



Waiting list grows for BC's Hereditary Cancer Program

Heather Kent

Budgetary constraints appear to be the major challenge facing British Columbia's 3-year-old Hereditary Cancer Program. Launched as a pilot project in 1996, it now has a 7-month waiting list at the Vancouver site of the BC Cancer Agency. In Victoria, the wait is 5 months.¹

Dr. Charmaine Kim Sing, the program's medical leader, told physicians attending a recent conference on breast cancer in Vancouver that the Ministry of Health has been asked to double the program's budget. It recently did this, and the budget now stands at \$400 000. Until last December, when a second genetic counsellor was hired, the program had only 1 counsellor, who was seeing only half of the 60 people referred each month; by September, 1494 patients had participated in the program.

Compounding the problem is the growing number of referrals from outside Vancouver. More than one-

quarter of the patients (27%) now come from the Fraser Valley, and 17% are from the Kelowna area in the BC interior. Staff are trying to cope with the case crunch by sending a genetic counsellor to Kelowna 3 times this year, and by launching a regular clinic in the Fraser Valley.

Once genetic testing is under way, only a single laboratory technician is available to analyse both *BRCA1* and *BRCA2* genes. Since both genes are complex and have many possible mutations, there is a lengthy wait for results.

Because of the delays, patients are offered the option of private testing in the US — at a cost of about US\$3000. Kim Sing said patients can also be fast-tracked into the program if the referring family doctor specifies that the case is urgent.

Karen Panabaker, the genetic counsellor who has been with the program since its inception, warned that genetic testing is never an easy process and that patients will need strong support: "This is not an individual thing — this is absolutely a family issue."

The testing has to be offered to a family member who already has breast cancer and can provide a DNA sample.

Panabaker said this can cause problems with other family members because families vary in their willingness to share knowledge that they may be at high risk, let alone their test results. If no one is willing or available to give a sample, this presents "a huge limitation in testing."

Geography also complicates the testing process when families are separated by large distances. Panabaker collaborates with genetic counsellors from across Canada, the US and Europe to link family data.

If a genetic mutation is found during DNA testing, young women may be faced with drastic treatment choices, such as prophylactic surgery. For single women, the impact of treatment on their future childbearing potential becomes an issue.

The issue also affects men. Their chance of inheriting the *BRCA1* gene is the same as for their sisters, and they may pass the gene on to their children. "When is the right time to tell your

children?" then becomes an important question.

Why would women still want to request testing, given the difficult decisions it may create? Panabaker said the bottom line is that family evaluation is critical for early detection of the *BRCA* genes and potential cancers for present and future generations.

Dr. Steven Narod, chair of breast cancer research at the University of Toronto, said that *BRCA*-related tumours are usually "bad, high-grade ductal cancers," and women at risk of developing these cancers face a choice of screening mammography, mastectomy or tamoxifen treatment.

Most of the cancers are diagnosed in women aged between 30 and 35, and prophylactic mastectomy for women is a "big challenge for those of us who would like a nonsurgical alternative," he said.

Heather Kent is a Vancouver journalist.

Reference

1. Kent H. Popularity of breast cancer program leads to referral protocols in BC. *CMAJ* 1998;159:832-3.

Because of the delays, patients are offered the option of private testing in the US — at a cost of about US\$3000.
