

the Cannabis Patient Registry

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SYLVIA THYSSEN

SINCE I have been involved in the struggle to initiate clinical studies into the therapeutic uses of marijuana, a significant amount of my time at MAPS has been spent trying to mobilize medical marijuana patients. Many contact the MAPS office for information and write letters describing their medical condition and the relief marijuana provides. In an effort to influence the decision of the National Institute on Drug Abuse (NIDA) on whether or not to provide marijuana to Dr. Abrams' pilot study (see page 11), I've had to scramble to locate medical marijuana patients, hoping to encourage them to write their representatives. At the National Organization for the Reform of Marijuana Laws (NORML) and Cannabis Action Network (CAN), there are files of notes and phone messages, often with just the name and number of a patient. Here at MAPS, over a dozen patients are on file. Dr. Lester Grinspoon and the Cannabis Buyers' Clubs have their own sizable files of cases, as do many patient advocates all over the country.

I've come to realize how useful it would be to consolidate information about the thousands of patients who use or have used marijuana for medical purposes. As a result, in the first quarter of 1995, MAPS submitted a proposal to the Drug Policy Foundation Grants Program to initiate the Cannabis Patient Registry. I'm happy to report that MAPS received its entire grant request of \$7,400.

What is the CPR?

The Cannabis Patient Registry is conceived as a database and archive specific to medical marijuana patients, their caregivers, and their legal support. Its goal is to contribute to the growing effort to protect the rights of seriously ill Americans who choose to self-medicate with marijuana by creating a central repository of letters, documentation, and contact information. Documents to be collected will include those relating to the patients' medical histories, extent of physician support,

legal problems if any, willingness to speak to the media, and extent of media coverage of their situations, if any.

What are the advantages of consolidating, updating, and expanding records of patients, caregivers, and attorneys? Primarily, it will assist patients in making their case to the American public and elected officials in an organized manner. In the political arena, the potential exists to mobilize strongly and effectively for media inquiry and lobbying efforts and to break the political logjams that are blocking even FDA-approved scientific research. In the scientific arena, the CPR offers researchers the opportunity to contact patients for possible inclusion in FDA-approved research projects or for more anecdotal data gathering. The CPR can also eventually serve as a support system for patients who want to be in touch with fellow patients, empathic doctors, and experienced legal counsel.

Is there really a need for the CPR?

What about the other organizations and people who already help patients? Many patients have benefited from the courageous

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efforts of Cannabis Buyers Clubs and individuals who provide marijuana to patients despite the law, and patient advocates who testify in court for people who've had trouble with the law. The CPR seeks to complement their efforts. It seeks to reach out as well to people who are very private about their choice, yet who want to contribute to data-collection and also improve their legal case for a medical necessity defense in the unfortunate event of their arrest.

The unique idea which the CPR wishes to field-test is that of a card of affiliation. Many people such as organ donors, people with acute allergies, diabetics and hemophiliacs carry identification about their medical conditions, in case of an emergency. The common emergency among medical marijuana patients is that of a possible arrest. The CPR is developing a network of affiliation for patients, physicians and attorneys so as to provide support for a medical necessity defense for patients who have the additional misfortune of running afoul of our perverse legal system. Patients whose doctors provide a letter to the CPR documenting their patient's need for the medical use of marijuana will receive a wallet-size card from the CPR that could be shown to law enforcement officers if necessary. While such a card will probably not prevent an arrest, documented preexisting affiliation with the CPR may be helpful in any subsequent court case, and can lend a sense of legitimacy to the stigmatized marijuana patient.

The CPR is also trying to provide information about the epidemiology of the medical use of marijuana – who are the people who use it, how many of them are there, in what form is it used, for what indication, and with what results? This information, though less useful than data from clinical trials, may be the best that can be collected until the political climate changes.

The Next 12 months

Over the next year, the CPR will endeavor to consolidate existing records from (including but not limited to) the offices of MAPS, NORML, CAN, Cannabis Buyers' Clubs and Dr. Lester Grinspoon. We will develop, implement, and evaluate questionnaires and database formats for patients, doctors, and lawyers, seeking the most useful instruments possible.

Any medical marijuana patient, past or current, will be invited to register with the CPR. Each patient will be asked, by phone or

written questionnaire, questions about their use, whether their doctor is supportive, what prescription drugs they've taken for their symptoms or illness, and whether they've been prescribed Marinol. In this way, anecdotal data can be gathered in an organized fashion in order to guide controlled research and lobbying efforts. Legal counsel in regard to lists of people engaging in illegal activity will be sought. An Internet presence will be developed for wider dissemination of questionnaires, testimonials, and information specific to medical marijuana patients and the status of marijuana research. Finally, information about physicians and attorneys who specialize or empathize with the situations of medical marijuana patients will be solicited. [A national 1-800 legal referral clearinghouse called the Legal Defense Network is being established for pro-marijuana attorneys to respond to the needs of activists in the Southeast. For more information or to get involved, call New Orleans Cannabis Action Network at (504) 861-2956.]

What about privacy?

Some people are more public than others about their medical marijuana use. Some communities are medical marijuana-tolerant. In other communities, patients may feel isolated, and may face (or have faced) severe penalty and criticism for their need for medication, either from law enforcement or from their own family or caregivers. The CPR is intended to document accurately as well as respect the various levels of privacy which a patient and his or her physician may desire. The information in the CPR is confidential and will not be freely distributed. To preserve the security of the database file, it will be encrypted. Direct access to the CPR will be limited to the staff of MAPS. Data about individual patients and physicians will be shared with other medical marijuana patients, physicians, advocates, and media only if the patients and physicians specifically authorize us to do so. The CPR will be used only to further strengthen the community of medical marijuana patients and their caregivers and advocates.

This report is the first public notice about the Cannabis Patient Registry. We encourage readers of this MAPS newsletter to help patients get in contact with the CPR. We will not give up on this issue until patients can be prescribed the medicines which they most need. •

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