

NEW PROJECT

cannabis patient registry update

Sylvia Thyssen

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THE CANNABIS PATIENT REGISTRY (CPR) is trying to assist cannabis patients by collecting information about the statistics of the medical use of cannabis – who uses it, how, and for what purpose. An in-depth introduction to the CPR appeared in MAPS V.5 No. 4. The CPR has been funded by a grant from the Drug Policy Foundation and is being established under my direction. The primary instrument of the CPR is the Personal Use and Medical History Questionnaire. It has been written and is now being reviewed and critiqued by others. The questionnaire is thirty questions long and takes 15 minutes to complete. Approximately a dozen patients have filled it out and given feedback on it.

I am communicating with a university-based researcher who has also developed several anonymous questionnaires intended for gathering data on general cannabis therapeutics and cannabis use and multiple sclerosis (MS), spasms or paralysis. Assisted by the Alliance for Cannabis Therapeutics and researchers in Scotland, he was able to pilot the survey with 120 MS patients who use cannabis medicinally. I am working towards standardizing portions of the CPR questionnaire and the researcher's general cannabis therapeutics questionnaire.

Many of the patients with whom I have spoken in recent months do not have supportive physicians. The physicians are often completely ignorant about the range of uses and the safety of cannabis. We are in the early stages of developing an information package for patients who request help in broaching the subject of cannabis therapeutics with their doctors.

I intend to proceed with the CPR in such a way as to protect the confidentiality of participants as much as possible. I am discussing with an attorney what constitutes a "privileged communication" to explore whether the CPR can be made immune from subpoena. If this is not possible, a special coding system will be developed.

The CPR's gathering of case histories is not the solution that will resolve the medical

cannabis controversy. However, faced as we are with setbacks in the effort to begin Dr. Abrams' clinical trial comparing smoked cannabis and the oral-THC capsule in patients with AIDS wasting syndrome (see p. 43), it is one project on which we can make progress right now.

Seeking Endorsement for Medical Cannabis

The American Public Health Association will be voting November 1 on a medical cannabis resolution submitted by Mary Lynne Mathre, RN, MSN. Mary Lynn Mathre works with the International Cannabis Alliance of Researchers and Educators (I-CARE) and with Patients out of Time (POT), which lobbies and educates all disciplines of health care professionals, their specialty and professional organizations, and the public at large about medical cannabis. If you or anyone you know might be willing to present a similar resolution to the American Medical Association, you may contact Patients out of Time, Fishpond Plantation, Howardsville VA, 24562 or email: mary_lynn@patient.win.net. Patients Out of Time also has an electronic bulletin board system that contains research data, historical records, legal cases, legislation and position papers by organizations supporting legal access to medical cannabis. It can be reached by modem at (804) 263-8237. •