PMMNG Steering Committee Meeting

September 18, 2024

Michael Riotto leading

Minutes taken by Barbara

**Atendees:** Barbara, Phil, Michael, Richard, Julie, Joel, Mike, Jack, Marilyn, Vicki, Meryle, Cindy, Jon

**Leadership:** Barbara will lead next steering committee meeting on January 8, 2025 at noon. Meryle will take minutes. The IMF will provide our group with our own zoom account free of charge. Barbara to follow up and inform Jack to cancel our subscription.

**Programs:**

October: Demystifying Clinical trials. Panel discussion

November: Insurance/Financial, Christina Bach presentation

December: End of year celebration

January: Palliative Care

February: ASH update

Michael suggested we invite Bryan from Spark Cures for a presentation.

**Communications:**

Michael is planning a social gathering inviting the entire group to be held possibly in early December. Phil has access to a lodge meeting space that holds 50 people. Cindy suggested doing one event indoors where we can wear masks if desired, and one event outdoors.

Marilyn is putting together a survey for the general membership to see how many people would be interested in a social gathering, whether wearing masks should be required, what social media platforms they use and would anyone want to be in charge of a facebook or instagram account for the pmmng, and what topics would they be interested in learning about.

**Membership:**

The IMF is printing 250 more flyers for us. Put them on the 12th and 15th floors of Pavillion (transplant floors). The IMF will NOT pay for printing our postcards. They only provide business cards for us and flyers.

**Finances:**

We have $400 petty cash and $5209 held by the IMF. We are no longer going to carry insurance for the group. If we decide to meet in person, we will revisit the insurance question.

**DEI:**

Phil, Barbara and Marilyn will be presenting at the Linconia Tabernacle Church in Trevose on Saturday, November 16. We have a table at the November 2nd LLS event at St Joe University.

**IMF patient and family Seminar:**

The PFS will be held on May 2, 3, 4, 2025 combined with a 5K walk in Philadelphia. Michael is working with the IMF for this event. Marilyn suggested we start advertising to our group soon to get them thinking about it and raising funds.

**Miscellaneous:**

The IMF is in discussions with Bruce Springsteen and Patty Scialfa on the possibility of them supporting MM since Patty was diagnosed 6 yrs ago.

Michael and his friend Tony will be meeting with Representative John Garamendi who was diagnosed with MM in July.

PMMNG flyers are being printed by IMF and they do not pay for printing our postcards. We should decide if we want to order more at our own expense. Since we are not paying for insurance this year, it may make sense to print cards.

Barbara is including a disclaimer imbedded in the monthly zoom invitation to stress that we are not doctors, and everyone should consult with thir physician before taking any advice. Mike will post this on the website, also.

**Support Group Leader Summit:**

Michaeldid a fantastic job of filling us in on the changes being made at the IMF for support groups. IMF plans on collaborating their efforts with Healthtree and the MMRF to provide more info and services to the MM community. They are forming a patient advisory committee to get feedback. They are working on studies about when to stop maintenance therapy, MRD testing through the blood, reducing doses of Dex, intervening early in cases of smoldering MM, PET scan or CT scan instead of just bone survey, what to do with the last residual cells, how to treat. They are continuing their work on advocacy. The IMF introduced their AI chat bot, myelo, which not only pulls from the IMF, but gives links to other relevant sites for your search.

Thank you all for a productive meeting!

Next meeting: Wednesday, January 8, 2025 at noon, Barbara leading