

STOPPING BREAST CANCER BEFORE IT STARTS - PUTTING PRIMARY PREVENTION ON THE NATIONAL BREAST CANCER AGENDA 13/11/00

Grand Committee Room, House of Commons. Sponsors: Alice Mahon MP and Dennis Skinner MP

A National Strategy and separate funding for primary prevention, rather than just treating breast cancer, was called for at a forum organised by Women's Environmental Network (WEN) in November. The forum marked the start of the next phase of WEN's work on the disease, building on the groundwork laid by the "Putting Breast Cancer on the Map" project.

The aim of the forum was to bring together all the stakeholders to begin discussion about how to put primary prevention at the top of the national breast cancer agenda. The objectives being:

- To promote the inclusion of primary prevention on the agendas of institutions involved in breast cancer.
- To promote collaboration between agencies with responsibility for health in recognition of social and environmental factors in breast cancer etiology.
- And to launch phase three of WEN's continuing work, reflecting women's major concerns about links between breast cancer and the environment.

Breast cancer campaigners and survivors, cancer charities, trade union representatives, MPs and health and scientific specialists all gathered at the House of Commons to contribute to the discussion about how to take this issue forward.

The audience heard that the Government spends £150 million a year on breast cancer and millions more go into research that is geared towards detection and treatment. Comparatively little effort is put into investigating possible causes and focusing on prevention of this disease before it starts.

"Women are encouraged to look to and change their own lifestyle rather than identify external factors which may cause or trigger the disease", said **Helen Lynn, WEN's Health Co-ordinator**. "There are a lot of unknowns in reference to the possible causes of breast cancer and no-one purports to have all the answers as yet. But the bottom line is, women would rather not have first hand experience of breast cancer in the first place".

Viewing the problem as one that can only be solved by a conciliatory approach and firm commitment by all involved, Helen believes that primary prevention is the only way to go if we are ever to see a reduction in the number of women this disease claims each day.

It is not that the prevention and environmental link is not recognized. A bold statement appears in the UK Government's "Our Healthier Nation" stating "Pollutants in the environment may cause cancer". Unfortunately there is no further reference to this statement anywhere in the document. Disappointingly targets are outlined to reduce deaths but what about incidence?

But there is a wealth of research, which suggests our environment - our homes, workplaces, the air we breathe and even our food - is contaminated with a cocktail of carcinogenic chemicals. WEN thinks this research provides enough suspicion in relation to these chemicals being harmful to the environment, wildlife and humans, to warrant implementation of a precautionary approach in absence of full scientific proof. We must learn by previous mistakes made in relation to BSE, tobacco and asbestos and learn to heed the early warning signs.

The current NHS Cancer Plan, A Plan for Investment and Reform, September 2000, aims to set out "the first ever comprehensive strategy to tackle the disease. It is the first time any government has drawn up a major programme of action linking prevention, diagnosis, treatment, care and research." "In the process the NHS will help tackle health inequalities. Prevention of disease and early intervention in the community would be of fundamental importance."

The approach outlined is one of intervening before ill health occurs, but in terms of preventative care the approaches mentioned refer only to routine screening, genetic tests, and new medicines, with suggested actions limited to smoking reduction, improved diet and screening. Occupational health is mentioned but not defined.

Campaigner and writer, Diana Ward, was diagnosed with the disease seven years ago. She said: "I've come to view breast cancer as the symbolic disease of our time. The disease that symbolises, more than any other, the risks women are exposed to simply by living in a seriously degraded environment."

Yet women are kept in ignorance of the risks by the lack of warnings from government, manufacturers and retailers. Life time exposure to the female hormone oestrogen is recognised as a significant risk factor for breast cancer. A risk factor that provides the key to understanding why hormone-disrupting chemicals are prime suspects in rising breast cancer rates across the population. On a daily basis we inhale, ingest and absorb them in myriad forms. We live our lives in ignorance of our involuntary exposure to multiple risks for breast cancer. Ignorance has to be a major risk factor for this disease. Information is absolutely essential.

