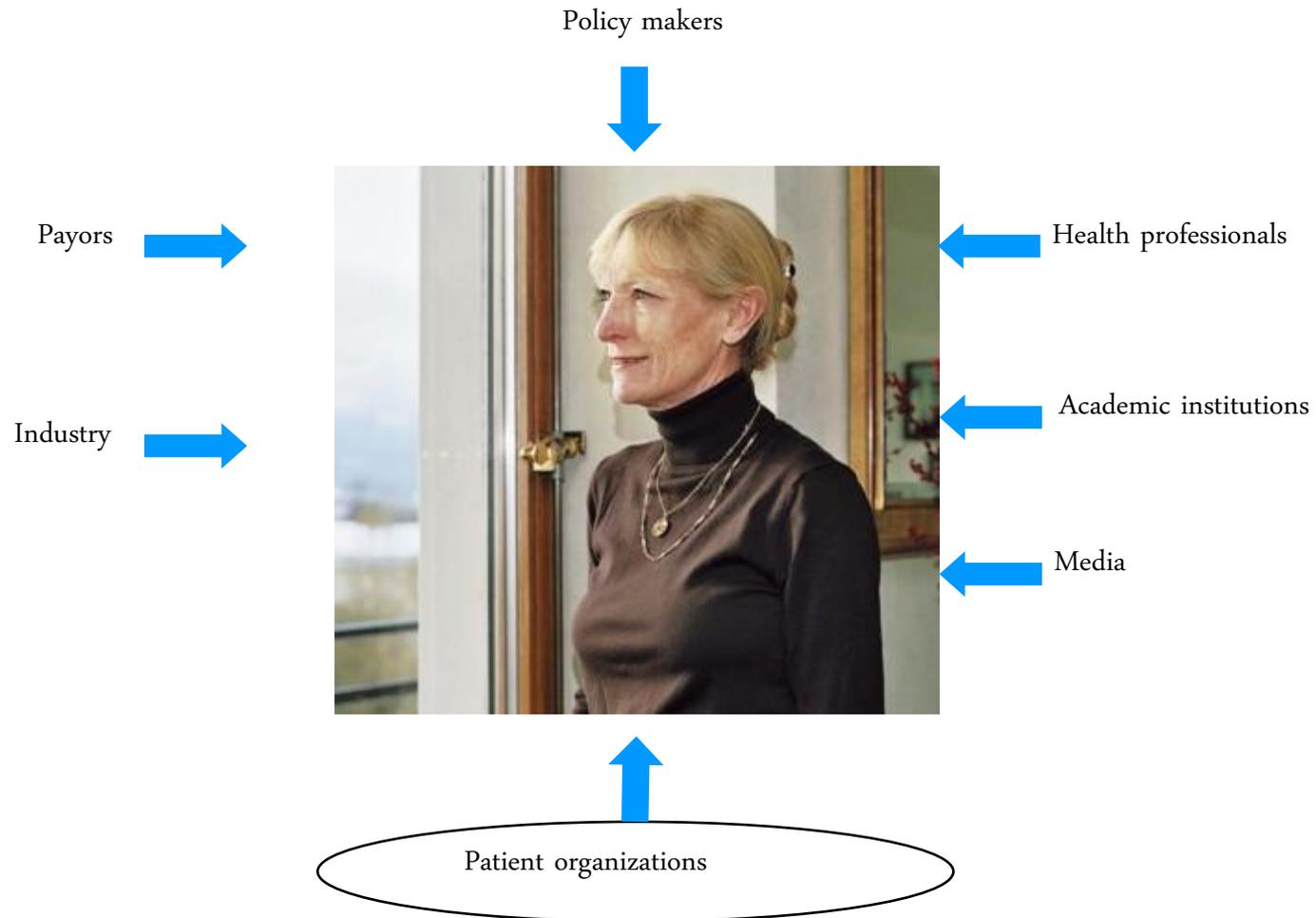


Cancer Advocacy

Jean Mossman

Moscow, 3 February 2011

Many players influence patient care



The role of cancer patient organisations

- Cancer patient organisations have an important role to play
 - Providing information to help patients and their carers cope with what they will face
 - Helping patients cope with practical challenges
 - Providing emotional support
 - Giving advice on how to take medicines
 - Helping patients make choices during their treatment
 - Telling patients about best care
 - Providing links to other patients
 - Represent patients' and carers' views to a range of stakeholders



