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**Lyme Action Group's Invited Response to the College of Physicians and Surgeons of Ontario's proposed Complementary Medicine Policy**

Thank you for inviting the Lyme Action Group (LAG) to review your complementary medicine proposal. We appreciate this opportunity.

LAG is a patient advocacy group of Lyme Patients in Ontario and is working for the public, political and medical awareness and recognition of the various stages of Lyme disease (Ld) and other Tick Borne Diseases (TBDs). We are working to put an end to the discriminatory lack of services for Ld patients and we advocate for patients' right to have access to more accurate laboratory testing for Lyme disease, as well as the right to make an informed choice in regard to appropriate treatment for this devastating infectious disease.

Although- at least in wording- the last policy is somewhat better than this current proposal, we still agree that the current policy on complementary medicine should be amended, since -in our experience- the way it has been put into practice in Ontario has had a severely detrimental effect on Ld patients. Chronic Ld will result in an immune collapse and much of the treatment for disabled Ld patients must be focused on strengthening the patients' own immune defense and thus complementary medicine approaches are most helpful. There is a large body of published medical studies, detailing vast clinical experience, which have shown that complementary medicine has a significant role to play in the treatment of Ld and its persistent co-infections.

In our opinion, Ld patients should be entitled to choose any number of complementary medical treatments for this debilitating condition- and it would be most beneficial if the Ld doctors who are trained in complementary medicine approaches could feel free to prescribe these safe and effective treatments, without the fear of this instigating a subsequent disciplinary investigation by the CPSO.

Ld patients in Ontario are now facing a precarious situation with the level of new infections increasing at an exponential rate. At the same time it is becoming near impossible to find a Ld doctor in this province who has some clinical Ld experience, and also has been specifically trained in the diagnosis and treatment of all TBDs- especially its chronic manifestations - and who can feel free to recommend an integrative and complementary medicine protocol for treating Ld. It is totally unacceptable to us that chronically ill Ld patients in Ontario now have to go to out of country in order to receive an accurate diagnosis and adequate treatment, at a grave personal cost.

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To further explain our position; we would like to refer you to ‘the Glasnost report’ (2001), as well as the “KPMG report” (2000), which was commissioned by the then Minister of Health in Ontario. Both reports found that the CPSO gives little regard to public interest issues and does not consider positive patient outcome when a question arises whether any given practitioner has met a certain “standard of practice”. Positive patient outcome, however, is what matters to all patients.

It cannot be over-emphasized that Ld patients do not want to be ‘protected’ from being able to choose what works well for us, nor do we want medical politics to intrude into the doctor-patient relationship, when we are receiving effective complementary treatment, from trained Lyme literate physicians. For the CPSO’s regulatory system to disregard positive patient outcome and extensive documentation that support responsible minority opinions will leave safe and effective emerging treatments vulnerable to suppression. This has to date had grave personal implications for Ld patients in Ontario.

To meet the needs of Ld patients in specific- and to allow for evolution in medicine in general- it is essential that the CPSO regulatory system protect diversity of medical opinions. However, it has been the experience of many people in Ontario, suffering from new and emerging conditions, that they are not taken seriously at first and that doctors who try to treat them are often discouraged when attempting to treat "new" diseases. This was the case when AIDS, Chronic Fatigue, Fibromyalgia first appeared -and the same now holds true for Lyme disease.

This policy proposal equates safe and effective treatments with the existence of Randomized Controlled Trials (RTC) and is introducing a demand for evidence that is very difficult to meet in the complementary field. It is our opinion that the policy draft, therefore, effectively puts out of reach therapies that could potentially be beneficial to patients, with little regard for the hardship this could cause.

It is our position that an experienced and well-trained Ld-physician must not be restricted from trying new and innovative methods, supported by responsible minority opinion, in treating this emerging illness/complex infectious disease. However, this proposed complementary policy unfortunately will make it even more difficult for Ld patients to find trained complementary physicians, as this draft to us appears markedly distrustful of the non-traditional medicine field in language, tone and intent while it makes general assumptions that are unacceptable.

