activities of AIDS awareness groups. As Carole Jones, a founding member of the organization, who is battling breast cancer, told us, Breast Cancer Action began:

> . . .from my attending the meetings here. I saw a real need for some kind of advocacy. The people outside who are not attending [the Sub-Committee meetings] expressed a lot of concern to me and so on, and we just had to do something about it [breast cancer]. (15:20)

Write Now, the first activity of Breast Cancer Action, is a national letter-writing campaign aimed at raising awareness around the issue of breast cancer. Although Breast Cancer Action has begun with small numbers of women, some of whom are still in active treatment, we expect that this group will create a ground swell of interest and activity. If we have contributed to this, in some small way, we are indeed honoured to have been involved.

We recognize, however, that the goals of finding improved early detection mechanisms, the causes of breast cancer, better treatment options and greater support services – indeed the goal of answering the many "unanswered questions" – cannot be left to a small group of women, some of whom are enduring the wicked side-effects of breast cancer treatment. Answering the questions of breast cancer needs to be a national goal, a national challenge. It is our fervent hope that Canadians will take up this challenge and that they will be joined by governments, hospitals, physicians and researchers.

APPENDIX 1

List of witnesses

In alphabetical order

Sub-Committee on the Status of Women
Third Session of the Thirty-Fourth Parliament

Associations and Individuals	Issue No.	Date
Breast Cancer Action	15	April 27, 1992
Carole Jones, Founder		
Breast Cancer Research and Education Fund (St-Catharines, Ont.)	11	February 25, 1992
Paula McPherson, Founder and Director;		
Betty Rigbey, member, Breast Cancer Support Group		
British Columbia Cancer Agency	9	February 11, 1992
Dr. Ivo Olivotto, Chair, Breast Tumour Group		
Burlington Breast Cancer Support Services Inc.	1	October 22, 1991
Pat Kelly, Co-Founder;		
Sylvia Morrison, Member		
Canadian Breast Cancer Foundation	2	October 29, 1991
Nancy Paul, Founder and Past President;		
Bette Johnson, National Administrative Director		
Canadian Cancer Society	8	February 4, 1992
Joan Loveridge, Chair, Patient Services, Ontario Division		
Canadian Society for Clinical Investigation	17	May 11, 1992
Dr. Michael Rieder, Director		
Efamol Research Institute, Nova Scotia	9	February 11, 1992
Sherri Clarkson, President;		
Dr. David Horrobin, Director of Research		

Associations and Individuals	Issue No.	Date
Falk Oncology Clinic	6	November 26, 1991
Dr. Rudy Falk, President		
Hamilton Regional Cancer Centre	7	December 2, 1991
Dr. William Hryniuk, C.E.O.;		
Dr. Mark Levine, Head, Department of Medical Oncology and Clinical Trials		
Health and Welfare Canada	1	October 22, 1991
Dr. Gerry Hill, Epidemiologist, Laboratory Centre for Disease Control		
Health and Welfare Canada	13	March 17, 1992
Dr. E.G. Létourneau, Director, Bureau of Radiation and Medical Devices, Health Protection Branch		
Health and Welfare Canada	15	April 27, 1992
Freda Paltiel, Senior Advisor, Status of Women		
Health and Welfare Canada	2	October 29, 1991
Dr. May Smith, Medical Consultant, Extramural Research Program, Health Services and Promotion Branch;		
Dr. F.S. Rolleston, Director, Scientific Evaluation, Medical Research Council of Canada		
Individual Presentation	4	November 19, 1991
Sharon Batt, Journalist		
Individual Presentation	10	February 18, 1992
Judy Caldwell, Vancouver, B.C.		
Individual presentations	14	March 30, 1992
Cynthia E. Webster, Physiotherapist and Patient Advocate (Vancouver, B.C.);		
Barry Toghill, Member, Men's Support Group (Hamilton, Ontario)		
Innoval Ltd.	9	February 11, 1992
Dr. Pierre Blais, Consultant	12	February 26, 1992
Je Sais/I Know, Quebec	9	February 11, 1992
Marcella Tardif, President		
Je Sais/I Know	6	November 26, 1991
Linda Wilson, Member, British Columbia		

