ONTARIO PET ACCESS PROGRAM [OPAP] REQUEST:

ID NUMBER: 21337

REASON: CERVICAL CANCER TREATMENT PLANNING WITH PET/CT

ALREADY IN POSSESSION OF OPAP:

1. Request faxed dated: 20/12/16
2. Medical Imaging:
    a. CT 1:10/2016
    b. MR: Date 1: 11/2016 Date 2: 12 2016
3. Medical imaging and treatment histories.
4. Relevant consults

ONCOLOGIST:

Dr. Oncologist: Ontario

PHYSICIAN DEALING WITH THIS APPLICATION:

Dr. David Webster Nuclear Medicine and PET Specialist

I have the full permission from both the patient ID:21337 and Dr. Oncologist to make this application on the patient's behalf.

INTRODUCTION:

Please refer to the document emailed to OPAP assistant to be distributed to PET ACCESS PANEL Members entitled:

- LETTER OUTLINING NEW APPROACH.

PLEASE NOTE:

- All my emails, communications and documents will be copied to Dr. Oncologist and the Patient ID:21337.
- Copies expunged of personal information will be made available to the public since we are living in an open, transparent, province where those representing the government must be held accountable for their actions and decisions affecting Ontario patients.

THEREFORE:

Since the OPAP committee members sit in judgment of whether or not this patient has a PET/CT or not and the patient is entitled to full and informed consent and information including risks and benefits:

- ***The patient will address her questions to the panel, and IT WILL BE THE PANELS RESPONSIBILITY TO FULLY ANSWER HER QUESTIONS AND BACK THEIR OPINIONS WITH THE APPROPRIATE DOCUMENTS.***

ASSUMPTIONS AT THIS POINT:

1. The OPAP members can assume that the patient is fully informed about the strengths and limitations of both CT and PET/CT as outlined in letter to the committee members.
    a. She also understands that an MR can be useful since it is best at visualizing soft tissue.
2. That she has a copy of the letter from the Minister of Health Dr. Eric Hoskins, and therefore her expectation is that the committees' answers will ***be fully compliant with what he has defined diagnostic imaging tests in the province of Ontario should contain.***

    "In Ontario, PET diagnostic services must be:

    - ***Effective (sensitive, specific, accurate)***
    - ***Have the potential to impact patient management***
    - ***Have benefits over other tests/imaging"***

    Dr. Hoskins, and rightfully so, was very concerned about the consequences of exposing patients to radiation from medical imaging devices.

    "You, as a clinician, would understand that **the benefits of exposure to radiation from a diagnostic intervention such as PET scans must be considered along with risks and limitations of the result of the scan.** *It is essential that the ministry also strives to achieve the correct balance."*

    Dr. Eric Hoskins August 2016

3. That the patient has a copy of the letter from a key physician involved in evaluating PET using evidence-based medicine. The physician has not challenged the statement:***" There is no scientific validity or baseless by which CCO can evaluate PET or any other diagnostic imaging technology."*** His answer to how he could defend it's use given the implications for patients like ID:21337 was:

- ***"I believe there is a role for Health Technology Assessment in assessing PET."***

Let me be very clear. My patient, Dr. Oncologist nor I will accept any assessment or defense of the committee's statements that are based on:

  - ***A Faith based I BELIEVE process.***

I will not have this critical and potentially life threatening process and a decision between a routine surgical procedure versus a mutilating procedure based on a someone's 'belief' they are right.

- ***Therefore the committee's opinions must meet the criteria of a scientifically based process as would be required to properly establish and be compliant with the statements of Dr. Hoskins.***
- ***In addition, since the physicians involved in her care would not be allowed to use an "I BELIEVE' defense of our care, this further makes clear the need for the OPAP's opinions and rulings to be based on validated methods of science and medicine.***

In addition, the patient is aware of the statement by Dr. Rodney Hicks:

- ***"Ontario has the most egregious and politically motivated agenda against PET in the world."***
  Dr. Rodney Hicks 2016

Also please note that patient ID:21337 is fully aware of the JNM paper by Dr. Hicks that confirmed that a ***'mere medical poster claiming PET was not useful for lung cancer:***