- 1) **The language and wording of the proposed policy is not acceptable**, in that the designation of the field of complementary medicine now is to be called “non-allopathic medicine”. This is, in our opinion, creating an unnecessary and artificial divide between the physicians in the practice of

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complementary medicine and the doctors of traditional medicine. Most complementary physicians draw on both allopathic and non-allopathic treatments-protocols, certainly those that treat chronic Ld usually have a wide knowledge, from a variety medical areas, including the complementary field, and have to practice truly **integrative medicine**.

- 2) **The tone of this proposed policy** would leave the reader with the assumption that significant potential harm can be caused by the 'non-allopathic' practising physician because of the insinuation that there always is a *supposed* 'lack of scientific rigor' behind complementary medicine approaches used by our physicians. In regard to chronic Ld, the vast clinical experience of doctors practising in this field and many in-depth medical studies (by such respected academic institutions as Columbia university) support the inclusion of complementary medicine in the treatment of this disease. The peer-reviewed literature in non-allopathic medicine in general has plenty of rigorous studies showing overall improvement and at times even sustained remissions for Ld patients who pursue non-traditional treatment methods. However, Lyme doctors who are using complementary medicine-practices are still at risk of being subjected to exhaustive CPSO investigations. It seems not to matter whether a complementary approach has been shown to be beneficial to the patient, nor does it appear to be of interest that the complementary methods employed are based on published and peer-reviewed reports and studies of vast combined clinical observations by Ld physicians.
- 3) **The intent of this proposed policy** appears to imply that the science of complementary medicine cannot be accepted unless it is fully 'evidence-based'. However, if we look closely at the strictly allopathic field of medicine; over the decades almost all leading medical publications have reported on grave research errors with resulting findings of fraud, conflicts of interest, and the resultant injurious harm to patients. The RTC, which this policy holds up as 'the gold-standard', can be fraught with inherent problems, such as (but not limited to) the participants being healthy young adults, not debilitated chronically ill patients- or the finding that the test-subjects in pharmaceutical trials often do not report side-effects (for fear of being dropped from the trial and loosing the income). In our opinion, therefore, to make a general assertion that the non-allopathic field must also be judged by these same so-called 'quality' assurance measures (which the allopathic field follows) is an irrational requirement. This requirement will potentially stifle innovation and access to therapies that work.

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- 4) **The assumption of this proposed policy** appears to be that patients must be 'protected' by our big brother, by putting in place more stringent CPSO policy requirements, so that we are not 'exploited' by complementary medicine physicians. Non-traditional medicine approaches are viewed with suspicion because of lack of so-called 'scientific evidence', and thus we – the patients- must be 'protected' against spending too much money on treatment and recovery. When a regulatory body such as the CPSO effectively tries to undermine a patient's autonomy we find this highly objectionable. Furthermore, limiting a patient's powers of consent by also asking the doctor to evaluate the patient's financial status before offering any treatment is totally unacceptable. It is only appropriate that these kinds of decisions are left to the patient, once all the available information (versus cost/ risk/ benefit) is on the table. Patients' right to full autonomy and informed consent are already required by the Healthcare Consent Act and the Professional Misconduct Regulations, under the Medicine Act. It is, therefore, particularly annoying to be told that this policy respects patients autonomy, in regard to health goals and treatment decisions, when in fact, by its demand for solid RCT evidence, the policy has effectively removed our range of choice.

We have reviewed your online members dialogue as well as the online questionnaire and see that you have crystallized out 3 major question areas, which we will attempt to answer below.

***Does the draft policy address all the important issues related to physician conduct? If not, what did we miss?***

*Answer: No. You did not clearly spell out that the doctor must provide the patient not only of the risk of a non- allopathic treatment-protocol, but also the risk associated with some allopathic treatments, so that the patient has all the relevant information on the table. This would involve informing of existing clinical complementary studies, and an explanation of how these may differ from the strictly allopathic pharmaceutical research trials. Also the assumption that a doctor must evaluate a patient's financial status before recommending any form of treatment is outrageous and must be dropped from the policy. Instead the Physician should be required to spell out the potential cost, both financial and otherwise, to a non-allopathic treatment approach vs an allopathic one vs non-treatment. In our opinion you also completely miss addressing what could potentially happen when these therapies are not being made available and there is resulting harm, both to the health of the patient as well as the grave personal financial implications (due to extended sick-leave- or prolonged disability- or from having to go out of country to access treatment in the case of chronic Lyme patients).*

