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May 15 2107

Ms. Christine Elliott Patient Ombudsman 393 University Ave Suite 1801 Toronto, ON M5G 1E6

RE:UPDATE ON "Carol"

Dear Ms. Elliott

I hope this letter finds all is well with you and your family. It has been some time since my last communication, although I have been 'one-armed wallpaper busy' as you will see. The problem, as usual, is that I'm doing all this advocacy work and working an incredibly busy 'regular job' very often with 12-15 hour days.

UPDATE ON "Carol":

Most unfortunately for "Carol", her situation has taken an unnecessarily tragic direction which is generating an enormous amount of personal stress for her and those closest to her. Some would have been unavoidable, but could have been dealt with at the very beginning of her investigation. The 'cruel and unnecessary' exponentially ramping up the stresses she is now having to deal with is the realization that this was done to her intentionally by a government that views her as mere 'red ink on a spreadsheet' and has used their Cancer Care Ontario Medical experts, 'to hit effectively her delete key'.

My experience is that in the end most patients want the truth as terrible as it might be. Once they get over the initial shock, most are able to move on with dignity and some sort of resolution. But how do you move on from what she envisions will be 'unresolvable' issues surrounding what in the end was having *mutilating radiation treatments that never should have happened if her physicians had not been forced to make bad decisions by the very people who are supposed to be determining what is best for cancer patients like her.*

- The PET/CT only allowed to be done AFTER her undergoing her 'radical radiation therapy' and thus with the intent of offering her a cure was correct in more than one facet.
 - 1. Even if there was a chance for a 'curative approach' the PET/CT demonstrated that 'normal sized CT nodes' had cancer. As these were not included in her 'therapy fields' and they cannot now be radiated, all those traumatizing radiation treatments she went through would be doomed to failure even if there had of been a chance at a curative attempt at therapy.
 - 2. Thus she was offered a 'false sense of hope' when the CCO physicians know well that conventional imaging with CT and MR is wrong on average 30 % of the time, as Caro's cases demonstrates in 'spades'.
 - 3. But worse, subsequent investigation has shown that the PET/CT was correct in that she already had Stage IV disease and this therapy WOULD HAVE BEEN CONTRAINDICATED and never should have happened!
 - 4. She suffered serious injuries to her rectum and bladder from this radiation therapy which will continue to unnecessarily impair her quality of life even further as she eventually succumbs to her disease.
 - 5. To add insult to injury, her CCO based physicians are demanding her follow-up imaging, I believe 3 CT exams and counting, will be the only way she can be imaged:
 - She will only be allowed a PET/CT IF THE CT IS NOT DEFINITIVE.
 - These 'Hippocratic Oath based' physicians are treating her as a fool, since of course since it was the LACK OF DEFINITIVENESS OF HER CT AND MR EXAMS THAT HAS PUT HER WHERE SHE IS TODAY!
 - This includes statements via Telehealth from Dr. Lorraine Margaret Elit Juravinski Cancer Centre her consulting Gynecologist.
 - McMaster Medical School has been THE group that set up and continues to run "unethical" bordering on "immoral experiments" on cancer patients.
 - "Carol" remarked to me how Dr. Anthes seemed 'intimidated' by this 'woman.'
 - Keep in mind, Dr. Anthes had been 'reprimanded', like her colleague and me, for daring to give the correct information to "Carol".

"Carol"'s case and suffering is the 'archetypical' example of why PET/CT became the accepted world standard of imaging management of most cancers and other disease as long as almost 20 years ago.

Most importantly, it demonstrates the 'cruel ramping up of stress on patients like "Carol"' directly because of the actions of Cancer Care Ontario medical experts.

I have sent the details in letters to Mr. Ralliaram, the Chairman of the Board of Cancer Care Ontario and Dr. Michael Sherar, President and CEO of CCO. I will copy you these letters and therefore will only refer to the key points. The details can be found in these letters.

WHAT CAN POSSIBLY BE DONE TO TRY AND EASE "Carol"'S UNNECESSARY STRESSES?

