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Database of breast cancer biospecimens and familial data

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Overview

The Cooperative Family Registry for Breast Cancer Studies (CFRBCS) is a database of information and biospecimens contributed by more than 5,000 families with a history of breast or breast/ovarian cancer. Established in 1995, the registry is funded by the US National Cancer Institute and collects data from six medical research institutions located in North America, Canada and Australia.

Content

The website is a comprehensive source of information about the registry, its affiliated sites and how to obtain specimens for research purposes. However, the site doesn't contain any core data or statistical information derived from the registry; access to this database is restricted to authorised users (eg principal investigators, committee and working group members, research staff).

The site contains a small amount of information aimed at patients: this explains the purpose and potential usefulness of the registry, and covers issues such as confidentiality and self-referral. The rest of the site is aimed at those involved in clinical research.

The registry can provide a variety of biological specimens, including tissue sections, peripheral blood lymphocytes, cell lines, plasma and pathology slides. It can also provide related family history, clinical, demographic and basic epidemiological data on exposure to risk factors. Further, it can provide follow-up epidemiological data and data on recurrence, new morbidity, and mortality in the participating families. Application forms for biospecimens or information are available on the website, although they must be printed and submitted in the traditional manner.

The site includes a fact sheet - basically a 'FAQs for researchers' - that explains the scope of the registry (ie collecting information and specimens, providing an interdisciplinary research resource, and identifying at-risk groups), how to apply for access to data/specimens and the criteria applied to such applications.

Full contact details and website links are given for all participating registries. The CFRBCS homepage has buttons linking to other subsites within the US National Institutes of Health website. There is no collection of useful or related links.

Miscellaneous

The site is small and well-designed and therefore very easy to navigate (although the navigation bar is missing from some pages). There are few images and little formatting. Access to the database is restricted by password.

Evaluation

The site is an excellent resource for patients and their relatives who have been asked to participate in the registry, and for scientists involved in interdisciplinary research into breast or breast/ovarian cancer. The text is very well written and succeeds in conveying the purpose of the registry and how to apply for samples or enrol as a patient.

References

1. The Cooperative Family Registry for Breast Cancer Studies. [<http://www-dccps.ims.nci.nih.gov/CFRBCS/index.html>]