**Special Commission to Study Pancreatic Cancer**

Meeting Minutes

April 23, 2019

3:00 -5:00 pm

**Date of meeting:** Tuesday, April 23, 2019

**Start time:** 3:05pm

**End time:** 5:02pm

**Location:** Charles River Conference Room, 10th Floor, One Ashburton Place, Boston, MA 02108

**Members present:**

* Joshua Nyambose—Department of Public Health
* Niels Puetthoff—Division of Insurance
* Jody Quinn—Pancreatic Cancer Action Network
* Janice Griffin—Pancreatic Cancer Action Network
* Cynthia Callahan, RN—Patient Advocate (Vice Chair)
* Brock N. Cordeiro—Patient Advocate (Chair)
* Doug Shatford—Pancreatic Cancer Caregiver
* Andrea Cleghorn—Survivor
* Brian Rosman, on behalf of Senator Jo Comerford—Massachusetts Senate
* Dr. Giles Whalen—UMass Memorial Health Care

**Members calling in:**

* Dr. Andrew Warshaw—Massachusetts General Hospital

**Members absent:**

* Lauren Peters – Executive Office of Health and Human Services
* Representative John Mahoney—Massachusetts House of Representatives
* Carole Siegel – Patient Advocate
* Dr. Brian Wolpin—Dana-Farber Cancer Institute

**Proceedings:**

The Chair called the meeting to order at 3:05pm.

**Vote: Dr. Whalen introduced a motion to accept the minutes of the February 6th meeting, which was seconded and unanimously approved, by roll call.**

The Chair addressed some issues of unfinished business: he explained that travel expenses reimbursement should be sought by members via their appointing authority and that the Commission will not be seeking the help of an outside consultancy to complete its final reporting.

The Vice Chair opened the discussion to Objective 1, patient and family unmet needs (see slide 3). She explained that she took discussion points from the prior meeting and categorized them into patient vs. family-focused unmet needs. She emphasized that for pancreatic cancer, participation in clinical trials is very low. Dr. Whalen asked what this rate is, and the Vice Chair could not provide an exact statistic but noted that it is very low (around 2%) and that with increased awareness of trial options, that rate could rise.

Mr. Shatford entered the meeting at 3:13pm.

Dr. Whalen agreed but noted that all of the topics on the slide are valuable needs for every significant type of cancer. The Vice Chair agreed but noted that for pancreatic cancer, the availability of programs is particularly low. Dr. Whalen brought up the issue of remote support groups, and the Vice Chair agreed that this idea warranted consideration.

Mr. Rosman inquired that regarding drug/treatment costs, if it was known how many patients had various forms of insurance coverage or how many were uninsured. He noted that if MassHealth doesn’t cover specific drugs for pancreatic cancer treatment, this area could warrant a policy response that the Commission may recommend. Dr. Whalen noted that the National Cancer Database via the American College of Surgeons show data of disease by status of insurance coverage. Mr. Rosman agreed and added that this data request may be appropriate for the Division of Insurance (DOI), Department of Public Health (DPH), or Center for Health Information and Analysis (CHIA). Mr. Puetthoff agreed to look into this issue on behalf of the DOI.

Dr. Whalen expressed an interest in further information regarding the percentage of patients in MA who are treated at the top 5 or 10 pancreatic cancer treatment centers, which may inform the Commission’s understanding of access and cost. The Vice Chair recalled a map shown at the last meeting showing that the three accredited centers were all in the Boston area; Dr. Whalen informed her that UMass had recently signed up for accreditation as well. The Vice Chair inquired whether data on patient volume in various medical centers was available via DPH; Mr. Nyambose replied that CHIA may be the best resource for that inquiry.

Mr. Nyambose went on to present on the Pancreatic Cancer Burden in MA, 2011-2015 (see slides 5-22).

The Vice Chair resumed presenting and opened a discussion on familial pancreatic cancer (see slide 23), hereditary pancreatic cancer (slide 24), and modifiable risk factors (slide 25). She noted that there is discussion on a national level around genetic testing for pancreatic cancer, but that she has not heard of any initiatives in MA to make such testing for patients standard practice. Ms. Quinn noted that testing is sometimes offered to patients; Dr. Whalen agreed and noted that standard practice would be to offer genetic testing for high risk members of a patient’s family.

