

Patient Advocacy Advisory Board Meeting

Wednesday, April 26, 2017

Conference Call

3:00 – 4:00 p.m.

Board Members Attending: Betsy de Parry, Cienna Breen (ZERO), Ana Fadich, Josh Mailman, Dorothy McGrath, Stephen Schwartz, Theresa Wickerham

SNMMI Staff Attending: Saima Hedrick, Linda Budzinski, Wayne Powell, Caitlin Kubler

Not Attending: Rosemary Ciotti, Maria De Leon, James Hendrix, Mary McGowan, Elridge Proctor, Pam Traxel

1) **Welcome**

a) **Introductions**

b) **Review minutes from 3/29/17**

The minutes from the committee's 1/22/17 meeting were reviewed and approved with one change to the numbering.

The following action item updates were discussed:

- The Patient/Caregiver Survey is nearing completion and will be distributed to PAAB members. They are asked to distribute and promote it to their constituents.
- The PAAB held its elections for Board Chair and Chair Elect. Stephen Schwartz was elected chair and Theresa Wickerham was elected Chair Elect. The board asked that the chair elect title be changed to Vice Chair. Staff will adjust internal documents accordingly.

2) **NRC Comment Request**

C. Kubler offered an overview of an ongoing request for comments by the Nuclear Regulatory Commission with regard to nuclear therapy procedures. The NRC is currently undertaking an information gathering process; this is not yet a rulemaking process. A full explanation of the request can be found at:

<https://www.regulations.gov/document?D=NRC-2017-0094-0001>

The NRC is requesting input on six questions:

1. Should the NRC develop an activity-based patient release threshold?
2. Should the NRC amend the regulations to clarify the time frame for the current dose limit in 10 CFR 35.75(a) for releasing Individuals? For example, should the regulations explicitly state that the criterion is a per year limit? If not, is there a different criterion that the NRC should consider?

3. Should the NRC continue to apply the same dose criteria of 5 mSv (0.5 rem), to all members of the general public, including family members, young children, pregnant women, caregivers, hotel workers, and other members of the public when considering the release of patients?
4. Should the NRC include a specific requirement for the release of a patient who is likely to expose young children or pregnant women to doses above the public dose limit?
5. Should the NRC have a specific requirement for the licensee to have a patient isolation discussion with patients in sufficient time prior to the administration to provide the patient time to make isolation arrangements or the licensee to make plans to hold the patient, if the patient cannot be immediately released?
6. Should the NRC explicitly include the time frame for providing instructions in the regulations (e.g., the instructions should be given prior to the procedure)?

Among the concerns SNMMI has with regard to the questions:

- Should NRC be regulating medicine?
- Have the issues/problems being evaluated been identified based on data or anecdotal evidence?

The NRC held a call on April 23 to take feedback on these questions; several PAAB members did attend portions of the call.

The next call is scheduled for May 23 at 9:00 a.m. Eastern time. Currently, the call is slated to include one hour devoted to each question; however, this may be shortened. Staff will send out a reminder to the PAAB several days prior to the call.

SNMMI is preparing draft comments on the questions and will share those with PAAB members within the next few weeks. Interested members are asked to share the SNMMI comments with their organizations and determine whether/how to contribute their own comments to the NRC.

The deadline for submitting comments to the NRC falls during the SNMMI Annual Meeting. Staff has requested an extension and feel optimistic based on NRC's feedback that the Society will be granted an extension.

3) Patient Education Day Planning (June 11, 2017)

a) Program

- S. Hedrick reported that she had reached out to Wendy Poach from Patient Centered Enhanced Care in Denver in an effort to identify a patient speaker for the prostate cancer breakout session but had not received a response. She asked whether any PAAB members could assist in contacting that group. C. Breen indicated she had another contact at the group and would reach out to them. She also indicated she would check with Drew Saelens to see whether he has contacted Blue Earth regarding assistance with the event.
- S. Hedrick reported that staff is working with the Alzheimer's Association to identify an early-state advisor and a local IDEAS Study neurologist for the Alzheimer's disease breakout.

b) Promotion

- D. McGrath indicated she is researching media outlets in the Denver area for potential interviews regarding the program. She will pass leads along to staff.
- Staff will go through the program to determine the sessions that might be of most interest to the patients in each of the four breakout categories so those sessions can be included in the promotions and will send them to the relevant PAAB members.
- S. Hedrick reiterated the importance of promoting the event. SNMMI will run advertising on Facebook and will be promoting the PED on social media. Retweets and reposts will greatly increase exposure and will facilitate engagement between patients and the nuclear medicine community.

4) Adjournment

ACTION ITEMS

- Staff will adjust internal PAAB-related documents to reflect the change in title from "Chair Elect" to "Vice Chair."
- Staff will send out a reminder to the PAAB several days prior to the May 23 NRC call.
- SNMMI will share draft comments on the NRC questions with PAAB members; interested members are asked to share the SNMMI comments with their organizations and determine whether/how to contribute their own comments to the NRC.
- D. McGrath will pass Denver-area media interview leads along to staff.
- Staff will go through the SNMMI Annual Meeting program to determine the sessions that might be of most interest to the patients in each of the four breakout categories so those sessions can be included in the promotions and will send them to the relevant PAAB members.
- PAAB members will promote the event to their Denver-area chapters and constituents and will provide retweets and reposts of SNMMI social media promotion.