

Patient Advocacy Advisory Board Minutes

January 30, 2019

Attendees: Stephen Schwartz; Josh Mailman; Anita McGlothlin; Marina Moses; Rosemary Ciotti; Ramon Llamas; Jeri Francoeur; Linda Budzinski; Karin Brough; Caitlin Kubler, Dalton Clark, Sukhjeet Ahuja
Guests: *Kristine Blackwood, Pari Moody, CJ Mahler, Arnold & Porter Staff*

1. Commencement

The meeting was called to order. Quorum was established. The minutes of the Dec. 19, 2018, meeting were approved. The Board welcomed staff from the law firm Arnold & Porter, who are serving as consultants to SNMMI regarding radiopharmaceutical reimbursement legislation and industry regulations.

2. Legislative Updates

a) **Medicare Diagnostic Radiopharmaceutical Payment Equity Act**—C. Kubler explained that Arnold & Porter have been engaged by SNMMI to assist with the current reimbursement legislation and industry regulations. She noted that another goal of the relationship is to increase SNMMI's exposure on the Hill and ensure the importance and benefits of nuclear medicine is properly communicated to the legislators; input from the patient community is critical to this objective.

S. Schwartz emphasized that PAAB members are willing to share their perspectives and the impact of the proposed legislation on their patient communities with the consultants.

i. **Strategic Plan**—K. Blackwood of Arnold & Porter reported that they have made significant progress in introducing SNMMI to a group of new Congressional representatives. She stated that the bill would be likely be re-introduced in 2019 and the coalition (SNMMI, MITA and CORAR) is identifying the best representatives to sponsor the bill, as well as companion legislation in the Senate.

She noted that Arnold & Porter are also very focused on making sure the legislators hear from their constituents (including patients) regarding the impact of the legislation on their lives.

K. Blackwood further explained that it is important to establish contacts on the House Energy and Commerce Committee, which has primary jurisdiction over Part B of Medicare. Arnold & Porter staff have had meetings with key democrats Debbie Dingell, D-MI, and Dave Loebsack, D-IA, and will also be reaching out to House Republicans on the Ways & Means and Energy and Commerce Committees, as well as Senate offices. K. Blackwood stated they are educating key legislators, and along with the original sponsors

(Seth Moulton, D-MA, and George Holding, R-NC) are hoping to add to the group of supporters.

K. Blackwood reported that they are planning to arrange site visits for the key representatives to tour major radiopharmaceutical facilities in their districts and to educate them about nuclear medicine.

L. Budzinski reported that former PAAB chair Betsy de Parry has agreed to accompany Michigan legislators on their tour of University of Michigan facilities. She asked that Arnold & Porter inform SNMMI where and when they are doing visits so PAAB members are given the opportunity to participate.

L. Budzinski noted that Coalition has developed a letter of support from patient groups and that organizations outside of the PAAB are welcome to sign on. J. Francoeur asked for talking points to discuss with possible endorsees. D. Clark will send her a list of drugs and diseases that are affected by the legislation along with the one-page talking points.

K. Brough will forward the roster of PAAB members to Arnold & Porter staff.

- b) **Nuclear Regulatory Commission Authorized User Training & Education Comments** — C. Kubler stated that SNMMI submitted a joint letter to the NRC along with ACNM on Jan. 28. The comments recommended against lowering training requirements and emphasized several key points, including the society's assessment that no shortage of Authorized Users exists and that the society believes it is of utmost importance to protect the public and provide the highest quality care. The comment letter is posted on the SNMMI website at www.snmmi.org/NewsPublications/NewsDetail.aspx?ItemNumber=31034

J. Mailman reported that he and his organization (NorCal CariNET Community) also submitted comments that echoed SNMMI's major points.

L. Budzinski noted that the input from the PAAB members provided during a specially scheduled call on January 9 with the chair of SNMMI's Government Relations Committee played an important role in developing the official response from SNMMI leadership.

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) **Program Outline/Speakers**—L. Budzinski reported that Dr. John Sunderland has agreed to provide a general session presentation on the basics of nuclear medicine and radiation safety. She noted that she has communicated to him the importance of speaking generally to all disease areas and not focusing solely on cancers.

The group discussed asking Dr. Emily Bergsland to speak again on clinical trials or finding another speaker for the topic. J. Mailman volunteered to research a speaker to address clinical trials across all disease areas.

L. Budzinski stated that SNMMI does plan to follow the same program format with the general session in the morning, a luncheon, followed by breakout sessions, a tour, and a reception in the afternoon.

- b) **Breakout sessions**—L. Budzinski reported after discussion with SNMMI staff and leadership that the breakout sessions topics will be prostate cancer, NETs and cardiac/coronary disease. The group was supportive of the three topics.

L. Budzinski stated she would rely on the help of the PAAB members relating to each topic (Men's Health Network, ZERO Cancer, NorCal CarciNET, WomenHeart) and would also like to try to get the American Heart Association involved in promoting the cardiac session.

R. Llamas, J. Mailman, and M. Moses offered to assist in developing their respective programs and enlist their local/regional contacts.

- c) **Marketing-** L. Budzinski encouraged all Board members to market the PED to all their members in the California area.

L. Budzinski asked the group to respond to the email regarding exhibiting at the conference by the end of February.

4. New Business

L. Budzinski noted that the MWM went very well and the SNMMI leadership is very pleased with the efforts of Outreach and the activities of the PAAB.

The meeting adjourned at 1:59pm

Action Items

- **Legislative Update** L. Budzinski asked that Arnold & Porter inform SNMMI where and when they are doing visits so PAAB members are given the opportunity to participate.

- **Legislative Update** D. Clark will send J. Francoeur a list of drugs and diseases that are affected by the legislation along with the one-page talking points.
- **Legislative Update** K. Brough will forward the roster of PAAB members to Arnold & Porter staff.
- **2019 Patient Education Day** J. Mailman volunteered to research a speaker to address clinical trials across all disease areas.
- **2019 Patient Education Day** R. Llamas, J Mailman and M. Moses offered to assist in developing their respective programs and enlist their local/regional contacts.
- **2019 Patient Education Day** L. Budzinski encouraged all Board members to market the PED to all their members in the California area.
- **2019 Patient Education day** L. Budzinski asked the group to respond to the email regarding exhibiting at the conference by the end of February.