***Is the revised draft policy clearly written?***

*Answer: No, this is not clearly written. Since this policy will be read by patients, not just physicians, it should be especially clear, but instead it is less understandable to an average reader than the previous policy was. The draft is furthermore formulated so that*

*an uninformed public is left with a clear distrust of the complementary field, in that the language used is full of thinly disguised innuendos. Without directly saying so it is suggesting to the patient to be 'wary' of most - if not all- complementary medicine approaches, since it is obviously not like the 'scientific' and 'evidence-based' allopathic medicine field. This policy proposal on the whole shows a fundamental disrespect for your fellow physicians and medical colleagues within the non-allopathic field.*

***If physicians recommend non-allopathic therapies, do you think their recommendations should be based on scientific evidence?***

*Answer: No. If a doctor recommends non-allopathic treatment, then this should be a matter between the patient and the doctor to decide upon, whether or not there is so-called 'scientific evidence'. It is implied in this proposed policy that RTC is the necessary evidence required before any given treatment should be recommended. However, over the decades, it has repeatedly come to light that the pharmaceutical industry's drug-trials have been less than stellar in performance, therefore, to rely solely on such 'evidence' can be misleading - and when it comes to non-allopathic remedies this question becomes utterly nonsensical. As is well known: Non-allopathic medicine relies on a range of evidence, with emphasis on patient outcome as well as the studies of combined vast clinical experience, as published in peer-reviewed articles.*

*In our opinion the deciding factors for recommending any form of treatment must be based 1) on the individual doctor's training and clinical experience, 2) a review of the allopathic treatment approaches (and whether they are supported by the scientific literature- or not) 3) a review of the non-allopathic options (and whether they are supported by peer-reviewed relevant published data- or not) and finally discussing with the patient the risk/benefits/cost of any treatment protocol. Only after these conditions are met can any given patient give informed consent. The question of informed consent is already covered in law, since the Healthcare Consent Act (1996) clearly states in section 11 (1) that the elements of consent are the following:*

- 1) The consent must relate to the treatment*
- 2) The consent must be informed*
- 3) The consent must be given voluntarily*
- 4) The consent must not be obtained through misrepresentation or fraud.*

**In conclusion:**

LAG is pleased to be asked to comment on your proposed Complementary Medicine Policy. However, we find this proposal to be unacceptable. If you are set on developing a separate policy for complementary Physicians to abide by, then a minimum starting point must be that the working-group actually has practising physicians from the complementary field on the committee, which has not been the case here. In keeping with the 1993 'Brett decision' we believe that the membership of any expert committees should include a range of expertise, relevant to the topic of consideration, including a diversity of views, and if necessary, drawing on expertise

from outside Ontario. Committee recommendations must allow for differences of professional opinions, if evolution of medicine is to be encouraged.

Furthermore, *The Regulated Health Professions Act* (RHPA) clearly sets out what a regulatory college is expected to do, that being to promote advancement in medicine, by ensuring that doctors always work toward increasing their knowledge-base and most importantly; that doctors must stay abreast of emerging issues and finally diligently work to protect the public interest. This obviously applies to both the complementary and the more traditional field of medicine.

We also strongly maintain that this attempt at a polarization between the allopathic and non-allopathic fields of medicine is an artificial construct and is not serving the public, nor is it in any way shape or form beneficial to Ontario's stricken chronic Lyme-patients, as we struggle to access any medical services for Ld and its many co-infections.

We appreciate this opportunity to have our say in this matter and look forward to further dialogue.

Sincerely and on behalf of LAG

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**SOURCES:**

**Evidence Based Guidelines for the Management of Lyme and Associated Diseases (ILADS 2005)** [http://www.ilads.org/files/ILADS\\_Guidelines.pdf](http://www.ilads.org/files/ILADS_Guidelines.pdf)

**Lyme and Tick Borne Diseases Research Center**  
<http://cumc.columbia.edu/dept/pi/nyspi/LymeDisease/>

**The Glasnost Report (2001)**

**KPMG's Report (2000); page 42.**

**The Brett Decision (1993) case of "Brett v. Board of Directors of Physiotherapy"**

**The Regulated Health-Profession act (RHPA)**

**The Kwinter Amendment (2000) s 5.1 of the Medicine Act**

**The Healthcare Consent Act (1996) section 11**

