

Patient Advocacy Advisory Board Meeting

June 28, 2017

1:00 – 2:00 p.m. ET

Board Members Attending: Stephen Schwartz (Chair), Theresa Wickerham (Vice Chair), Cienna Breen, Rosemary Ciotti, Giuseppe Esposito, MD, James Hendrix, Ramon Llamas (Men’s Health Network), Josh Mailman, Mary McGowan, Dorothy McGrath, Maureen Rigney

SNMMI Staff Attending: Saima Hedrick, Linda Budzinski

1) **Welcome and Call to Order**

a) **Introductions and Establishment of Quorum**

Quorum was established.

New PAAB Member M. Rigney of the Lung Cancer Alliance introduced herself to the group.

L. Budzinski noted that the new term roster has been created and asked members to review their listings for accuracy. She also noted that she would be updating the PAAB page on the DiscoverMI website and asked members to send her any updates to their bios by July 3.

b) **Review agenda**

The agenda was approved without changes.

c) **Review minutes from 6/10/17**

The minutes from the committee’s 6/10/17 meeting were reviewed and approved with no changes. The following notes were made with regard to the action items:

- i. **Future Meetings.** S. Schwartz noted that the meeting date/time (1 p.m. ET on the last Wednesday of the month) would remain the same. He suggested that most meetings would be done via conference call but that, if appropriate, some may be done via GoToMeeting or another video option. L. Budzinski informed members that she would be sending out a “cancel” notice for the existing standing appointment and send out a new one for the same date/time so that the old board members would be removed and new board members would be added.
- ii. **NRC Comments.** Members had been asked to submit their comments on patient release procedures to the Nuclear Regulatory Agency by June 27. Members reported that:
 - NorCal Carcinet submitted comments.
 - ThyCa submitted comments.

- FORCE was considering submitting comments; R. Ciotti indicated she would check to see whether they had done so.
 - WomenHeart’s Scientific Advisory Board was reviewing and considering submitting comments; M. McGowan indicated she would check to see whether they had done so.
 - Lymphoma Research Foundation was considering submitting comments; S. Schwartz indicated he would check to see whether they had done so.
- iii. **PAAB Member Engagement.** S. Schwartz noted that the SNMMI this year plans to elevate the relationships with each of the PAAB groups, holding senior-level meetings to find ways to better collaborate so the Board can improve existing programming and explore new opportunities.
- iv. **Advocacy Efforts.** S. Hedrick noted that SNMMI is interested in reaching out to PAAB organizations and their government relations personnel to obtain advice and guidance on how best to mobilize the patient community for advocacy efforts. M. Rigney indicated the Lung Cancer Alliance would be willing to provide expertise, and M. McGowan stated that WomenHeart also would be willing to assist; they have done extensive training for Hill Day types of activities and have a video on YouTube to educate patients on advocacy tactics. M. McGowan will send the group a link to the video. S. Hedrick noted that the SNMMI is leaning toward holding a Hill Day in the coming year. S. Schwartz suggested that he, G. Esposito, and S. Hedrick hold a call to determine how best to proceed with advocacy.

2) 2017 – 2018 PAAB Initiatives

S. Hedrick informed the Board that several of SNMMI’s Outreach Working Groups will be working on patient-centered materials in the coming year, including treatment guidelines and “What to Expect” videos. The PAAB will be asked to review these materials to ensure they are patient-friendly.

In addition, SNMMI will be doing roadshows to educate referring physicians and patients regarding various nuclear medicine therapies (and specifically NET and prostate cancer), and PAAB members may be asked to help reach out to their constituents in those communities to help publicize the events.

With regard to the website, R. Ciotti reminded the group of the prior action item on 504 compliance. SNMMI staff will follow up with the IT staff.

3) Patient Education Day Debriefing

S. Schwartz noted that the post-event evaluations reflect that the content of the event was excellent. The only downside is that more patients did not attend. Among the topics discussed:

- **Registration.** Online registration was extremely cumbersome. S. Hedrick noted that SNMMI will work with our registration contractor to fix the issues. Ideally, we will have them add a “patient” selection on the first screen that allows PED registrants to skip all of the physician-related questions. If that is not doable, SNMMI will need to create a separate registration process and figure out how to

integrate the PED registrants with all of the other conference registrants. It was agreed that registration should be short and easy for patients.

- **Event recordings.** The events were recorded. PAAB members indicated that once they have been uploaded to the web, they will promote them to their respective patient constituents. Ideally, staff should provide a way for the PAAB member organizations to embed the videos into their own websites, newsletters, and emails.
- **Live streaming.** PAAB members asked that SNMMI look into live streaming the event, or at least the General Sessions. Staff will research this.
- **Introductory remarks.** J. Mailman suggested that it would be worthwhile to have someone frame the day's sessions and activities with introductory remarks that point out some of the highlights attendees can expect during the day. This will make it easier for patients to digest the large amounts of material being presented. It was suggested that a doctor and a patient be asked to review all of the presentations in advance and prepare these remarks.
- **Promotion.** Two suggestions were made related to promotion:
 - Pull testimonials from the evaluation survey and use on the website (include names only if permission is granted).
 - The site of the 2018 PED (Philadelphia) has great potential for drawing people from a very wide and populous area. It would be worthwhile to promote the morning and lunch to all patient groups (beyond the groups that will be interested in the afternoon breakouts) because the morning and lunch sessions are exceptional and so even if those patients leave after lunch, they will have learned a great deal and found the event worthwhile.

S. Schwartz asked that all PAAB members review the PED Procedures; mark them up with comments, suggestions, changes, and additions; and submit their comments to staff. Staff will revise accordingly.

ACTION ITEMS

- PAAB members will review their roster listings and their bios on the DiscoverMI website and submit any changes to L. Budzinski by July 3.
- L. Budzinski will send out a new calendar invite for the PAAB monthly calls, to be held at 1 pm ET on the last Wednesday of each month.
- R. Ciotti, M. McGowan, and S. Schwarz will check to see whether their respective organizations submitted comments to the NRC and will report back to S. Hedrick.
- M. McGowan will send PAAB members a link to WomenHeart's patient advocacy education video.
- S. Schwartz G. Esposito, and S. Hedrick will hold a call to determine how best to proceed with advocacy efforts.
- SNMMI staff will follow up with IT staff regarding making the DiscoverMI site 504 compliant.
- SNMMI staff will work with the Annual Meeting registration contractor to fix the online registration issues encountered this year.

- PAAB members will promote the PED videos to their respective patient constituents once they have been posted to the SNMMI website.
- Staff will provide a way for the PAAB member organizations to embed the videos into their own websites, newsletters, and emails.
- Staff will research the possibility of live streaming the 2018 PED event.
- In 2018, the PAAB will ask a doctor and a patient speaker to review all of the presentations in advance and prepare introductory remarks regarding highlights of the day's sessions and activities.
- Staff will pull testimonials from the 2017 PED evaluation survey and use them for promotion on the website (including names only if permission is granted).
- PAAB members will be asked to promote the 2018 PED morning and lunch programs to all patient groups (beyond the groups that will be interested in the afternoon breakouts).
- PAAB members will review the PED Procedures; mark them up with comments, suggestions, changes, and additions; and submit their comments to staff. Staff will revise accordingly.