



## **Patient Advocacy Advisory Board Meeting**

Wednesday, May 31, 2017

Conference Call

1:00 – 2:00 p.m. ET

**Board Members Attending:** Betsy de Parry, Cienna Breen, Rosemary Ciotti, Ana Fadich, James Hendrix, Josh Mailman, Dorothy McGrath, Stephen Schwartz, Theresa Wickerham

**SNMMI Staff Attending:** Saima Hedrick, Linda Budzinski, Caitlin Kubler

**Not Attending:** Maria De Leon, Mary McGowan, Elridge Proctor, Pam Traxel

### 1) **Welcome**

#### a) **Introductions**

#### b) **Review minutes from 4/26/17**

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

### 2) **NRC Comment Request**

C. Kubler shared with the PAAB members SNMMI's draft letter providing comments addressing the NRC's six questions related to patient release protocols. She stressed that this is an information-seeking process and not a rule-making process. The SNMMI Government Relations Committee will be reviewing/revising the draft letter and presenting it for approval by the SNMMI Board of Directors at the Annual Meeting. The Committee welcomes input from the PAAB.

PAAB members offered the following comments on the draft letter:

- T. Wickerham noted that it is not unusual for a patient to receive more than one procedure in a 24-hour period.
- J. Mailman asked that the Committee reconsider limiting Question E to I-131.

C. Kubler thanked the PAAB for their input and indicated that she would pass it along to the Committee. She indicated that the best next step would be for PAAB-member organizations to develop letters referencing support for the SNMMI letter (as opposed to signing onto the letter). Comments are due to the NRC on June 27.

Upon finalization of the letter by the Committee, Outreach staff will share the final draft with the PAAB for reference in developing their own letters. Staff will notify PAAB members of the Board's decision on approval of the letter so the patient organizations can finalize their letters in time for the deadline.

### 3) Patient Education Day

#### a) Program

- Speakers and content have been finalized for all sessions. Staff has held or has scheduled calls with each set of speakers to review content and logistics.
- The Patient/Caregiver Survey yielded 699 responses. J. Mailman reported that among the findings, participants report heightened fear and a lack of good information being provided for scans (as opposed to therapies). He indicated he will conduct a mini onsite survey of attendees at the PED to see what effect education has on patient perceptions.

#### b) Promotion

- S. Hedrick noted that SNMMI's social media posts are not being shared by the PAAB-member organizations, with the exception of a share from ZEROcancer. She urged members to retweet and share the promotions being posted at [https://twitter.com/discover\\_mi](https://twitter.com/discover_mi) and <https://www.facebook.com/DiscoverMI.org/> PAAB members agreed to give a final push for promotion in the week leading up to the event.

### 4) Adjournment

PAAB members thanked Betsy de Parry for her service as 2016-2017 Chair. She thanked them for their participation and hard work and noted that they are in good hands going forward under the leadership of Stephen Schwartz as Chair and Theresa Wickerham as Vice Chair.

### ACTION ITEMS

- Upon finalization of the NRC comments letter by the SNMMI Government Relations Committee, Outreach staff will share the final draft with the PAAB for reference in developing their own letters. Staff will notify PAAB members of the Board's decision on approval of the letter so the patient organizations can finalize their letters in time for the deadline.
- PAAB members will give a final push for promotion in the week leading up to the PED event.