



Patient Advocacy Advisory Board Meeting

Wednesday, July 27, 2016

Conference Call

1:00 – 2:00 p.m.

Board Members Attending: Betsy de Parry (Chair), Josh Mailman, Brandon Leonard, Dorothy McGrath, Theresa Wickerham, Pam Traxel

SNMMI Members Attending: Giuseppe Esposito, MD

SNMMI Staff Attending: Virginia Pappas, Saima Hedrick, Linda Budzinski

Not Attending: Ivy Ahmed, Rosemary Ciotti, James Hendrix, Sheila Ross, Stephen Schwartz

- **Introduction** *Betsy de Parry*

- **Quorum**

- Quorum was established.

- **Minutes from 6/11/16**

- The minutes from the 6/11/16 meeting were reviewed and approved.

- **Action items**

- D. McGrath indicated she had begun work on a model letter to send to state governors regarding Nuclear Medicine Awareness Week. She planned to send the letter to her own state house first and then distribute to the group. She indicated she could do this before the next call.

J. Mailman indicated that the best way to reach AAA as a tenant in the Empire State Building to request the lights on the building be turned red in recognition of NMAW would be through a lymphoma group. He offered to speak to S. Schwartz about this.

Staff reported that they have scheduled a meeting with SNMMI IT staff on August 9 to discuss needed changes to the DiscoverMI.org website.

The committee determined that it is not necessary or desirable for anyone other than SNMMI staff to serve as admins for the patient Facebook page. Saima reiterated that PAAB members are welcome to contribute posts as individuals and on behalf of their organizations when appropriate.

- **Patient Education Day Debrief**

- Committee members reviewed all aspects of the PED and provided feedback:

- a) **Access:** J. Mailman noted that the elevator closest to the PED activities was unavailable. This presented difficulties, particularly with respect to accessing the exhibit hall tour.
- b) **Signage:** Committee members expressed that there needs to be more, better, and specially branded signage for all PED activities, including the reception. The fact that the morning session switched rooms, while necessary, added an element of confusion. S. Hedrick noted that ensuring proper room sets will be a priority for the future.
- c) **Registration:** The committee felt the online pre-registration process was easy and straightforward. S. Hedrick noted that she has requested more extensive training for registration personnel so they are better prepared to process patient registrations. She indicated that there may be a way to improve the pre-conference registration process so that they have credentials similar to SNMMI Annual Meeting attendees but that that is not yet certain.
- d) **Luncheon:** P. Traxel stated that she found the luncheon to be a terrific opportunity to talk and that it became a very interactive function at the event.
- e) **Breakout Sessions:** Committee members expressed the desire to increase the time allotment for the breakouts to two hours if possible as attendees tend to be most interested in this portion of the program. They indicated they like the format with a patient, NM expert, and physician specializing in the disease area. D. McGrath suggested offering refreshments in the afternoon as people get hungry/thirsty during the session.
- f) **Exhibit Hall Tour:** P. Traxel stated that she found there was not enough time for the tour as people were very interested in stopping and talking to the exhibitors. She said they lost some people and felt that overall the schedule was too full for the audience.
- g) **Reception:** There were no comments with regard to this function.
- h) **Survey:** There were no comments with regard to the survey. S. Hedrick reported that to date, the survey had received 12 responses, and she urged committee members to encourage the attendees they knew to fill it out.
- i) **Other:** J. Mailman expressed concern that one of the General Session speakers may have provided content with regard to cumulative effects of NM that was contrary to SNMMI's guidance on the topic. G. Esposito indicated this is the number one question among patients and asked whether it would be possible for the Society to provide a statement on it. V. Pappas indicated that the Society will convene a group of members to explore what was being said and decide if and how that issue needs to be addressed.

B. Leonard suggested providing thank you gifts to PED speakers.

S. Hedrick indicated staff will be putting the pre- and post-conference data, as well as videos on the SNMMI website shortly after the August 9th meeting with the SNMMI IT staff.

- **2017 PAAB Plan**

The committee reviewed the Draft FY17 Patient Advocacy Advisory Board Plan, including the following initiatives:

- **Liaising with PAAB Member Organizations.** SNMMI staff and leadership plan to meet with each PAAB member organization to identify areas of mutual interest and discuss the possibility of collaborative projects. B. de Parry indicated she would like to see this as a primary focus for the year.

S. Hedrick noted that the Society is exploring use of the Ursula Mary Kocemba–Slosky, PhD, Professional Relations Fellowship program to facilitate these discussions this fall.

P. Traxel said she felt these conversations are extremely important to determine areas of alignment between SNMMI and the PAAB member organization and suggested each PAAB board member be invited to participate in his/her organization’s respective meeting. B. de Parry expressed her agreement that it would be ideal to have the PAAB board member as a participant and would really help the member in understanding how the organizations might work together. V. Pappas indicated that this would be an option on a case-by-case basis pending interest and availability.

- **Patient Education Day.** The PAAB will hold its 6th Annual Patient Education Day on June 11 in conjunction with the SNMMI Annual Meeting in Denver, Colorado. Comments made during the PED discussion will be considered and implemented as appropriate during the planning phases of the event.
- **Patient Hill Day.** The PAAB will hold a patient-focused Hill Day to emphasize the value of nuclear medicine and molecular imaging in patient-focused healthcare. S. Hedrick indicated that Outreach staff plan to meet with the SNMMI Health Policy & Regulatory Affairs staff to determine the optimal time to hold this event.
- **Patient Website Optimization.** In FY17, the PAAB aims to improve the user-friendliness of the DiscoverMI.org website. As noted earlier, Outreach staff will meet with IT staff on August 9 to begin the process.
- **What to Expect Videos.** One of the main goals for the coming year is to raise awareness about nuclear medicine and molecular imaging via short videos that detail what a patient can expect when undergoing a particular procedure.

S. Hedrick reported that the Society is determining whether the funding for this objective exists or whether there is a need to raise funds. Staff are currently putting together proposals and plans are to begin creating the videos in 2017.

B. de Parry noted that videos are more effective than webinars and so there are no plans at this point to create webinars. However, S. Hedrick noted that if there is a desire among PAAB member organizations to create a webinar, such projects could be considered on a case-by-case basis.

- **Other Business**

The committee had no other business.

- **Adjournment**

The meeting adjourned at 1:58 p.m.

ACTION ITEMS

- D. McGrath will send a letter re: Nuclear Medicine Awareness Week to governor and then distribute to the group. She plans to do this before the next PAAB call.
- J. Mailman will contact S. Schwartz regarding AAA, a tenant within the Empire State Building that may be able to request that the lights on the building be turned red in recognition of Nuclear Medicine Awareness Week.
- V. Pappas will convene a group of members to explore the issue surrounding guidance on the question of cumulative effects of NM.
- S. Hedrick indicated staff will be putting the pre- and post-conference data, as well as videos on the SNMMI website shortly after the August 9th meeting with the SNMMI IT staff.
- Outreach staff will meet with the SNMMI Health Policy & Regulatory Affairs staff to determine the optimal time to hold the Patient Hill Day.