



## **Patient Advocacy Advisory Board Meeting**

Wednesday, October 26, 2016

Conference Call

1:00 – 2:00 p.m.

**Board Members Attending:** Betsy de Parry (Chair), Ivy Ahmed, Rosemary Ciotti, Maria De Leon, Brandon Leonard, Mary McGowan, Pam Traxel, Theresa Wickerham

**SNMMI Members Attending:** Giuseppe Esposito, MD

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

**Not Attending:** James Hendrix, Dorothy McGrath, Elridge Proctor, Stephen Schwartz

### 1) **Introduction** *Betsy de Parry*

#### a) **New Member Introductions**

S. Hedrick noted that the PAAB welcomes three new members this year: Maria De Leon, Michael J. Fox Foundation; Mary McGowan, WomanHeart; and Elridge Proctor, Lung Cancer Alliance

#### b) **Establish Quorum**

Quorum was established.

#### c) **Minutes from 7/27/16**

The minutes from the committee's 7/27/16 meeting were reviewed. The committee noted an error in the date/time. Minutes were approved with the correction.

### 2) **Updates**

a) **Meetings with PAAB Member Organizations:** R. Ciotti offered an overview of the meeting her organization (FORCE) held with SNMMI staff and with SNMMI Slosky Fellow Katherine Zukotynski, MD, in which the two organizations discussed common objectives and opportunities for collaboration.

S. Hedrick indicated that SNMMI will be reaching out to additional PAAB-member organizations to schedule similar meetings.

b) **Update on Cumulative Effects of Radiation:** B. de Parry and J. Mailman reported that the SNMMI leadership has been holding discussions on the topic of the risks associated with nuclear radiation. This is an important topic and there is a desire to develop patient-friendly educational materials on it, particularly materials that explain that the risks of exposure are independent and not cumulative. Dr. Fred Fahey is a potential resource for this. There are a couple of challenges to this

proposed effort: (1) There is not complete consensus on the topic, and (2) some commercial imaging products carry FDA-mandated warnings on this topic and so any statement SNMMI/PAAB make on it will need to address those warnings and any potential conflicts that exist between the warnings and the statement. The Outreach Committee will be asked to review and review an existing pamphlet for accuracy and patient accessibility.

- c) **eviCore Guidelines:** S. Hedrick reported that SNMMI has submitted a letter to eviCore regarding their proposed guidelines, which would exclude coverage for <sup>18</sup>F Fluciclovine, <sup>11</sup>C-Choline, and <sup>68</sup>Ga DOTATATE. The Society also requested that several pertinent patient organizations send letters. The guidelines were scheduled for release on November 1. J. Mailman indicated that he sent a letter and enlisted several other organizations to do so as well, including NANETS. B. Leonard noted that Men's Health Network was in the process of drawing up a letter and would send it in before the deadline.

### 3) Website Changes and Review

S. Hedrick walked members through a number of revisions to the DiscoverMI website to make it more patient-friendly, to improve navigation, and to add more images. The committee noted that the site has been much improved and offered several suggestions:

- Add a very simple but prominent "Patient Information" tagline to the top banner.
- For the "Disease" and "Procedures" pages, consider using larger images for the subcategories or getting rid of the images and using a design element with the type.
- Consider making each "disease/procedure" pop out when the user mouses over it to add motion to the page.

Staff will discuss these suggestions with the SNMMI Marketing and IT Departments and will continue making improvements to the site.

### 4) Other Business

- a) **Annual Meeting Patient Education Day Sessions.** PAAB members were asked to consider topics and contact S. Hedrick if they would be willing and able to help organize a breakout session related to their organization's disease area. A decision on which breakout sessions to hold will be made during the Board's November call.
- b) **Next PAAB Meeting.** PAAB members indicated the existing timing (1 p.m. ET on the last Wednesday of the month) is generally a good time to hold the call. L. Budzinski will send out an email reminder for a November 30 call.

### ACTION ITEMS

- Staff will ask the Outreach Committee to review and review an existing SNMMI pamphlet on cumulative effects of radiation for accuracy and patient accessibility.

- B. Leonard will work with his colleagues at Men's Health Network to draw up a letter to eviCore and send it in before the 11/1/16 deadline.
- Staff will discuss PAAB suggestions re: the DiscoverMI redesign with the SNMMI Marketing and IT Departments and will continue making improvements to the site.
- PAAB members will consider topics for the 2017 Patient Education Day and will contact S. Hedrick if they are willing and able to help organize a breakout session related to their organization's disease area.
- L. Budzinski will send out an email reminder for a November 30 PAAB call.