# Advocate Power Grows in Breast Cancer Research

Massive increases in the funding of breast cancer research have been achieved in America by the pressure group, the National Breast Cancer Coalition (NBCC). In just 4 years the NBCC boosted the U.S. government annual spending on breast cancer research 6-fold —from $87 million to more than $530 million. They want $2.6 billion invested between now and the year 2000.

But NBCC members also want to work in partnership with scientists and clinicians to decide what research gets done—a power some scientists view as inappropriate. The NBCC believe that breast cancer advocates should have "a seat at the table" in research decisions in all countries. This became clear at the first World Conference on Breast Cancer Advocacy held in Brussels recently, where advocates were encouraged to develop strategies to change the way breast cancer research and treatment is carried out all over the world.

In the U.S.A., the NBCC engineered not only expansion of National Cancer Institute funds, but, after a fight, a huge fund for breast cancer research coming under the defence budget. Ms Frances Visco, President of the NBCC, said, "We brought about the multi-million dollar breast cancer research programme within the department of defence that has now attracted 7000 research proposals." And even more revolutionary, "consumers"—women with, or who have had breast cancer and represent a group of other women—have a "seat at the table" in the allocation of that money.

Initially, the U.S. scientific establishment was unhappy at having consumers involved in the selection and prioritising of research. Former Congress woman, Ms Pat Schroeder, said, "The scientists were terribly threatened by this, and accused the consumer representatives of politicising Science." However, in the 1980s auditors of previously funded NIH research were severely critical of the breast cancer research (according to Ms Schroeder, only one trial was found and that was in men and male rats were used in pre-clinical studies). Since this sort of oddity had not changed when the auditors went back 3 years later, the scientific establishment could no longer patronise consumers off research-selection panels.

Ms Ngina Lythcott, U.S.A., Dean of Swarthmore College in Swarthmore, Pennsylvania, said that the breast cancer research funding in the Department of Defence did not always require prior data, unlike the NCI. The NBCC viewed this as an opportunity to broaden research and start really innovative research that addressed consumer concerns. Most recently the three major funding priorities have been:

- First ideas grants.
- Training grants for scientists.
- Translational research.

Ms Lythcott said "We recognise the importance of good Science and insist that the research we fund always follows the rigours of good Science. We believe consumers bring to the conversation what the breast cancer priorities of survivors are. In working with scientists we have found they also want to see what breast cancer survivors would like to see worked out in terms of research."

The NBCC "Project LEAD" is likely to be a good source of advocates trained to be involved in such decisions. Project LEAD is a programme that educates advocates in basic scientific and medical language and concepts, and in the way breast cancer research decisions are made. (Project LEAD stands for Leadership, Education and Advocacy Development.) Project LEAD graduates seek out and participate on a research board, section or committee. This way informed, educated advocates bring consumer views to the process of research.

At the Brussels meeting, approximately 270 advocates from all over Europe and the rest of the world studied the American model. It is therefore likely that research funding panels all over Europe will feel increasingly sophisticated pressure to include consumers in their decisions. In return, they could perhaps benefit from the extra funding that political pressure applied by powerful advocacy can generate.

## From Europe

# EORTC Board for 1997–2000

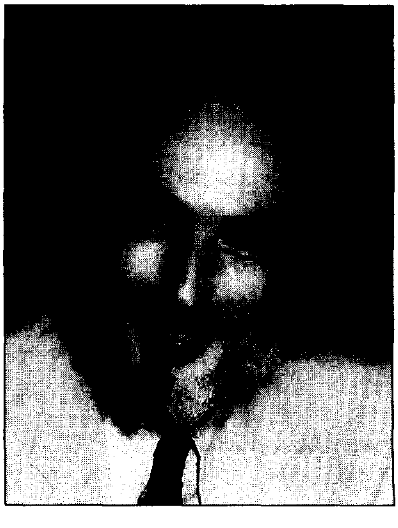
The European Organisation for Research and Treatment of Cancer (EORTC) has elected a new EORTC Board to lead it through to the millennium.

The major changes will be reported in this issue and the next issue of the Journal. This issue announces the new President, Vice-President, Secretary General, and Treasurer of the EORTC, as well as the new Director of the EORTC Data Centre. The next issue announces the new chairmen of the various committees and divisions.

*President: Professor Jean-Claude Horiot*

Professor Jean-Claude Horiot has held the position of Professor of Radiotherapy at the University of Dijon since 1972, becoming Head of the Department of Radiotherapy at the Centre GF Leclerc, Dijon in 1983.

He is President of the Federation of European Cancer Societies (FECS). He is also a Past-President of the European Society for Therapeutic Radiology and Oncology (ESTRO) and President of the International Society for Radiation Oncology (ISRO). He served as Secretary General of the EORTC Board until now, and it was mainly due to his efforts that quality assurance procedures covering the clinical aspects of cancer treatment became one of the priority areas of the EORTC treatment division.



President of the EORTC
Professor Jean-Claude Horiot