

## Patient Advocacy Advisory Board Minutes

October 31, 2018

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**Attendees:** Stephen Schwartz; Josh Mailman; Tricha Shivas; Dorothy McGrath; Anita McGlothlin; Jeri Francoeur; Ana Fadich, Drew Saelens; Ramon Llamas; Linda Budzinski; Karin Brough; Caitlin Kubler, Dalton Clark, Sukhjeet Ahuja

### 1. Commencement

Chair Stephen Schwartz called the meeting to order. Quorum was established. The minutes of the Sept. 26, 2018, meeting were approved. S. Schwartz noted that Jim Hendrix from the Alzheimer's Association will no longer be on the PAAB and a new member from the organization will be appointed.

### 2. Legislative Update/Call to Action

D. Clark reported on the status of HR 6948, the Medicare Diagnostic Radiopharmaceutical Payment Equity Act of 2018. The legislation was co-sponsored by Reps. Holding (R-NC) and Moulton (D-MA) and was drafted by a coalition made up of SNMMI, CORAR and MITA and addresses the appropriate reimbursement of diagnostic radiopharmaceuticals used in an out-patient setting. D. Clark stated that HPRA staff has visited 18 congressional offices and sent 13 letters of support from SNMMI members. He noted that in all the meetings the support of the patient groups is a key talking point.

- a) Letter of Support—L. Budzinski stated that four 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. She noted that SNMMI is also reaching out to other patient advocacy organizations not represented on the PAAB for support.
- b) C. Kubler asked if any of the PAAB members were interested in drafting an Op-Ed article in support of the legislation. She noted that the Coalition would draft sample language and talking points. The article would highlight the importance of the legislation from the patient perspective and would appear in the legislative trade press, such as possibly Politico or Bloomberg.

HPRA staff emphasized the window of opportunity to move the bill forward between the mid-term elections on Nov. 6 and the end of the legislative year.

### 3. PAAB Member Involvement in AUC Development

S. Ahuja, SNMMI Director of Evidence & Quality explained the process SNMMI uses to produce Appropriate Use Criteria documents for nuclear medicine procedures. He explained that in 2014 legislation was passed that will require physicians to consult an approved AUC before ordering any advanced imaging starting in January 2020. In 2015 SNMMI began developing AUCs for nuclear medicine

procedures and the goal is to have an AUC library of all applicable practices. SNMMI is recognized by CMS as one of the three qualified entities to develop and endorse these AUCs. S. Ahuja stated that SNMMI plans to develop five new AUCs on the following topics:

- Evaluation and treatment of differentiated thyroid cancer
- Prostate cancer imaging
- Infection imaging
- Gastrointestinal transit
- PET Myocardial perfusion imaging

He explained that once the AUC development groups—which are made up of members of SNMMI as well as other relevant societies, such as, for example, the American Society of Clinical Oncology and the American Urological Association—have reached a draft form, Quality & Evidence staff would like to have patient advocacy representatives review the documents to ensure patient values and preferences are incorporated. S. Ahuja asked for PAAB member volunteers to review the appropriate AUC drafts and offer input.

J. Mailman shared his experience in developing the AUC for Somatostatin Receptor PET Imaging in NETs and encouraged PAAB members to participate in the AUC development process in their respective areas of expertise.

S. Ahuja stated that early 2019 is a realistic timeline for review of these AUCs. Outreach staff will provide PAAB members with a list of the AUCs currently under development and will reach out to the corresponding PAAB-member organizations to ask for help identifying someone to conduct the review(s).

#### 4. PAAB Initiatives

- a) **2019 Patient Education Day Program** - Scheduled for June 23 in Anaheim, CA in conjunction with the annual meeting.

S. Schwartz asked PAAB members to review the attached Patient Education Day Procedures document and offer feedback.

He noted that one general comment on last year's program was that it was too centered on cancer topics. S. Schwartz asked the group to begin identifying the topics for the breakout sessions. It is likely that there will be capacity for three breakout sessions; one will most likely be designated as a breakout on NETs.

L. Budzinski asked PAAB members to contact her if they would like their organization's disease to be the subject of a breakout session. She also asked for suggestions for the general session and the lunch program.

S. Schwartz noted that changing the speakers/format for the morning sessions might add to the program's effectiveness. The group offered several suggestions for the General Session program, including:

- a session in the form of a panel with a moderator
- a patient to speak about the patient experience
- how to best advocate for patient needs, either in the political arena and/or on an individual level (i.e., for coverage and reimbursement)
- a speaker from FDA to discuss the process of bringing a drug to market and an overview of drugs currently in the pipeline
- existing topics (what is nuclear medicine/radiation safety/clinical trials)

D. McGrath suggested that the patients be recognized at the beginning of the program, and S. Schwartz agreed, noting that it would be helpful to ask all populations to stand, including patients, caregivers, industry, physicians, etc., to better understand who is in the audience.

The PAAB is asked to consider all of the suggestions and begin narrowing down the most compelling/useful ideas for the patient audience in the next call.

## 5. New Business

T. Shivas thanked the PAAB for the opportunity to serve and noted that Marina Moses, Program Director from WomenHeart, will serve on the Board starting with the November call.

### Action Items

- **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.
- **Legislative Update/Call to Action** C. Kubler asked if any of the PAAB members were interested in drafting an Op-Ed article in support of the legislation.
- **PAAB Member Involvement in AUC Development** S. Ahuja asked for PAAB member volunteers to review the appropriate AUC drafts and offer input.
- **PAAB Member Involvement in AUC Development** Outreach staff will provide PAAB members with a list of the AUCs currently under development and will reach out to the corresponding PAAB-member organizations to ask for help identifying someone to conduct the review(s).
- **2019 Patient Education Day** S. Schwartz asked PAAB members to review the attached Patient Education Day Procedures document and offer feedback.
- **2019 Patient Education Day** L. Budzinski asked PAAB members to contact her if they would like their organization's disease to be the subject of a breakout session.

- **2019 Patient Education Day** The PAAB is asked to consider all of the suggestions and begin narrowing down the most compelling/useful ideas for the patient audience in the next call.

**The meeting adjourned at 2:03 pm**