

Patient Advocacy Advisory Board Minutes

March 28, 2018

Attendees: Ana Fadich; Rosemary Ciotti; Jeri Francoeur; Ramon Llamas (Men's Health); Stephen Schwartz; Tricha Shivas (WomenHeart); Theresa Wickerham; Maureen Rigney; Linda Budzinski; Wayne Powell; Karin Brough

1. Commencement

S. Schwartz called the meeting to order. Quorum was established. The minutes from the Feb. 28, 2018 meeting were approved. The agenda for the current meeting was approved. L. Budzinski introduced the new SNMMI Outreach Coordinator, Karin Brough.

Review of 2/28/18 Meeting Action Items

- i.* S. Schwartz set aside discuss of the progress on Action Items for the Group's reports on the Patient Fly-in and the Patient Education Day.

2. Report on Separate Reimbursement/Pass Through Legislation

W. Powell reported that the Capitol Hill Fly-in meetings with Hill staffers and representatives were well received and effective. He reported that shortly thereafter provisions reforming pass-through payments slightly were enacted via the 2018 Budget Bill. The bill reverses CMS's decision to push some items off of pass-through on 1/1/2018 for two years and mandates that GAO do a study of issues surrounding the removal of items from pass-through status. Unfortunately, that study is not due to be completed till 2021. We will encourage GAO to get the study done sooner and will probably continue to seek a permanent fix in the meantime – though that will be difficult to achieve with Congress awaiting the findings of GAO. He also noted that because of this congressional guidance, CMS may not push items off of pass-through status at the end of this year.

3. Patient Fly-in Review

The group shared their various experiences in the meetings with legislators. J. Francoeur indicated that the combination of the industry representatives and patients in each group was very effective. R. Ciotti reported that the overall feeling was very positive. She noted that hill staffers were interested in why CMS was not addressing the issue more directly.

J. Francoeur echoed the positive feedback from the meetings and noted that including the patient's viewpoint was very important. S. Schwartz emphasized the need to recognize the varying levels of education in the meetings with staffers and representatives and making sure their message is clear and understood. He also noted that the groups participating should coordinate follow-up efforts to ensure the message is consistent with SNMMI objectives and reduce redundancies.

L. Budzinski stated that the Alpine Group wants to follow-up with a coordinated letter writing campaign. L. Budzinski will discuss the letter writing effort with Alpine Group and report back PAAB members.

W. Powell explained that a more effective approach to communicating with legislators and the Hill might involve a coalition of more diverse groups that involves many medical societies and many issues. This coalition would look at overhauling coverage and the payment process. He stated that he is currently discussing this with SNMMI leadership and that it may be a more viable approach going forward.

W. Powell stated he is in discussion with ACR regarding Anthem and that the feedback indicates there is support from the AMA and with legislators on the state level. L. Budzinski and W. Powell will follow-up with group members regarding any post Fly-in Day feedback from the staffers and representatives. That may take a while though since we are reconsidering our strategy because of the recently passed legislation.

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

- a. Program-** L. Budzinski stated that no new speakers had been confirmed and there were no program changes. The PED page is up on the SNMMI website and registration is live. She will be sending the program to PAAB members for review along with the list of exhibitors the group will be targeting during the exhibit hall tour. L. Budzinski will be in contact with J. Mailman regarding the lunch topic and less expensive live streaming options. L. Budzinski reported that SNMMI may be applying some of the sponsorships secured through the Value Initiative to the PED. S. Schwartz is working with LRF to finalize the speakers for the Lymphoma session.
- a. Travel-** Various travel arrangements were discussed, along with the SNMMI reimbursement policy. PAAB members need to notify L. Budzinski of their travel plans, including length of stay and mode of transport ASAP. K. Brough will follow up to ensure all participating PAAB members are accounted for.
- b. Marketing-** L. Budzinski noted that SNMMI is taking advantage of marketing opportunities through a Life Sciences contact at the Philadelphia Convention and Visitors Bureau who will distribute information on the PED to appropriate mailing lists. The group discussed the language for the ribbons attached to attendee's nametags. L. Budzinski will ensure that SNMMI provides ribbons to specifically identify PAAB members as well as Patient Advocates.

The meeting adjourned at 1:56pm.

Action Items

- a. Fly-in Day Follow-up** L. Budzinski will discuss the letter writing effort with Alpine Group and report back PAAB members.
- b. Fly-in Day Follow-up** L. Budzinski and W. Powell will follow-up with group members regarding any post Fly-in Day feedback from the staffers and representatives.

- c. ***Patient Education Day Program*** L. Budzinski will be sending the program to PAAB members for review along with the list of exhibitors the group will be targeting during the exhibit hall tour.
- d. ***Patient Education Day Program*** L. Budzinski will be in contact with J. Mailman regarding the lunch topic and less expensive live streaming options.
- e. ***Patient Education Day Program*** S. Schwartz is working with LRF to finalize the speakers for the Lymphoma session.
- f. ***Patient Education Day Travel*** K. Brough will follow up to ensure all participating PAAB members are accounted for.
- c. ***Patient Education Day Marketing*** L. Budzinski will ensure that SNMMI has ribbons to specifically identify PAAB members as well as Patient Advocates.