Why I became interested in moving CancerBACUP into patient advocacy

In the UK before 1998 survival rates for cancer patients were poor.

- Cancer services were affected by
 - Uneven access to treatment (postcode prescribing)
 - Shortage of cancer-trained staff
 - Funding problems
 - Shortage of radiotherapy machines
 - Shortage of diagnostic equipment
- In CancerBACUP we answered around 35,000 calls to nurses each year
 - Recorded the subject of enquiry
 - Heard about access problems
 - Clinicians unwilling to speak out

CANCER WAS NOT A PRIORITY FOR GOVERNMENT

The concept of advocacy

Information

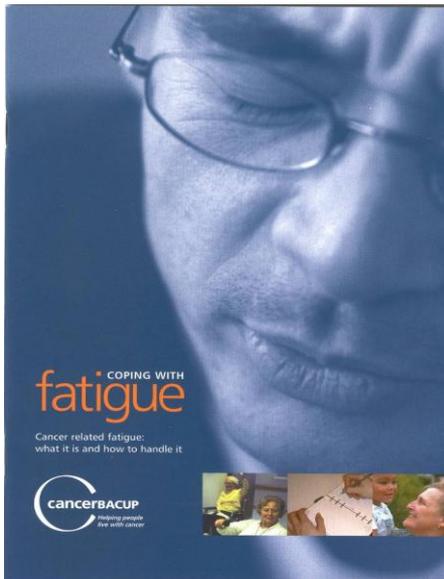
Helps individual patients understand what is happening

continuum



Advocacy

Individuals and groups use information to press for better care



One in three authorities in breach of cancer guidelines

ONE IN THREE health authorities has failed to commit itself to paying for the best treatment for ovarian cancer, in contravention of official guidelines.

Research commissioned by the cancer charity Cancerbacup shows that the authorities have not included Taxol, a drug originally derived from the Pacific yew tree, for all women who could benefit from it in their cancer plans.

Taxol has been shown to improve survival in women with advanced ovarian cancer by a year but many health authorities have refused to pay the £10,000 per head annual cost of the drug until more evidence is available. This led to a flurry of reports of "postcode prescribing" with patients in one health authority provided with the

