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### **Patient Advocacy Advisory Board Meeting**

Saturday, June 11, 2016

San Diego Convention Center – Room 27B

7:30 – 9:30 p.m.

**Board Members Attending:** Josh Mailman (Past Chair), Ivy Ahmed, Rosemary Ciotti, Brandon Leonard, Dorothy McGrath, Stephen Schwartz, Theresa Wickerham, Pam Traxel

**SNMMI Members Attending:** Giuseppe Esposito, MD; Henry VanBrocklin, PhD

**SNMMI Staff Attending:** Saima Hedrick, Ali Haider, Linda Budzinski

**Not Attending:** Betsy de Parry (Chair), James Hendrix, Sheila Ross

1) **Welcome, Josh Mailman**

J. Mailman informed the PAAB of the groundbreaking approval of the new imaging tracer for NETs just a few days prior to this meeting. The NET community is very happy about this and it is an example of what can be accomplished with passionate advocates and conversations with key agencies.

a. **Roster#**

Participants introduced themselves to the group. It was noted that the American Heart Association has discontinued its involvement in the PAAB. SNMMI is researching other heart-related organizations (such as Woman Heart) to try to bring another group aboard. In addition, there is currently an open position for the Lung Cancer Alliance. Sheila Ross will fill that open position temporarily.

b. **Minutes from 5/3/16#**

The minutes from the 5/3/16 meeting were reviewed and approved.

i. **Action items#**

Most action items have been addressed or were slated to be further addressed during the Annual Meeting, including items pertaining to the website and the draft MOU.#

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With regard to Nuclear Medicine Awareness Week, D. McGrath had not yet drafted a model letter to send to state governors, but she planned to do so in the coming weeks. She also indicated she would contact the White House as well. J. Mailman indicated he knows a group involved in nuclear medicine that is a tenant within the Empire State Building and he would contact them to make an introduction so that SNMMI could ask them to request that the lights on the building be turned red for a day or for the week. #

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## 2) Discussion about General MOU#

Committee members reviewed a draft MOU for use in fostering collaboration with patient advocacy organizations. SNMMI would like to send the MOU to leaders of the PAAB members' organizations for review, discussion, and signature. The objective is to elevate the relationships between SNMMI and these organizations, to ensure that these organizations support what the Board members are doing as individuals; and to explore in-kind activities that can be developed to contribute to the overall effort of patient advocacy. Among the suggestions from Board members:

- Language of the MOU should be less formal and more patient-focused
- Might want to consider calling it something less formal, i.e., "Partnership Agreement" rather than "Memorandum of Understanding"
- Replace the term "cancer" with "diagnostics" throughout
- A cover letter should accompany the document explaining its purpose
- Should use very clear language that this is meant to help "allay fears for patients," which is a shared goal
- Should contain information about how to do social media if that is something that is required
- It needs to be clarified whether this document does or does not supersede any existing agreements between the organizations
- Consider making it sound less "legal" as organizations may balk at the time and expense required to have their legal departments review it. In particular, reconsider the language re: cost and intellectual property

S. Hedrick agreed to revise the document accordingly and develop a cover letter for review by the board. She asked the committee to check to see whether their organizations have any such documents with other groups that could be used as models. It was noted that this document should be referred to as a partnership agreement and not an MOU.

The committee discussed a target date for getting the MOUs completed and executed. SNMMI does not want the organizations to simply sign and return the document; it is intended to foster conversation between each group's leadership and the leadership of SNMMI (specifically V. Pappas, S. Hedrick, H. VanBrocklin, and G. Esposito). The committee determined that a target date would be October; however, this is a "moving target date."

## 3) Website Review, A. Haider#

A. Haider provided an overview of SNMMI's plans for data and moving the organization's work to the cloud. He understands the Board's desire to make the patient site 508 compliant and will look into that. He would like to know the Board's goals for the patient site so he can determine the best available tools. J. Mailman indicated that much of that information has been produced in the past. SNMMI Staff will provide Ali with all the specific concerns about the website (captured in previous minutes).

## 4) Patient Education Day Preparation

Currently 118 people are pre-registered, and there may be some walk ins. The breakdown for breakout sessions is:

- Prostate Cancer: 28
- Neuroendocrine Tumors: 68
- Breast Cancer: 13

Attendees will receive their badges at registration and will also be checked in at the door, where they will receive a bag with the Patient Education Day program, brochures, and pens. They will get a dot on their badge indicating which breakout session they selected.

Staff and Board members will be stationed near registration to assist in directing people to the correct room.

Board members indicated that they asked people staffing the registration desk about Patient Education Day and they were not knowledgeable about it. S. Hedrick indicated that she met with the manager in charge and was assured that this would be taken care of. She will speak to them again in the morning, as well as to the people at the SNMMI Info Desk, to ensure they are prepared to assist those attending Patient Education Day. Board members suggested additional signage be prepared for future meetings (similar to what was done in St. Louis), and S. Hedrick indicated that would be a priority for the future.

J. Mailman reviewed the results of a survey provided to registrants regarding their concerns about nuclear medicine. Speakers received copies of the results to help them as they prepared their presentations.

After the breakouts, Board members are to lead tours of the exhibit hall, stopping at the booths specified by S. Hedrick for their specialty. The following Board members offered to lead the tours:

- Prostate Cancer: B. Leonard and I. Ahmed
- Neuroendocrine Tumors: J. Mailman and S. Schwartz
- Breast Cancer: R. Ciotti and D. McGrath

S. Hedrick concluded the discussion of the Patient Education Day by encouraging all Board members to attend the Sunday evening reception. It is a way for SNMMI to recognize them for all their work.

It was noted that Outreach may need to purchase ribbons that say "Patient Advocate." It may also be helpful to have a desk at registration dedicated to Patients. Directional signage for this event is very important since patients are not familiar with the convention atmosphere and are looking for the "Patient Education Day."

## **5) Other Business**

J. Mailman asked why there is no patient designation to become a member of SNMMI. He pointed out that they had about eight or nine patients in the Saturday categorical educational session, including people who flew from as far away as Florida and Tennessee.

D. McGrath asked whether it is possible to make Board members administrators on the Facebook page. S. Hedrick assured them that anyone can put a post onto that page but she was not sure whether it is possible to make them admins. She said she would check. She also offered to check with Laurie Callahan in Communications regarding whether there are other potential opportunities for Board members to participate in SNMMI PAAB social media outreach.

S. Hedrick indicated that in future discussions, she would like to explore the feasibility of joint advocacy events with the Board members' groups. Would their organizations be willing and able to send people to participate in advocacy days on a large scale? Board members mentioned that ZERO does a good job with advocacy training, showing how patients and caregivers can create an "army" on state and national levels. This may be something that can be discussed at the leadership meetings between the PAAB organizations and SNMMI.

## 6) Adjourn

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### ACTION ITEMS#

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- D. McGrath will draft a model letter to send to state governors and will contact the White House regarding Nuclear Medicine Awareness Week.
- J. Mailman will make an introduction to SNMMI to a group involved in nuclear medicine that is a tenant within the Empire State Building so that the Society can ask them to request that the lights on the building be turned red in recognition of Nuclear Medicine Awareness Week.
- S. Hedrick will revise the Partnership Agreement document according to the committee's feedback and develop a cover letter for review by the board. If any committee members have such documents within their organizations, they are asked to provide them to her to be used as models.
- SNMMI Staff will work with A. Haider to address concerns regarding the DiscoverMI website as captured in previous meeting minutes.
- S. Hedrick will research whether Board members can be made admins for the patient Facebook page and whether there are other potential opportunities for them to participate in SNMMI PAAB social media outreach.

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