

Patient Advocacy Advisory Board Minutes

February 28, 2018

Attendees: Rosemary Ciotti; Jeri Francoeur; James Hendrix; Ramon Llamas (Men's Health); Josh Mailman; Dorothy McGrath; Stephen Schwartz; Tricha Shivas (WomenHeart); Theresa Wickerham; Linda Budzinski

Commencement

S. Schwartz called the meeting to order. Quorum was established. The minutes from the January 31, 2018 meeting were approved. The agenda for the current meeting was approved. L. Budzinski noted that Amber Robinson was no longer with SNMMI and the Committee wished her well in her new position.

Review of 1/31/17 Meeting Action Items

- a. **PED Sponsorships-** L. Budzinski reported that she has reached out to Cardinal Health and Progenics Pharmaceuticals for a lunch sponsorship and plans to connect with other larger companies that may be willing to sponsor this. SNMMI is considering livestreaming portions of the conference and is looking for a sponsor. L. Budzinski is looking into other less expensive options such as Facebook Live. J. Mailman agreed to serve as a resource and had additional companies to recommend as sponsors. He will follow up with Linda when he is in the Washington area. S. Schwartz suggested looking into using area college students to perform videography and streaming.
- b. **PAAB Overview-** S. Schwartz reported that he and L. Budzinski held a conference call last week with J. Francoeur and updated her on the PAAB's history and initiatives.

Mid-Winter Meeting Recap

S. Schwartz, J. Mailman, and L. Budzinski reported on the discussions of the Outreach Committee at the Mid-Winter Meeting. L. Budzinski reported that the Chapter Champions program was rolled out to the chapter administrators. The champions have not yet been selected, but she will continue to follow up on that. J. Mailman noted a concern that the efforts to recruit patient advocates on a local level (as specified in the Chapter Champion "job descriptions") could be problematic as many patients are not equipped to advocate effectively. L. Budzinski noted that most of the activities would entail patient education and agreed that it would be important to ensure that aspect of the program is handled properly.

Policy Update on Outpatient Imaging Policy and Patient Fly In

S. Schwartz asked for any updates on letters regarding the imaging policy and Anthem. None of the groups indicated they had sent letters. In anticipation of the March 14 fly in, the Board had a lengthy discussion regarding the complexity of reimbursement issues, referencing the need for proper coding of diagnostic drugs and the benefits of alternative higher value scans that will ultimately be less evasive and offer better patient care. J. Mailman stressed the need to have more information on the topic before he goes to Capitol Hill in order to have a more targeted message. S. Schwartz noted the importance of the Board developing a clear objective through the briefing breakfast at the fly in.

L. Budzinski will email the Board a call-in number for all PAAB members not in attendance who want to listen in on the briefing.

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

- a. *Program-*** J. Mailman gave an update on the NET Breakout session, which he is moderating. He stated that a nuclear medicine oncology physician, a GI physician, and a visiting international expert on nuclear medicine and neuroendocrine tumors are on the panel. He plans to allot ample time for questions and will hopefully use the live streaming function to bring in question from an outside audience.

It was agreed that the format of last year's lunch, with an interactive portion, was educational and also spurred good conversations at the table. L. Budzinski and J. Mailman will explore topics for this year's lunch.

L. Budzinski noted that Dr. Ryan Mark, a urologist, and Dr. Robert Flavell, a nuclear medicine physician, will present at the breakout session on Prostate Cancer. R. Llamas indicated he is working with local support groups to line up a patient speaker and has some good leads.

S. Schwartz reported that for the Lymphoma portion of the program he is working with LRF to finalize the speakers.

L. Budzinski noted that the registration will go live on Monday, March 5, and asked members to forward any updates on speakers. She noted a schedule change to the program to include a tour of the EXPO hall for attendees that would only be attending the morning session and asked for help from PAAB members to lead the group.

S. Schwartz addressed the topic of registration and making it easier. L. Budzinski reported that the registration process has been totally revamped and greatly simplified. There will also be a designated patient registration counter on site and self-serve kiosks. She will send the registration link to PAAB for their review.

S. Schwartz asked that ribbons be supplied to identify PAAB members at the event.

- b. *Marketing*** S. Schwartz reported he is following up with the Lymphoma Research Foundation and will encourage outreach to their local communities to increase attendance. He mentioned using LRF *Ask the Doctor* as a tool to market the PED. L. Budzinski noted the SNMMI Marketing staff will be creating flyers that will be distributed to the PAAB for their assistance in getting the word out to their patient groups. SNMMI has also engaged the Philadelphia Convention and Visitors Bureau to assist with

marketing the Annual Meeting and possibly Patient Education Day to area hospitals and medical centers.

Other Business

a) **DC Fly-in-** L. Budzinski confirmed the names of the eight PAAB members attending the Fly-in and provided information on travel logistics. It was determined that there was not ample time to meet as a group before the breakfast. Attendees are encouraged to share travel information. The breakfast will be taking place at the Alpine Group offices and L. Budzinski will be sending out details to attendees.

b) **SNMMI Social Media and outreach-** L. Budzinski explained SNMMI Smart Briefs and will be distributing them to PAAB members on a monthly basis. Members are encouraged to distribute them as they see fit. L. Budzinski asked the Board to think about plans for using Social Media. J. Mailman suggested PAAB members forward their Twitter and Facebook addresses to L. Budzinski.

The meeting adjourned at 1:58pm.

Action Items

- **PED Sponsorships** L. Budzinski will connect with potential sponsors.
- **PED Sponsorships** L. Budzinski is looking into other less expensive live streaming options such as Facebook Live.
- **PED Sponsorships** J. Mailman will follow up with Linda on potential PED sponsors when he is in the Washington area.
- **Policy Update on Outpatient Imaging Policy and Patient Fly In** L. Budzinski will email the Board a call-in number for all PAAB members not in attendance who want to listen in on the briefing
- **Patient Education Day Program** L. Budzinski and J. Mailman will explore topics for the luncheon.
- **Patient Education Day Program** R. Llamas is working with local support groups to line up a patient speaker for the Prostate Session.
- **Patient Education Day Program** S. Schwartz is working with LRF to finalize the speakers for the Lymphoma session.
- **Patient Education Day Program** L. Budzinski will send the registration link to PAAB for their review
- **Patient Education Day Program** S. Schwartz asked that ribbons be supplied to identify PAAB members at the event.
- **Patient Education Day Marketing** S. Schwartz reported he is following up with the Lymphoma Research Foundation and will encourage outreach to their local communities to increase attendance
- **Patient Education Day Marketing** L. Budzinski noted the SNMMI Marketing staff will be creating flyers for distribution through the PAAB organizations. SNMMI has also engaged the Philadelphia Convention and Visitors Bureau to assist with marketing PED and possibly patient education day to area hospitals and medical centers.
- **DC Fly-In** L. Budzinski will send out details on the fly in to attendees
- **SNMMI Social Media and Outreach** L. Budzinski explained SNMMI Smart Briefs and will be distributing them to PAAB members on a monthly basis

- ***SNMMI Social Media and Outreach*** J. Mailman suggested PAAB members forward their Twitter and Facebook addresses to L. Budzinski