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Dr. Robin McLeod
Vice President
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Cancer Care Ontario
620 University Avenue
Toronto, Ontario
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RE: **ANSWERS TO PATIENT QUESTIONS**

Dear Dr. McLeod

The following is a series of questions Ms. Carol Dunne has respectfully asked members of PET ACCESS to answer. So far they have refused. Although she was allowed to have a PET/CT AFTER her treatment, she had made clear that she also had asked them to answer her well informed and critical questions about her management to date and now proposed management after her radiation therapy. This is particularly critical since the PET/CT showed that ***by not having the PET/CT BEFORE her radiation therapy, she has missed a critical treatment window.***

In addition she has now been repeatedly told that for follow-up and in keeping with the CCO 'seal of approval', she will only be allowed CT exams, and will only be allowed another PET/CT ***if the diagnostic CT is not definitive!*** She and her treating physician are fully aware that by it's very nature, and the reason the world moved to PET/CT long ago, is because ***CT IS NOT DEFINITIVE, and has been called "the view from 10,000 feet in the era of PET/CT imaging."***

Her case represents the archetypical example of the limitations of serial CT exams. The very reason she missed the critical treatment window, and in fact the PET/CT has suggested that she might be Stage IV and never should have had the radical radiation therapy, ***is because of the very inherent limitations of serial CT scans.***

I had mistakenly thought I'd sent this letter to you along with my letter of response to your letter of March 24 2017. It had contained some of the general questions that patients will be appropriately demanding from those charged with making critical decisions regarding

their investigations and follow up for their cancers. This letter will contain very specific questions from Ms. Carol Dunne, who has given me permission to use her name in letters addressed to those who are assessing/blocking PET/CT access for Ms. Dunne. I will also send a copy of a letter I send to PET ACCESS on her behalf, in case you have not seen it yet.

QUESTIONS FROM MS CAROL DUNNE:

1. Given that PET ACCESS has acknowledged that there is no scientific basis or validity to justify using HTA, ***how does the PET ACCESS justify the use of the HTA to assess any roles for PET for cervical cancer patients?***
2. Since PET ACCESS has not used science to determine the role of PET in cervical cancer ***I would like a detailed explanation of how decisions were made not to have routine to PET for my cervical cancer, how you will decide if I get a PET/CT after my treatment, and then why I will not be allowed to have a routine PET/CT to now follow my progress.***
 - Ms. Dunne understands the analogy of why it would indicate severe lack of understanding, indeed perhaps incompetence, for a physicians to order a 'Skeletal Survey' for osteoblastic metastasis to determine whether the patient should have a functional 'bone scan', ***please make very clear to me why I had to have a high radiation dose diagnostic CT with contrast to determine whether I could have a PET/CT.***
3. Please outline in detail with appropriate references ***the benefits of the radiation I have received from my CT investigations, including the CT I am booked for in April.***
4. I have been told repeatedly that I cannot have another PET/CT, but must have serial CT exams. I will only be allowed another PET/CT if the CT exams are not definitive. Given the fact that the very serious and distressing situation I am in ***is because of the inherent NON-DEFINITIVE NATURE OF DIAGNOSTIC CT EXAMS*** please explain with appropriate documentation the following:
 - ***What critical information will the diagnostic CT provide for my physicians THAT CANNOT BE SUPPLIED AND BETTER WITH THE PET/CT given the baseline PET/CT showed the 'normal CT' findings contained active disease?***
5. Why have the members of PET ACCESS, clearly playing a key role in my cervical cancer management, ***refused to answer the questions that I am entitled to both ask, and expect answers to these questions and concerns I have?***
 - ***Are you prepared to have the PET ACCESS Members prove that CCO committees are about 'openness, transparency and accountability' and demand that they answer my questions immediately?***

I would ask and expect that all the answers to my questions meet with the expectations that our Minister of Health, Dr. Eric Hoskins, has specified are necessary for diagnostic

imaging tests to be deemed useful and fundable in Ontario. Most importantly, Dr. Hoskins, as am I, is very concerned about the overexposure of patients to radiation from diagnostic imaging tests, ***it is critical that the benefits of the radiation I have and will receive from my diagnostic CT exams be made very clear with the backing medical literature.***

Respectfully Submitted on Behalf of Ms.Carol Dunne.

Dr. Dave Webster

CONSENT FROM MS DUNNE FOR ME TO USE HER NAME AND REPRESENT HER TO THE VARIOUS CCO GROUPS.

Email March 11:

Hi Dave

Yes it is okay to use my name

I totally agree a pet /ct should be the follow up because of the pelvic / lung findings but now to get the pet access to see it through my eyes !! Fingers crossed and praying

Thanks again Carol

Mrs. Carol Dunne
Thunder Bay Ontario

CC: Letter to PET ACCESS on behalf of Ms. Carol Dunne.
Letter to Dr. Webster from Dr Eric Hoskins