



Patient Advocacy Advisory Board Meeting

Wednesday, January 25, 2017

Conference Call

1:00 – 2:00 p.m.

Board Members Attending: Betsy de Parry (Chair), Rosemary Ciotti, James Hendrix, Josh Mailman, Dorothy McGrath, Anna Pugh (American Cancer Society), Stephen Schwartz, Theresa Wickerham

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

Not Attending: Ivy Ahmed, Maria De Leon, Ana Fadich, Mary McGowan, Elridge Proctor

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

a) **Introductions**

b) **Establish Quorum**

Quorum was established.

c) **Review minutes from 11/30/16**

The minutes from the committee's 11/30/16 meeting were reviewed and approved with no changes.

The following action item updates were noted:

- IT staff is working with the Society's vendor to discuss making DiscoverMI.org 508 compliant. R. Ciotti indicated she believes the program to make it compliant can be an overlay to the site.
- SNMMI has brought on a new Health Policy & Regulatory Affairs Director, Wayne Powell; the possibility of a Patient Hill Day will be discussed with him once he has had an opportunity to begin developing his priorities and goals. In the meantime, the Board will "stand by," ready to assist with advocacy efforts as needed.
- Dr. Emily Bergsman is willing to present a session at the 2017 PED if desired; J. Mailman shared her slide deck and a recording of her presentation with the group.

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

a) **General Session:** The committee discussed several potential General Session presentations and decided to move forward with three ideas:

- **What Is Nuclear Medicine?** – This would include a discussion of the history of nuclear medicine. Potential speaker is Fred Grant, MD.
- **Understanding Clinical Trials** – Speaker: Emily Bergsland, MD – J. Mailman will invite Dr. Bergsland to present
- **Radiation Safety** – Potential speaker is Fred Fahey, DSc, FSNMMI.

- b) **Breakout Sessions:** The Board discussed creation of several disease-specific breakout sessions. There will be three, possibly four, sessions. S. Hedrick will check with the Meetings Department to see if we can secure enough meeting space for four. The sessions will focus on:
- **Thyroid:** S. Hedrick has discussed this with ThyCA and they expressed interest in assisting with programming and promotion.
 - **NET:** J. Mailman is willing and able to take the lead on this.
 - **Prostate:** This is an important topic at this time because of advances being made; however, S. Hedrick indicated concern that we do not currently have the robust level of patient advocacy support needed in this area because longtime PAAB members Brandon Leonard (Men's Health Network) and Ivy Ahmed (ZERO) are no longer able to participate. J. Mailman indicated he will provide some contacts from potential organizations, and D. McGrath said she has a contact that may be able to assist in identifying resources as well.
 - **Alzheimer's** (tentative): This would include a discussion of the IDEAS study. J. Hendrix indicated there is a chapter in Denver that would be able to assist with planning and promotion.
- c) **Networking Luncheon** – Last year's lunch worked well; S. Hedrick will speak with J. Mailman to see if he would be willing to facilitate something similar this year.

3) Radiation Safety Fact Sheet

The Board reviewed a draft Radiation Safety Fact Sheet. Members noted that a link needs to be added to the I-131 Fact Sheet where indicated.

B. de Parry asked Board members to further review the Fact Sheet after the call and provide comments to staff by COB on January 26.

4) Patient Survey

S. Hedrick noted that SNMMI would like to take the survey on patient concerns administered as part of the 2016 PED and expand its distribution to the memberships of the PAAB groups. SNMMI would be happy to include one or two disease-specific questions upon request so the groups can gather more granular data for their own purposes.

B. de Parry asked Board members to inform staff by February 1 if there are one or two questions their organizations would like to add to the survey and to let staff know by February 15 if their organizations would be able to partner with SNMMI in disseminating the survey.

5) Adjournment

ACTION ITEMS

- J. Mailman will invite Dr. Emily Bergsland to present at the 2017 PED.
- S. Hedrick will check with the SNMMI Meetings Department to see if the PAAB can secure enough meeting space for four breakout sessions.

- J. Mailman will provide contacts from potential prostate patient advocacy organizations, and D. McGrath will ask her contact for assistance in identifying resources as well.
- S. Hedrick will speak with J. Mailman to see if he would be willing to facilitate a networking luncheon at this year's PED.
- Board members will review the Radiation Fact Sheet and provide comments to staff by COB on January 26.
- Board members will review the Patient Survey and inform staff by February 1 if there are one or two questions their organizations would like to add to the survey and will let staff know by February 15 if their organizations would be able to partner with SNMMI in disseminating the survey.