Without trying to sound overly dramatic, it is simply true for "Carol", that you and your team are her only hope in the relatively short time she has, that she may get some resolution to what will otherwise haunt her and her family in their remaining time. Indeed I am even regretting that I brought this to her attention. The end would have ultimately been the same for her disease in a way but she would have thought she was at least 'getting the best care available as the CCO website would inform her'.

Yet now she understands that the province she has worked in; called her home; raised her family in; and until recently thought she was lucky to live in, turns out to be fundamentally no different than some Banana Republic or, perhaps Zimbabwe, where lives like her's are meaningless, and there is no shortage of government 'experts' to carry out the will of politicians who view people like "Carol" as a way of reducing deficits. Worse, the so called 'safe-guards' in the Ontario Ombudsman's Office, and three different Ombudsmen, dismissed the unprecedented accusations against the government; buried their investigations from the public; and have publically congratulated the Liberals on their handling of PET!

• Just try and imagine how disorientating and shocking this must be to her and her family and friends

However, there is still another chance for her <u>which you could potentially make happen for her</u> and offer her the opportunity to be allowed to make informed decisions on how she manages the next phase of her life. It would also mean for "Carol", that out of her suffering some good would come and would inevitably 'open the doors' for others being offered 'palliative/non-curative' therapies to try and prolong her life, hopefully with some quality.

One advantage of PET is that it can provide early monitoring of the response to palliative therapies she may choose. The CCO 'seal approval' approach will typically be six cycles of poisons followed then by a CT which will in most cases be all but useless, and they will simply recommend *more CT scans!*. With PET/CT we can get a baseline scan, and then after as little as one or two cycles repeat the scan. If the tumour is showing a significant reduction in the amount of sugar it is consuming, it offers evidence, it may be worth continuing:

• However, very often the FDG PET/CT demonstrates that the tumour is not responding, and may be worse.

- She can then make the informed decision to stop the poisons and go for quality of life without the further suffering of therapies doomed to fail.
 - This is a major reason why FDG PET/CT is the cornerstone of imaging in the era of Personalized Medicine.

However, as it currently stands the 'sun will rise in the west' before she will would have this potential benefit, *since this is not the answers Dr. Hoskins wants from his CCO 'medical experts'*.

Keep in mind the tragic irony of the fact that even as Dr. Anthes was dealing with "Carol", she as was asked to review the most recent effort of the McMaster PET research group dedicated to getting the answers Hoskins needs. The paper was regarding whether PET/CT was of any use in Cervical Cancer:

 You guessed it, the 'preordained FAITH BASED AND AGENDA DRIVEN PROCESS USING HTA, DETERMINED THERE WAS NO ROLE FOR PET/CT IN CERVICAL CANCER!!

How can this NOT be considered an assault on "Carol"?

OUTSTANDING ISSUES RELATED TO "Carol":

- 1. Firstly she has in her possession a letter from Dr. Eric Hoskins expressing the 'pride' he and Ms. Wynne has in the efforts of CCO on PET in Ontario.
 - a. Dr. Hoskins has repeatedly refused, even though required by provincial law, to provide a response to issues brought to his attention on this issue.
 - b. Surely it is time Dr. Hoskins and Ms. Wynne send a 'personal letter' explaining to "Carol" and her family, why they are so proud of CCO's efforts and supply the information no one else will so she will understand that what Dr. Hoskins is overseeing for her "is just what is best for her".
 - c. Failing that they need to explain to "Carol" personally what it is that Ms. Wynne and her Liberal government has against cancer patients like "Carol".
- It was made clear that "Carol" didn't just want to get the PET/CT but clearly she was and remains entitled to have her well informed questions and concerns addressed.
 - a. PET ACCESS has dismissed her concerns, and will not even explain why and this with the full support of Dr. McLeod, Vice President Clinical Programs and Quality Initiatives Cancer Care Ontario.
 - b. Likewise, the PET Steering Committee has refused to acknowledge or address her concerns..

