

December 1st, 2008

To the Honourable Leona Aglukkaq, Minister of Health Canada

Re Clinical Trials Registration

I recently became aware of clinical trials – how new drugs and medical treatments reach the general population.

The Issue:

Canada does not have a Public Registry of Clinical Trials.

Less than 20% of drugs that go through Phase 1 clinical trials ever make it to the market place. Since we don't have a central clinical registry, the following questions arise:

- 1) **What** is to stop researchers from duplicating the 80% of experiments on human beings that have negative outcomes?
- 2) **Where** are researchers able to locate information on failed clinical trials if there is no record of them ever occurring?
- 3) **When** researchers assure a terminally-ill volunteer that the donation of their living body to a Phase 1 cancer study will benefit future cancer research, can this promise be fulfilled if there is no mechanism to transfer the results if the data is negative?
- 4) **Who** can Canadian researchers apply to in order to learn about these failed studies? Such information could prevent the waste of research dollars, time and citizens' lives.

It is my understanding that Health Canada has visited the issue but has deemed further study necessary in order to find a "Canadian approach", despite:

- ❖ the initiatives of the International Committee of Editors of Medical Journals (ICMJE) – of which the Canadian Medical Association Journal is a member
- ❖ the directive of the World Health Organization (WHO)

Why should Health Canada respond positively to this call... to protect patients and promote transparency / accountability. I respectfully request that Health Canada immediately establish a Public Registry of all clinical trials conducted in Canada.

If this task is too daunting, please inform me, via letter, as to your rational. I look forward to your timely response.

Regards,

Pat Maddocks

National Chairperson

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