BY JEREMY LAURANCE
Health Editor

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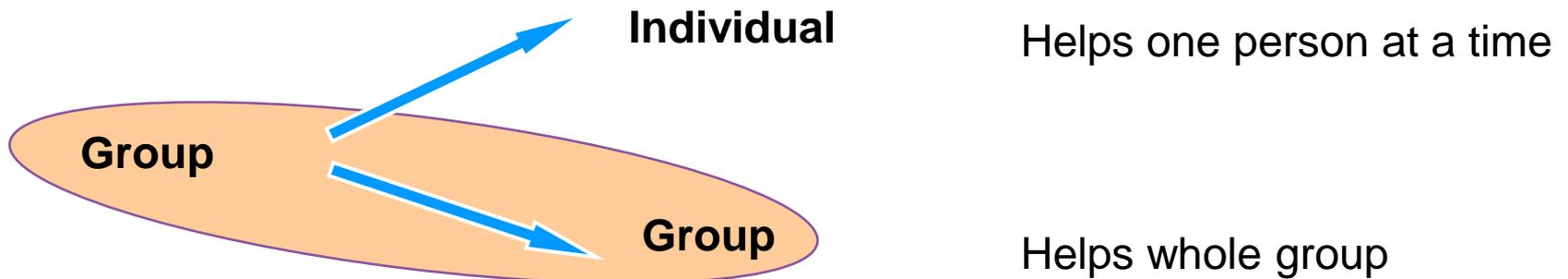
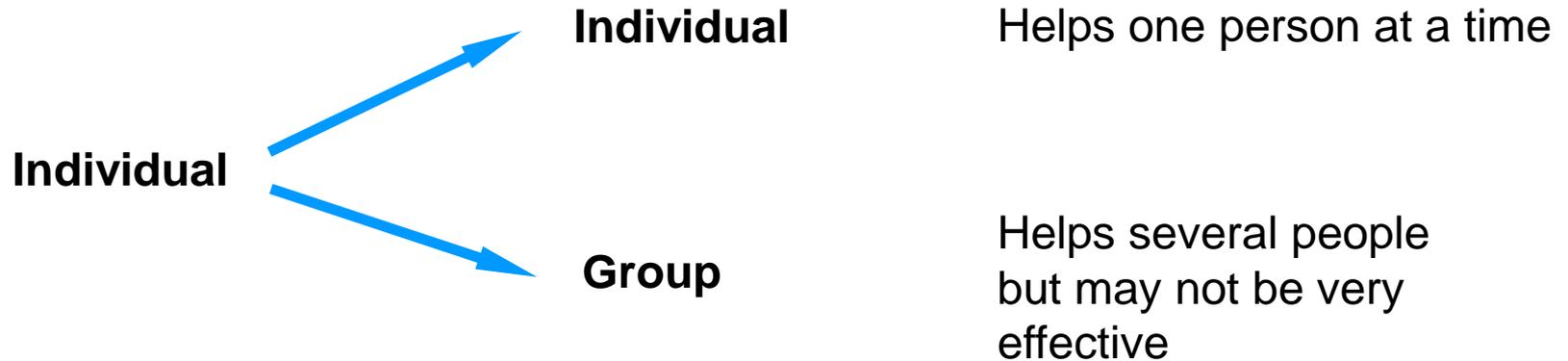
Guidance from the National Cancer Guidelines Steering Group issued last July recommended that paclitaxel (Taxol) combined with platinum should be the first-line treatment for ovarian cancer. The research by Cancerbacup found all health authorities were aware of the guidelines but only two-thirds were following them. The National Institute for Clinical Excellence, the government body responsible for issuing advice on new treatments, is due to report on Taxol and the other taxanes in the spring.

Jean Mossman, chief executive of Cancerbacup, said:

"Official guidelines and recommendations must be updated and implemented quickly to avoid delays in access to innovative treatments. The difficulties NHS patients have experienced in getting paclitaxel, or in the provision of advanced radiotherapy for lung cancer, typify the problems that may otherwise occur in the future."

Professor Peter Selby, director of clinical research at the Imperial Cancer Research Fund, said: "We are pleased to see that the Government has made some commitments, but cancer services need new money to make a real difference. We must have high-quality care available for all cancer patients and that will, without doubt, cost more than we are currently spending."

Advocacy in action



Excellence and equity in cancer care

A comprehensive cancer strategy

- Improve the prevention of cancer
- Ensure equal access to the highest standards of care
- Provide patient-centred care through the NHS
- Increase government spending on a national agenda for cancer research
- Develop better treatments and implement them quickly

Some achievements

- Established a parliamentary cancer group and annual meeting 'Britain Against Cancer'
- Pressed for access to treatment for ovarian cancer patients and subsequent treatments for range of cancers
- Government made cancer a priority
 - National Cancer Plan
 - Increased funding
 - More staff
 - More equipment
 - Standards for time to diagnosis and treatment

Patient groups can influence at many levels

- NHS Cancer Care Working Party
- NHS Cancer Information Strategy Steering Group
- Steering Group to develop NHS user surveys in cancer
- NHS Direct Online Advisory Group
- NHS Direct Working Group
- International Union Against Cancer COPES Programme Steering Committee
- UKCCCR (now NCRI) Breast Subcommittee
- British Oncological Association Council member
- Reviewer for British Journal of Cancer & European Journal of Cancer

All Party Group on Cancer

Briefing Number One

This briefing is the first in a series of bulletins which will be sent out by the All Party Group on Cancer to all MPs, providing them with relevant and concise information on cancer treatment and research developments.

