



# **The need for improvement in cancer treatment: Patients' Perspective**

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# Facts about breast cancer in Sweden and BRO

- 33 local organizations with 11 000 members
- National Health Insurance
- BRO has governmental funding
- National cancer registry since 1958
- 6800 breast cancer diagnoses and 1500 deaths
- 5-year survival app. 90 %
- Appr. 89 000 breast cancer survivors
- Law on tissue banking

# Stating the obvious: there is a need for improvement in cancer treatment

- Cancer is a complex and devastating illness which impacts the whole of a patient's life.
- Cancer touches every family in Europe: every minute another three families lose someone they love to cancer.
- Many of these deaths could be avoided if the cancer was detected early.
- Many of these deaths could be avoided if the best treatment and care was available to all patients.

# The patient's despair:

- Mostly no experience of cancer
- Not knowing about common symptoms
- Not knowing what questions to ask the doctor
- Difficulties in making decisions about treatment
- Fear of death sentence

# Hope for the future

- It is now possible to make dramatic worldwide strides against cancer—even in the poorest countries—through public health efforts targeting prevention and early detection, as well as advances in cancer treatment. The opportunity for collective action has never been greater and the need has never been more urgent;

**World Cancer Declaration 2006**

# Mobilizing individuals for action

- Increase the number of opportunities that empower people living with cancer and those touched by cancer to fully participate in community, regional, and country cancer control efforts. Examples include training (e.g., media and advocacy) and partnership development (e.g., coalition building and collaboration) that create compelling voices for action.

**World Cancer Declaration 2006**

# Actions of the cancer patient organisations in Sweden

- From Comforting Comrades to Powerful Partners through:
- Empowerment
- Advocacy
- Awareness
- Lobbying
- Fundraising

# Example of actions:

- Empower patients - active and well-informed patients get better treatment and better results
- Empower families and friends
- Raising awareness
- Lobbying for screening and better treatment
- Support - no-one should face a cancer diagnosis alone

# Mobilizing for a national cancer control strategy

- Consensus from 8 patients organisations
- Informal network since 8-10 years
- Started off by uniting in a consensus document
- Main goals to achieve a national cancer control strategy and to secure patients' associations influence on national cancer control strategy
- Decision about national cancer control strategy by the government
- Implementation ongoing

# Second goals

- Prevention
- Screening
- Shorter waiting times
- Improved information
- Eradicating regional differences
- More resources for care and research
- Information about second opinion

# Advocacy actions and support provided today

- Help lines
- Open house
- Support groups
- Web site with <100 000 hits a month:
  - Information about breast cancer
  - Information about the right to second opinion
  - Three sets of questions to ask
  - Ask the breast cancer specialist

# What patients and advocates can do

- Contribute to better treatment
- Partner with doctors and nurses
- Contribute to better care
- Influence politicians and policy makers
- Help other patients
- Fundraising
- Contribute to increased awareness
- Promote a healthier life style
- Participate in clinical trials

# Hope for the future

- The new vision of the world cancer control community is a world where cancer is eliminated as a major threat for future generations. It is a world where cancer control knowledge and competencies are equitable, shared and accessible, where new scientific findings are transferred to clinical settings, where disparities in prevention, early detection, treatment, and cure of cancers are systematically reduced and eventually eliminated, and where all cancer patients receive the best possible care.
- **World Cancer Declaration 2006**