

Patient Advocacy Advisory Board Minutes

September 26, 2018

Attendees: Stephen Schwartz; Josh Mailman; Tricha Shivas; Dorothy McGrath; Rosemary Ciotti; Anita McGlothlin; Jeri Francoeur; Matt Marks (ZERO Cancer); Ramon Llamas; Linda Budzinski; Karin Brough; Wayne Powell

1. Commencement

Chair Stephen Schwartz called the meeting to order. Quorum was established. The minutes of the Aug. 29, 2018, meeting were approved.

2. Slosky Fellow Visit/Hill Day - L. Budzinski provided an update on the Sept. 19 Hill visits. She explained that J. Francoeur and D. Saelens shared with the visiting Slosky and Henkin Fellows the objectives of their patient groups and how they collaborate with SNMMI in patient education and advocacy.

The group—including Slosky Fellow Nicole Nardecchia of Yale, Henkin Fellow Aria Razmaria of UCLA, PAAB members Jeri Francoeur and Drew Saelens, as well as SNMMI HPRAs and Outreach Department Staff—met with staff from the offices of Sens. Harris-CA, Blumenthal-CT, Murphy-CT, and Feinstein-CA, as well Rep. Esty-CT. HPRAs and PAAB members advocated for more favorable radiopharmaceutical reimbursement policies and increased patient access to imaging centers. J. Francoeur and D. Saelens provided input from the patient perspective and made recommendations. W. Powell also thanked the legislators for the recently passed increase in NIH funding. J. Francoeur reported that all the visits went well, and that the legislative staff were informed and receptive.

3. Legislative/Regulatory/Coverage Updates-W. Powell reported that he and staff from CORAR (Council on Radionuclides and Radiopharmaceuticals) met with Congressman Buddy Carter, R-GA, to ask him to introduce a new bill addressing new radiopharmaceutical reimbursement guidelines. Rep. Carter declined, but recommended SNMMI contact Rep. Holding, R-NC. HPRAs are working with Holding's staff and have submitted the draft bill to legislative counsel. They would like to have the bill introduced in the next week. W. Powell noted that HPRAs staff has weekly conference calls with other interested groups on this issue and will be following up when the bill is introduced.

L. Budzinski pointed out that when the bill drops, SNMMI will be mobilizing our members and reaching out to PAAB members to organize their membership to show their support for the legislation and sign on to a "Dear Colleague" letter. Other lobbying efforts and Hill visits will likely be part of a grassroots efforts to get the bill passed.

W. Powell reported that Washington State's Health Technology Assessment Group has issued a draft evidence review on PET for lymphoma. SNMMI is getting input from the PET Center of Excellence and

will get a letter to the Washington group by Oct. 1. W. Powell encouraged PAAB Members to share any information on which coverage policies are affecting their constituencies. (wpowell@snmmi.org)

4. PAAB Initiatives

- a) **Pangea-ePatient article(s)**-L. Budzinski reported Outreach has submitted an article to the magazine. The two-page article in the Oct. 1 issue highlights the resources SNMMI offers for patients and referring physicians. When the article is published she will forward the link to PABB members to share. L. Budzinski stated that for future issues the magazine would like to do interviews with patients and survivors that have had nuclear medicine therapies or imaging. She noted that one PAAB member has volunteered and she asked if anyone else from the Board, or someone in their organization would like to participate.
- b) **2019 Patient Education Day**- Scheduled for June 23 in Anaheim, CA. K. Brough will send the membership a document outlining the procedures for developing the PED program that the group put together several years ago. S. Schwartz asked that PAAB members review the document and submit any updates based on "lessons learned" this year. The group also should start thinking about what topics and speakers they would like on the 2019 program. The group will discuss this further on the next call.
- L. Budzinski will consult with SNMMI meetings staff and determine the number of breakout sessions possible based on the layout of the meeting site. She will report back to the Board.
- c) **DiscoverMI.org**-L. Budzinski noted that some updates are being made to the DiscoverMI.org pages and that sometime in the coming months, PAAB members will be asked to review the material related to their specific diseases and provide feedback.

5. New Business

- a) **New Practiced-Based Working Group**- L. Budzinski explained that there is a new tech-centered Working Group, the Practice-Based Working Group. One of their first objectives is to review the website from the perspective of a patient as well as a referring physician and offer suggestions for improvements. The Working group has already held several calls and offered valuable feedback on specific pages.

S. Schwartz reminded members that the website information and content accuracy needs to be sanctioned by the appropriate organization on the PAAB.

Action Items

- **Legislative/Regulatory/Coverage Updates** W. Powell noted that HPRA staff has weekly conference calls with other interested groups on this issue and will be following up when the bill is introduced.
- **Legislative/Regulatory/Coverage Updates** SNMMI will be mobilizing our members and reaching out to PAAB members to organize their membership to show their support for the legislation and sign on to a “Dear Colleague” letter.
- **Legislative/Regulatory/Coverage Updates** SNMMI is getting input from the PET Center of Excellence and will get a letter to the Washington group by Oct. 1. W. Powell encouraged PAAB Members to share any information on which coverage policies are affecting their constituencies. (wpowell@snmmi.org)
- **Pangea-ePatient article(s)** When the article is published she will forward the link to PABB members to share.
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The meeting adjourned at 1:52 pm