

# **CGC Update Patient Newsletter**

## **Fall 2001**

Welcome to the Autumn Edition of the CGC newsletter, which brings many new updates in the area of Cancer Genetics. We hope this newsletter finds you and your families happy and healthy.

Sincerely,

Ellen T. Matloff, MS  
Genetic Counselor and Director  
Cancer Genetic Counseling

Karina L. Brierley, MS  
Genetic Counselor  
Cancer Genetic Counseling

## **Researching Your Family History on the Internet**

Many experienced genealogists know that the Internet is a great source of family history information, but for a beginner it can seem daunting and frustrating. This article is an introduction to the resources that are available on the Internet as well as some sites that will help you get started.

### **First steps**

Your family history search should begin with information that you already know or can easily access from your records. Start by recording information (date and place of birth, marital information, etc.) about yourself and your immediate family members. There are some resources on the Internet that can make even these initial steps easier. *Downloadable forms* can help you keep your information neat and orderly. If you have more information to store and organize, there are also various *genealogy software programs*, some of which are available as shareware or as free demos to try out before you buy the complete package. In addition, many of the larger directories have sections for beginners that include a variety of useful tips, articles, reference books, and links to other Internet resources.

### **What's next?**

Once you have recorded and organized all of your readily available information, the next step is to fill in the gaps. The Internet offers a variety of ways to gather additional family history information. Using general search engines to search for your family surname (last name) often produces an overwhelming list of results, many of which will not be useful to you. However, there are some better places to start that are more likely to produce valuable information. Genealogy experts often suggest starting with *census records* and *vital records* (birth, marriage, and death certificates). Although not every census record is available on the Internet, many have been entered into Internet-accessible databases and several projects are working towards making all census records available in this format. In general, only older vital records (prior to 1900) are available on the Internet. However, there are sites that offer forms, instructions, and contact information for obtaining newer records.

### **Additional Internet sources of family history information**

In addition to census and vital records, there are numerous *genealogy-specific databases, directories, and search engines*. The directories provide indexed lists of other Internet sites with genealogical information. Specialized databases contain diverse sources of additional family history information including cemetery transcriptions, church records, military records, land records, and lists of ship's passengers. Genealogy-specific search engines allow you to search only genealogical sites. This can help you narrow your search and avoid sorting through the hundreds of irrelevant sites that can be produced by using general search engines.

The Internet also offers opportunities to expand your search by exchanging information with other individuals who are doing genealogical research. *Mailing lists and message boards* allow individuals to post questions or queries to a wide audience. On these message boards, you can get answers to general genealogy research questions or even get answers to specific questions about your family history from other individuals researching the same surname.

Finally, if you are still unable to find answers to your family history questions, you can expand your search by using general search engines. To make this experience less frustrating and more fruitful, visit some of the genealogy websites that give *tips for more effective use of general search engines* for genealogical research.

## **Internet Resources for Genealogy**

### **Genealogy Directories and Databases**

#### **www.CyndisList.com**

This site is an indexed directory of over 100,000 genealogy sites in over 150 categories. Some categories of interest include a beginner's section, supplies (including forms), "how to", census related sites, search engines, and software and computers.

#### **www.USgenweb.org**

This site is run by a volunteer organization whose mission is to make census records and other genealogical resources available on the Internet. It includes a section called "help for researchers" which has helpful advice and links to other sites for beginners. It also contains searchable databases of transcribed public domain records including census records, wills, and public documents.

#### **genealogy.about.com**

If you can get beyond the distracting advertisements, this site offers a variety of helpful "how to" articles and an indexed directory to numerous genealogy sites including a "beginner's corner" section. One particularly useful article gives hints for using general search engines for genealogical research. This article can be found at [genealogy.about.com/library/weekly/aa041700d.htm](http://genealogy.about.com/library/weekly/aa041700d.htm)

#### **www.familysearch.org**

This site, run by the Church of Jesus Christ of Latter-Day Saints, allows you to search many of the records in their vast database including vital records, census records, and the social security death index. You can also order additional genealogy research materials that are not currently available in their online database.

### **Free Genealogy Forms**

#### **www.ancestry.com**

Downloadable forms are available for free through the “record” tab on this site. The site also has databases and message boards but some services require a subscription fee for access.

**[www.genealogy-mall.com/freechar.htm](http://www.genealogy-mall.com/freechar.htm)**

Several different genealogy forms can be printed directly from this website for free.

### **Genealogy-Specific Search Engines**

**[familytreemaker.genealogy.com/all-search.html](http://familytreemaker.genealogy.com/all-search.html)**

This site includes a search engine called the “internet family finder” which allows you to search an index of websites, family archives, and online data for your family surnames.

**[www.genealogytoolbox.com](http://www.genealogytoolbox.com)**

This site includes a search engine that lets you search genealogy specific websites and it also has an indexed directory that includes alphabetical listings of sites related to specific surnames.

### **Vital Records**

**[www.cdc.gov/nchs/howto/w2w/w2welcom.htm](http://www.cdc.gov/nchs/howto/w2w/w2welcom.htm)**

This site provides instructions, addresses, phone numbers, and prices for obtaining copies of vital records from each state and territory.

