Encouraging research into Lymphoedema:

A report on the summit held on 25 & 26 February 2000

Prepared by:

Redman S, King E.
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BACKGROUND

There is considerable community concern about lymphoedema.

Primary lymphoedema is caused by an alteration in the lymph conducting pathways. Although congenital lymphoedema can occur soon after birth, it more commonly presents itself after puberty.1 Lymphoedema can also occur secondarily to treatment for other conditions, such as cancer.

Lymphoedema following treatment for breast cancer has received the most attention. Women with breast cancer have highlighted their concerns about lymphoedema in consultations with the National Breast Cancer Centre and in the report Making a difference from the first national conference for women with breast cancer, held in 1998. 2

However, a report published by the National Breast Cancer Centre in 1996 3 demonstrated that there was little high quality research into lymphoedema following treatment for breast cancer. As a result, little is known about the prevalence of lymphoedema, risk factors for its development or the effectiveness of different approaches to treating the condition. Without this research, it is not possible to develop evidence-based recommendations which might assist in preventing or effectively managing lymphoedema among women following treatment for breast cancer. The report therefore called for the development of a strategic program in lymphoedema research.

The summit Encouraging research into lymphoedema was planned in response to this report. It was hoped that by bringing together researchers, clinicians, consumers and research funding agencies it might be possible to begin to foster high quality and collaborative approaches to lymphoedema research. The summit was jointly funded by the Office for the Status of Women, the Commonwealth Department of Health and Aged Care and the National Breast Cancer Centre.

AIMS OF THE SUMMIT

The objective of the summit was to foster high quality research into lymphoedema in Australia. The specific aims were:

- To identify researchers studying lymphoedema and establish a collaborative lymphoedema research network
- To develop a register of lymphoedema research programs in Australia
• To further research into lymphoedema which develops as a result of treatment for breast cancer by:
  ⇨ critically appraising research methodologies
  ⇨ agreeing upon several priority research projects with robust methodologies including those addressing: the prevalence of lymphoedema; risk factors and opportunities for prevention; and the effectiveness of treatment
  ⇨ developing strategies for funding these priority projects
• To begin the development of a strategic plan to encourage research into:
  ⇨ primary lymphoedema
  ⇨ secondary lymphoedema arising from causes other than treatment for breast cancer

**APPROACH**

**Pre Summit Planning**

A Steering and Advisory Group was established to assist in planning the Summit. The members of these groups are listed in Appendix 1.

To successfully achieve the aim of identifying priority research protocols an interactive workshop was planned. It was agreed that in accepting registrations for the Summit, a multidisciplinary participation should be sought. In total, eighty-six people attended the summit; participants are listed in Appendix 2.

Several documents were developed to assist participants in the Summit:

• *Lymphoedema: prevention, diagnosis and treatment, a literature search 1990-2000*. This document lists abstracts of all of the located published research about lymphoedema since 1990.

• *Lymphoedema following treatment for breast cancer: some potential approaches to answering priority research questions*. This document provided a set of draft protocols about possible approaches to designing research to explore lymphoedema following treatment for breast cancer. It was developed by a small expert working group – the membership is shown in Appendix 3. The protocols addressed strategies for: measuring lymphoedema; assessing prevalence; exploration of risk factors and opportunities for prevention including the role of sentinel node biopsy; and assessing the effectiveness of treatment for lymphoedema.

These documents were circulated to registrants prior to the Summit.
Pre Summit Events

Two events were planned for the evening before the Summit to assist in raising awareness of lymphoedema and to ensure that participants were aware of the cost to sufferers of lymphoedema.

- Reception at Government House, Adelaide: Sir and Lady Neal hosted a reception for participants in the Summit and those with lymphoedema at Government House. Approximately seventy people attended the reception, the majority of whom were consumers.

- Public meeting: Senator the Honorable Jocelyn Newman, Minister for Family and Community Services and Minister Assisting the Prime Minister for the Status of Women, opened the public meeting. This meeting created an opportunity for those experiencing lymphoedema to talk about the condition and its impact on their lives. It also highlighted research priorities for lymphoedema. The meeting was attended by approximately one hundred and twenty people. The program for the public meeting is attached in Appendix 4.

SUMMIT

The program for the Summit is attached in Appendix 5.

The initial session included a background to the purpose and anticipated outcomes of the Summit. Participants then joined workshop sessions to consider approaches to developing research in a range of areas. Participants had access to several resource documents to assist in this process as outlined above.

