

Patient Advocacy Advisory Board Minutes

March 6, 2019

Attendees: Stephen Schwartz; Dorothy McGrath; April Ross; Matt Marks; Marina Moses; Rosemary Ciotti; Ramon Llamas; Linda Budzinski; Karin Brough; Caitlin Kubler, Dalton Clark

1. Commencement

The meeting was called to order. Quorum was established. The minutes of the Jan. 30, 2019, meeting were approved.

2. Policy Updates

a) **Medicare Diagnostic Radiopharmaceutical Payment Equity Act-D.** Clark reported that Health Policy staff recently met with nearly 30 congressional offices to discuss the legislation. He noted that in each meeting the patient perspective has been a critical element. He thanked PAAB members for their support with Hill visits and endorsing the Letter of Support.

- i. Letter of Support—L. Budzinski stated that only minor changes (updated numbers) were made to the original letter that was drafted in November. Currently six PAAB member organizations have endorsed the letter. She noted there is still time for additional endorsements if members want to discuss support with their organization's leadership. Non-PAAB patient groups are also welcome.

L. Budzinski asked PAAB members supporting the letter to approve the logos (sent in an email earlier) or to send new logos if necessary.

- ii. Letter Writing Campaign—D. Clark stated that SNMMI Health Policy staff have identified several potential sponsors of the legislation in both the House and Senate (Isakson (R-GA), Loeb sack (D-IA), Dingell (D-MI), Toomey (R-PA), Casey (D-PA), Scott (R-SC), Budd (R-NC). He noted that Letters of Support from patients or patient groups located in the states and districts represented by these members of Congress would have a great impact. D. Clark explained that if any members are willing to send a letter to their legislator, Health Policy staff is willing to draft the body of the letter and allow the specific patient or patient group to add their personal testimony.

He reported that Health Policy staff will be taking Rep. Loeb sack (D-IA) on a tour of the University of Iowa Nuclear Medicine facilities on March 15. He asked PAAB members to contact him directly (dclark@snmmi.org) with any suggestions of patients from their organizations with ties to Iowa that might be interested in sending a personal letter of support to coincide with that visit; deadline is March 13.

S. Schwartz mentioned the CEO of the LRF who is a graduate of the Univ of Iowa. He will

follow up with SNMMI staff with her contact information.

- iii. Testimonial for Infographic—D. Clark explained that Health Policy is working on a patient infographic for the meetings with legislators and asked for testimonials from patients based their experiences with any of the applicable drugs or diagnostic pharmaceuticals. PAAB members should contact D. Clark if they have any input.

- b) **NRC Advisory Committee on the Medical Use of Isotopes Patients’ Rights Advocate**—C. Kubler reported that NRC has issued a call for nominations for the Patients’ Rights Advocate position on their Advisory Committee on the Medical Use of Isotopes. She explained that the Advocate is tasked with presenting the patient perspective to the Advisory Committee on various medical issues related to the use of isotopes and radiopharmaceuticals. It is a four-year term and the projected annual time commitment is 160 hours, including attendance at two annual conferences. The position offers some monetary compensation. She noted that the candidate can be an individual who is not part of a formal organization.

S. Schwartz suggested member Josh Mailman as a potential nominee.

L. Budzinski will reach out to J. Mailman to determine his level of interest. She asked anyone else interested, or who knows of a patient that would be interested to contact her directly. The deadline for nominations is April 22.

3. Local PR Campaigns

L. Budzinski stated that Outreach leadership has expressed interest in reaching out to local media to promote the latest nuclear medicine procedures and treatments. This is part of overall effort to find new ways of increasing awareness and knowledge of Nuclear Medicine.

The Committee would like to highlight the patient perspective. L. Budzinski noted that this is simply a heads up of a future initiative and patients may be called on to provide testimonials and speak to the press about their experiences.

D. McGrath suggested that SNMMI draft generic press releases on the critical topics and distribute them to PAAB and SNMMI members. She indicated that the members could then add their local contact information and distribute it locally. L. Budzinski agreed that this would be a worthwhile effort and will discuss with Communications staff.