**[www.health.state.pa.us/hpa/obd.htm](http://www.health.state.pa.us/hpa/obd.htm)**

This site, run by the Pennsylvania Department of Public Health, contains websites and addresses for obtaining vital records from each state.

## **Research Updates**

### **Is Tamoxifen Effective in Reducing the Risk of Breast Cancer in BRCA1 and BRCA2 Carriers?**

*The American Society of Clinical Oncology Meetings, May 2001 [abstract].*

Dr. Mary Claire King and colleagues studied the 315 cases of breast cancer that developed during the NSABP Breast Cancer Prevention Trial (BCPT). In review, women at high-risk to develop breast cancer based on age, previous biopsy history, or family history were enrolled in the BCPT study and randomized to either tamoxifen or placebo. The trial showed that, overall, tamoxifen was associated with a 49% reduction in the development of breast cancer. The current study demonstrated that of the women who developed breast cancer in the BCPT trial, 8 were BRCA1 carriers [5 on tamoxifen, 3 on placebo] and 11 were BRCA2 carriers [3 on tamoxifen, 8 on placebo]. This study did not provide information about the overall number of BRCA carriers on tamoxifen vs. placebo who did not develop breast cancer. Until we have this information, we are unable to conclude exactly how effective tamoxifen is in reducing the risk of breast cancer in BRCA carriers.

### **The Impact of Prophylactic Bilateral Mastectomy on Breast Cancer Risk in BRCA Carriers**

*NEJM 2001;345(3):159-64.*

This study from the Netherlands followed 139 cancer-free, female BRCA carriers for an average of three years. Of these women, 76 (55%) chose to have prophylactic mastectomy and 63 (45%) chose to be followed by surveillance only. None (0%) of the women who had prophylactic surgery developed breast cancer in this time period, while 8 (12.6%) of the women followed by surveillance developed breast cancer. Of those eight breast cancers, four were associated with at least one positive lymph node. These data suggest that prophylactic mastectomy reduces the risk of breast cancer in BRCA carriers at three years follow-up.

### **Oral Contraceptive Use and the Risk of Ovarian Cancer**

*NEJM 2001;345(4):235-40.*

This analysis of Jewish women in Israel included 840 ovarian cancer patients and 751 women who had never had cancer. 244/840 (29%) of the women with ovarian cancer carried one of the common Jewish BRCA mutations, while only 13/751 (1.7%) of the control population were BRCA carriers. This study found that oral contraceptive use had less of a protective effect in BRCA carriers than in other women. A major limitation of this study, however, is that it included only 13 unaffected BRCA carriers, and therefore cannot draw definitive conclusions regarding the impact of oral contraceptive use on cancer-free women who carry a BRCA mutation.

## **The Yale CGC Program Welcomes a New Genetic Counselor**

The Cancer Genetic Counseling Program is pleased to welcome **Karina L. Brierley, MS** to our team. Karina received her Bachelor's degree in Neuroscience from Bowdoin College and her Master's Degree in Genetic Counseling from Brandeis University. During her graduate training, Karina completed clinical internships at Yale, Boston Children's Hospital, and Dana Farber Cancer Institute. Her thesis research involved surveying obstetricians and gynecologists about their knowledge, interests, and current practices with regard to providing breast and ovarian cancer genetic counseling. Welcome, Kari!

## **Your Contribution to Research...**

The field of cancer genetics is a young one, and recent genetic discoveries over the past 2-3 years have made clinical genetic testing a reality for several types of cancer. However, because the field is so new, we are lacking long-term data in many areas (the effect of prophylactic surgery or chemopreventive drugs on carriers of cancer susceptibility genes, the percentage of carriers who develop cancer by a certain age, etc.). In order to contribute to research in these areas while also protecting your confidentiality, we have created the Coded Information Sharing protocol. This protocol allows us to share unidentified patient data (pedigree data, clinical data, pathology information) with researchers *without* the patient identifying information (names, dates of birth, addresses, unit numbers) that may compromise confidentiality.

Also, if you qualify for a research trial, our program may contact you to let you know about the trial. We will not give your confidential patient identifying information to any researchers without your written permission. In these ways, we aim to contribute to research while protecting your confidentiality.

## **Yale Cancer Genetic Counseling Clinics**

### **Yale**

Monday mornings at the Yale Physicians Building

(203) 785-5938

### **Greenwich, CT**

Once a month at the Bendheim Cancer Center

Greenwich Hospital

(203) 785-4253

### **Norwalk, CT**

Once a month at the Whittingham Cancer Center

Norwalk Hospital

(203) 852-2148

### **Danbury, CT**

Once a month at the Praxair Cancer Center

Danbury Hospital

(203) 785-4253

## **CGC Update**

This newsletter is produced by the:

**Cancer Genetic Counseling Program  
Yale Cancer Center  
333 Cedar Street  
Box 208028  
New Haven, CT 06520-8028  
(203) 785-5938**

Written by:

Karina L. Brierley, MS  
Ellen T. Matloff, MS

Edited by:

Heidi G. Edmonds