

The treatment registry is designed to collect information on treatments, that is then organized into treatment regimens by AIDS experts and disseminated to PLWAs, community-based groups (not in the diagram, but part of dissemination) and physicians. Physicians report back to the monitoring unit the success of suggested treatment regimens. Those that do not work, or do not work as well as other regimens are then eliminated from the registry. People with HIV infection will be part of both the clinical/scientific and the external review committees. (Note: CRI = Community Research Initiative; CTN = Clinical Trials Network)

Design by George Smith

## THE AIDS NATIONAL TREATMENT REGISTRY

A potential world first for Canada

Dr. Kathryn Taylor speaks enthusiastically of the National Treatment Registry for AIDS, a world first. Taylor only learned that she was to be in charge of studying the creation of such a registry a few hours before Health and Welfare minister Perrin Beatty made the announcement public on April 24th.

Since then, Dr. Taylor, who is director of the Physician Behaviour Research Unit at the University of Toronto, says she hasn't slept much. With seven other people at the unit, she is designing a system that would give care-givers and HIV positive patients access to the newest and most accurate information on treatment for AIDS.

AIDS ACTION NOW! has been pushing for over a year for such an instrument and Taylor swears that the people in Ottawa who gave her the mandate to research share the same vision. Dr. Taylor sees the Registry as a world first, a databank that would be integrating both traditional and alternative therapy. "That," says the researcher, "will be the greatest challenge. How to collect information on all the available therapies and how to keep on top of it." The Registry would have a very stringent evaluation of all forms of treatment included and would be designed for doctors and patients, another first.

In their work Dr. Taylor and her colleages are studying other types of registries already set up, and at the end of their research they will have consulted about 400 people in Canada, the U.S. and elsewhere through their contacts with the World Health Organisation.

They are setting up focus groups in collaboration with the Canadian Aids Society and Canadian Hemophiliac Society and consulting with doctors to see how they would use the system. Talks were also to be held with IBM and Bell Canada to figure out the practical aspects of the registry.

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