centres to decide whether to notify those who have received the "theoretically" infectious products. At the moment, few do.

The 300-member Canadian Creutzfeldt–Jakob Disease Society, which is based in Calgary, says about 300 000 Canadians have received blood from withdrawn lots and 2500 of them have been notified. After a multimillion dollar withdrawal in July 1995, only a few governments and hospitals decided to notify recipients.

In Calgary, for example, the city's health authority notified all hospitals, which in turn informed patients. In Toronto, the Hospital for Sick Children sent letters notifying parents, and St. Michaels Hospital contacted patients' attending physicians; it was then up to the doctor to decide whether to notify the patient, and 28.7% decided against it. British Columbia created a hot line that people could call if they wanted to know whether the blood they had received was from a withdrawn lot.

Dr. Andrew Kaegi, the director of the Red Cross Blood Centre in Calgary, says it's not fair to notify people when there's no proof CJD is even transmitted by blood, and there's no way of diagnosing the disease, much less treating it. CJD is a neurodegenerative disorder — 1 of 4 human prion-related dementias — that typically affects people between age 60 and 65. It is always fatal. Symptoms include presenile dementia, myoclonus and progressive motor dysfunction. Its incubation period ranges from 18 months to 30 years, but survival time is short once symptoms appear and patients generally live less than a year. The incidence of CJD is relatively rare globally, with between 0.5 and 1 case per million people annually.

"Notification has done a lot of harm"

Kaegi attributes the decision to notify blood recipients to a "fit of enthusiasm" that followed the discovery of the variant form of CJD in the UK — there have been no documented cases of this variant form in Canada — and to fear of another blood scandal. "I think people went off a little half-cocked," says Kaegi, who became director of the Calgary blood centre after that city's massive CJD notification effort in 1995. "We were trying to be proactive here, and I see the damage."

Kaegi recently attended a meeting of the CJD society and "was surrounded by a dozen people who were scared silly every time they forgot a number or a key. Many went to see a physician or psychiatrist about their fears. This notification has done a lot of harm. I think we have to take some of the blame here for notifying people about a disease that's exceedingly rare and, to our knowledge, not transmitted by blood."

But do blood recipients want to be notified? Dr. Lynn Boshkov, an assistant professor at the University of Alberta, asked 1216 Alberta residents this question, and 67.8% of respondents said they did want to know. However, 54.3% agreed that contacting recipients would do more harm than good and 62.4% said the money would be better spent on educating the public about the risks associated with blood products.

During the conference, Boshkov said results indicated that people should have more individual choice. In a survey of patients and families who were notified at the Hospital for Sick Children, 84% said they wanted to be notified if there was another recall (see p. 771).

In 1996, delegates at another national conference sponsored by Health Canada decided that the public did have a right to be informed but didn't determine how this should be done. At this year's conference they were still debating the same question. And even though it wasn't geared to creating guidelines, organizer Graham Sher ex-

Physicians' help needed in CJD study

If you are treating someone with Creutzfeldt–Jakob disease, Health Canada would like to know. The Laboratory Centre for Disease Control is conducting 2 studies: a general surveillance for new variant-CJD, for which there have been no reported cases in Canada, and a 5-year case-control study to assess the risk the transfusion of blood products holds for the development of CJD.

Dr. Neil Cashman, coprincipal investigator at the Centre for Research in Neurodegenerative Diseases at the University of Toronto, says 4 similar studies haven't had a big enough sample, although all of them revealed no evidence of risk. "Our study is 5 times bigger than the next biggest and in that sense it's unique. We have a better chance of seeing a link." The study will look at an estimated 100 patients between 1996 and 2000, and results are expected late in 2000.

To protect confidentiality, physicians are being requested to ask patients or their families if they'd like to take part in the study. It involves giving a blood sample for genetic testing, a 2 to 3 hour interview and a chart review to obtain a complete history, including record of transfusions. To speak to a study member, phone 888 489-2999.