THE HONOURABLE LEONA AGLUKKAQ, MINISTER OF HEALTH.

Recently, through *Research *with* Respect*, a program of the "Bear Ring 'U" 'n Mind" Foundation, I have been made aware of how Phase I cancer clinical trials are conducted in Canada. I am writing directly to you, to convey my alarm and concern with the lack of effective organization and regulation inherent in our present system of clinical trials.

I am dismayed that Canada **does not** have its own national Public Clinical Trials Registry, available in both official languages and that those involved in the medical research industry – researchers, doctors, pharmaceutical companies – are not required to post basic identifying information on their studies on a publicly available site, not even for the riskiest of trials, the Phase I clinical trial. As well, they are **not** required to post information on the public clinical trial registries of other countries. Many Canadians are unaware of this lapse in safety and if they were aware, would consider it reprehensible.

As you know, a Phase I cancer clinical trial discerns the safety margins of an investigational treatment. It is a dangerous undertaking and the motivation for many citizens is one of unselfishness and generosity: knowing that their own medical condition is terminal, they agree to offer themselves as test subjects to determine safe dosage for humans, subsequent to the completion of experiments on lab animals.

Phase I volunteers want their legacy to be that they made a difference. They hope that the knowledge gained will help others. They place their trust in researchers, anticipating – as mandated by the WMA's Declaration of Helsinki - they will be treated ethically and fairly. Because these clinical trial subjects are told by researchers that HC has approved these experiments on human beings, they believe that the knowledge gained will benefit, at the very least, their fellow Canadians and, eventually, all mankind. We must not let such conscientious citizens down.

Minister Aglukkaq, if you, as Minister of Health establish mandatory registration of all clinical trials on a Public Clinical Trials Registry, then all stakeholders – researchers, medical practitioners and the public - would have a beginning point to ascertain clinical trial activity and subsequent findings. Duplication of international research efforts would be eliminated. And human lives might be saved.

I urge you to move to protect these vulnerable and venerable members of our society, by providing the accountability and transparency of a Public Clinical Trials Registry.

I definitely applaud and support the motions made in The House by The Hon. Judy A. Sgro, MP, York West:

- That government introduce legislative measures to require mandatory registration of all clinical medical trials conducted within Canada.
- That government introduce the legislation and regulatory framework required to establish and fund a national (public) registry of clinical trials in Canada.

This letter is to encourage HC to follow through on its October 18th, 2012 announced intention to list publicly all drug clinical trials being conducted in Canada.
I look forward to viewing online – in the very near future – HC's version of a Canadian Public Registry of Clinical Trials.

Yours sincerely,

Signature: _____ **Date:** _____

Print Name: _____ The courtesy of a reply is requested.

Address: _____

BY CONTACTING THE FEDERAL MINISTER OF HEALTH.

THIS IS YOUR CHANCE TO TAKE ACTION: MAKE YOUR VOICE HEARD ON THESE

IMPORTANT POLICY ISSUES:

- Mandatory registration of ALL clinical trials conducted in Canada
- Registration of clinical trials on one specific country's public registry
  just as a stop-gap measure until
- Canada establishes it own bi-lingual Public Registry of Clinical Trials

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Honourable Leona Aglukkaq, P.C., M.P.

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To send a Letter of Support to The Honourable Judy A. Sgro:

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