**Special Commission to Study Pancreatic Cancer**

Meeting Minutes

May 28, 2019

3:00 -5:00 pm

**Date of meeting:** Tuesday, May 28, 2019

**Start time:** 3:06 pm

**End time:** 4:51 pm

**Location:** Conference Room 1, 11st Floor, One Ashburton Place, Boston, MA 02108

**Members present:**

* Joshua Nyambose—Department of Public Health
* Jody Quinn—Pancreatic Cancer Action Network
* Brock N. Cordeiro—Patient Advocate
* Doug Shatford—Pancreatic Cancer Caregiver
* Andrea Cleghorn—Survivor
* Dr. Giles Whalen—UMass Memorial Health Care
* Dr. Andrew Warshaw—Massachusetts General Hospital
* Carole Siegel – Patient Advocate
* Tyler Lang, on behalf of Senator Jo Comerford—Massachusetts Senate

**Members absent:**

* Lauren Peters – Executive Office of Health and Human Services
* Representative John Mahoney—Massachusetts House of Representatives
* Janice Griffin—Pancreatic Cancer Action Network
* Dr. Brian Wolpin—Dana-Farber Cancer Institute
* Cynthia Callahan, RN—Patient Advocate
* Niels Puetthoff—Division of Insurance

**Proceedings:**

The Chair called the meeting to order at 3:06pm.

**Vote: Dr. Warshaw introduced a motion to accept the minutes of the April 23rd meeting, which was seconded and unanimously approved.**

Dr. Whalen arrived at 3:08pm.

The Chair introduced the idea of breaking into subgroups to discuss the topics of prevention, screening, education, and support programs in the Commonwealth, and then opened the floor to discussion.

Dr. Whalen expressed that the Commission had already discussed these topics and suggested that rather than break into subgroups, that the group as a whole work together to start making policy recommendations; “It would be nice to cure pancreatic cancer, but they can’t legislate that. So what are sensible opportunities in policy?” Addressing prevention, he noted that many of the conditions associated with pancreatic cancer are associated with many other conditions, so the Commission could consider aligning with other initiatives, such as those that are anti-smoking or promote healthy weight. He encouraged the group to think about what can be done that is “pancreatic cancer specific.” He mentioned the idea of genetic testing for those known to have pancreatic cancer so that the mutations that contribute to the disease can be better understood, but drew a distinction that testing those who are at risk may not be a practical response. He emphasized that a “modern” approach to policy recommendations may be to promote research that “creates the algorithms” of what puts someone at risk, such as a new onset of diabetes type 2 in conjunction with weight loss, or to support policies that would require insurance companies to cover imaging in such circumstances.

The Chair conceded that forfeiting the idea of work groups would be acceptable as long as the recommendations were drafted expeditiously. Dr. Whalen agreed, noting that the group should “look at each of those [areas]” with the lens of policy practicality. Ms. Quinn agreed.

Dr. Warshaw mentioned that in addition to the topics listed in the charge, that the Commission should also address new developments in pancreatic cancer treatment, along with the regionalization of care. He raised the question about whether care should take place at small community hospitals or high-volume academic hubs. He noted that published evidence has supported the notion that care should be required to take place in larger institutions, and that this is a point for potential legislation.

Ms. Siegel questioned if it makes sense to disseminate information about the connection with newly-diagnosed diabetes to patients and primary care physician. She suggested working with diabetes organizations to coordinate messaging and public outreach. She also raised her desire to include policy recommendations in support of clinical trials. Dr. Warshaw agreed, noting that the treatment that exists today is “automatically multidisciplinary,” so institutional resources need to be in place to facilitate this coordination. He also mentioned the importance of education given that half of patients with pancreatic cancer do not receive treatment, “whether it’s ignorance or a sense of nihilism, they never get referred for treatment, even potentially curative or effective treatment.” Ms. Quinn confirmed that this is true, especially outside of the Boston-metro area.

Dr. Whalen noted that this falls into the category of policy proposals to increase research. He explained that there is huge potential for improved treatment and survival rates, such as the progress that has been seen in lung cancer. Regarding regionalization, he noted that a great barrier is infrastructure; people are dissuaded from traveling for care even though improved survival rates are possible. Dr. Warshaw replied that “the idea of regionalization is not going to be invented here,” noting that in countries like Germany, regionalization is state policy; you cannot perform pancreatic cancer surgeries in community hospitals, and that Massachusetts, being a relatively small state, this is not “an insurmountable problem.” He emphasized that while you will not be able to convince every patient to travel for care, that it is possible to explain to them that better care is possible, and that they have a choice.

Dr. Whalen noted that a policy element of such a system would be to create the infrastructure, the pipeline, to facilitate the transfer of patients from smaller hospitals. Dr. Warshaw replied that as part of the consolidation of community hospitals with academic medical centers, that networks are becoming increasingly accessible (e.g. Cooley Dickinson has a shuttle to MGH). Dr. Whalen agreed that this is a great policy suggestion.

Mr. Lang inquired about the availability of data on patient outcomes in academic institutions compared to community health centers. The group discussed and it was determined that this institution-specific data may be difficult to attain. Dr. Warshaw noted that there is a lot of published data showing that site of care is an important factor in ultimate patient outcome.

Ms. Quinn mentioned that one difficulty surrounding clinical trials is how time-consuming it is for researchers to write grants, and asked whether state government can provide any funds to compensate this time. Dr. Warshaw explained that if you receive an NIH grant, you are obligated to spend all of your time doing that grant, including overtime, so this idea may not be feasible.

