PMMNG Steering Committee Minutes January 10, 2024

Attendees: Christina, Barbara, Phil, Meryle, Julie, Cindy, Michael R, Jack, Mike B, Marilyn, Richard, Vicki, Joel

Facilitator: Jack

Minutes recorded by Barbara

* Jack suggests we look into AI generated meeting summary on zoom.
* Barbara and Michael retreive the PMMNG emails and will refer to Marilyn, Meryle, Mike, Michael for requests to speak to a patient. We need to stress we are talking as a friend, not a healthcare professional. We will refer any patients or caregivers who want to speak to someone to those who are already a MM coach. Refer to Healthtree or LLS. Oncolink also has a list of resources we can refer to. Michael, Meryle and Cindy are coaches for Healthtree.
* We started the ongoing discussion of what we want our group to be. Most people stress they miss talking to other people in person. We will try to open meeting at 1:00 and let people know that we are available at that time. Christina can also send 2 people in a breakout room if they so desire. Jack will try to arrange a meeting in NYC for all those who want to meet in person. Richard has offered his house for a gathering from that area. Plans to be arranged.
* To help make a decision, Barbara, Meryle, Michael, Joel, Julie and Richard will be sent the link to the IMF quarterly zoom meeting where they will be addressing hybrid meetings. That meeting should be the end of February.
* **Programs**- February is ASH, March, Dr Garful will discuss cellular therpies, April will be Molly Davis speaking about “Its OK to not be OK”. We discussed adding a topic for meetings on Health Literacy, and being your own advocate. The next quarter to be planned in February.
* **PMMNG Finances and Insurance –** Phil paid our insurance for this year. We will address insurance in the third quarter in order to decide if we need to keep carrying it. Our balance with the IMF is $5159. And we have $584.50 in petty cash.
* **Diversity and Inclusion-** Phil submitted an OP ED to the Philadelphia Tribune for publishing. Have not heard back from them about whether they will publish it. No politicians are interested yet about MM for their community. Cindy and Christina discussed whether Penn has an outreach program for the underserved community. Marilyn reminded us that March is Myeloma Action Month, and we can show a 2 minute video from the IMF at Saturdays meeting about how each person can do their share to bring attention to MM. Michael is invited back to Doylestown Baptist Church for another presentation. Meryle will find out where there is a health fair and if we are able to attend. Cindy will join meeting if she is available. The next diversity meeting is
* **Hybrid meeting committee,** Richard and Meryle will wait until after the IMF presentation on hybrid meetings. We will decide if we want to survey the group about interest in in- person meetings.
* **PMMNG brochures-** Christina, Phil, Barb and Michael will meet to design oa new card we can leave at Penn, Jefferson and Temple hospitals and have available for others to distribute to their doctors.
* **Rideshare programs-** The Cancer Support Community, Abramson Cancer Center and American Cancer may have services available for those who need rides, have food insecurity, etc. They would need to contact the social worker at their facility in order to be referred for this. We will discuss this at a general meeting to get the word out to patients who may need those services. It was suggested to put up the link to oncolink, American cancer and LLS at the beginning of the meeting to announce the availability of these services. We need to know what the parameters are to be eligible.

Next Steering Committee meeting will be Wednesday, April 10 at noon. Barbara will facilitate, we need someone to take minutes!