- ***Was used as the 'excuse' for the Ontario government to dismiss the findings of a non-government, science based approach, headed by Dr. Al Driedger. Thus reducing the committee recommendation of 24,000 Ontario patients would benefit immediately from a PET scan to ZERO patients would benefit due to 'lack of quality evidence' which was determined using a non-scientifically validated process by CCO medical experts.***
- ***THAT THIS 'MEDICAL POSTER' WAS 'PROMOTED' TO A LEVEL A PAPER TO DETERMINE ROLES FOR PET IN LUNG CANCER.***

This represents an important example of how CCO has evaluated PET. The patient, and Dr. Oncologist have expressed significant and well founded concerns about how she has had her cervical cancer managed based on the 'dictates' of Cancer Care Ontario 'medical experts'.

REASONABLE CONCLUSION AT THIS POINT:

- Given that the recommendations from CCO groups directly impacting patient ID:21337 were not based on science it is either a 'Faith Based' process or:

    - ***An evaluative process that is AGENDA DRIVEN, or perhaps by both.***

Key Points Relevant to this Case ID 21337.

1. ***This application was made on 20/12/2016 and has still not been resolved. This has lead to extraordinary and unnecessary stress to the patient.***

    a. ***This case will be settled immediately or actions may have to be taken against PET ACCESS.***
    b. This has dramatically increased her already high levels of stress and will be taken into consideration if any further steps or actions are required for her to get a rapid response for her request for a PET/CT exam.
2. As made clear in the document sent to the OPAP, no further information will be sent ***until the members explain in detail with backing documentation how the information will be evaluated.***

    a. Any reasons offered in defense of a 'non-science Faith Based and/or agenda driven' system will be reviewed with the patient, her physicians and if necessary a legal opinion will be requested.

QUESTION 1 TO OPAP FROM PATIENT ID: 21337

1. Why would the committee members use a scientifically baseless process to evaluate the information and make decisions that will profoundly affect my quality of life and prognosis?

QUESTION 2 TO OPAP FROM PATIENT ID21337:

2. Please make absolutely clear to me how the information you have requested and the questions you have asked Dr. Oncologist to answer ***will be assessed given that the process will not be based on science?***

QUESTION 3 TO OPAP FROM PATIENT ID21337:

I find it hard to believe that a process simply based on 'faith' has been what has defined Cancer Care Ontario's evaluation of PET/CT.

3. Therefore I believe it is reasonable to assume that it was ***"agenda driven".*** I would respectfully request that you either confirm this statement and outline in detail what agenda has been used to assess the roles of PET/CT in cervical cancer, or effectively and fully refute Dr. Hicks accusation, and make clear what did 'guide' the assessment of PET/CT in cervical cancer.

SPECIFIC RESPONSES TO QUESTIONS FROM THE APPLICATION:

PAGE 1:

Please provide the **conventional staging imaging……"**

WHY IS PET BEING REQUESTED:

If the PET shows active disease in the pelvis, then the patient will undergo a very aggressive and mutilating surgery call a "radical hysterectomy and pelvic exenteration".

If the PET does not show active 'macroscopic cancer' (no method of imaging can detect very small cancers.), then the patient will have a simple hysterectomy.

- **Major difference for the patient.**

But surely this begs the obvious question:

- ***Why didn't CCO's CONVENTIONAL IMAGING with CT and MR confirm whether there was active disease or not?***

Therefore and in keeping with the expectations of Dr. Hoskins:

QUESTION 4 TO OPAP FROM PATIENT ID21337:

4. I would respectfully request that you send all the relevant documents that my investigation, ***from day 1 which involved 'anatomical only' based imaging procedures:***

   SUBPARTS TO QUESTION 4:

   1. That the CT investigations demonstrate the favoured ***"Effective (sensitive, specific, accurate)"*** way to most appropriately direct my management.
   2. In addition include the data, if not already established in answering

the above question that the CT exams were the preferred investigation to most likely ***impact my management.***

3. That the CT exams I have had ***have benefits over other tests/imaging" which would most importantly involve risks and benefits.***
4. That given the universally acknowledged and cumulative risks of radiation exposure to me ***MAKE VERY CLEAR THE BENEFITS OF <u>ALL</u> MY CT EXPOSURES IN LIGHT OF THE FACT THAT IT HAS NOT BEEN ABLE TO DETERMINE THE CRTICAL QUESTION OF WHICH SURGERY I SHOULD HAVE.***

<u>THEREFORE AS MADE CLEAR IN LETTER TO OPAP COMMITTEE MEMBERS:</u>

- Unless they are able to make absolutely clear how their non-science methodology would stand up as a defense against 'malpractice' in Ontario, **any such references to back their position will not be accepted.**

<u>QUESTIONS PAGE 2 OF APPLICATION FORM:</u>

- What will a PET scan demonstrate that cannot be proven by other means?