To her previous questions, she has a new and **VERY CRITICAL QUESTION**. Given the terrible and unnecessary situation she has been forced into because of the lack of definitiveness of her CT and MR imaging::

- c. SHE ABSOLUTELY DESERVES TO HAVE A FULL AND LITERATURE BACKED EXPLANATION AS TO WHY SHE NOT ONLY WAS REFUSED A PET/CT AS PART OF HER INITIAL WORK-UP, BUT NOW SHE MUST BE FOLLOWED BY CT.
- d. <u>This explanation must be in keeping with the stated criteria laid out by Dr. Hoskins for Diagnostic Imaging tests for use in Ontario.</u>
 - i. MOST IMPORTANT OF ALL, THESE EXPERTS MUST ADDRESS HER QUESTIONS MAKING CLEAR THE BENEFITS TO "Carol" OF ALL THE RADIATION SHE HAS RECEIVED AND WILL CONTINUE TO RECEIVE FROM ALL BUT USELESS CT EXAMS.

ASIDE:

I realize that the way your office is structured you cannot go directly after the physicians and hospitals who were forced to practice what clearly is incompetence, and pretty clear grounds for malpractice lawsuits.

- What about the possibility of getting a patient's physician who would be willing to have the complaint of incompetence registered against them?
- It would seem the obvious defence for the physician and a clear way of shifting the blame to those who made the decisions, by offering up the defense, it is the CCO and government physicians who ultimately are directly responsible for what in fact are acts of incompetence given accepted position in the rest of the civilized medical world.,
- Her ability to cope with she faces will be made all the more difficult having to live with what has been intentionally, and continues to be done to her by government physicians.

By the way the new 'logo for CCO' is"

■ "CCO | Our future health built with care"

This borders on not just criminal and indeed was found to be the case in Australia, but deliberately insulting the intelligence of "Carol" and the endless other patients who Ms. Wynne and Dr. Hoskins have, and continue to 'throw under the bus' but calling it:

PATIENTS FIRST HEALTH CARE IN ONTARIO!

CONCLUSIONS:

We are all very hopeful, Ms Elliott, that you and your team will act quickly to try and mitigate as much as possible the cruel and unnecessary suffering she and her family is struggling with. Then of course, I hope we can begin the process of ending this "unethical" and "bordering on immoral" assault on Ontario's patients once and for all.

I will include a short additional letter outlining other developments I have been involved with. In addition I will send all other relevant documents to Mr. Chris Mondszein, the lawyer I am now sending documents to that I hope will be helpful in resolving these egregious and demoralizing issues.

This includes the fact that Dr. Michael Sherar, the President and CEO of Cancer Care Ontario has asked to meet with me in Toronto in the next two weeks. I am choosing to take this as a good sign, but I believe, prudently, I sent him a letter asking him to outline what he would like to talk about; what he hopes to accomplish; who might be there; and perhaps whether I should be bringing a lawyer!

When I come to Toronto for the meeting if you felt there might any further use in meeting, or perhaps meeting with Mr. Mondszein, I would be more than delighted to do so.

Perhaps it might be helpful for you to see the case of a frail 85 year old woman who had repeated stabs with a large 15 cm needle into her chest, when in fact if she had of been given the *PET/CT BEFORE*, *SHE WOULD NOT HAVE NEEDED TO GO THROUGH THIS TERRIFYING AND HIGH RISK PROCEDURE*.

The unnecessary cruelty to this poor weakened 85 year old that the PET/CT showed she had Stage IV, terminal lung cancer, and even if she needed a biopsy there was a safer and more comfortable land 'less scary' place to biopsy. Instead, she is yet another person tossed on the pile of victims Ms. Wynne and Dr. Hoskins approve of.

As impossible and surreal as this seems, it has been and continues to be the reality of how tens of thousands of some of Ontario sickest and most distressed patients and their loved ones are knowingly and deliberately treated by Ontario Government physicians.

How can this be? The time has come to finally carry out the 'ethics' review demanded in the CANM motions in 2005 in the hopes that this will never happen again, at least in Canada.

Sincerely

Dave Webster