One of the main initial requests received by the Officers of the Group has been for clear and up-to-date cancer statistics. This first briefing sets out some key figures.

Cancer in the UK

Cancer is the major cause of death in the UK. 1 in 3 people will get cancer at some stage in their lives and approximately 160,000 people will die from cancer each year (Cancer research Campaign Factsheet; Mortality UK 1994).

Survival for cancer patients in the UK is worse than the European average for all the major solid tumours (i.e. excluding cancers of the blood and lymph systems) with a few exceptions such as stomach cancer. Examples are given in Table 1 and Table 2.

It was concern at data such as this that prompted the Calman-Hine review of cancer services, which was published in 1995 (the APG considered the

current state of implementation around the country of this review at its second meeting in July 1998). The Calman-Hine Report identified the need to provide good quality cancer care across the country, irrespective of location or ability to pay. Central to its recommendations was the need to standardise treatment and to develop protocols for management that would be applied widely.

Surgery remains the primary treatment for solid tumours. However, for those cancers that have spread beyond the initial site, treatment additional to surgery is required (known as adjuvant therapy). In the UK, the provision of adjuvant therapy is substantially lower than in much of Europe (see Table 3). The average spend per person on chemotherapy is £0.95 in the UK, compared to £1.29 in France and £6.24 in Germany.

Statistics Bulletin

September
1998



- Founded in 1998 to keep cancer at the top of the political agenda, the APPG on cancer brings politicians together to help improve cancer services
- Funding from multiple pharma companies

Table 1: Survival Rates

Tumour Site	Eng.& Wales	USA	Switzerland	Denmark	Finland	France	Germany	Italy
Oesophagus	7%	11%	6.3%	15.0%	6.4%	4.9%	7.3%	4%
Lung	4%	14%	11.8%	6.2%	9.1%	8.7%	8.1%	6%
Kidney	35%	59%	46.9%	31.4%	35.9%	41.0%	52.7%	46.7%
Stomach	8%	21%	23.3%	11.6%	15.9%	17.2%	19.3%	16.3%
Bowel	42%	61%	48.5%	35.4%	40.7%	37.7%	37.6%	31.9%
Pancreas	2%	4%	2.8%	2.6%	2.0%	3.0%	6.2%	2.4%
Brain	8%	29%	13.1%	11.4%	22.9%	not available	17.2%	12.6%
Breast	68%	84%	75.7%	68.1%	73.5%	71.4%	68.4%	70.8%
Cervix	65%	69%	64.5%	61%	62.3%	64%	61.3%	64%
Ovary	29%	46%	28.9%	26%	34%	31.4%	31.7%	36.9%



LIVING WITH OVARIAN CANCER

A CancerBACUP
Care Survey

PRODUCED FOR CancerBACUP BY
PROFESSOR DAVID TAYLOR AND JEAN MOSSMAN

- Health authority survey
- Anonymous return – no ‘naming and shaming’
- Circulated to Health Authority Chief Executives & Chairmen and parliamentarians