During his address, **Professor Klim McPherson of the London School of Hygiene and Tropical Medicine** said, "It seems to me that the primary prevention agenda in breast cancer in terms of prevention and not just detection is immature. We do not have the appropriate infrastructure, implementation, experimenting and advocacy strategies for prevention." He said the primary prevention agenda is an agenda without infrastructure, essentially what we are doing is living on the back of the NHS treatment agenda, which is demand led." And added "I don't have any problem with trying to keep the waiting lists down, its seems a laudable objective, but it interferes quite dramatically with a prevention agenda, because it's always going to be second place".

Professor McPherson explained that establishing risk factors is very difficult; there is a problem in the fact that people recognise that there are clusters of disease, but more often than not when they are investigated properly they turn out to be not proven risk factors.

Professor Charles Coombes, Director of the Cancer Research Campaign Laboratory, recommended good diet, greater breast awareness and more genetic screening as ways to cut deaths but said, "When you've done the thing of preventing obesity, reducing alcohol and eating more fruit and vegetables, what is there left to do than make efforts to reduce the carcinogens that surround us."

Genetic predisposition accounts for approximately 5% of breast cancers, but, as Professor Coombes posed, what about the other 95% of women? Given similar city environment, diet, habits and lifestyles, why is it that some women get breast cancer and others don't?

In conclusion he said, "I don't think it is too far fetched to say that reduction in breast cancer incidence could result from cleaning up the environment...in the absence of evidence."

Professor Andrew Watterson of Sterling University spoke of lack of attention given to occupational health risks and the hazards women face both in the workplace, in the home and in the wider environment. This "triple jeopardy" indicates "we need to look at the exposures that might occur in the workplace and then the home and then the wider environment".

Also setting standards for acceptable risks of exposure is often done on white males aged 18-25, women are often the "invisible group". But it is ironic that it is this "invisible group" including representatives from NGO's and a variety of environmental and women's groups which is leading the way on prevention.

There is also a “big mismatch between what people want and the scientific agenda.” He argued for the scientific agenda to be changed to one of precaution, reminding us that if we wait to cross every t and dot every i, to go into detailed epidemiological studies on every cluster and every chemical, however good the epidemiologists are, they are not going to be able to address the problem.

“Will we be doing harm by reducing pollution? No. If we create a cleaner environment will we be doing any harm? No. If we adopt toxic reduction programmes, will we be doing any harm? No. So, if we wanted to use the precautionary principle to stop known and suspected carcinogens that would be a sensible policy, “ he concluded.

Themes from Discussion

A general consensus was reached that we need a new independent working group /committee/ organisation that might push this agenda forward. This needs to include:

- A National Strategy and separate funding for primary prevention.
- A new infrastructure with a multi-disciplinarian approach involving all stakeholders.
 - This group could:
 - Bring together all groups looking at hormonal cancers.
 - Ensure that, prevention, which is now marginal, is a central focus.
 - Involve and build alliances with community and consumer groups especially those who have been working on the issue already.
 - Work on strategies to reduce chemicals.
 - Call for implementation of the Precautionary Principle.
 - Investigate ways of using new Human Rights legislation as a tool.
 - Ensure that prevention that is currently being carried out by women in private is put on the public health agenda.
 - Mobilise public opinion.
 - Utilise existing bodies such as the Science and Technology Committee to push this agenda forward.
 - Look at what is being done already on primary prevention and where we can input new ideas for future strategies.
 - Provide information so that people can make informed choices and participate in the debate.
 - Call for action on prevention before, or as well as, research.

In terms of research:

- Promote the idea that primary prevention needs to be separate from treatment/research agenda.
- Amend the National Cancer Plan to include primary prevention and review the limitations of genetic testing.
- Advocate testing of breast tissue for chemical contaminants.
- Take action to ensure that there is a bigger margin of risk built into assessment of chemicals.
- Bear in mind and publicise the gender dimension in research.
- Take into account the narrative as well as the toxicological evidence.
- Advocate proper training of people in the area of primary prevention.
- Make sure research and findings get disseminated across disciplines to broaden focus.
- Investigate the role of drug companies in the research agenda.
- Encourage a broader research agenda that includes previously neglected areas of research.

