

## Patient Advocacy Advisory Board Minutes

August 29, 2018

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**Attendees:** Stephen Schwartz; Josh Mailman; Theresa Wickerham; Tricha Shivas; Dorothy McGrath; Rosemary Ciotti; Anita McGlothlin; Jeri Francoeur; Linda Budzinski; Karin Brough; Wayne Powell joined the call, in progress.

### 1. Commencement

Chair Stephen Schwartz called the meeting to order. Quorum was established. (Anita McGlothlin joined the call, in progress.) The minutes of the June 23, 2018, and the Aug. 2, 2018 meetings were approved.

- 2. Slosky Fellow Visit/Hill Day** - L. Budzinski explained that the new date for the Slosky visit will be either Sept. 18 or 19. The Slosky fellow and the Henkin fellow will both be meeting with patient group representatives (PAAB Members) and visiting Capitol Hill to meeting with legislators and staff. She asked for volunteers from the PAAB to meet with the fellows and accompany them on their visits to legislators. The main issue to address with legislators is the ongoing radiopharmaceutical reimbursement issue. J. Mailman and S. Schwartz said they would be unavailable and noted the date selected was on a major religious holiday.

### 3. Patient Education Day Feedback

- a) **Evaluations**-J. Mailman noted the relative low number of responses and the need to capture feedback from more attendees. S. Schwartz suggested having some incentive to complete the surveys, e.g. entering respondents in a raffle and make a formal request that attendees complete the surveys at the end of sessions.
- b) **Recommendations and content suggestions**-T. Shivas stated that she felt the general session was too specific to cancers and should have addressed more general nuclear medicine topics. She also felt that the speakers promoted an agenda that there was no risk to nuclear imaging procedures. Shivas stated that from a patient advocacy perspective, the program should focus on patient education. The group agreed that it is important to advise the general session speakers to broaden the scope of their talks and to address risk. They also felt it may be beneficial to include breakout sessions on diseases other than cancer at future meetings; future surveys will include a question asking for session topic suggestions.

R. Ciotti suggested that with the increased visibility of Alzheimer's disease, the latest IDEAS Study results may be an appropriate topic for next year's program.

J. Mailman reported that he has a large NET network in the California area and can likely generate substantial interest in another session addressing the latest advances in NET.

L. Budzinski reported that SNMMI leadership is always very supportive of the Patient Education Day program. This year's SNMMI Annual Meeting was considered very successful, attendance was up and the feedback on the shorter week, opening ceremony, layout of the meeting and exhibit hall was all positive.

#### 4. Legislative Update

W. Powell provided the Committee these updates on relevant advocacy issues:

- Rocky Mountain Health Care, a small insurer in Colorado, has issued a coverage policy statement on Xofigo which said that only oncologists can prescribe it. As many oncologists are not authorized to use the drug, SNMMI Health Policy and Regulatory Affairs staff have spoken with authorities in Colorado and feel the error will be corrected shortly.
- Tennessee BCBS and TN Medicare have issued a draft coverage policy for PET for cardiac indications which expands coverage. HPRA staff is drafting a letter that asks them to also include some additional indications. A draft evidence review by Washington State on PET for lymphomaoncologica has been issued and we are working with the PET Center of Excellence and the re-started Third Party Payer Subcommittee to develop SNMMI's comments.
- Washington State is issued a revised PET for Thyroid policy. SNMMI HPRA staff will be evaluating the policy and submitting comments if needed.
- The proposed CMS physician payment rule for 2019 has been issued. The biggest change is in response to physicians' complaints regarding the amount of paperwork required for justifying their billing for office visits. CMS has ruled that only basic documentation is required, and they will pay all claims at a level 2. W. Powell stated that this is concern for patients because it could encourage physicians to see as many patients as possible and reduce the amount of time they spend on each office visit. The comment period closes September 10. There are some technical problems with CMS's proposal and SNMMI along with the AMA and several physician groups have collaborated on a letter that is posted on the SNMMI website.
- In the spring, SNMMI asked Aetna to expand its coverage of Gallium<sup>68</sup>. Aetna has changed its coverage guidelines in accordance with the SNMMI recommendations.
- SNMMI has succeeded in getting the AMA to add new cardiac PET CPT codes, which will take effect in 2020. HPRA is also working on more SPECT/CT codes.
- W. Powell encouraged PAAB Members to share any information on which coverage policies are affecting their constituencies. ([wpowell@snmmi.org](mailto:wpowell@snmmi.org))

#### 5. New Business

- a) **Pangea-ePatient-** ePatient is a magazine and website that targets referring physicians and patients. SNMMI will have a two-page article promoting Nuclear Medicine in the next issue. L. Budzinski stated the editors also would like to do interviews with patients and survivors that have had nuclear medicine therapies or imaging. She asked for volunteers from the PAAB or references to patients at

their organizations to participate in the article. L. Budzinski will send the link to the magazine to PAAB members and encouraged them to share it with their patient group members.

- b) **DiscoverMI.org-** L. Budzinski noted that the PAAB needs to review the website as it relates to their respective disease areas. Many updates are currently underway to pages and factsheets, so once those have been complete, the group will begin reviews.

The group recognized Theresa Wickerham who has been diagnosed with high grade soft tissue sarcoma. She is undergoing further diagnosis and will begin treatment shortly. PAAB members and SNMMI staff offered their support and wished her the best.

### **Action Items**

- **Slosky Fellow/Capitol Hill Visit** She asked for volunteers from the PAAB to meet with the fellow and accompany them on their visits to legislators
- **Patient Education Day** The group agreed that it is important to advise the general session speakers to broaden the scope of their talks and to address risk. They also felt it may be beneficial to include breakout sessions on diseases other than cancer at future meetings; future surveys will include a question asking for session topic suggestions.
- **Legislative Update** W. Powell encouraged PAAB Members to share any information on which coverage policies are affecting their constituencies. ([wpowell@snmmi.org](mailto:wpowell@snmmi.org))
- **LePatient** L. Budzinski asked for volunteers from the PAAB or references to patients at their organizations to participate in the article.
- **LePatient** L. Budzinski will send the link to the magazine to PAAB members and encouraged them to share it with their patient group members.

**The meeting adjourned at 1:52 pm**