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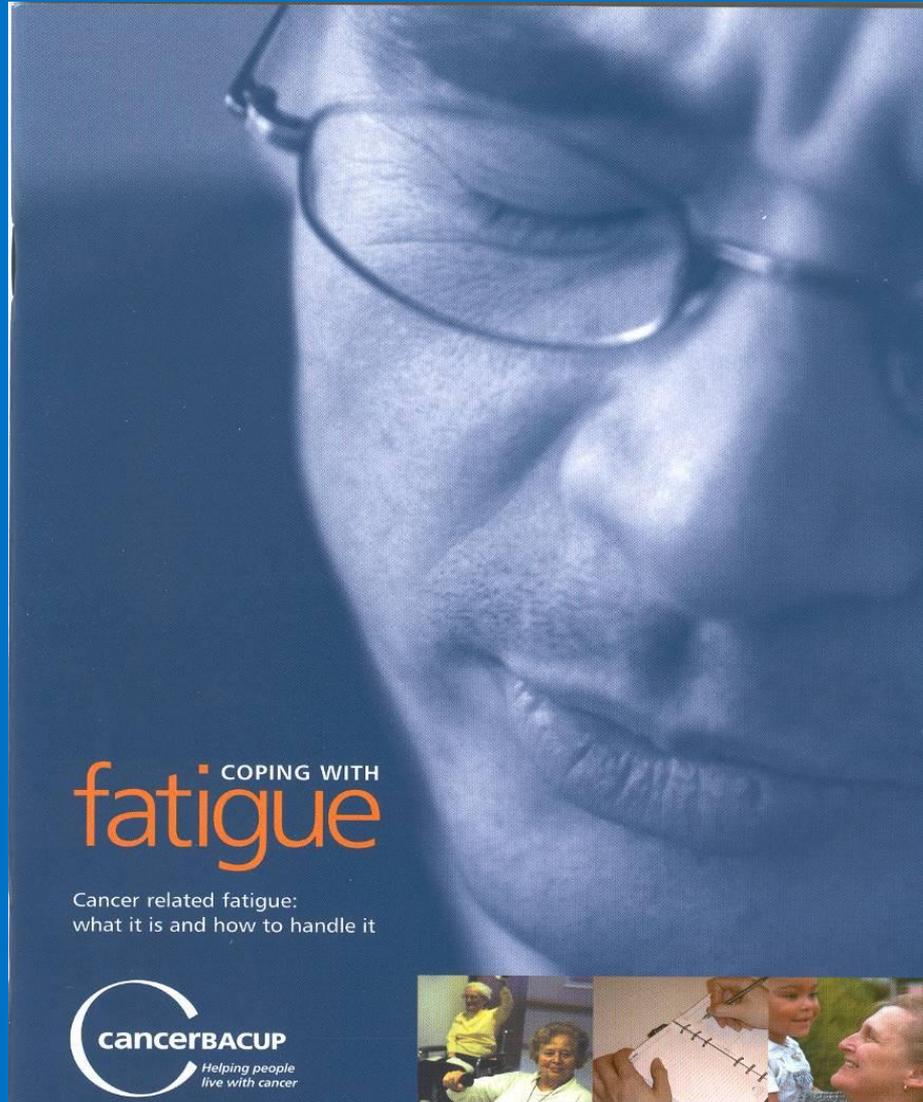
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Patient Information Campaigns



- CancerBACUP Fatigue Campaign
- Started with two booklets produced by industry
- CancerBACUP edited and produced 'Coping with Fatigue'
- Updated and revised
- One of most popular booklets

Grass roots advocacy

- Train patients and carers to be effective representatives
- Involve them in local decision making processes
- Letter writing campaign
- Take leaflet to own doctor
- Tell story to local media

Advocacy voice gets stronger: Women in the UK fighting for Herceptin

Herceptin campaign to be raised with minister



DIETED HERCEPTIN: clockwise from above left, Mary Peets, Alison Poole, Dorothy Griffiths, Lynn Burton, Elaine Barber and Jo-anna Lease

MPs join battle for cancer drug

BY EMMA FITZGERALD

NORTH Staffordshire's MPs have met to decide their action plan for lobbying the Government and health officials for the breast cancer drug Herceptin. They discussed the life-saving treatment as they threw their sup-

portunities and has been kept alive by the drug for the past four years. The 50-year-old believes there are at least 20 women waiting for the drug in North Staffordshire.