In the final session of the day, each workshop reported its major outcomes and these were summarised into principles and priority research projects as outlined below. These resolutions were agreed by participants in the Summit.

OUTCOMES OF THE SUMMIT: PRINCIPLES

It was agreed that several principles would be important in developing the outcomes from the summit:

- Research protocols should be developed to be high quality representing excellent research as agreed by peer review. It was agreed that unless this was achieved the resulting research findings would be unlikely to improve outcomes for those with lymphoedema.

- The proposals should seek to avoid duplicating work which is already ongoing and to develop a collaborative approach. International links should be considered.
Consumers should be integrally involved in the further development of the proposals and in the implementation and interpretation of the resulting research.

Where possible, opportunities should be sought to broaden research projects to explore issues of relevance to different types of lymphoedema.

OUTCOMES OF THE SUMMIT: WORKSHOPS

The Summit identified six priority areas to foster research into lymphoedema:

1. **A consensus meeting about research strategies for primary lymphoedema**

   One workshop group considered priority projects for primary lymphoedema using as a resource the research abstracts collated for the summit in the document titled *Lymphoedema: prevention, diagnosis and treatment: a literature search 1990-2000*.

   The group felt that considerable progress had been made during the workshop. However, there was a need for further work to define priority issues and to develop strategies for their resolution.

   A consensus meeting was proposed as the next step. The aims of this meeting would be to:

   - Develop a consensus about the definition of, and diagnostic criteria for, primary lymphoedema
   - Establish a working group to focus on:
     - research for treatment of primary lymphoedema
     - research about the education needs related to primary lymphoedema
     - strategies to foster collaborative research and joint tendering
     - approaches to establish postgraduate support
   - Identify national structures and infrastructure to support research into primary lymphoedema

2. **A workshop about research into lymphoedema secondary to treatment other than that for breast cancer**

   One workshop group considered priorities in research about lymphoedema which is secondary to treatment for disease other than breast cancer.
This group proposed two major strategies. First, it was recommended that projects addressing breast cancer seek to incorporate a broader focus where possible. Second, a further workshop was proposed to refine and develop priorities and research strategies. Priorities would be likely to include the psychological and social impact of lymphoedema and the efficacy of compression garments.

3. Measurement of lymphoedema following treatment for breast cancer

A workshop group considered strategies for measuring lymphoedema following treatment for breast cancer.

The group agreed that the measurement studies were a high priority. Reliable and valid measures of arm morbidity and lymphoedema would be necessary for all of the other research projects relating to lymphoedema following treatment for breast cancer. Establishing nationally agreed approaches to measurement would also assist researchers to compete more effectively for competitive research funds.

The group agreed in broad terms the research protocol circulated with the papers. This proposed a series of linked studies to establish: the reliability and validity of several alternative ‘gold standard’ measures for lymphoedema; a self report measure with high agreement with the ‘gold standard’ objective measure; a measure of the impact of arm morbidity and lymphoedema on women’s quality of life.

4. Sentinel node biopsy study

One workshop group considered the role of sentinel node biopsy as a preventive strategy for lymphoedema of the arm following treatment for breast cancer. A protocol developed by the Royal Australasian College of Surgeons for a trial of sentinel node biopsy in Australia was circulated prior to the workshop and used as the basis for discussion.

The group felt that the Royal Australasian College of Surgeons proposal was important and had a high degree of urgency for funding; there is a small window of opportunity before sentinel node biopsy becomes widely established in an untested manner. There would be an opportunity to incorporate some of the research questions relating to measurement and to risk factors into this study.

This group also considered approaches to studying risk factors for the development of lymphoedema following treatment for breast cancer. A detailed draft protocol had been circulated with the papers. It was agreed that rigorous studies to assess risk factors for lymphoedema would be costly and difficult; it was felt that the measurement and prevalence studies would yield information on which to plan a risk factor study.
5. **Prevalence of lymphoedema following treatment for breast cancer**

One workshop group considered strategies for assessing the prevalence of lymphoedema following treatment for breast cancer.

The group identified several already funded projects which might contribute valuable information about the occurrence of lymphoedema. However, the importance of a major national prevalence study was agreed. It was recognised that a prevalence study could not occur without agreed approaches to the measurement of lymphoedema.