Associations and Individuals	Issue No.	Date
McGill University	3	November 6, 1991
Dr. Richard Margolese, Herbert Bloch Professor of Surgical Oncology (Chairman, Cancer 2000);		
Manitoba Health, Working Group on Breast Cancer Screening	15	April 27, 1992
Sandra Gessler, Programme and Policy Analyst, Women's Health Directorate;		
Dr. Charlyn Black, Assistant Professor, Department of Community Health Services, Faculty of Medicine, University of Manitoba		
Mount Sinai Hospital, Toronto	4	November 19, 1991
Dr. Louis Ciminovitch, Director, Samuel Lunenfeld Research Institute		
National Breast Screening Study	5	November 20, 1991
Dr. Anthony B. Miller, Director		
National Cancer Institute of Canada	11	February 25, 1992
Dr. David Beatty, Executive Director		
National Cancer Institute of Canada	3	November 6, 1991
Dr. Geoffrey Howe, Director, Epidemiology Unit		
National Cancer Institute of Canada	8	February 4, 1992
Dr. Joe Pater, Director, Clinical Trials		
National Cancer Institute of Canada	2	October 29, 1991
Dr. Robert Phillips, Member of the Board of Directors, (Director of Cancer Research, Hospital for Sick Children, Toronto)		
National Capital Society of Plastic Surgeons	16	May 4, 1992
Dr. Abdel Raouf Ismail, President		
National Needs Study	7	December 2, 1991
Dr. Mary Vachon, Principal Investigator (Senior Mental Health Research Consultant, Clarke Institute)		
Ontario Breast Screening Program	5	November 20, 1991
Dr. Danièle Perrault, Medical Director, Ottawa Breast Screening Clinic		
Ontario Cancer Institute	6	November 26, 1991
Dr. Norman Boyd, Head, Epidemiology and Statistics		

Associations and Individuals	Issue No.	Date
Ontario Cancer Institute	3	November 6, 1991
Dr. Alastair Cunningham, Chairman of the Advisory Committee on Cancer Control (Professor of Medical Biophysics, University of Toronto)		
Ontario Cancer Treatment and Research Foundation	1	October 22, 1991
Dr. E. Aileen Clarke, Director, Division of Epidemiology and Statistics		
Patient Participation Study	7	December 2, 1991
Dr. Lesley Degner, Principal Investigator (Professor of Nursing, University of Manitoba)		
Pharmaceutical Manufacturers Association of Canada	17	May 11, 1992
Gordon Postlewaite, Executive Director and Secretary Treasurer, Health Research Foundation;		
Leonora F. Marks, Director of Publications		
Queen's University Medical School	16	May 4, 1992
Dr. E.E. Sterns, Professor of Surgery		
Toronto Bayview Regional Cancer Centre	4	November 19, 1991
Dr. Kathleen Pritchard, Head, Department of Medical Oncology		
Y-ME, National Organization for Breast Cancer Information and Support, U.S.A.	10	February 18, 1992
Sharon Green, Executive Director		
YWCA of Canada	8	February 4, 1992
Noelle-Dominique Willems, Director, Public Affairs;		
Annette Willborn, Director, Human Resources, Winnipeg;		
Ruth Hanton, Director, Fitness-Wellness, Toronto		

APPENDIX 2

List of witnesses

In order of appearance

Sub-Committee on the Status of Women
Third Session of the Thirty-Fourth Parliament

Associations and Individuals	Issue No.	Date
Health and Welfare Canada	1	October 22, 1991
Dr. Gerry Hill, Epidemiologist, Laboratory Centre for Disease Control		
Ontario Cancer Treatment and Research Foundation	1	October 22, 1991
Dr. E. Aileen Clarke, Director, Division of Epidemiology and Statistics		
Burlington Breast Cancer Support Services Inc.	1	October 22, 1991
Pat Kelly, Co-Founder;		
Sylvia Morrison, Member		
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Dr. May Smith, Medical Consultant, Extramural Research Program, Health Services and Promotion Branch;		
Dr. F.S. Rolleston, Director, Scientific Evaluation, Medical Research Council of Canada		
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Nancy Paul, Founder and Past President;		
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McGill University	3	November 6, 1991
Dr. Richard Margolese, Herbert Bloch Professor of Surgical Oncology (Chairman, Cancer 2000);		

Associations and Individuals	Issue No.	Date
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National Cancer Institute of Canada	3	November 6, 1991
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Mount Sinai Hospital, Toronto	4	November 19, 1991
Dr. Louis Ciminovitch, Director, Samuel Lunenfeld Research Institute		
Individual Presentation	4	November 19, 1991
Sharon Batt, Journalist		
Toronto Bayview Regional Cancer Centre	4	November 19, 1991
Dr. Kathleen Pritchard, Head, Department of Medical Oncology		
National Breast Screening Study	5	November 20, 1991
Dr. Anthony B. Miller, Director		
Ontario Breast Screening Program	5	November 20, 1991
Dr. Danièle Perrault, Medical Director, Ottawa Breast Screening Clinic		
Je Sais/I Know	6	November 26, 1991
Linda Wilson, Member, British Columbia		
Falk Oncology Clinic	6	November 26, 1991
Dr. Rudy Falk, President		
Ontario Cancer Institute	6	November 26, 1991
Dr. Norman Boyd, Head, Epidemiology and Statistics		
Hamilton Regional Cancer Centre	7	December 2, 1991
Dr. William Hryniuk, C.E.O.;		
Dr. Mark Levine, Head, Department of Medical Oncology and Clinical Trials		
National Needs Study	7	December 2, 1991
Dr. Mary Vachon, Principal Investigator (Senior Mental Health Research Consultant, Clarke Institute)		

