



## **Patient Advocacy Advisory Board Meeting**

June 10, 2017

4:00 – 5:30 p.m. MT

Colorado Convention Center, Denver, CO

**Board Members Attending:** Stephen Schwartz (Chair Elect), Theresa Wickerham (Vice Chair Elect), Giuseppe Esposito, MD, James Hendrix, Ramon Llamas (Men's Health Network), Josh Mailman, Dorothy McGrath, Henry VanBrocklin, PhD

**Board Members Absent:** Betsy de Parry, Cienna Breen, Rosemary Ciotti, Maria De Leon, Mary McGowan, Elridge Proctor, Pam Traxel

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

### **1) Welcome and Call to Order**

#### **a) Introductions**

#### **b) Review minutes from 5/31/17**

The minutes from the committee's 5/31/17 meeting were reviewed and approved with no changes.

#### **c) PAAB Member Engagement**

S. Schwartz discussed the need for strong engagement from all PAAB members, including participation on calls. It was noted that one of the Board members is unable to make the regularly scheduled monthly calls (held on the last Wednesday of the month at 1 pm ET) due to a conflicting standing commitment at that day/time. Board members agreed that while that day/time seems to work well for most members, it would not be a problem to switch to the third Wednesday of the month if that worked better. Staff will work to address this concern.

The PAAB recognized the leadership of outgoing Chair Betsy de Parry.

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

C. Kubler noted that the SNMMI Board had approved a finalized version of a comment letter to the Nuclear Regulatory Commission regarding its patient release programs. She emailed a link to the press release and letter to the PAAB members and encouraged them to develop their own comment letters using the SNMMI letter as a model and/or referring to it within their own letters.

PAAB members will work with the leaderships of their respective groups to draft and submit letters as deemed appropriate.

### **3) Strategic Plan and Value Initiative**

H. VanBrocklin reviewed with the PAAB the SNMMI's newly developed Strategic Plan and Value Initiative, which specifically includes language related to outreach and involvement of patient advocacy groups. Among the more immediate goals/tactics:

- a) **Patient Guidelines Factsheets.** Several of the SNMMI Outreach Working Groups will be developing patient guidelines. The PAAB will be involved in ensuring these materials effectively meet the needs of patients and caregivers.
- b) **"What to Expect" videos.** Similarly, videos will be developed to complement the guidelines and PAAB members will be consulted to provide a patient perspective.
- c) **Advocacy Summit/Hill Day.** S. Hedrick noted that SNMMI is looking for ways to expand its patient advocacy efforts at both the federal and state levels. She asked whether it would be feasible/advisable to form a task force made up of advocacy staff at the PAAB member organizations to advise the Society on how to best increase activities on the Hill and within the states. Among the input:
  - J. Hendrix noted that the Alzheimer's Association advocacy activities are handled through a separate lobbying group, the Alzheimer's Impact Organization. He indicated that he would be happy to put SNMMI in touch with Rob Egge for further discussions.
  - R. Llamas shared that Men's Health Network has participated in large lobby days with other cancer-related organizations and that the key to success is to develop a uniform "ask" that all participating organizations can unite behind.
  - Approaching these organizations regarding advocacy efforts would best be done as part of a more comprehensive conversation regarding collaboration and common interests.
  - It was recommended that SNMMI work with a dedicated imaging coalition.
  - The PAAB will discuss more in-depth in future meetings. Before reaching out, it would make sense for SNMMI to discuss on what the goals of advocacy would be so that it is clear what the Society would be asking. It was suggested that SNMMI identify a model they would like to use, such as AHA, that would fit the Society's objectives.

#### 4) Patient Education Day Preparation

##### a) 2017 Member Assignments

PAAB members discussed individual assignments to facilitate logistics for the June 11 Patient Education Day. S. Schwartz noted that he would like these details decided further in advance in the future.

##### b) Ways to Improve for 2018

A couple of areas for improvement were identified, including:

- Online registration needs to be simplified and more patient-friendly.
- Promotion could be improved; suggestions included identifying local active SNMMI members and asking them to invite their patients to the PED as well as asking the leadership to help identify local champions to promote the event. This can begin 6 months before the event.
- Layout of the rooms and signage could be better planned in advance. A motion was made to send S. Hedrick to the programmatic pre-convention

walk through in future years. The motion passed. *S. Hedrick will attend future walk-throughs*

- PED paddles could be manned by hired temps.

The PAAB agreed to hold a debriefing call following the meeting to identify additional areas for improvement. Staff will adjust the PED protocols with the agreed upon suggestions.

#### **ACTION ITEMS**

- Staff will work to examine options for date calls/times to promote full participation on PAAB calls.
- PAAB members will work with the leaderships of their respective groups to draft and submit NRC comment letters as deemed appropriate.
- The PAAB will discuss more in-depth goals for advocacy so that SNMMI can approach their organizations for help developing a more robust patient advocacy program at the federal and state levels.
- The PAAB agreed to hold a PED debriefing call to identify areas for improvement. Staff will adjust the PED protocols with the agreed upon suggestions.