

Patient Advocacy Advisory Board Minutes

January 31, 2018

Attendees: Rosemary Ciotti; Ana Fadich; Giuseppe Esposito, MD; Jeri Francoeur; James Hendrix; Ramon Llamas (Men's Health); Josh Mailman; Dorothy McGrath; Maureen Rigney; Stephen Schwartz; Tricha Shivas; Theresa Wickerham; Linda Budzinski; Amber Robinson

Commencement

S. Schwartz called the meeting to order. Quorum was established. The agenda and minutes from the December 14, 2017 meeting were approved.

Review of 12/14/17 Meeting Action Items

- a. **PED Budget Report-** L. Budzinski noted that the budget for PED allows all programs to move forward as planned. J. Mailman mentioned that a sponsor is needed for the lunch break. L. Budzinski will connect with Triple A and Progenics Pharmaceuticals. SNMMI is currently considering options for livestreaming, and will update the PAAB once a decision has been finalized. S. Schwartz recommended that the Patient Education Day Procedures should be revised to include securing sponsorship for lunch if it is not already included.
- b. **PAAB Overview-** L. Budzinski and S. Schwartz will provide an overview on the PAAB's history and initiatives to J. Francoeur, Susan G. Komen Foundation.

Mid-Winter Meeting Recap

SNMMI leadership has identified outreach to patients as a priority. Along with the PAAB, all Outreach Working Groups are responsible for contributing to this goal. SNMMI Chapters are also working with Outreach in appointing Chapter Champions to perform outreach at the regional level to patients and physicians. PAAB members need to discuss ways to assist the Chapters in connecting with patients once the Chapter Champions have been selected. There was concern in patient involvement in outreach at this level due to a lack of training. M. Djekidel noted that patients would not be directly involved in public speaking; however Outreach leadership is open to feedback/concerns that should be addressed. The Chapters should make their final selections by the end of the month.

The Outreach Domain Grid was finalized at MWM. L. Budzinski will send PAAB members the updated Grid

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J. Mailman noted that even though this year's MWM seemed smaller than previous years there were more exhibitors in the exhibit hall.

Policy Update on Outpatient Imaging Policy

L. Budzinski and W. Powell distributed a one-page fact sheet on the Anthem policy changes and its effects on the medical community to the group. As Anthem is making exceptions to the policy based on medical and patient community feedback, the group is encouraged to make their voices heard. PAAB members should notify L.

Budzinski if their organizations have written letters regarding the change. M. Rigney mentioned that Lung Cancer Alliance sent a letter to Anthem Blue Cross Blue Shield in October. PAAB is encouraged to provide any feedback regarding the policy changes and how it's affecting their patient groups to L. Budzinski and S. Schwartz.

Patient Advocacy Booths

SNMMI has sold out of available non-profit exhibit booth space at the Annual Meeting. The following seven PAAB members will exhibit: Alzheimer's Association, Lung Cancer Alliance, Men's Health Network, NorCal CarciNET, Susan G. Komen Foundation, WomenHeart and ThyCa. In addition, tables will be available outside of the breakout rooms, so groups with information related to prostate cancer, NET, and lymphoma are welcome to put their materials out on those tables during the PED program.

Patient Education Day Program (June 24, Philadelphia, PA)

- **General Sessions**

- What is NM/MI? - Dr. Phelps (accepted)
- Radiation Safety - Dr. Fahey (accepted)
- Understanding Clinical Trials - Dr. Bergsland (accepted)

- **NET Breakout Sessions**

- Patient Perspective – Josh Mailman (accepted)
- Oncologist's Perspective – Dr. Bergsland (accepted)
- NM Perspective – TBD

- **Prostate Cancer Breakout Sessions**

- Patient Perspective – TBD
- Oncologist's or Urologist's Perspective – TBD
- NM Perspective – TBD

- **Lymphoma Breakout Session**

- Patient Perspective – TBD
- Oncologist's Perspective – TBD
- NM Perspective – TBD

- a. **Program-** L. Budzinski asked PAAB members to find patients to present at both the Prostate and Lymphoma breakout sessions. She is currently looking for nuclear medicine specialists and oncologists to fill the open slots. The deadline to finalize speakers is February 28. J. Mailman noted that while he is looking for a nuclear medicine specialist for the NET Breakout session, it will be a slightly different session as he is trying to secure the President of NANETS as a speaker to represent GI. NET will have four different perspectives including patient, oncologist, GI and NM.

