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Parkinson Disease Vermont Chapter

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November 5, 2009

Ms. Wendy Morgan
Office of the Attorney General
109 State Street
Montpelier, Vermont 05609

Reference: Comments on Requiring Disclosure of Free Samples

Dear Ms. Morgan:

The following written comments are being submitted in response to the review by the Vermont Attorney General in conjunction with the Vermont Health Care Reform Commission. This is in reference to the disclosure of information regarding the provision of samples to health care providers by manufacturers of prescription samples.

The consequence of requiring the disclosure of samples will lead to no samples at all. This will definitely be the case if the reporting and distribution is submitted to the Attorney General's office and probably more so if this medical disclosure is made available to the public. I am opposed to this proposal because it will eliminate the availability of medicines provided for patients of need in Vermont, especially for those individuals who face every hour and every day managing serious health issues from chronic illness and disease. I have already witnessed the notices and cutbacks in programs and support from medical companies in Vermont who will no longer provide samples because of the strict restrictions and disclosure that have been proposed to the Vermont General Assembly.

Your office as well as the Health Care Reform Commission really needs to spend time talking and listening to individuals who live with chronic illness daily to fully understand how the force of this regulation will impact both the quality and quantity of life as-well-as the medical care or treatment options provided to Vermonters. Too many times recommendations are proposed by the medical care community without even asking the medical patient if the disclosure process might effect their availability or desire for treatment, particularly if the individual may not be aware that access to certain medications have been removed or restricted. These comments and how this will affect treatment for neurological disease and other chronic disease patients in Vermont, needs to be included as part of the data submitted, information on record, and recommendations that reach the Vermont General Assembly.

As an advocate in the medical care for Vermonters, I have first-hand knowledge about the importance and access to free samples. At age forty-four I was diagnosed with Parkinson's Disease (PD) followed four years later with Diabetes that required both basal and bolus insulin therapy in addition to my oral medication therapies. Today, I manage multiple medications and five injections daily relying on my medical team of doctors to administer and provide the best options available to help me live well with chronic disease. My exposure to the pharmaceutical contributions between Vermont doctors and area non-profits increased in 2004, when I was asked to serve on the Executive Committee for the Vermont Chapter of the American Parkinson's Disease Association (APDA). In 2006, I began my current tenure as president for the chapter, and while I have served on various national and non-profit organizations, nobody could have prepared me for the life altering experience such a hard hitting disease would bring while serving the needs of the membership in Vermont for the APDA. For example, when looking at options available for people in Vermont with Parkinson's disease, free samples are quite honestly huge, and without the availability or assistance from the pharmaceutical communities, I am afraid there will be more personal bankruptcies than I have already witnessed in Vermont because of the chronic challenges created by this disease.

I like many Vermonters with PD have benefited from the availability of free prescription samples and have had certain lifestyle activities improved by the availability of support tools and medical devices offered by the pharmaceutical vendors. My greatest concern comes from those who have the potential to make life altering decisions regarding prescription medication distribution without discussing, focusing, or meeting the challenges or needs of the Vermont patient. This is especially the case for those who may be suffering from neurological disease or a combination of chronic illness, requiring specific and private prescription administration under a doctor's care and with private medical observation for the patient and provider. These are sometimes the last hope and treatment opportunities available for the more advanced patient with PD.

This requirement will eliminate access to those who need free samples for financial reasons; but more importantly for those patients who would not otherwise begin or start therapy in the first place. The management of medications is extremely difficult for individuals with neurological conditions and when combined with additional chronic illness, the availability and choices of medication is best left for the doctor and patient to discuss, choose, and implement. This proposal clearly impacts Vermonters with PD and will also eliminate patients starting on therapy right away, optimizing dosing or a choice of drug before committing to a particular course of treatment, and helping patients who might not be able to afford these medicines on their own. Most importantly, this will not benefit current research and prescription drug trials for patients with Parkinson's Disease and access to the latest or best treatment options will be removed in the State of Vermont.

I urge you to recommend to the Vermont General Assembly that we have enough regulations over pharmaceuticals here in Vermont, don't make it even more difficult for patients to gain access for medicines that may protect their quality of life. And please, if you are going to regulate access for prescription samples in Vermont, at least allow an individual or a group of individuals who require these best available health care options to share their personal experiences before the Vermont Health Care Reform Commission, prior to forwarding a list of recommendations that will surely impact existing patient care and treatment options before the Vermont General Assembly.

Sincerely,

Michael J. O'Connor

Michael J. O'Connor, Williston, Vermont
President, Vermont Chapter of APDA