In summary it was felt:

- We need to reform those organisations with responsibility for health and make them more accountable and responsible to citizens to make sure they reflect the interest of those they represent.
- We need to remember the political nature of the agenda and make sure those who represent us at government level, both local and national, are aware of the issues that concern us. This is a collective issue, not individual, and it needs a collective solution.
- We are the ones we have been waiting for!

A possible idea mooted for funding such an initiative was to get pharmaceutical companies to donate 1% of their profits to government to fund an independent working group on prevention.

“Imagine a woman standing by an icy mountain river. A team of four risk assessors stand behind her, reviewing the situation. The toxicologist says that she ought to wade across the river, because it is not toxic, only cold. The cardiologist says she ought to cross the river, because she looks to be young and not already chilled. Her risk of cardiac arrest, therefore, is low.

The hydrologist says she ought to cross the river, because he has seen other rivers like this, and probably this one is not more than four feet deep and it probably has no whirlpools at this location. Finally, the Environmental Protection Agency (USA Organisation) policy specialist says that the woman ought to cross the river, because compared to global warming, ozone depletion, and loss of species diversity, the risks of her crossing are trivial.

The woman refuses to wade across. “Why?” the risk assessors ask. They show her their calculations, condescendingly explaining to her that her risk of dying while wading across the river is one in forty million.

The woman refuses to cross. “Why?” the risk assessors ask again, frustrated by this woman who clearly doesn't understand the nature of risks. The woman points upstream and says, “Because there is a bridge.”

(Mary O'Brien – Alternatives Assessment: part of Operationalising and Institutionising the Precautionary Principle).

In appreciation of the fact that many were unable to attend the forum because of flooding and/or reduced rail services, we're sending the enclosed report to everyone listed below for whom we have an address. This is not a definitive list. Please let us know of any errors or omissions.

FORUM PARTICIPANTS

CHAIR: Jane Stephenson
Chair of the Board, United Kingdom Breast Cancer Coalition (UKBCC)

SPEAKERS: Helen Lynn, WEN Health Co-ordinator
Diana Ward, Steering group member WEN's breast cancer project
Professor Charles Coombes, Director Cancer Research Campaign Laboratory
Professor Klim McPherson, Professor of Public Health Epidemiology, London School of Hygiene and Tropical Medicine

Professor Andrew Watterson, Head of Occupational and Environmental
Research Group, Stirling University

IN ATTENDANCE: *Alice Mahon MP, *Joan Ruddock MP.

INDIVIDUALS:

Judy Adams, *Lake District*; Angela Caplan, *London*; Kate Cawley; Shirly Cremin-Cullen, *Birmingham*;
Dr. Phillipa Darbre, *School of Animal and Microbial Sciences, University of Reading*; Ruth Doniach-
Durant, *Middlesex*; Dianne Dowling, *Devon*; Martine Drake, *Middlesex University*; Joan Hammond,
Cardiff; Lesley Johnson, *Oxfordshire*; Felicity Mankin, *London*; Chris Newman, *London*; Jo Noble;
Fionola O'Driscoll, *London*; Gillian Pollard, *London*.

REPRESENTATIVES OF ORGANISATIONS:

Judith Brodie, *CancerBACUP* David Buffin, *Pesticides Action Network (PAN-UK)*
Michelle Burton, *Soil Association* Charlotte Cole, *The Women's Press*
Penny Craddock, Director, *Women's National Cancer Control Campaign (WNCCC)*
Alison Craig, *PEX* Anna Craven, *Oxfordshire Cancer Services Advisory Group*
Dr. Jack Cuzick, *Imperial Cancer Research Fund* Elizabeth Davies, Director *UKBCC*
Jill Day, Regional Women's Officer (East Midlands) *Unison*
Maureen Dennis, *Lincolnshire Against Cancer & Green Network*
Clare Dimmer, Secretary *BREAST UK* Gloria Freilich, Director *Cancerkin*
Sahra Gibbon, Forum Volunteer; *WEN*,
Heather Goodare, Chair *BREAST UK* Wendy Hachmoller, *IC-I Health Rights*
Yvonne Kershaw, *Lincolnshire Against Cancer & Green Network*
Kathryn Leebron-Smyth, *Cancerkin* Ann Link, Co-ordinator *WEN*
Jean Muir, *WEN member* Carol Newman *Age Concern* Alun Owen, *TUC-Unison Wrexham*, Kathy
Page - *BREAST UK*,
Dr. Santilal Parbhoo - Director, *Cancerkin* Enrica Passafonti, volunteer *WEN* Laura Potts, *Free
Radicals*
Judith Spencer-Knott, *Macmillan Cancer Relief* Liz Sutton Press/Information Officer *WEN*
Janet Veitch, *Women's National Commission* Dr. R. Walker, *Tenovus Cancer Information Centre
Cardiff*
Gwynne Wallis, *WEN Local Group Southampton* Arlene Wilkie, *Breast Cancer Campaign*.

APOLOGIES

Maria Adebowale - Director, Environmental law Foundation.
Catherine Ball - *WEN Local Group Kent*.
Professor Valerie Beral - Director, *ICRF Cancer Epidemiology Unit, University of Oxford*.
Deborah Burton - *Ban Lindane campaign*.
Rhoda Cansick - *Devon*.
Vera Chaney - *Green Network*
Sue Clarke - *Healthcare Practice R&D Unit, Salford University*.
Dr. Rosy Daniel - *Bristol Cancer Help Centre*.
Professor Lesley Doyal - *School of Policy Studies, University of Bristol*.
Patricuia Fairbrother - Board member *UKBCC*.
Mary Foster - Board member *UKBCC*.
Dr Eva Gamarnikow - *Policy Studies, Institute of Education London*.
*Nusrat Ui Ghani - *Breakthrough Breast Cancer*.
Lone Hummelshoj - *Endometriosis Association*.
Sarah Illingworth - Board member *UKBCC*.
Dr. Ann Johnson - *Hon. Consultant Surgical Oncologist, Mt Vernon Hospital*.
Margaret King - Board member *UKBCC*.
Dr. Jackie Lukes - *Hull University*.

Audrey Lyndley - Free Radicals.
Gwynne Lyons - World Wide Fund for Nature (WWF).
Sara Marsden - National Health and Safety Co-ordinator, T&GW Union.
Sara Mckenna - Board member UKBCC.
Cherry Mackie - Lynda Jackson Macmillan Centre, Mt. Vernon Hospital.
Fiona McTaggart - WEN member.
Heather McIntosh - NHS Centre for Reviews and Dissemination; University of York
Professor Gordon McVie - Director General, Cancer Research Campaign.
Delyth Morgan - Director, Breakthrough Breast Cancer.
Dame Gill Oliver - Director of Service Development, Macmillan Cancer Relief.
Suzannah Olivier - Author.
Rory O'Neill - Editor "Hazards" Magazine.
Joan Oram - Bradley Environmental Action Team.
Laura Patterson - Fawcett Society.
Dr. Cathy Read - Senior Registrar Public Health Medicine, SchARR.
Johanna Rowe - WEN Local Group, Berkshire.
Teresa Tate - Medical Advisor, Marie Curie Cancer Care.
Mary Taylor - FOE.
Owen Tudor - TUC.
Scottish Breast Cancer Care.
Dr. Michael Warhurst - FOE.
Nicholas Young - Chief Executive, Macmillan Cancer Relief.

M.P's: Bob Ainsworth, Dr. Peter Brand, Roger Castle, *Yvonne Cooper - Minister for Public Health, Ian Duncan-Smith, Louise Ellman, *Linda Gilroy, John Gummer, Mike Hancock, Baroness Jay of Paddington - Minister for Women, Ieuan Wyn Jones, Michael Lord, Dr. Doug Naysmith, David Rendel, Marion Roe, Dennis Skinner, Richard Squire, Rachel Squirry, *Dr. Jenny Tonge, Jim Wallace.
*Member of All Party Parliamentary Group on Breast Cancer (APPGBC).