

Patient Advocacy Advisory Board Meeting

Wednesday, March 29, 2017

Conference Call

1:00 – 2:00 p.m.

Board Members Attending: Rosemary Ciotti, James Hendrix, Josh Mailman, Dorothy McGrath, Drew Saelens (ZERO Cancer), Stephen Schwartz, Theresa Wickerham

SNMMI Staff Attending: Saima Hedrick, Linda Budzinski

Not Attending: Betsy de Parry, Maria De Leon, Ana Fadich, Mary McGowan, Elridge Proctor, Pam Traxel

1) **Welcome**

a) **Introductions**

b) **Establish Quorum**

Quorum was established.

c) **Review minutes from 2/22/17**

The minutes from the committee's 1/22/17 meeting were reviewed and approved with no changes.

The following action item updates were discussed:

- Rather than have a PED-specific hashtag, the group thinks it will be more effective to use the main hashtag (#SNMMI17) as this will get more views and will show the Society's membership the level of activity at the patient event.
- Staff are working out an internal technical issue regarding the registration process for the PED. Once the issue has been resolved, promotional materials and social media messages will be distributed to PAAB members for assistance in promoting the event.
- J. Mailman is reviewing the Patient/Caregiver Concerns Survey and will provide edits to Saima by 3/31.
- SNMMI is considering offering an incentive for survey responses in the form of a donation to a worthy cause; PAAB members noted that the Society needs to check on potential restrictions to such a donation and that staff should be alert for possible fraud entries (i.e., click bots) in the case of an incentive offering.
- J. Mailman discussed the concept of a potential mini-PED roadshow; he is involved in the planning of an event in Walnut Creek, CA. This event could potentially be recorded. S. Hedrick indicated that such events are not currently budgeted but that they industry support could make them possible. She said she would discuss with the SNMMI Director of Development.

- The Radiation Safety Factsheet is complete and posted on the DiscoverMI site at <http://www.snmml.org/Patients/About/content.aspx?ItemNumber=22909&navItemNumber=22912>

2) Chair Nominations

Current PAAB Chair Betsy de Parry has announced her resignation from the Board effective June 2017. Nominations for a new chair are being accepted until March 31. PAAB members are asked to email nominations to L. Budzinski at lbudzinski@snmml.org; self-nominations are accepted. L. Budzinski will create a ballot for voting, which will be open the week of April 3.

3) Patient Education Day Planning (June 11, 2017)

a) **Program:** Speakers are confirmed for the general sessions as follows:

- What Is Nuclear Medicine? –Michael Phelps, MD
- Understanding Clinical Trials –Emily Bergsland, MD
Note: Dr. Bergsland will be asked to concentrate on trials relevant to the four afternoon breakout sessions and on trials for known agents.
- Radiation Safety –Fred Fahey, DSc, FSNMMI

The status of each breakout session is as follows:

- Neuroendocrine Tumors:
 - Emily Bergsland, MD (confirmed)
 - Tom Hope, MD (confirmed)
 - Lisa Bodei, MD (invited)
 - Josh Mailman (confirmed)
 - Local patient TBD
- Thyroid Cancer:
 - Douglas Van Nostrand, MD (confirmed)
 - Josh Klopper, MD (invited)
 - Brian Haugen, MD (invited)
 - Tommy Stewart, patient/advocate (confirmed)
- Alzheimer's:
 - Jon McConathy, MD (confirmed)
 - James Hendrix (confirmed)
 - Early stage advisor TBD (J. Hendrix/S. Hedrick to invite)
- Prostate Cancer:
 - Phillip Koo, MD (confirmed)
 - Local oncologist TBD (Men's Health Network has extended several invitations; if those do not come through, staff will ask for recommendation from Dr. Koo)
 - Local patient/advocate TBD (D. Saelens to reach out to BlueEarth)

J. Mailman noted that for the Prostate Cancer session, there is a great opportunity to discuss the future of imaging and treatment as PSMA gets approved. He stated that it could be a huge draw for patients and a strong program and recommended

that staff should reach out to Dr. Baum or staff from Memorial Sloan Kettering and/or Hopkins on this.

b) **Promotion:** The Board discussed several promotional ideas, including:

- S. Hedrick will contact the Denver area Alzheimer's Association chapter to assist with promoting the event.
- In addition to the PED program, patients are eligible to attend SNMMI events as well. Staff will go through the program to determine the sessions that might be of most interest to the patients in each of the four breakout categories so those sessions can be included in the promotions. D. McGrath asked that sessions related to colon cancer be identified as well as she plan to promote the event to that population as well.
- Staff will explore purchasing online cost-per-click keyword advertising via Google and Facebook, targeting the Denver area.

4) Adjournment

ACTION ITEMS

- Once a technical issue affecting PED registration has been resolved, promotional materials and social media messages will be distributed to PAAB members for assistance in promoting the event.
- J. Mailman is reviewing the Patient/Caregiver Concerns Survey and will provide edits to Saima by 3/31.
- S. Hedrick will discuss potential support for mini-PED roadshows with the SNMMI Director of Development.
- PAAB members will email chair nominations to L. Budzinski at lbudzinski@snmmi.org by March 31.
- L. Budzinski will create a ballot for voting for the chair, which will be open the week of April 3.
- J. Mailman will ask Dr. Bergsland to concentrate her session on trials relevant to the four afternoon breakout sessions and on trials for known agents.
- J. Hendrix/S. Hedrick will work to identify and invite an early stage advisor to provide a patient perspective for the Alzheimer's Disease breakout session.
- If needed, staff will reach out to Dr. Phillip Koo to ask for recommendations for an oncologist for the Prostate Cancer breakout session.
- D. Saelens will reach out to BlueEarth for assistance in identifying a patient/advocate for the Prostate Cancer session.
- S. Hedrick will contact the Denver area Alzheimer's Association chapter to assist with promoting the PED.
- Staff will go through the SNMMI Annual Meeting program to determine the sessions that might be of most interest to the patients in each of the four breakout categories so those sessions can be included in the promotions. They will do the same for the colon cancer related sessions.
- Staff will explore purchasing online cost-per-click keyword advertising via Google and Facebook, targeting the Denver area.