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Editorial

In 1996, a certain amount was known about the genetics of breast cancer, specifically about the roles of BRCAl and BRCA2, yet there was virtually no evidence base to inform clinical management decisions. At the same time, publicity surrounding discoveries in the molecular genetics laboratories had raised awareness of the potential significance of family history in determining risk of breast cancer. In many countries, demand for risk assessment and screening led to the establishment of scattered "cancer family clinics", often on an ad-hoc or experimental basis and with little co-ordination of policies, organisation or funding.

This clearly met the definition of a "new development in health care" so an application was made to the EC by a partnership of eleven European centres for Demonstration Programme status. The success of that application provided essential support for exchange of ideas and experience and for the gathering of data on a scale that would have been impossible for any single centre.

For the past three years, the Programme has been carried through in a spirit of friendly and positive collaboration. Despite differences in the organisation of health care across Europe, the issues surrounding provision and evaluation of services for women at risk of familial breast cancer are common to all and the participants have benefited enormously from mutual support.

Besides the eleven partners, many other groups have participated in the Programme meetings and, through the programme, major contributions have been made to National research meetings in Portugal, Turkey and elsewhere. There has been particularly effective outreach to the countries of Eastern Europe, as reflected in their contributions to the final symposium in Heidelberg. This volume brings together the papers given at that meeting, with additional reports of studies directly relevant to the Demonstration Programme.

In addition, the Programme has been influential in providing an extended network of interested professionals supporting them not only within their own professions but also in their interactions with colleagues from other specialities. Examples include establishment of a Hellenic Cancer Genetics Society and an Italian Network of Cancer Genetics Centres.

The most important outcome of the Demonstration Programme is the clear evidence that young women at increased risk of breast cancer benefit from enrolment in a structured clinical/mammographic screening programme. A very large database has been established and the infrastructure is in place for continuing collaborative clinical research to build on this productive beginning.

In the immediate future, work could focus on three issues; first, refinement of individual risk estimates, taking account of major germline predisposing mutations, polymorphisms at potential modifying genes and the influence of environmental factors; second, matching management strategies to specific categories of risk and, third, comprehensive economic evaluation of clinical services for familial cancers.

All of these topics are presaged in this collection of papers which should be of interest to everyone involved in the clinical care of cancer families or in related research. On behalf of all the partners, the editors are pleased to record their gratitude to the EC for the imaginative and timely support that made possible the Programme of work forming the core of this volume.

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