Other breast cancer sufferers involved in the campaign include Mary Peets, Elaine Barber, Alison Poole, Lynn Burton and Jo-anna Lease.

prepared to get as many women as possible and march to Parliament if we need to.

"He said he hopes that won't be necessary and we're just hoping he's right and the MPs will be able to get the NCT to fund this."

Mr Farrelly said the MPs agreed to seek a meeting with local health officials over the summer.

Department for Culture, Media and Sport



Don't put your business at risk!

Only 3 weeks left to apply for your new licence.

If you sell, supply or provide:

- alcohol;
- public entertainment;
- hot food or drink after 11pm

You need a new licence or certificate - even if you already have one.

Licensing laws are changing. Don't run the risk of going out of business.

You must act now to meet 6 August 2005 deadline.

For an application form, help in applying, or more information contact your local authority licensing team or visit www.culture.gov.uk/alcohol_and_entertainment

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Date	Airport	Destination	Nts	Cash & hand	Price*
29 Jul 05	Birmingham	Crete	4	1 st 5K	£350
05 Aug 05	Manchester	Samos	7	2 nd 5K	£270
07 Aug 05	Birmingham	Costa Brava	7	2 nd 5K	£284
05 Aug 05	Manchester	Skioshva	7	3 rd 5K	£285
16 Jul 05	Birmingham	Costa Blanca	7	2 nd 5K	£294
04 Aug 05	East Midlands	Azores	7	2 nd 5K	£299
05 Aug 05	Manchester	Corfu	7	2 nd 5K	£324
02 Aug 05	Birmingham	Turkey	14	2 nd 08	£330

Campaigning materials available

RESOURCES FOR MODULE 1:

- [Building your case for change in the new NHS \(3826 kb\)](#) 
- [Lobbying and Influencing Decision Makers \(1492 kb\)](#) 
- [Lobbying and Influencing Decision Makers workshop handout \(22 kb\)](#) 
- [Mobilising your Membership workshop presentation \(1573 kb\)](#) 
- [Personalised medicine seminar presentation \(415 kb\)](#) 
- [Research Matters campaign briefing \(285 kb\)](#) 
- [Social Media Campaigners Toolkit \(4199 kb\)](#) 
- [Winning Ways Slides \(1298 kb\)](#) 
- [Winning Ways Workshop handout \(470 kb\)](#) 

Now you've planned what you're going to do next, get the tools and resources you need to make difference in [Module 2: Building a Relationship with your MP](#) and [Module 3: Make an impact with your Campaign Report](#).



