

Patient Advocacy Advisory Board Minutes

April 25, 2018

Attendees: Ana Fadich; Rosemary Ciotti; Stephen Schwartz; Tricha Shivas (WomenHeart); Theresa Wickerham; Maureen Rigney; Jim Hendrix; Josh Mailman; Karlin Schroeder (Parkinson's Foundation); Linda Budzinski; Karin Brough

1. Commencement

S. Schwartz called the meeting to order. Quorum was established. The minutes from the March 28, 2018 meeting were approved with one correction. The agenda for the current meeting was approved with the date changed to April 25. L. Budzinski noted that a representative from the Parkinson's Foundation, Karlin Schroeder, was participating in the call, as the Foundation is considering placing a patient advocate on the PAAB. L. Budzinski encouraged members to share their experiences and the benefits of participation.

Review of 3/28/18 Meeting Action Items

- i. Fly-in Day-L. Budzinski reported that she received sample letters from The Alpine Group to be used to follow-up with legislators. She noted that the letters have not been distributed because the bill has not yet been introduced. SNMMI will make the sample letters available when the applicable legislation is presented.

2. Patient Education Day (June 24, Philadelphia, PA)

- a. **Program**-L. Budzinski noted one correction to the list of exhibitors with the addition of WomenHeart. T. Wickerham and S. Schwartz asked that the PED flyer emphasize that the program is free, by making the type bold or larger. He asked the group to review the program and offer any comments or suggestions. L. Budzinski will request the changes noted.
J. Mailman stated that he is working on the lunch topic.
S. Schwartz noted that attending Patient Education Day is very beneficial to patients and caregivers and that the Philadelphia location presents a great opportunity to reach a broader audience. He asked that Board Members take the time to reach out and promote the event. J. Hendrix also noted the value of the program and the positive feedback from past attendees.
J. Mailman stated that he is working with UPenn and encouraged the group to distribute videos and any promotional materials. L. Budzinski is researching recording and live streaming options for the event.
- b. **Travel**-L. Budzinski asked members to proceed in making their travel arrangements. She will be sending out hotel room confirmations in early May. SNMMI will be covering two nights and two days of expenses for PAAB members. Please contact her with any travel related questions or concerns. L. Budzinski will check on whether train reservations, as well airline need to be made through the SNMMI contact and get back to the group.

- c. **Marketing**-L. Budzinski stated that SNMMI continues to work with various Philadelphia patient and medical groups as well the Philadelphia Convention and Visitors Bureau to promote the event. L. Budzinski will get registration figures out to the group on a regular basis.

3. Slosky Fellow September Visit

L. Budzinski explained that each year SNMMI names a one of its members a Slosky Fellow. This individual will be visiting the SNMMI offices for a tour and department meetings. During their time with the Outreach Department he/she often meets with patient group representatives. This year the fellow will be visiting on Sept. 19th. L. Budzinski will be asking to visit area PAAB-member offices, or will ask PAAB members to come to the SNMMI's Reston office or to participate in a conference call to educate the Fellow on the objectives of the group.

4. Website Update

- a. **Brain and Prostate**- L. Budzinski stated the SNMMI Brain Imaging Outreach Working Group has completed a "What to Expect" video on DaT SPECT that is now available on DiscoverMI website. Additionally, the group has completed *On the Horizon* web items on addiction and traumatic brain injury. She stated that the Prostate Working Group has also updated their factsheet titled, Prostate Cancer and Molecular Imaging. She noted that a video provided by ThyCa addressing radioiodine therapy for thyroid cancer is also up on the website.

5. New Business

a. Discussion of possible Parkinson's Foundation as new PAAB member

The Board was asked to provide feedback and insights into their experiences on the PAAB for the benefit of a prospective new member from the Parkinson's Foundation. J. Hendrix (Alzheimer's Association) stated the PAAB had been very helpful at the point of intersection between the patient and advances in radiopharmaceuticals and the impact that nuclear medicine has on the patient. T. Wickerham stated that being on the group has doubled the exposure of ThyCa-related issues. J. Mailman stated that the PAAB has been invaluable in getting two important diagnostic components approved for his rare disease. S. Schwartz stated that the SNMMI has committed resources to the need to understand the patient perspective.

D. McGrath noted that when her patient group (Colon Cancer Alliance) visits the Hill for SNMMI, the presence of a patient helps to put a face on the disease and makes it far more impactful, which leads to favorable legislation. Ciotti also noted the value sharing between the different organizations. R. Ciotti (FORCE) stated that group has been very impactful when there is an issue with imaging and reimbursement and is also a great resource to provide education.

L. Budzinski explained that the one objective of the SNMMI Outreach Department is to increase the Society's interaction with patient groups. K. Schroeder thanked the group for sharing their perspectives. She stated that she would meet with the Parkinson's Foundation team and determine if they have someone who is the right fit for PAAB membership.

The meeting adjourned at 1:46pm.

Action Items

- a. SNMMI will make the sample letters available when the applicable legislation is presented
- b. ***Patient Education Day Program*** L. Budzinski will request the changes to the program noted.
- c. ***Patient Education Day Program*** J. Mailman stated that he is working on the lunch topic.
- d. ***Patient Education Day Program*** L. Budzinski is researching recording and live streaming options for the event.
- e. ***Patient Education Day Travel*** L. Budzinski will check on whether train reservations, as well as airline need to be made through the SNMMI contact and get back to the group.
- f. ***Patient Education Day Marketing*** L. Budzinski will get any registration updates out to the group on a regular basis.
- g. ***Slosky Fellow*** L. Budzinski will be asking to visit area PAAB-member offices, or will ask PAAB members to come to the SNMMI's Reston office or to participate in a conference call to educate the Fellow on the objectives of the group.