L. Budzinski will put together a rough outline of the program including time allotted for the tour and lunch. The general session room will hold 150 people theater style. The breakouts will hold 150 theater, 75 theater, and 70 rounds. If needed, the room with rounds could be converted to theater-style seating.

- b. **Marketing-** SNMMI will begin promoting a separate marketing campaign for the General Sessions in March to gain a wider audience. R. Llamas is talking with patient groups in Philadelphia to push attendance and will inform the group on progress. J. Mailman mentioned that UPenn will be heavily involved in marketing the NET Breakout Session.

S. Schwartz emphasized the importance of using resources from each PAAB organization instead of trying to reinvent the wheel for planning and promotion. He met with the CEO of the Lymphoma Research Foundation to discuss PED and how they can work collectively on local outreach with the Chapter Champions. LRF is putting together a marketing proposal on how to bring the lymphoma community to PED. S. Schwartz will follow-up with LRF on how to use their expertise and resources regarding local outreach. S. Schwartz, L. Budzinski, G. Esposito and M. Djekidel will discuss all options on a follow-up call and present to the PAAB.

Other Business

- a) **Men's Health Network PCORI Grant-** R. Llamas wrote a concept paper that outlines PCORI as a funding source for a patient focused national-level meeting in late 2018/early 2019. MHN has a relationship with PCORI and will submit a proposal to them in June once the concept is fully fleshed out. The grant is in the amount of \$50,000.
- b) **DC Fly-In-** Blue Earth is interested in collaborating with SNMMI on hosting a fly-in for patients in March. L. Budzinski was not clear on the topic matter; however, since it may be an opportunity for PAAB to serve as a resource. L. Budzinski will connect with Blue Earth and provide an update for the group. A face-to-face meeting of the PAAB would be scheduled in conjunction with the fly-in if it does happen. A budget is available for an in-person meeting, and opportunities will be discussed once the fly-in has been settled.

The meeting adjourned at 1:46pm.

Action Items

- **PED Budget Report** L. Budzinski will connect with Triple A and Progenics Pharmaceuticals
- **PED Budget Report** SNMMI is currently considering options for livestreaming, and will update the PAAB once a decision has been finalized
- **PED Budget Report** S. Schwartz recommended that the Patient Education Day Procedures should be revised to include securing sponsorship for lunch if it is not already included.
- **PAAB Overview** L. Budzinski and S. Schwartz will provide an overview on the PAAB's history and initiatives to J. Francoeur, Susan G. Komen Foundation
- **Mid-Winter Meeting Recap** PAAB members need to discuss ways to assist the Chapters in connecting with patients once the Chapter Champions have been selected
- **Mid-Winter Meeting Recap** L. Budzinski will send PAAB members the updated Grid
- **Policy Update on Outpatient Imaging Policy** PAAB members should notify L. Budzinski if their organizations have written letters regarding the change
- **Policy Update on Outpatient Imaging Policy** PAAB is encouraged to provide any feedback regarding the policy changes and how it's affecting their patient groups to L. Budzinski and S. Schwartz
- **Patient Education Day Program** The deadline to finalize speakers is February 28

- ***Patient Advocacy Booths Program*** L. Budzinski will put together a rough outline of the program including time allotted for the tour and lunch
- ***Patient Education Day Marketing*** R. Llamas is talking with patient groups in Philadelphia to push attendance and will inform the group on progress
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