Mr. Shatford mentioned that another item the Commission should consider is aftercare for family members. He discussed his family’s personal experience and shared how difficult it has been for him and his children since the passing of his wife. Dr. Whalen noted that this would fall under “support,” and mentioned that while pancreatic cancer tends to occur in older adults, there are of course patients in younger families, which is “an important part of the story.”

Ms. Cleghorn noted that aside from surviving the disease, there is a separate issue of “surviving the treatment.” She shared her difficulties after undergoing the Whipple procedure, and emphasized that this should be a consideration for support recommendations.

Dr. Whalen noted that “the problems and gap are fairly glaring,” but encouraged the group to consider what “one could recommend to the state to do” that would be practical and actionable.

Ms. Siegel mused that regarding minors suffering the loss of a parent, perhaps their school can be alerted to direct them to support resources. Dr. Whalen replied that in larger institutions, there are support groups specific to all kinds of cancer, but he encouraged the group to consider “what is specific to pancreatic cancer and what is generic to watching someone die?”

Ms. Nymabose mentioned a DPH program called “Cancer Prevention and Control” funded by the CDC, which requires each state to present a 5-year plan on all cancer-related activities. Dr. Whalen noted that this could be an opportunity, and that the more generally applicable the solution, the more likely it is to be implemented.

Mr. Lang suggested that it may be helpful for the group to hone in on a smaller list of action times to focus on, and to come up with concrete steps around them. He noted that while pancreatic cancer does not kill as many individuals compared to other cancers, that “in the public eye it has a lot of grab, and that’s a useful advocacy tool.” He encouraged the group to consider which 2-3 items are the most powerful, which would be easier for Senator Comerford to support than a wide array of recommendations. He then inquired of the patient advocates and survivors, whether receiving the news of their diagnosis and then connecting to needed services had been a challenge.

Ms. Quinn noted that she and her husband were well-connected, but that in her experience working with the Pancreatic Cancer Action Network, she has heard of this being a prominent issue, specifically around primary care physicians not having adequate information. The Chair offered that he had the opposite experience from Ms. Quinn, with his family not knowing his father’s diagnosis until they read his death certificate; those connections weren’t made for his family.

Mr. Lang offered that there are a lot of other players in similar prevention work that already advocate for great policies, that there’s already a framework to tap into. Dr. Whalen suggested that the group start working on prevention recommendations. Dr. Warshaw expressed that it “feels like open water to talk about all cancers,” and reminded the group that they have been tasked with what can be done specific to pancreatic cancer.

Ms. Siegel inquired whether it could be justifiable to advocate for genetic testing for individuals who are only aware of one family member with history of pancreatic cancer. Dr. Warshaw replied that he could support such a policy, but highlighted that availability and cost of testing can be substantial. Ms. Siegel agreed and noted that this screening could also contribute to research.

Dr. Whalen noted that a potential avenue for policy recommendations could be to address the shortage of genetic counselors and that some support could be provided for people in school. He noted that this is a good policy opportunity.

Amy Kaplan (Commission Secretary) proposed that members email her draft recommendations that she would collect, organize into category, and then bring to the next meeting for members to consider, edit, and narrow down.

Mr. Lang agreed and noted that regarding genetic counselors: policy could include increased funding for telegenetic services. Dr. Whalen added that because it is a “moving field,” recommendations could include caveats that “if such a gene were found that conferred a high risk..” etc.

Dr. Warshaw pushed the group to consider what is effective. He noted that prevention and the alignment of obesity and smoking initiatives will probably not “move the needle,” but that early detection or detecting pre-malignant conditions will, and that in order to identify those, you have to expand to other areas.

Dr. Whalen suggested that the group “move past ‘prevention-lite’” and say that they would endorse the efforts of the DPH and really focus on specifics related to pancreatic cancer. Ms. Siegel reiterated the importance of connecting with newly-diagnosed diabetes patients. Dr. Whalen replied that a mandate to support imaging for those with new-onset diabetes would only pick up a small percentage with pancreatic cancer, but that such a mandate could say that new-onset diabetes is a valid reason to have imaging services covered by insurance. Ms. Siegel agreed, that such a policy would make insurance more likely to cover imaging “without a fight.”

Dr. Warshaw noted that this is an interesting point, around “influencing the state and how it should spend its resources to promote something.” He noted however, that “sometimes the insurance companies need a real hard shove.” He did agree that if the state supported, a policy to change the thinking about this, then perhaps some headway could be made. He noted that the money spent on patient care is referred to by insurers as the “medical loss ratio.”

Mr. Lang noted that such a policy could be aligned with screening recommendations, to propose that insurers cover someone who fits into that screening criteria.

Dr. Warshaw highlighted a line from the charge that includes policy recommendations to “effectuate an early diagnosis and treatment.”

Ms. Quinn noted that each member of the group has a unique perspective to offer, and that moving forward, all perspectives should be taken into account when developing policy recommendations.

The Chair opened the discussion to how the next meeting should run. Ms. Cleghorn expressed concern that the Commission is “running out of time.”Amy Kaplan (Commission Secretary) reiterated the plan for the next meeting, that she would send an email to members with a chart of potential recommendation topics, to be populated by members based on their comfort with each topic. She encouraged members to review previous meeting minutes, as many potential recommendations had already been discussed.Dr. Whalen agreed with Ms. Kaplan’s approach, as did Mr. Shatford.

**Vote: Dr. Whalen introduced a motion for the meeting to adjourn, which was seconded and unanimously approved.**

The meeting was adjourned at 4:51pm.