

PMMNG Steering Committee Minutes October 11, 2023

Attendees: Christina, Barbara, Phil, Maddie, Jon, Meryle, Julie, Joel, Cindy, Michael R, Colleen, Jack, Mike B, Marilyn, Kate

Facilitator: Barbara

Remembering Doug: We spent some time offering memories of Doug with Kate in our midst. She then offered each of us the individual acknowledgements which she and Doug had prepared. Very touching.

Leadership Transition:

- Key folders of historic information have been placed on Google Drive. Currently, there are 7 members of the Steering Committee that are considered “owners” of these folders and as such can have full access to them. Other SC members can be given access on a needs basis
- Shared leadership is seen as working well. No other SC member is interested in taking on the leadership role
- Meryle and Barbara will share attending the IMF support group leader quarterly meetings. Barbara will let Robin Tuohy know about Meryle’s participation.
- Today marks the end of Maddie’s transition. She is now officially in an “emeritus” role and although she will now be on the sidelines, she is available for help should it be needed.

Communications:

- It will be up to Barbara and Michael’s discretion as to what information that comes into the group inbox is forwarded on to the PMMNG. Exception to this will be if there are requests to recruit patients for market research studies and the like which need SC discussion before dissemination. If there are many prospective emails to send out to the group at one time, batching them was discussed.
- There was discussion about whether to send out notices to PMMNG about various group’s fundraising efforts. Adding a tab to our website was suggested as a possible alternative to communicating through email. Although Mike B. indicated that adding a tab is possible, I don’t think a decision was made on this topic.

Programs

- November – Insurance-Christina

- December – End of Year party; Program committee will need other volunteers to help out with ideas.
- January, 2024 – Understanding Lab results – Colleen
- February – ASH update; Christina and team will ask Dr. Vogl
- Additional spring program idea – Toxic Positivity with Christina and Molly (one of her students)

Patient-Caregiver Split meetings – discussion about some of the challenges with our split meetings; too few caregivers, lack of engagement. Consensus that group needs to relook at how we are addressing caregivers. Some ideas include:

- A myeloma 101 for caregivers (Colleen gives this talk often)
- Michael reported that many groups give 10 minutes at each meeting for caregivers to meet
- Christina shared that there is a CAR-T caregiver concierge support staff at PENN who might be a presenter
- Sub-group was formed to talk a look at all of this – Christina, Meryle, Barbara, Colleen

Face-to-Face meetings – some discussion about having some face-to-face opportunities for the SC since we have members who have never been in person with others.

- Julie and Meryle volunteered to research how this might be implemented
- Jack offered to do the same with those closer to NY
- Micheal reported that most other support groups in the US are having some face-to-face meetings

IMF Support Group Leader Summit : Michael gave a very detailed summary of his experience at the IMF summit in Houston. He wrote up some notes so details are not going to be placed here. We are so fortunate to have had Michael represent us. He learned a lot and did very effective networking.

Finance & Ins: Petty cash has \$582, and the IMF is holding \$5791 for our group. We can let people know that they can send a donation to the IMF and have it go into our account there. Designate the PMMNG as the beneficiary of the donation.

Diversity: Michael will be making a presentation at the 10:30 AM service on 10/15 at the 2nd Baptist Church in Doylestown. Other members of the DEI committee will be present. Great opportunity for more people in communities of color to learn about MM resources, including our group.

Socializing – Some discussion about better meeting social needs of the PMMNG. Barbara suggested adding time to our monthly meeting for just catching up. Having the Zoom meeting open 30 minutes before the actual planned aspects could be tested out in a future meeting.

Future topics to be addressed:

- Survey about face-to-face meetings
- Brochure development
- Hybrid meeting location

Next meeting Date/Time:

Facilitator: