

Patient Advocacy Advisory Board Meeting

Wednesday, February 22, 2017

Conference Call

1:00 – 2:00 p.m.

Board Members Attending: Betsy de Parry (Chair), Cienna Breen (ZERO Cancer), Rosemary Ciotti, Ana Fadich, James Hendrix, Dorothy McGrath, Drew Saelens (ZERO Cancer), Stephen Schwartz, Pam Traxel

SNMMI Staff Attending: Saima Hedrick, Linda Budzinski

Not Attending: Maria De Leon, Josh Mailman, Mary McGowan, Elridge Proctor, Theresa Wickerham

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

a) **Introductions**

b) **Establish Quorum**

Quorum was established.

c) **Review minutes from 1/25/17**

The minutes from the committee's 1/25/17 meeting were reviewed and approved with the correction of a typo to Dr. Emily Bergsland's name.

The following action item updates were noted:

- Dr. Emily Bergsland has agreed to participate in the 2017 PED.
- S. Hedrick has confirmed that sufficient space is available at the 2017 PED to add a fourth breakout session.
- J. Mailman has agreed to facilitate a Patient Empowerment Luncheon at the 2017 PED, and staff is working on securing sponsorships to cover the costs of the lunches.

2) **Patient Education Day Planning (June 11, 2017)**

a) **Program:** Speakers are identified for the general sessions as follows:

- **What Is Nuclear Medicine?** –Michael Phelps, MD
- **Understanding Clinical Trials** –Emily Bergsland, MD
- **Radiation Safety** –Fred Fahey, DSc, FSNMMI

SNMMI staff will send invitations and confirm each of these speakers.

Speakers need to be identified for each of the breakout sessions. The typical format for the breakouts is:

- Patient/Patient Advocate provides introductory remarks (5-15 minutes)

- Health care professional discusses disease and the role of nuclear medicine in diagnosing/treating disease from the perspective of a referring physician.
- Nuclear medical physician offers more technical perspective on how the imaging/treatment works and the process for administering

SNMMI staff will line up the NM speaker for each of the four sessions.

For the patient/patient advocate speaker and the health care professional speakers, the following PAAB-member organizations are asked to assist in identifying and confirming speakers:

- Neuroendocrine Tumors: NorCal CarciNET (J. Mailman)
- Thyroid Cancer: ThyCa (T. Wickerham)
- Alzheimer's: Alzheimer's Association (Jim Hendrix)
- Prostate Cancer: ZERO (Drew Saelens and Cienna Breen) and Men's Health Network (Ana Fadich)

The deadline for confirming speakers is March 3 to allow for sufficient planning and promotion.

It was noted that the national Alzheimer's Association office will have a booth at the SNMMI Annual Meeting; S. Hedrick indicated that if the local chapters of the participating groups wish to have tables outside of the PED sessions, they are welcome to do so.

b) **Promotion:** The Board discussed ways to promote the event, including:

- The event and preliminary schedule are currently posted on the DiscoverMI.org website.
- Once the program has been finalized, staff will develop a print program and flyers that PAAB members can provide to their respective audiences.
- A PED-specific hashtag will be developed for use on social media.
- Staff will develop and disseminate a series of suggested Facebook and Twitter posts for use by PAAB members. The Board reviewed a sample of the types of posts from 2016 and agreed it would be useful to develop those for 2017. It is recommended that Board members post twice per week.
- The board agreed it would be helpful to provide testimonials from past attendees on the value of the program. Staff will work on finding and including testimonials.

3) Patient Survey

The Board reviewed a draft of the patient survey, including suggested edits/additions from PAAB-member organizations. The Board evaluated each suggested change and provided guidance on them. Among the changes discussed:

- Should leave "patient" as is.
- Add question re: location.
- Add in question re: type of institution.

- Not feasible to determine efficacy.
- Need to add question to ascertain if they are nuclear medicine patient, and need to offer explanation of types of procedures included in NM.
- Suggested thyroid-specific questions were approved.
- Suggested lymphoma-specific questions were approved.

Staff will make the changes noted in SurveyMonkey and distribute the link to PAAB members to test and to determine the approximate time taken to complete.

S. Schwartz suggested providing an incentive for completing the survey in the form of a small donation to an appropriate charitable organization. S. Hedrick will check on the budget to see whether this is a possibility.

4) Radiation Safety Factsheet

PAAB members were provided a final draft of the Radiation Safety Factsheet. B. deParry offered two suggested edit to the “Questions to Ask Your Doctor” portion of the document. Staff will make the edits and finalize.

5) New Business

S. Hedrick noted that the PAAB has received a request from J. Mailman to consider staging a roadshow similar to the PED General Sessions in the San Francisco Bay area to provide patients there with education on nuclear medicine.

The PAAB discussed this possibility, including whether it is feasible in terms of time and money and whether it would make sense to do this on a regional basis, in areas other than the regions where future PED sessions are planned.

S. Hedrick will do some research on potential costs, etc., for further discussion on the March PAAB call.

6) Adjournment

ACTION ITEMS

- SNMMI staff will send invitations and confirm each of the 2017 PED General Session speakers.
- PAAB-member organizations identified to assist with each of the four PED breakout sessions will identify and confirm patient/patient advocate and healthcare provider speakers (deadline March 3) for their respective breakouts.
- SNMMI will identify and confirm speakers for the NM section of each of the four PED breakouts.
- Once the PED program has been finalized, staff will develop a print program and flyers that PAAB members can provide to their respective audiences.
- A PED-specific hashtag will be developed for use on social media.
- Staff will develop and disseminate a series of suggested Facebook and Twitter posts for use by PAAB members.
- Staff will include attendee testimonials in the PED promotional program.

- Staff will make the changes suggested by the PAAB to the Patient Concerns survey in SurveyMonkey and distribute the link to PAAB members to test and to determine the approximate time taken to complete.
- S. Hedrick will check the PAAB's budget to see whether it is a possibility to provide an incentive for survey completion.
- Staff will make the suggested edits to the Radiation Safety Factsheet and finalize.
- S. Hedrick will research potential costs, etc., for developing a potential mini-PED roadshow for further discussion on the March PAAB call.