

Patient Advocacy Advisory Board Minutes

December 14, 2017

2:00 – 3:00 pm ET

Attendees: Stephen Schwartz; Theresa Wickerham; Mehdi Djekidel, MD; Ana Fadich, MPH, CHES; Jeri Francoeur; James Hendrix; Ramon Llamas (Men's Health Network); Josh Mailman; Dorothy McGrath; Tricha Shivas (WomenHeart); Linda Budzinski; Wayne Powell; Amber Robinson

1. Commencement

a. *Welcome and Call to Order*

S. Schwartz called the meeting to order with a warm welcome to L. Budzinski for her return to SNMMI and for her new position as Outreach Director. Quorum was established and the Agenda was approved.

b. *Approval of Meeting Minutes from 11/7/17*

The minutes from the November 7th meeting were amended as follows. The minutes were approved with this amendment> Section 3: Patient Advocacy Booth- "There will be a non-profit professionals pavilion at the **Annual Meeting**"

The PAAB reviewed the action items from the November 7th meeting with the following comments:

- **Patient Advocacy Booth-** The PAAB discussed the new floorplan. L. Budzinski will resend the application link. Interested members should email the application to Catherine Lamb, SNMMI's Associate Director of Corporate Relations, at CLamb@snmmi.org and CC L. Budzinski by the end of the year. Outreach will send the Board a list of PAAB members who are exhibiting.
- **Lymphoma Research Foundation-** S. Schwartz has a call out to LRF to follow-up on a proposal.
- **Patient Education Day-** PED hosts general sessions in the morning and disease-focused sessions in the afternoon. L. Budzinski noted that one of SNMMI's priorities is to focus on prostate cancer as there are new breakthroughs surrounding it. S. Schwartz noted the importance of aligning with the Society's goals. The breakout sessions for PED 2018 will focus on Lymphoma, NET and Prostate. There is not space for a fourth session.

S. Schwartz discussed the importance of strategizing and working with other groups like LRF and Men's Health to coordinate marketing efforts to increase attendance for PED. All patients are invited to PED regardless of their disease type. The morning general sessions provide a broader spectrum of information than the afternoon breakout sessions and are beneficial to all patients. Philadelphia is an easily accessible market so the group hopes to see bigger attendance.

2. Policy Update on Outpatient Imaging Policy

W. Powell noted that as of July 1st, Anthem started implementing a policy that won't cover MRIs or CTs in a hospital setting, except under limited circumstances. On July 1st the policy change affected Indiana, Missouri,

Kentucky and Wisconsin. On September 1st the policy expanded to Colorado, Georgia, Nevada, New York and Ohio. It's due to expand to California, Connecticut, Maine and Virginia.

SNMMI has been told, although undocumented, that the policy change will be applied to PET, SPECT-CT and related hybrid procedures. There is concern that the changes are financially driven instead of providing a benefit to patients.

Patients could miss out on necessary care due to not being able to receive comparable tests, not having access to local outpatient facilities depending on where they live, and imaging centers not being able to transmit information in a usable format to the patient's primary radiologist or nuclear medicine physician. PAAB members are encouraged to send W. Powell examples of patient limitations as a result of the policy changes at wpowell@snmmi.org. W. Powell is working with ACR and will use these examples as talking points with Congress, state legislatures and insurance companies.

As of November 2nd exceptions have been made to the policy, including not enforcing it for patients under 10 years old, excluding it in situations where patients have known contrast allergies, and if the patient will be visiting the hospital for a surgery either right before or after needing the image.

ACR has a number of sample letters available online. SNMMI will post letters online as well early next year.

One member noted that Anthem's press release on the policy change may lead to further misunderstanding of the changes as the wording of the release might lead to the misconception that the coverage had to be doctor approved.

There was a question about the extent of lobbying within the industry. W. Powell stated he is not aware of industry being significantly engaged in this. AMA hosted a meeting last week and invited the medical societies; however, there wasn't a lot of interest in or support from the medical community, with the exception of emergency room physicians.

W. Powell reminded the group that Congress will be slammed with other items in the near term.

S. Schwartz recommended that he, L. Budzinski, and W. Powell put together a memo for the Board that would allow them to reach out to their constituents to get more information on how Anthem's policy change is affecting the community.

3. Outreach/PAAB Organizational Chart

SNMMI has restructured the organization into a Domain focused operation. Each department represents a Domain that aligns with the Society's Value Initiative and Strategic Plan. During a call with the Outreach Committee, it was decided that one of the Outreach Domain's priorities is to focus on reaching more patients.

L. Budzinski presented an Outreach Chart that details the organizational structure as well as the initiatives and members of the PAAB. Chapters are included in the organization structure as Outreach is working with them to develop an Outreach Chapter liaison role that will help promote Outreach efforts at the local Chapter level. The Chapters will hold a meeting at the Mid-Winter Meeting and they will be tasked with selecting one liaison per Chapter to fulfil this role. PAAB members may be asked for help in establish connections between these liaisons and the patient groups within their regions.

If PAAB members are interested in connecting with the Chapters regarding their organizations' more localized initiatives, they are asked to CC L. Budzinski, M. Djekidel and G. Esposito on all communications. The Chapters have fewer resources than the Society; however, the Society will help as much as possible when there are aligning goals.

PAAB members are encouraged to review the Chart and send updates to L. Budzinski at LBudzinski@snmmi.org

4. Finalize Patient Education Day Program

L. Budzinski discussed the possibility of promoting the morning sessions as a half day program to patients. SNMMI will develop separate promotional materials that PAAB members can send out through their organizations. The PAAB will sit down with support groups in early January to discuss speakers, the agenda, outreach strategy and marketing plan. R. Llamas noted Men's Health Network's interest in helping with planning and promotion for PED and the Prostate Cancer breakout session.

L. Budzinski will provide a budget report during the next conference call.

S. Schwartz offered to connect with J. Francoeur on PAAB history and Patient Education Day as she is new to the PAAB representing the Susan G. Komen Foundation.

5. Other Business

a. Insurance Reimbursement

- J. Mailman noted that the Gallium-68 Working Group has been discussing the challenges with the Anthem reimbursement.
- J. Mailman discussed his survey on [Understating Financial Toxicity](#) .The two biggest drivers for financial concern after insurance are traveling to get treatment and imaging costs. Patients are concerned not only whether insurance will pay for services, but the amount that will be covered.

b. Meetings

- L. Budzinski will look into the possibility of a face-face meeting for the PAAB and will discuss options on the next call. S. Schwartz noted the timing is right for an in-person meeting as planning will soon begin on PED and L. Budzinski is coming on board as Outreach Director.
- The next PAAB meeting is scheduled for Wednesday, January 31st at 1pm EDT.
- Calendar invites will be sent out to the group for each month until PED.

The meeting adjourned at 2:58pm.

Action Items

- **Patient Advocacy Booth-** L. Budzinski will resend the application link
- **Patient Advocacy Booth-** Outreach will send the Board a list of PAAB members who are exhibiting.
- **Policy Update on Outpatient Imaging Policy-** S. Schwartz recommended that he, L. Budzinski, and W. Powell put together a memo for the Board that would allow them to reach out to their constituents to get more information on how Anthem's policy change is affecting the community.
- **Outreach/PAAB Organizational Chart-** PAAB members are encouraged to review the Chart and send updates to L. Budzinski at LBudzinski@snmmi.org
- **Finalize Patient Education Day Program-** L. Budzinski will provide a budget report during the next conference call.
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