The group considered the draft protocols for a prevalence study circulated prior to the meeting; these were agreed in broad terms.

6. **Treatment options for lymphoedema following treatment for breast cancer**

A workshop group considered strategies to evaluate treatment for lymphoedema of the arm.

It was agreed that establishing the effectiveness of treatment for lymphoedema was a high priority for consumers. However, the group emphasised that there were currently many different treatments and that careful thought was required in selecting the treatments for trial. It was also agreed that there may be ethical issues in establishing a minimal intervention control group for women seeking treatment for established lymphoedema.

The group felt that the draft protocol circulated prior to the meeting about evaluating the effectiveness of treatment was not sufficiently developed. It was agreed that further work was needed and that the most appropriate next step might be to focus on strategies to prevent the progression of early lymphoedema. It was agreed that a further workshop would be necessary to develop a viable protocol for assessing the effectiveness of treatment for lymphoedema.

**Consensus about priority projects**

The final session of the summit considered a report from each of the workshops. The priorities identified by the workshop groups were confirmed by the summit and included the following:

- A further workshop to explore priorities for research into primary lymphoedema and strategies for implementation
- A further workshop to explore priorities for research into lymphoedema secondary to causes other than breast cancer and strategies for implementation
• A further workshop to define research questions in relation to exploring the effectiveness of treatment for lymphoedema with a special focus on the value of different strategies in preventing early lymphoedema from progressing

• Research to develop agreed, reliable and valid strategies for the measurement of lymphoedema

• The proposed trial of sentinel node biopsy as it offers an opportunity for prevention.

It was agreed that prevalence studies of lymphoedema following treatment for breast cancer and of other types of lymphoedema was also a priority. However, these would depend upon the establishment of appropriate measurement techniques and were therefore seen as a second step.

**OTHER OUTCOMES FROM THE SUMMIT**

The Summit had also aimed to develop a network of lymphoedema research and to foster opportunities for collaboration. Three other outcomes will assist in this process:

• Register of ongoing lymphoedema research: Participants in the Summit were asked to identify any research in which they were involved. The resulting register of research will be available via the Centre’s web site and will be kept up to date. The first edition of the register is available from the Centre.

• E-mail list of those interested in lymphoedema research: All participants in the Summit have been sent an invitation to join an email list server which will be operated by the Centre to provide updates about recent research in lymphoedema and an opportunity to contact others interested in lymphoedema research.

• Protocols: Based on the report *Lymphoedema following treatment for breast cancer: some potential approaches to answering priority research questions* and discussions at the Summit, the Centre will prepare a series of draft protocols for research in lymphoedema following treatment for breast cancer. It is anticipated that this will be available by the end of August 2000.
REFERENCES


APPENDIX 1:  STEERING AND ADVISORY GROUPS FOR THE LYMPHOEDEMA SUMMIT

STEERING GROUP

Mr Andrew Benson  
Health Priorities Management, Commonwealth Department of Health and Aged Care

Ms Sandra Gagalowicz  
Health Priorities Management, Commonwealth Department of Health and Aged Care

A/Prof David Gillett  
Surgeon, Strathfield Breast Clinic

Ms Elizabeth King  
Project Officer, National Breast Cancer Centre

Assoc Prof Neil Piller  
Department of Public Health, School of Medicine, Flinder’s Medical Centre

Prof Sally Redman  
Director, National Breast Cancer Centre

Ms Heather Wain  
National Breast Cancer Foundation

Ms Kate White  
Senior Lecturer in Nursing, Australian Catholic University and consultant to the National Breast Cancer Centre on this project

Ms Robyn Wicks  
Consumer, Breast Cancer Action Group NSW and Counsellor, BreastScreen Western Sydney

ADVISORY GROUP

Ms Karen Bentley  
Assistant Secretary, Office for the Status of Women

Ms Megan Collier  
Coordinator Breast Cancer Support Service, Queensland Cancer Fund

Mrs Sally Crossing  
Consumer, Breast Care Action Group, NSW

Mrs Liz Dart  
Secretary, Lymphoedema Association of Victoria

Ms Brenda Lee  
Coordinator, Lymphoedema Unit, Mount Wilga Hospital, Representative for the Australian Physiotherapy Association