The beginnings of cancer advocacy in Europe

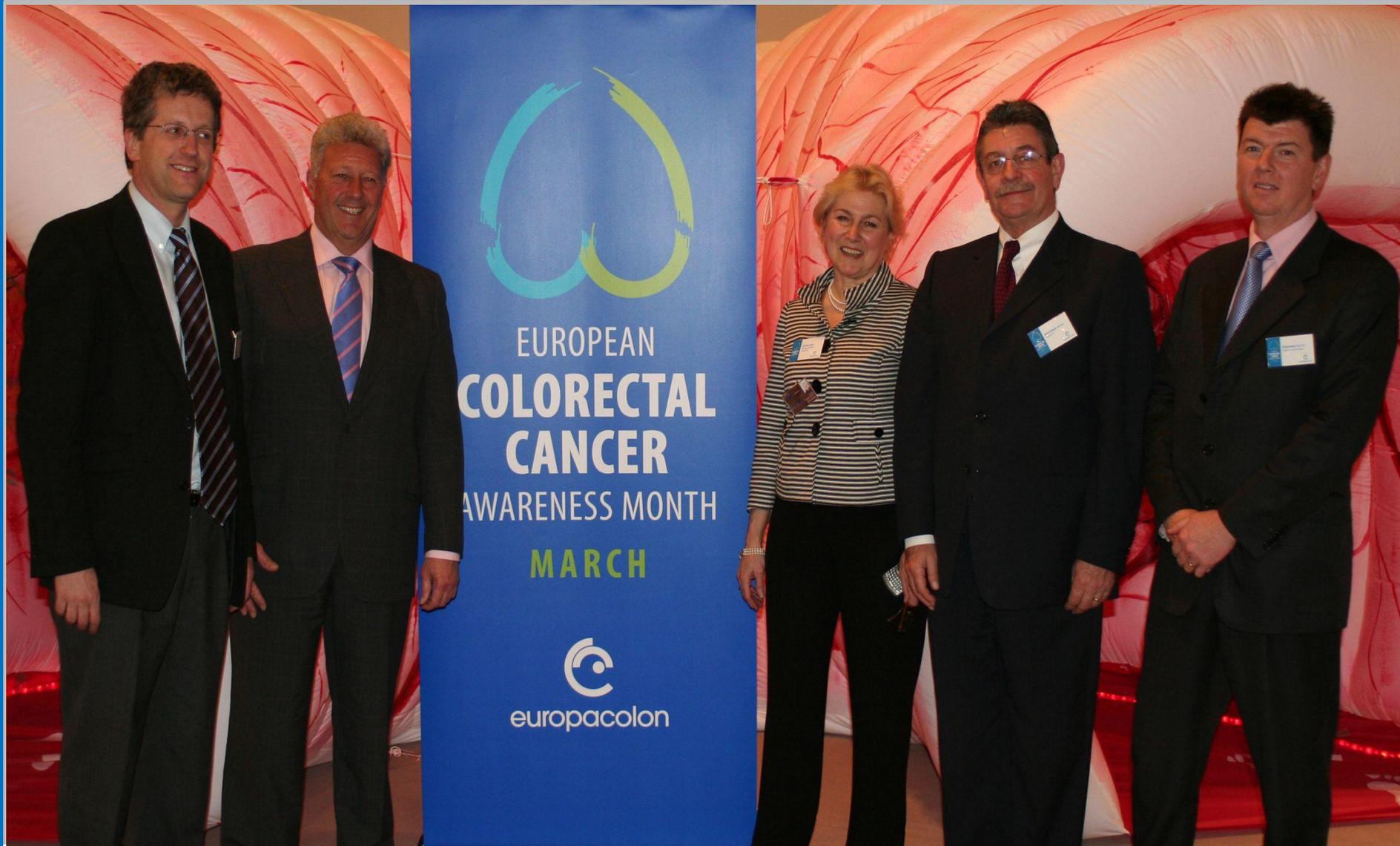
A REPORT ON THE

First World Conference On Breast Cancer Advocacy— Influencing Change

**March 13 - 16, 1997
Brussels, Belgium**



European Colorectal Cancer Awareness Month 2008



Lessons learnt

- Advocacy is a powerful tool
 - It has made a real difference for cancer patients and their carers in Europe
- Take ideas from other cancer groups, other diseases, other areas
 - Keep an eye on what gets coverage
- Campaigns take energy and enthusiasm
 - You need these to get other people interested
- Preparation is key to success
 - Plan carefully
- Make sure you have case studies and spokespeople ready
 - Media training makes a difference
- Don't be caught out
 - Prepare for disasters
- Campaigns are long term

The patient voice is strong

“As breast cancer survivors, we are in the best position to fight for and insist on better screening, diagnostic and treatment facilities as well as continued research to find a cure for this disease.”



Susan Knox

Executive Director, Europa Donna

Summary

- Advocacy can make a real difference to cancer patients
 - Not an overnight change
- Need to be organised
 - Have a clear set of goals
 - Work in partnership where you can
- Learn from the experience of others
 - Many different approaches you can use
- Celebrate success