

## Patient Advocacy Advisory Board Minutes

December 19, 2018

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**Attendees:** Stephen Schwartz; Josh Mailman; Dorothy McGrath; Anita McGlothlin; Marina Moses; April Ross; Rosemary Ciotti; Matt Marks (ZERO Cancer); Linda Budzinski; Karin Brough

### 1. Commencement

The meeting was called to order. Quorum was established. The minutes of the Oct. 31, 2018, meeting were approved. The Board welcomed new members Marina Moses from WomenHeart and April Ross from the Alzheimer's Association and each gave a brief self-introduction.

### 2. Legislative Update/Call to Action

- a) Bill Status—L. Budzinski gave a legislative report and an update on the status of HR 6948, the Medicare Diagnostic Radiopharmaceutical Payment Equity Act of 2018. She noted that she was currently attending a strategic planning meeting with representatives from MITA and CORAR regarding the legislation. She reported the bill would likely be re-introduced in 2019 and the coalition is seeking the best representatives to sponsor the bill as well as companion legislation in the Senate. L. Budzinski noted that there will be some changes to the language of the bill, which she will share with PAAB members when available.

SNMMI will be seeking support for the new legislation from members of the PAAB, and a Hill Day is likely. L. Budzinski noted that SNMMI is also reaching out to patient advocacy organizations not represented on the PAAB for support; PAAB-member assistance in involving other groups is welcome.

L. Budzinski noted that SNMMI has contracted with the law firm of Arnold & Porter to assist in their advocacy efforts. The firm has extensive experience with the radiopharmaceutical industry and the lead attorney on the project has worked for CMS and holds both medical and law degrees. She noted that SNMMI's Health Policy staff will be working extensively with the consultants and with coalition leadership over the coming months.

- b) Letter of Support—L. Budzinski stated that five organizations on the PAAB have signed on to the joint letter. One has declined. Other members are consulting with their leadership. She encouraged any members who have questions or concerns to make an appointment to speak with SNMMI staff and representatives from the coalition. Anyone interested should email her directly, [lbudzinski@snmmi.org](mailto:lbudzinski@snmmi.org).

J. Mailman stated that after meeting with SNMMI leadership and representatives from MITA and CORAR he felt his initial concerns regarding patient access and availability were sufficiently addressed and his organization (NorCal CariNET Community) is now comfortable supporting the legislation.

- c) Op-Ed Status-J. Mailman reported that he and his organization (NorCal CariNET Community) have agreed to provide an Op-Ed article in support of the legislation. He noted that the article would highlight the importance of the legislation from the patient perspective.

### 3. 2019 Patient Education Day

The 2019 Patient Education Day Program is scheduled for June 23 in Anaheim, CA in conjunction with the annual meeting.

- a) General sessions—The group reviewed ideas generated during the previous call for general session topics. L. Budzinski reminded the group that while introducing new topics and formats may be desirable, that the attendees are largely patients that have not been previously exposed to the many of topics; therefore, repeating some of the basics might be necessary. She asked whether PAAB members felt having a single session combining the introduction to nuclear medicine session with radiation safety would be possible to make room for additional topics. The group agreed that one longer session combining the two topics might be doable. S. Schwartz reminded the group that the general session speakers should be aware of the need to address nuclear medicine more broadly and not focus on solely on cancers. J. Mailman suggested as potential speakers Drs. Henry Van Brocklin and Fred Fahey.
- b) Breakout sessions—L. Budzinski stated that PAAB member J. Mailman has expressed an interest in having a breakout session addressing NETs. No other members have yet asked to have a breakout session on their disease topic. S. Schwartz indicated that the LRF would be willing to again have a session addressing lymphoma if there is not a demand for others.

L. Budzinski asked for input on relevant topics for other sessions. J. Mailman suggested the topic of nuclear medicine advances in prostate cancer treatment. R Ciotti agreed that prostate cancer would be a worthwhile topic and also suggested a session on Alzheimer's disease. L. Budzinski noted the both of these topics are currently very important areas for SNMMI.

A. Ross agreed to have a separate call with L. Budzinski to explore the possibility of a session on Alzheimer's.

L. Budzinski said she would take all the topic suggestions into consideration and begin looking for speakers. She asked PAAB members to let her know if they have any additional suggestions.

**The meeting adjourned at 1:42pm**

### **Action Items**

- **Legislative Update/Call to Action** L. Budzinski noted that there will be some changes to the language of the bill, which she will share with PAAB members when available.
- **Legislative Update/Call to Action** She encouraged any members who have questions or concerns to make an appointment to speak with SNMMI staff and representatives from the coalition.
- **2019 Patient Education Day** A. Ross agreed to have a separate call with L. Budzinski to explore the possibility of a session on Alzheimer's.
- **2019 Patient Education Day** L. Budzinski said she would take all the topic suggestions into consideration and begin looking for speakers. She asked PAAB members to let her know if they have any additional suggestions.