Associations and Individuals	Issue No.	Date
Patient Participation Study	7	December 2, 1991
Dr. Lesley Degner, Principal Investigator (Professor of Nursing, University of Manitoba)		
National Cancer Institute of Canada	8	February 4, 1992
Dr. Joe Pater, Director, Clinical Trials		
YWCA of Canada	8	February 4, 1992
Noelle-Dominique Willems, Director, Public Affairs;		
Annette Willborn, Director, Human Resources, Winnipeg;		
Ruth Hanton, Director, Fitness-Wellness, Toronto		
Canadian Cancer Society	8	February 4, 1992
Joan Loveridge, Chair, Patient Services, Ontario Division		
Efamol Research Institute, Nova Scotia	9	February 11, 1992
Sherri Clarkson, President;		
Dr. David Horrobin, Director of Research		
British Columbia Cancer Agency	9	February 11, 1992
Dr. Ivo Olivotto, Chair, Breast Tumour Group		
Je Sais/I Know, Quebec	9	February 11, 1992
Marcella Tardif, President		
Innoval Ltd.	9	February 11, 1992
Dr. Pierre Blais, Consultant		
Y-ME, National Organization for Breast Cancer Information and Support, U.S.A.	10	February 18, 1992
Sharon Green, Executive Director		
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Judy Caldwell, Vancouver, B.C.		
National Cancer Institute of Canada	11	February 25, 1992
Dr. David Beatty, Executive Director		
Breast Cancer Research and Education Fund (St-Catharines, Ont.)	11	February 25, 1992
Paula McPherson, Founder and Director;		
Betty Rigbey, member, Breast Cancer Support Group		

Associations and Individuals	Issue No.	Date
Innoval Ltd.	12	February 26, 1992
Dr. Pierre Blais, Consultant		
Health and Welfare Canada	13	March 17, 1992
Dr. E.G. Létourneau, Director, Bureau of Radiation and Medical Devices, Health Protection Branch		
Individual presentations	14	March 30, 1992
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Barry Toghill, Member, Men's Support Group (Hamilton, Ontario)		
Manitoba Health, Working Group on Breast Cancer Screening	15	April 27, 1992
Sandra Gessler, Programme and Policy Analyst, Women's Health Directorate;		
Dr. Charlyn Black, Assistant Professor, Department of Community Health Services, Faculty of Medicine, University of Manitoba		
Breast Cancer Action	15	April 27, 1992
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Health and Welfare Canada	15	April 27, 1992
Freda Paltiel, Senior Advisor, Status of Women		
National Capital Society of Plastic Surgeons	16	May 4, 1992
Dr. Abdel Raouf Ismail, President		
Queen's University Medical School	16	May 4, 1992
Dr. E.E. Sterns, Professor of Surgery		
Canadian Society for Clinical Investigation	17	May 11, 1992
Dr. Michael Rieder, Director		
Pharmaceutical Manufacturers Association of Canada	17	May 11, 1992
Gordon Postlewaite, Executive Director and Secretary Treasurer, Health Research Foundation;		
Leonora F. Marks, Director of Publications		

APPENDIX 3

Briefs Submitted

Sub-Committee on the Status of Women
Third Session of the Thirty-Fourth Parliament

BATT, Sharon, Montreal, Quebec

CEDOLIA, Mona, Oakville, Ontario

CORRINGHAM, Dr. R.E.T. and Dr. Anthony Ho
(Northeastern Ontario Regional Cancer Centre)

deBANÉ, Paul, Drummondville, Quebec

GILKA, Dr. Libuse, Helios' Centre, Ottawa, Ontario

GORDON, Dr. Richard, University of Manitoba

HANSON, Ruth M., Picton, Ontario

SHULMAN, Dr. Eve, Ottawa, Ontario

THOMPSON, Betty, Kitchener, Ontario

WILLBORN, Annette, Manitoba YM-YWCA

WILLIS, Craig I., Toronto, Ontario

WILSON, Linda, Je Sais/I Know, British Columbia

Request for Government Response

Pursuant to Standing Order 109, your Committee requests that the Government table a comprehensive response to the Report within 150 days.

A copy of the relevant Minutes of Proceedings and Evidence (*Issue No. 9, which includes this report)* is tabled.

Respectfully submitted,

BARBARA GREENE
Chair.