Prof Sue Nikoletti  
School of Nursing and Public Health, Edith Cowan University

Ms Maree O’Connor  
President, Australian Lymphology Association

Mr Stuart Renwick  
Surgeon, Royal Prince Alfred Hospital

Mr Neil Wetzig  
Chair, Breast Section, Royal Australasian College of Surgeons
# APPENDIX 2: LIST OF PARTICIPANTS WHO ATTENDED THE ENCOURAGING RESEARCH INTO LYMPHOEDEMA SUMMIT

The workshop on Saturday was attended by 87 people, who are listed below in alphabetical order:

<table>
<thead>
<tr>
<th>Name</th>
<th>Role and Affiliation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dr Fiorella Alberico</td>
<td>Senior Medical Officer, Lymphoedema Clinic, Mercy Hospital for Women</td>
</tr>
<tr>
<td>Ms Maureen Bartel</td>
<td>President, Lymphoedema Support Group of SA</td>
</tr>
<tr>
<td>Ms Jane Beith</td>
<td>New South Wales Department of Health</td>
</tr>
<tr>
<td>Mr Andrew Benson</td>
<td>Health Priorities Management, Department of Health and Aged Care</td>
</tr>
<tr>
<td>Ms Karen Bentley</td>
<td>Assistant Secretary, Office for the Status of Women</td>
</tr>
<tr>
<td>Dr Stephen Birrell</td>
<td>Surgeon, Head of the Breast Unit, Flinders Medical Centre</td>
</tr>
<tr>
<td>Ms Christine Borserio</td>
<td>Consumer, Lymphoedema Support Group of NT</td>
</tr>
<tr>
<td>Ms Philippa Bourke</td>
<td>Physiotherapist, Representative for the Lymphoedema Association of Australia</td>
</tr>
<tr>
<td>Mrs Robyn Box</td>
<td>Physiotherapist, Port Moresby N.C.D., Papua New Guinea</td>
</tr>
<tr>
<td>The Hon Dean Brown MP</td>
<td>Minister for Human Services, South Australia</td>
</tr>
<tr>
<td>Mrs Carlene Butavicius</td>
<td>Vice-President, Breast Cancer Action Group of SA</td>
</tr>
<tr>
<td>Dr Colin Carati</td>
<td>Assistant Dean, School of Medicine, Flinders University, SA</td>
</tr>
<tr>
<td>Ms Louisa Collins</td>
<td>Centre for Public Health Research, Queensland University of Technology</td>
</tr>
<tr>
<td>Dr Bruce Cornish</td>
<td>School of Physical Science, Queensland University of Technology</td>
</tr>
<tr>
<td>Mrs Sally Crossing</td>
<td>Consumer, Breast Care Action Group of NSW</td>
</tr>
<tr>
<td>Ms Chris Dale</td>
<td>Department of Physiotherapy, Royal Hobart Hospital, Tasmania</td>
</tr>
<tr>
<td>Mrs Liz Dart</td>
<td>Secretary, Lymphoedema Association of Victoria</td>
</tr>
<tr>
<td>Dr Margaret Davy</td>
<td>Gynaecological Oncologist, Representative for the National Health and Medical Research Council</td>
</tr>
<tr>
<td>Dr Rosalind Deacon</td>
<td>Physiotherapist, Lymphoedema Unit, Bendigo Health Care Group</td>
</tr>
<tr>
<td>Ms Jenny Donovan</td>
<td>Consumer, Lymphoedema Support Group of SA</td>
</tr>
</tbody>
</table>
Mrs Jan Douglas  Consumer, Lymphoedema Support Group of SA
Dr Adrian Esterman  Epidemiologist, Flinders Medical Centre, SA
Mrs Susan Fitzpatrick  Executive Officer, Centre for Clinical Research in Cancer, Anti-Cancer Council Victoria
Mrs Sue Fraser  Consumer, Lymphoedema Support Group of SA
Ms Sandra Gagalowicz  Health Priorities Management, Department of Health and Aged Care
A/Prof David Gillett  Surgeon, Strathfield Breast Clinic, NSW
A/Prof Afaf Girgis  Cancer Education Research Program, New South Wales Cancer Council
Dr Peter Graham  Radiation Oncologist, St George Hospital, NSW
Mrs Jenny Green  President, Lymphoedema Support Group of NSW
Ms Sheila Hirst  Breast Care Initiative Group, Victorian Department of Human Services
Mrs Joan Ince  Consumer, Action for Breast Cancer, SA
Mrs May Jackson  Consumer, Riverland Breast Cancer Support Group, SA
Mr Jim Kollias  Breast Endocrine Surgical Section, Royal Adelaide Hospital, SA
Ms Elizabeth King  Project Officer, National Breast Cancer Centre
Dr Kerry Kirke  Executive Director, Anti-Cancer Foundation of South Australia
Ms Louise Koelmeyer  Occupational Therapist, NSW Breast Cancer Institute
Mrs Vanessa Lambert  Consumer, Action for Breast Cancer, SA
Ms Brenda Lee  Coordinator, Lymphoedema Unit, Mount Wilga Private Hospital
Ms Meg Lewis  Breast Care Nurse, Women's Health Centre, Royal Adelaide Hospital
Mrs Elizabeth Libregts  Consumer, Action for Breast Cancer, SA
Mrs Norma Lloyd-Penning  Consumer, Lymphoedema Support Group of WA
Ms Sue Lockwood  Consumer, Breast Cancer Action Group of VIC
Dr Helen Mackie  Rehabilitation Specialist, Mount Wilga Hospital, NSW
Mr Peter Malycha  Surgeon, Royal Adelaide Hospital, SA
Ms Lenore Manderson  Professor of Women's Health, University of Melbourne
Mr Michael Mason  Physiotherapist, Adelaide Lymphoedema Clinic, SA
Mrs Pat Matthew  Consumer, Breast Cancer Action Group of TAS
Ms Kay Matthews  
Chief Physiotherapist, Peter MacCallum Cancer Institute, VIC

