

KCONFAB Q&A

What is kConFab?

The Kathleen Cunningham Foundation Consortium for Research into Familial Aspects of Breast Cancer (kConFab) is a unique research co-operative which brings together epidemiologists, medical oncologists, surgeons, radiation oncologists, molecular biologists, geneticists, genetic counsellors, statisticians, psychologists and pathologists who work together to create a resource to solve pressing clinical, genetic and epidemiological problems of familial breast/ovarian cancer. Almost every research group in Australia with a major commitment to the research of familial breast/ovarian cancer is represented in kConFab.

What are kConFab's aims?

The risk of developing breast cancer is not spread evenly across the population. In Australia, about 120,000 women carry mutations in high risk genes and about half of them will develop breast and/or ovarian cancer. For these women and their families, breast cancer is a genetic disease that strikes particularly hard, often and early. In some families, the exact genetic cause of the disease can be identified – for example a mutation in BRCA1 or BRCA2. But in the majority of families, the gene(s) are still unknown. Our lack of knowledge about familial cancer results in significant decision-making dilemmas for cancer patients, for unaffected individuals who carry known mutations in known genes, and for women with a strong family history but unknown mutation status. These dilemmas can be resolved only through further research studies, in which biological sample and comprehensive genetic, epidemiological, clinical and psychosocial data are collected in a systematic fashion from large numbers of high risk families and made available to the breast cancer researchers around the world. By coordinating the efforts of its members across the entire spectrum of familial breast cancer, kConFab is creating a genetic, biological, epidemiological and clinical resource of immense value to both basic and clinical researchers.

What makes kConFab unique?

kConFab is regarded, both nationally and internationally, as a model for how genetic and epidemiologic studies of this type can and should be done. What makes kConFab unique is the large number of families and individuals who are enrolled in the study and the depth of information available about each of them. Furthermore, researchers who use kConFab material agree to return their results of their research to kConFab after publication, thereby further enhancing the resource. By collecting biological samples, environmental and epidemiological data from affected women and their close relatives of all in these families, kConFab is creating an increasingly powerful resource for researcher to, for example,

- find new genes that cause or contribute to inherited breast cancer

- understand the environmental factors that affect the onset and course of the disease in high risk groups
- more accurately predict the consequences for a person who carries a mutation in BRCA1, BRCA2 or other predisposing genes
- Search for genes that delay or ameliorate breast cancer in women who inherit mutations in high risk genes.
- Improve counselling/psychological support to women/families at high risk
- Improve surveillance and early detection of disease in high risk women

How is kConFab organized?

kConFab has six expert committees, each of which monitors a specific aspect of kConFab's work and develops policies and protocols. For example, our Ethical Reference Committee considers all ethical issues that affect, or arise from, the work of the consortium. The committee prepares Information Sheets, Consent Forms and annual reports that are submitted to Institutional Human Research Ethics Committees at the sites around Australia where kConFab recruits families. The committee also monitors requests from researchers who want to use Kconfab specimens and data to ensure that proposed projects have the appropriate ethical clearances and conform to ethical guidelines. kConFab's other expert committees committee deal with Psychosocial and Clinical issues, Biospecimens, Pathology, Mutation Detection and Review, Database and Analysis.

Each expert committee has one or more representatives on kConFab's Executive Committee, which meets twice each year to review kConFab's ongoing activities and future plans, and to approve changes in policy or procedure.

How does kConFab maintain contact with the breast cancer community?

- A consumer representative is a permanent and influential member of kConFab's chief policy committee – its Executive Committee. At each meeting, the representative, who has full voting rights, reports any issues that may be of concern to the breast cancer community. The representative acts as a liaison between kConFab and major national breast cancer organizations
- kConFab's newsletter, published every six months, is widely distributed within the breast cancer community. The newsletter includes updates on relevant research findings and medical advances, alerts readers to research projects and clinical trials that may be relevant to them, and contains stories of individual women 's experience of breast cancer.
- Many of kConFab's members attend and give talks to - local groups of women with breast cancer; families at high risk of developing the disease; and to community organizations and charities that raise money for breast cancer.

- Finally, kConFab organizes a three-day annual international conference on medical, psychosocial and genetic aspects of familial cancer. In addition to researchers and clinicians, the conference attracts community and consumer representatives at least one of whom gives a presentation.

Who pays for kConFab's work?

All of kConFab's activities are supported by competitive grants from the National Health & Medical Research Council, the State Cancer Councils and the National Breast Cancer Foundation.

Who uses the specimens and data collected by kConFab?

Researchers working anywhere in world may apply to use kConFab specimens and data in ethically, approved, peer-reviewed and funded research projects. At present, kConFab data and materials are supplied free of charge. However, when many samples or large amounts of data are requested, kConFab reserves the right to ask the researcher for funds to cover handling and shipping costs. A list of projects currently supported by kConFab is available at <http://www.kconfab.org/research/index.asp>