4. 2019 Patient Education Day

The 2019 Patient Education Day Program is scheduled for June 23 in Anaheim, CA, in conjunction with the annual meeting.

- a) **Annual Meeting Logistics (travel, exhibiting, PAAB meeting)**—The PAAB meeting is scheduled for Saturday, June 22 3:30-5pm. Patient Education day is June 23.

L. Budzinski noted that members should have received an Outlook Invite for the PAAB meeting. She asked members to please respond regarding their participation.

L. Budzinski stated that SNMMI will cover member's travel expenses and two nights hotel stay. K. Brough will send an email to determine who will be attending the conference and their dates of stay.

PAAB members will need to use the SNMMI travel portal, which will be emailed to them.
Six members have indicated they will be exhibiting at the conference.

- b) **General Session**—L. Budzinski reported that Dr. Sunderland will present the General Session Nuclear Medicine and Radiation Safety session. J. Mailman is working identifying a speaker for a clinical trials session. L. Budzinski will follow up with him to confirm the speaker.

c) **Breakout Sessions**

- i. NET—J. Mailman is working on confirming the speakers for session.
- ii. Prostate—L. Budzinski reported that she has identified a potential physician (Dr. Frankis Almaguel) to present the Nuclear Medicine perspective, and that Dr. Almaguel may be able to provide a local urologist speaker as well. She will confirm the speakers in the next week or two. L. Budzinski indicated that a patient speaker is needed. She asked Men's Health Network and ZERO Cancer for assistance finding potential patient speakers from their organizations in the California area.
- iii. Cardiac Disease—L. Budzinski stated that she has two potential leads on speakers for the cardiac session, for the nuclear medicine and cardiologist perspectives. She asked that WomenHeart assist in finding a potential local patient speaker.

- d) **Marketing-** L. Budzinski reported that they will be finalizing the program and begin working on the PDF flyer as well as the web page promotion over the next several weeks.

L. Budzinski encouraged all Board members to market the PED to all their members in the California area.

Outreach staff will research prostate cancer and cardiac support groups in the California area and reach out to them in an effort to increase attendance.

L. Budzinski noted that the entire PED program will be taped and posted on the SNMMI website.

The meeting adjourned at 1:42pm

Action Items

- **Letter of Support** L. Budzinski asked PAAB members supporting the letter to approve the logos (sent in an email earlier) or to send new logos if necessary.
- **Letter Writing Campaign** He asked PAAB members to contact him directly (dclark@snmmi.org) with any suggestions of patients from their organizations with ties to Iowa that might be interested in sending a personal letter of support to coincide with that visit; deadline is March 13.
- **Letter Writing Campaign** S. Schwartz mentioned the CEO of the LRF who is a graduate of the Univ. of Iowa. He will follow up with SNMMI staff with her contact information.
- **Testimonial for Infographic** PAAB members should contact D. Clark if they have any input.
- **NCR Patients' Rights Advocate** L. Budzinski will reach out to J. Mailman to determine his level of interest. She asked anyone else interested, or who knows of a patient that would be interested to contact her directly. The deadline for nominations is April 22.
- **Local PR Campaigns** L. Budzinski agreed that this would be a worthwhile effort and will discuss with Communications staff.
- **Annual Meeting Logistics** She asked members to please respond regarding their participation in the PAAB meeting.
- **Annual Meeting Logistics** K. Brough will send an email to determine who will be attending the conference and their dates of stay.
- **PED General Session** L. Budzinski will follow up with him to confirm the speaker.
- **PED Prostate Cancer Breakout Session** She asked Men's Health Network and ZERO Cancer for assistance finding potential patient speakers from their organizations in the California area.
- **PED Cardiac Disease Breakout Session** She asked that WomenHeart assist in finding a potential local patient speaker.
- **PED Marketing** L. Budzinski reported that they will be finalizing the program and begin working on the PDF flyer as well as the web page promotion over the next several weeks.
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