The Vice Chair noted that many families are still unaware of the availability of pancreatic cancer genetic screening, especially if they were not directly involved in the care of a patient. Dr. Whalen agreed that raising awareness about this practice would be beneficial, but that it would be less reasonable to suggest that everyone with pancreatic cancer should undergo genetic testing, and that issues of insurance coverage may arise.

Mr. Rosman suggested that the Commission focus on modifiable risk factors, and recommend policy decisions such as an increase in tobacco prices, or investment in obesity prevention via higher taxation of sugary drinks, etc. Mr. Nyambose agreed and noted that many of these risk factors are associated with many other health concerns, so a path forward would be to collaborate with pre-existing anti-tobacco or obesity prevention programs and to make them aware of the relationship between their initiatives and pancreatic cancer.

The Vice Chair opened the discussion for objective 2 (see slide 26). She asked members whether they were aware of any targeted prevention programs in the Commonwealth specifically for pancreatic cancer. Dr. Warshaw replied that there were none, only programs aimed at reducing smoking and other risk factors. Mr. Rosman inquired what a prevention strategy would look like, given the multifactorial causation of the disease. Ms. Quinn offered that increasing public awareness of the risk factors, such as through ads on the T, would be helpful. Mr. Rosman countered that this idea is geared more towards early diagnosis than prevention. Mr. Nyambose agreed, and noted that the American Cancer Society states that “there is no way to prevent it, but there are ways to lower your risk: don’t smoke, stay a healthy weight, lower your alcohol use.”

Ms. Griffin noted that “we can’t talk about prevention until we talk about awareness and education and early detection, and only then can start thinking about other things. But if not enough people are aware of pancreatic cancer, how can we move further into the conversation?” Dr. Warshaw noted that “it’s very easy to talk about prevention, screening, early testing, but all of those are at best rudimentary. There is no screening or early diagnosis. By the time you can see something on a scan, it’s not an early diagnosis. You have to be careful about promoting awareness, because you have to be realistic in that regard. If you think about former President Jimmy Carter, who had multiple family members with pancreatic cancer, he was a classic case. Johns Hopkins had the challenge of screening him, but there was no strategy. They had to do an ultrasound every 6 months. We don’t have early diagnostic tests. I think we have to be careful about raising unfair expectations.” Dr. Whalen agreed and warned of “alarm fatigue,” which may backfire.

The Chair proposed that the Commission recommend that people receive genetic testing for pancreatic cancer; Dr. Whalen asked him who specifically he thought should be tested, and noted that it may not be useful to recommend that everyone receive testing. The Chair specified that testing should be recommended for those who are at high risk. Ms. Quinn agreed that it can be recommended, and that the patient can decide whether or not to take the opportunity. Dr. Warshaw disagreed, and noted that while “genetic testing has a wonderful ring to it, at this moment its promise is limited.” He explained that it would have to be determined which genetic abnormalities warrant further testing, and expressed concern about “raising too much expectation.”

Dr. Whalen agreed and pushed the Commission to consider what specific recommendation would be made. He noted that even those who are positive for the mutation will probably not be impacted, and that the greatest risk factor is age. He warned against “trying to cure the human condition.” He conceded that identifying people who are at high risk of getting pancreatic cancer genetically, especially those who are young, makes sense in order to develop early screening mechanisms, but this would all require a higher incidence of disease than what currently exists.

Mr. Puetthoff suggested that perhaps a question about family history of pancreatic cancer should be added to routine new patient forms for physician intake. Dr. Warshaw noted that the most important thing to be aware of is new-onset diabetes. The Chair suggested that physician intake forms should include a chart of the most prevalent cancers, and that new patients should indicate what family histories they have across these cancer types.

Ms. Griffin inquired if there was a definition of “high risk” for pancreatic cancer; Dr. Whalen answered that there are grades of risk. Dr. Warshaw called into question the value of a high risk label, and noted that even if screening reveals a tumor, the chance is slim that it is usefully treatable. He expressed that knowing that one is high risk can be negative, in living with a “sword over your head” for not a lot of upshot. Dr. Whalen agreed that finding risk may not be very relevant to patient outcomes but can drive high costs, and that “proving the negative” can lead to interventions that may lead to complications—“building a storm of damage done by the medical world to a patient who doesn’t really have a problem.” He noted that the focus should instead by on encouraging people to contribute to studies. He summarized that “in the end, we’re talking about prevention, and we have to actually know how we’d prevent it or why people are getting it.”