Minutes of Proceedings

THURSDAY, MAY 21, 1992
(25)

[*Text*]

The Sub-Committee on the Status of Women met *in camera* at 9:14 o'clock a.m. this day, in Room 306, West Block, the Chairman, Barbara Greene, presiding.

Members of the Committee present: Edna Anderson, Dawn Black, Mary Clancy and Barbara Greene.

In attendance: From the Research Branch of the Library of Parliament: Sandra Harder, Research Officer.

In accordance with its mandate under Standing Order 108(2), a study of breast cancer (*See Minutes of Proceedings and Evidence, dated Tuesday, October 22, 1991, Issue No. 1*).

The Sub-Committee commenced consideration of a draft report.

At 10:45 o'clock a.m., the sitting was suspended.

At 11:00 o'clock a.m., the sitting resumed in the Chair's office, Room 285 Confederation Building.

At 1:30 o'clock p.m., the Committee adjourned to the call of the Chair.

WEDNESDAY, JUNE 3, 1992
(26)

The Sub-Committee on the Status of Women met *in camera* at 3:40 o'clock p.m. this day, in Room 285 Confederation Bldg., the Chair, Barbara Greene, presiding.

Members of the Committee present: Edna Anderson, Dawn Black, Mary Clancy and Barbara Greene.

In attendance: From the Research Branch of the Library of Parliament: Sandra Harder, Research Officer.

In accordance with its mandate under Standing Order 108(2) a study of breast cancer (*See Minutes of Proceedings and Evidence, dated Tuesday, October 22, 1991, Issue No. 1*).

The Sub-Committee resumed consideration of a draft report.

At 5:00 o'clock p.m., the Committee adjourned to the call of the Chair.

MONDAY, JUNE 8, 1992
(27)

The Sub-Committee on the Status of Women met *in camera* at 3:43 o'clock p.m. this day, in Room 307, West Block, the Acting Chairman, Alan Redway, presiding.

Members of the Committee present: Edna Anderson, Dawn Black, Mary Clancy, and Barbara Greene, and Alan Redway.

In attendance: From the Research Branch of the Library of Parliament: Sandra Harder, Research Officer. *From the Committees Directorate of the House of Commons:* Eugene Morawski, Committee Clerk.

In accordance with its Order of Reference dated Thursday, May 30, 1991 (*See Minutes of Proceedings of the Standing Committee on Health and Welfare, Social Affairs, Seniors and the Status of Women, Issue No. 2*), and its mandate under Standing Order 108(2), a study of breast cancer (*See Minutes of Proceedings and Evidence of the Sub-Committee on the Status of Women, dated Thursday, October 22, 1991, Issue No. 1*).

The Sub-Committee resumed consideration of a draft report.

By unanimous consent, it was agreed,—That the draft report on breast cancer, as amended, be adopted as the Sub-Committee's Second Report and that the Chair be authorized to present the report to the Standing Committee on Health and Welfare, Social Affairs, Seniors and the Status of Women.

At 4:28 o'clock p.m., the Committee adjourned to the call of the Chair.

Christine Fisher
Clerk of the Sub-Committee

Minutes of Proceedings

THURSDAY, JUNE 11, 1992
(12)

[*Text*]

The Standing Committee on Health and Welfare, Social Affairs, Seniors and the Status of Women met *in camera* at 9:36 o'clock a.m. this day, in Room 371, West Block, the Chair, Barbara Greene, presiding.

Members of the Committee present: Edna Anderson, Barbara Greene, Barbara Sparrow and Stan Wilbee.

Acting Members present: Dawn Black for Jim Karpoff and Shirley Maheu for David Walker.

In attendance: From the Research Branch of the Library of Parliament: Tom Curren, Sandra Harder and Odette Madore Research Officers.

The Chair presented the Second Report of the Sub-Committee on the Status of Women.

It was agreed,—That the Committee ask the Chair to present the Second Report of the Sub-Committee on the Status of Women as the Fourth Report of the Standing Committee to the House of Commons.

It was agreed,—That pursuant to Standing Order 109, the Committee request that the Government table a comprehensive response to this Report.

It was agreed,—That the Committee print 5,000 copies of this Report, in tumble bilingual format, with a distinctive cover page.

It was agreed,—That pursuant to Standing Order 120, the Committee retain the services of Louis Majeau (SPEC Enr.) as French language reviser, effective June 12, 1992, to assist in the production of the report on breast cancer and that he be paid at an hourly rate of $55.00, not to exceed $599.00 per working day in accordance with the contracting policy of the House of Commons; the total value of the contract, including expenses, must not exceed $2,000 plus the goods and services tax, if applicable.

At 9:42 o'clock a.m., the Committee adjourned to the call of the Chair.

Eugene Morawski
Clerk of the Committee