



Patient Advocacy Advisory Board Meeting

Wednesday November 30, 2016

Conference Call

1:00 – 2:00 p.m.

Board Members Attending: Betsy de Parry (Chair), Rosemary Ciotti, Brandon Leonard, Josh Mailman, Mary McGowan, Dorothy McGrath, Stephen Schwartz, Pam Traxel, Theresa Wickerham

SNMMI Staff Attending: Saima Hedrick, Kathleen Sheehan, Linda Budzinski, Caitlin Kubler

Not Attending: Ivy Ahmed, Maria De Leon, James Hendrix, Elridge Proctor,

1) **Welcome** *Betsy de Parry*

a) **Introductions**

b) **Establish Quorum**

Quorum was established.

c) **Review minutes from 10/26/16**

The minutes from the committee's 10/26/16 meeting were reviewed and approved with no changes.

The following action item update was noted:

- Men's Health Network did submit a letter to eviCore in support of SNMMI's position to include coverage for certain imaging agents. B. Leonard reported that they received a response that indicated the company will not do so until certain additional criteria are met. J. Mailman indicated his organization received a similar letter which further stated that research published in the Journal of Nuclear Medicine does not meet their standards for consideration because of the fact that the publication accepts advertising. Both members offered to circulate their letters to the full committee.

2) **Updates**

- a) **Website:** S. Hedrick encouraged members to review the DiscoverMI.org site, which has undergone a number of changes requested by the PAAB. Most recently, the "Videos" section of the site has been significantly upgraded. Additional images and input are still being sought for some of the pages, and the site's masthead is still under revision. The site is not currently 508 compliant; staff will continue to work with IT to explore the feasibility of doing so. She noted that all PAAB member organization logos are now on the site with the exception of Woman Heart. M. McGowan indicated she would send a logo for use on the site.

- b) **Radiation Safety Materials Development:** B. de Parry reported that she and Mehdi Djekidel, MD, held a call earlier in the week to discuss existing materials produced by SNMMI and other organizations regarding radiation safety and the need to revise the SNMMI factsheet to ensure accuracy and patient-friendliness. Dr. Djekidel has offered to make a first pass at a revision for subsequent review by the PAAB.

3) Capitol Hill Day, SNMMI HPRA Director Kathleen Sheehan

SNMMI's new Director of Health Policy & Regulatory Affairs (HPRA) Kathleen Sheehan introduced herself and led a discussion on a proposed Capitol Hill Day for the PAAB. The timing and the content of such an effort will depend a great deal upon the direction of the incoming Congress and Administration. There would be some advantage to reaching them early in the year when they are in the most formative stages of determining policy, but there would also be some advantage to waiting to see which issues emerge as most relevant.

K. Sheehan offered several observations on the new Administration, stating that incoming Health Secretary Tom Price is known to be an opponent of the Affordable Health Care Act and existing physician payment systems. She said she believes the Administration will most likely fast track certain FDA activities. She said she believes the new Administration will have a focus on patients and the development of new treatments but that they may not have a strong understanding of the role of imaging. There are a lot of unknowns at this time, and she is in the process of evaluating the landscape and determining which issues and messages SNMMI should focus on in the coming year.

She and the PAAB decided it would make most sense for her to continue to develop a plan for the Society moving forward and to circle back with the PAAB to provide guidance on how they can best support that plan.

4) Patient Education Day Topic Proposals

B. de Parry directed board members' attention to an excerpt of the minutes from a recent Outreach Committee call in which the committee provided suggestions for potential topics for the 2017 Patient Education Day. The PAAB discussed these suggestions and other possibilities for the General Session portion of the day. Among the topics of potential interest:

- Radiation safety information.
- Evaluating the reliability of medical information provided via websites, journals, etc. J. Mailman indicated he had recently participated a session on understanding clinical trials and studies along with Emily Bergsman, MD, at UCSF. The session was directed toward patients and patient advocates and was well received. S. Hedrick noted that patients who are better educated and more skilled at understanding such studies and reports make better advocates, which is an important objective of the Society's patient outreach efforts. J. Mailman offered to reach out to Dr. Bergsman and share the relevant slide deck with the group.

- Questions patients should ask their doctors. D. McGrath stated she has a list of questions that could be used as a basis for such a presentation and offered to share that with the group.

The PAAB then discussed potential disease-specific topics for breakout sessions.

Possible topics include:

- *Colon Cancer:* D. McGrath stated she would be willing to approach the Denver area Colon Cancer Alliance if that topic is of interest.
- *Thyroid Cancer:* T. Wickerham noted that Denver has a strong ThyCa Chapter.
- *Lymphoma:* S. Schwartz noted that SNMMI will be meeting with the leadership of the Lymphoma Research Foundation and he hoped to discuss their possible participation at that time.
- *Prostate Cancer:* J. Mailman noted that there are a lot of new developments in this area with regard to clinical trials and international therapy activities. B. Leonard indicated he believed MHN would be willing to assist in developing a program if this topic is selected.

B. de Parry and S. Hedrick noted that decisions on topics need to be made by early February, and titles and speakers need to be confirmed in March to ensure inclusion in the SNMMI's Annual Meeting promotional materials.

5) SNMMI/PAAB Member Collaboration

- a) **Patient Concerns Survey Distribution.** The patient concerns survey administered for the 2016 Patient Education Day yielded some very useful information, and the Society would like to significantly expand on the poll to get a broader understanding of the concerns of patients, particularly in light of the fact that PED attendees may not offer a true representation of the concerns of the general patient population. S. Hedrick asked whether PAAB member organizations would be willing to publicize the survey to their members and encourage participation via their newsletters and other communications channels.

D. McGrath indicated that she would ask the Colon Cancer Alliance but stated she would be willing to post a link to the survey on her own social media outlets. S. Hedrick asked that all PAAB members consider this request. Staff will create a survey link and provide it to the members, and any and all participation would be appreciated.

- b) **SNMMI/PAAB Member Leadership Meetings.** To date, SNMMI has met with leadership staff from FORCE and will schedule a meeting with the Lymphoma Research Foundation to discuss areas of mutual concern and potential collaboration. S. Hedrick asked PAAB members to explore whether their respective organizations would be willing and able to participate in such meetings going forward.

ACTION ITEMS

- B. Leonard and J. Mailman will circulate their eviCore response letters to the PAAB members.
- Staff will continue to work with IT to explore the feasibility of making DiscoverMI 508 compliant.
- M. McGowan indicated she will send S. Hedrick a WomanHeart logo for use on the DiscoverMi site.
- K. Sheehan will provide guidance to the PAAB on how they can best support SNMMI's advocacy efforts with the new Administration and Congress as the Society's goals and messages continue to develop.
- J. Mailman will reach out to Dr. Emily Bergsman regarding a potential session at the 2017 PED and will share the presentation slide deck with the group.
- D. McGrath will share a list of questions patients should ask their doctors with the group for potential use as the basis of a 2017 PED session.
- D. McGrath will ask the Colon Cancer Alliance whether they are willing to help publicize SNMMI's patient concern survey to their members and will post a link to the survey on her own social media outlets.
- SNMMI staff will create a survey link and provide it to PAAB members to share with their organizations and ideally promote to the organizations' members.
- PAAB members will explore whether their respective organizations are willing and able to participate in SNMMI/PAAB member leadership meetings to discuss mutual areas of concern and potential for collaboration.