The question, in the Era of Personalized Medicine, is of course reversed by the OPAP panel members.

<u>QUESTION 5 TO OPAP FROM PATIENT ID:</u>

Unless it has been made clear in your answers to my questions outlined above:

5. Please make clear to me what a CT could provide that a PET/CT cannot?

<u>SUMMARY AND FINAL QUESTION TO OPAP COMMITTEE MEMBERS</u>

Dr. Webster has gone over recent 'science based' studies demonstrating that PET/CT has clear advantages over my investigation with CT. It would have been the most appropriate imaging device to determine subsequent steps in my management from day one in keeping with the statements from the paper by Worsley et from British Columbia that claimed: ***'PET/CT more appropriately guided the oncologists and patients in determining how to proceed in more than 80% of cases compared to 'conventional imaging' such as the CCO 'seal of approval' serial CT exams.***

<u>QUESTION 6 TO OPAP FROM PATIENT ID21337:</u>

6. Why, and particularly in light of the fact that I am no closer to the answers

to critical information Dr. Oncologist and her colleagues need to determine which surgery I require, ***WASN'T A PET/CT PART OF MY INITIAL WORKUP?***

In answering this question understand that I am fully aware that:

a. *By being investigated with a PET/CT from the beginning, the low dose CT component of the scan would have detected any significant masses that the CT would have been able to identify; that the PET has the potential to identify metastasis in nodes 'meeting normal CT size criteria; but most importantly the PET would have been able to assess the glucose metabolism of the cellular constituents of any concerning masses,* ***and a CT scan, or serial CT scans have almost ability to do so, but do significantly increase my overall radiation exposure and put me at risk of a reaction to the IV contrast.***

QUESTION 7 TO OPAP FROM PATIENT ID21337:

7. Therefore in light of all the above answers to my questions, and the appropriate evidence which would stand up to a legal challenge:

- **Will the OAPA Panel immediately allow me to have a PET/CT exam or not?**
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It goes without saying, that if the answer is no, and all the appropriate documents fully compliant with the expectations of Dr. Hoskins are not supplied to back your reasoning and conclusions, my patient will have no alternative but to consider other options in pursuing her critical need for a PET/CT exam.

Respectfully Submitted by:

Dr. Dave Webster and Patient ID:21337

LETTER TO ME FROM PATIENT ID:21337

Hi Dr Webster,

I give you my consent to discuss my case. Here is the summary I promised to send.

I am a 65 year old retired/casual Registered Nurse of 40 years. Prior to the diagnosis of Cervical/Uterine Cancer, I was active and in good health. Following my treatments of external Radiation and Chemotherapy in

Thunder Bay, and Brachytherapy in London, the request for a Pet Scan by Dr Oncologist was submitted mid December.

I have had monthly follow up appointments during the course of my treatments by a Gynecologist/Oncologist from Hamilton. The Doctors in Hamilton recommended a hysterectomy post treatment with a probable Radical Cystectomy. I was informed at that time I would have a small window time frame post treatment to make my decision. I was given two options: The first option was surgery. The second option was no surgery with possible palliative care if the Cancer recurred or metastasized. Big decision to make.

I am not the person to not think, not wonder, not imagine, not obsess or ever give up on anything life has handed me. There is a basic motivated force called fear and because I am afraid, I do not want to pull back from living. My life's path of the unknown is draining me physically and emotionally. I feel it is unfair that what happens in a decision of persons can change the course of a whole life time. That those persons can take over my life and take away the chances and the say of myself. The added stress involved with the wait for a panel's decision is totally unfair. Unknown equals fear and anxiety.

Signed: Patient ID:21337