Mrs Jo Maxian  
President, Lymphoedema Association of Victoria

Dr Margaret McCredie  
Chief Epidemiologist, Department of Preventive and Social Medicine University of Otago, New Zealand

Ms Margaret McMahon  
Senior Physiotherapist, Royal Adelaide Hospital, SA

Ms Alex Miller  
Nurse, Flinders Surgical Oncology Unit

Mrs Beverley Mirolo  
Chief Executive Officer, Haematology and Oncology Clinics of Australasia, QLD

Ms Andrea Morrison  
Physiotherapist, Austin and Repatriation Medical Centre, VIC

Ms Rosaline Mullen  
Consumer, Lymphoedema Support Group of NSW

Prof Sue Nikoletti  
School of Nursing and Public Health, Edith Cowan University WA

Ms Maree O’Connor  
President, Australasian Lymphology Association, VIC

Mr David Oliver  
Surgeon, Cancer Foundation of Western Australia

A/Prof Ian Olver  
Department of Medical Oncology, Royal Adelaide Hospital, SA

Mrs Shirley Paull  
Coordinator, Action for Breast Cancer, SA

Dr Janice Perkins  
Head, Behavioural Science in Relation to Medicine University of Newcastle, NSW

A/Prof Neil Piller  
Lymphoedema Assessment Clinic, Flinders Surgical Oncology Unit, SA

Dr Natasha Posner  
Department of Social and Preventive Medicine, University of Queensland

Ms Maureen Ramsden  
Clinical Liaison Officer, Tasmanian Cancer Council

Dr Sally Redman  
Director, National Breast Cancer Centre

Ms Hildegard Reul-Hirche  
Physiotherapy Department, Royal Brisbane Hospital, QLD

Dr David Roder  
Epidemiologist, SA Cancer Registry, SA Health Commission

Prof Alan Rodger  
Director, William Buckland Radiotherapy Centre, VIC

Ms Kate Scally  
Occupational Therapist, Charles Gairdner Hospital, WA

Ms Marion Shanahan  
Health Economist, Centre for Health Economics Research and Evaluation, NSW