Mr. Rosman suggested that individuals at high risk should perhaps have access to certain diagnostic tools, and questioned whether there are barriers to that kind of care; he noted this is an area for potential recommendations. He also noted that regarding modifiable factors, that the pancreatic cancer community could “loudly join” with the anti-smoking movement. He emphasized the need to “focus on things where there’s policy action possible.” Dr. Whalen agreed, noting that if the Commission determined that genetic testing in a high risk population is valuable, the policy response would be to support access to testing via insurance. Mr. Rosman added that there may be an element of physician education. Dr. Warshaw agreed, adding that among primary care physicians (PCPs), including in MA, almost 60% of patients who get pancreatic cancer and have a potentially curative disease are never referred for treatment because of “a sense of futility among PCPs and others who say ‘I’ve never seen it cured.’” Mr. Rosman replied that a response to this would be a DPH module to educate PCPs. Dr. Whalen pushed back, noting that mandatory CMEs are not well-received by physicians and that “it is such a blunt instrument that it provokes only resentment,” but perhaps additional curricula in medical schools, or awareness initiatives of the issue to PCPs and their nurse practitioners, could be recommended. Mr. Rosman inquired as to whether these educational initiatives had occurred in other states; Dr. Whalen replied that he could look into that.

Ms. Quinn and the Chair noted the lack of general awareness of pancreatic cancer throughout the state. Mr. Rosman reiterated that the Commission should focus on finding actionable recommendations, targeted at improving conditions, rather than just building awareness. He encouraged members to consider, “what can state government do?”

Ms. Cleghorn noted that the next step should be addressing early warning signs. Dr. Whalen replied that the early warning signs are very vague and common, and are often identified in retrospect after a diagnosis. He argued that instead, the focus could be on the correlation between pancreatic cancer and new onset diabetes, but questioned what can actionably be done by the state on this issue. The Vice Chair agreed, and noted that new onset diabetes patients should be closely monitored for symptoms in the first three years after a diabetes diagnosis. Ms. Cleghorn inquired about whether this link was found in both types 1 and type 2 diabetes; Dr. Warshaw noted that the Mayo Clinic Group released a recent publication proposing a model for concentrating diagnoses with diabetes, and that the majority found were linked to type 2, not type 1. Dr. Whalen asked if pancreatic cancer diagnoses made close to a new onset diabetes diagnosis were in an earlier stage of cancer growth; Dr. Warshaw replied that it is not universal, but that the prevalence of earlier stage cancer is indeed higher in this group.

Mr. Rosman asked about the barriers to high risk screening programs; he mused that “it’s either not enough doctors referring them, not enough patients asking for them, and not enough insurers covering it. You want to first make sure it’s covered, that doctors are recommending it, and that patients ask for it.” The Vice Chair noted that there was proposed legislation in 2015 regarding high risk screening that would increase premiums by 2 cents per month per member. Mr. Rosman noted that this proposal would only affect commercial insurers covering individuals and small groups, not MassHealth or Medicare, and that “we can’t force large self-insured employer groups to cover anything.” He also noted that pancreatic cancer patients are more likely to be covered by Medicare than MassHealth, due to the average age of diagnosis. He further explained that the legislature passes mandatory benefit bills once or twice a year, and that while it “becomes all politics,” it’s something that the Commission could recommend.

The Vice Chair noted that the number of patients diagnosed via screening programs is low. Mr. Rosman suggested that if that is true, that it becomes an epidemiological question as to whether it is a rational recommendation. Dr. Whalen agreed that while it would be a legitimate thing to look into, it may not ultimately be a reasonable recommendation. Mr. Rosman suggested that the Commission could recommend that DPH convene an expert panel to examine a cost-benefit analysis of screening.

Dr. Whalen reiterated his warning about trying to “fight the human condition.” He noted that “there are worthwhile recommendations to make that are realistic and that are fiscally reasonable and sensible. But [the Commission] is trying to boil the ocean right now, but needs to focus it down.” He noted that the Commission should agree that there is no current prevention program in MA. Mr. Rosman noted that the Commission could recommend supports for additional research.

**Vote: Ms. Quinn introduced a motion for the meeting to adjourn, which was seconded and unanimously approved, by roll call.**

The meeting was adjourned at 5:02pm.