Ms Denise Sharp  
Clinical Nurse, Calvary Public Hospital, ACT
<table>
<thead>
<tr>
<th>Name</th>
<th>Position and Affiliation</th>
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<tbody>
<tr>
<td>Mrs Nerida Smith</td>
<td>President, Lymphoedema Association of Queensland</td>
</tr>
<tr>
<td>Mr Andrew Spillane</td>
<td>Surgeon, Sydney Breast Cancer Institute</td>
</tr>
<tr>
<td>Mrs Shirley Suleyman</td>
<td>Consumer, Lymphoedema Support Group of SA</td>
</tr>
<tr>
<td>Ms Ann Thelander</td>
<td>Nurse, Mitcham Rehabilitation Clinic, SA</td>
</tr>
<tr>
<td>Mrs Margaret Tobin</td>
<td>State Co-ordinator, Breast Cancer Support Service, Anti-Cancer Foundation, SA</td>
</tr>
<tr>
<td>Ms Heather Wain</td>
<td>National Breast Cancer Foundation</td>
</tr>
<tr>
<td>Ms Tina Watkins</td>
<td>Physiotherapist, Department of Human Services</td>
</tr>
<tr>
<td>Ms Ann Weeden</td>
<td>State Co-ordinator Breast Cancer Support Service, New South Wales Cancer Council</td>
</tr>
<tr>
<td>Ms Anna Wellings-Booth</td>
<td>Consumer, Breast Cancer Action Group of ACT</td>
</tr>
<tr>
<td>A/Prof Neil Wetzig</td>
<td>Chair, Breast Section, Royal Australasian College of Surgeons</td>
</tr>
<tr>
<td>Dr Sue Whicker</td>
<td>General Practitioner, Royal Australasian College of General Practitioners</td>
</tr>
<tr>
<td>Mrs Barbara White</td>
<td>Consumer, Lymphoedema Support Group of WA</td>
</tr>
<tr>
<td>Ms Kate White</td>
<td>Senior Lecturer in Nursing, Australian Catholic University, NSW</td>
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<tr>
<td>Ms Robyn Wicks</td>
<td>Consumer, Breast Cancer Action Group NSW and Counsellor, Breast Screen Western Sydney</td>
</tr>
<tr>
<td>Mr Danian Yang</td>
<td>Surgeon, Edith Cowan University, WA</td>
</tr>
<tr>
<td>Dr Helen Zorbas</td>
<td>Clinical Director, National Breast Cancer Centre</td>
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LYMPHOEDEMA FOLLOWING TREATMENT FOR BREAST CANCER: SOME POTENTIAL APPROACHES TO ANSWERING PRIORITY RESEARCH QUESTIONS.

A/Prof David Gillett  Surgeon, Strathfield Breast Clinic
Dr Peter Graham  Radiation Oncologist, St George Hospital
Ms Elizabeth King  Project Officer, National Breast Cancer Centre
Ms Sue Lockwood  Consumer, Breast Cancer Action Group VIC
Dr Margaret McCredie  Chief Epidemiologist, Department of Preventive and Social Medicine University of Otago, New Zealand
Ms Maree O'Connor  President, Australian Lymphology Association
Dr Janice Perkins  Head, Behavioural Science in Relation to Medicine, University of Newcastle
A/Prof Neil Piller  Department of Public Health, School of Medicine, Flinder’s Medical Centre
Professor Sally Redman  Director, National Breast Cancer Centre
Dr David Roder  Epidemiologist, SA Cancer Registry, SA Health Commission
Mr Neil Wetzig  Chair, Breast Section, Royal Australasian College of Surgeons
Ms Kate White  Senior Lecturer in Nursing, Australian Catholic University and consultant to the National Breast Cancer Centre on this project
Appendix 4: Public Meeting Program

Lymphoedema: how can research improve care?

Public Meeting

Friday 25 February 2000, 6:30pm - 9:00pm

Adelaide Festival Centre, King William Road, Adelaide

6:30 PM  RECEPTION AND LIGHT BUFFET

7:15 PM  WELCOME
MRS JANET MCDONALD, MC.

7:10 PM  OPENING ADDRESS
SENATOR THE HON JOCELYN NEWMAN, MINISTER FOR FAMILY AND COMMUNITY SERVICES AND MINISTER ASSISTING THE PRIME MINISTER FOR THE STATUS OF WOMEN

7:20 PM  PRIMARY LYMPHOEDEMA: A CONSUMER’S PERSPECTIVE
MS LIZ DART, SECRETARY OF THE VICTORIAN LYMPHOEDEMA ASSOCIATION.

7:30 PM  BREAST CANCER RELATED LYMPHOEDEMA: A CONSUMER’S PERSPECTIVE
MS ROBYN WICKS, MEMBER OF THE BREAST CANCER NETWORK AUSTRALIA.

7:40 PM  LYMPHOEDEMA: A CLINICIANS PERSPECTIVE
A/PROF NEIL PILLER, LYMPHOEDEMA ASSESSMENT CLINIC, FLINDERS SURGICAL ONCOLOGY CLINIC, DEPARTMENT OF HEALTH.

7:50 PM  OPEN FORUM: HOW CAN RESEARCH IMPROVE CARE FOR LYMPHOEDEMA?
FACILITATOR: MS LYN SWINBURNE, CHAIR, BREAST CANCER NETWORK AUSTRALIA.
PANEL: A/PROF DAVID GILLETT, SURGEON
DR KERRY KIRKE, ANTI-CANCER FOUNDATION, SOUTH AUSTRALIA
MRS LIZ DART, VICTORIAN LYMPHOEDEMA ASSOCIATION
MS MAREE O’CONNOR, AUSTRALASIAN LYMPHOLOGY ASSOCIATION,
A/PROF NEIL PILLER, LYMPHOEDEMA ASSESSMENT CLINIC
MS ROBYN WICKS, BREAST CANCER NETWORK AUSTRALIA

8:25 PM  WHERE TO NEXT?
DR SALLY REDMAN, DIRECTOR, NATIONAL BREAST CANCER CENTRE

8:30 PM  CONCLUSION OF EVENING FORUM
MRS JANET MCDONALD.

PLEASE NOTE THAT THE ROOM WILL BE AVAILABLE UNTIL 9:00 PM
Appendix 5: Workshop Program

Encouraging Research into Lymphoedema
Saturday 26 February, 2000
Adelaide Commonwealth Centre, 55 Currie Street

9AM REGISTRATION AND COFFEE

9.45am  What are the issues?

Kerry Kirke – Chair

9.50am  Purpose and overview of the summit  Sally Redman
10.10am Why is more research needed?  Shirley Suleyman
10.20am How can research funds be attracted?  Margaret Davy
10.35am What impedes lymphoedema research?  Open forum

11AM MORNING TEA

11.15am  Workshop 1  Concurrent workshop sessions  Facilitator

A  Primary lymphoedema: developing a research strategy  Neil Piller
B  Secondary lymphoedema: developing a research strategy  Maree O’Connor
C  Measurement of lymphoedema resulting from breast cancer treatment  David Gillett
D  Prevalence of lymphoedema resulting from breast cancer treatment  David Roder

Participants can choose to attend one of the above workshops. Participants who choose the primary and secondary lymphoedema topics will be asked to continue in the same group during Workshop 2.

12.30PM LUNCH BREAK
# Appendix 5: Workshop Program

## 1.05PM  
**AFTERNOON PROGRAM**

### 1.10pm  
**Workshop 2**  
**Concurrent workshop sessions**  
**Facilitator**

<table>
<thead>
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<th>Workshop</th>
<th>Topic</th>
<th>Facilitator</th>
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<tbody>
<tr>
<td>A</td>
<td>Primary lymphoedema: developing a research strategy</td>
<td>Neil Piller</td>
</tr>
<tr>
<td>B</td>
<td>Secondary lymphoedema: developing a research strategy</td>
<td>Maree O’Connor</td>
</tr>
<tr>
<td>C</td>
<td>Options for preventing lymphoedema following treatment for breast cancer: risk factors and sentinel node biopsy</td>
<td>Neil Wetzig</td>
</tr>
<tr>
<td>D</td>
<td>Evaluating the effectiveness of treatment for lymphoedema secondary to breast cancer treatment</td>
<td>Peter Graham</td>
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### 2.25PM  
**AFTERNOON TEA**

### 2.35pm  
**Where to next?**

**Margaret McCredie – Chair**

<table>
<thead>
<tr>
<th>Time</th>
<th>Topic</th>
<th>Facilitator</th>
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<tr>
<td>2.40pm</td>
<td>Priorities in encouraging lymphoedema research: workshop reports</td>
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<td></td>
<td>I  Primary lymphoedema</td>
<td>Neil Piller</td>
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<td></td>
<td>II Secondary lymphoedema</td>
<td>Maree O’Connor</td>
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<td></td>
<td>III Breast cancer related lymphoedema</td>
<td>Helen Zorbas</td>
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<tr>
<td>3.10pm</td>
<td>Attracting funds for the priorities</td>
<td>Margaret Davy</td>
</tr>
<tr>
<td>3.20pm</td>
<td>Where to next?</td>
<td>Open forum</td>
</tr>
<tr>
<td>3.50pm</td>
<td>Outcomes from the summit</td>
<td>Sally Redman</td>
</tr>
</tbody>
</table>

### 4PM  
**CONCLUSION OF WORKSHOP**