

PMMNG Steering Committee Minutes October 4, 2020

In attendance: Maddie, Marilyn, Christina, Joel, Richard, Jack, Phil, Barbara, Doug, Kate, Cindy, Sharon, Ken

Committee Membership

Discussion regarding Mingtoy LaMar, Social Worker intern of Christina Bach. Christina shared Mingtoy qualifications and her hope that there would be mutual benefit from her addition to the steering committee.

The committee approved and she will be welcomed to attend meetings during her internship.

Margie Fishman has been invited to join but has not yet made the decision to do so.

Program Committee Planning

Programs are set for 2020 and will include a holiday zoom meeting in December. Program committee will work creatively on the details.

Multiple topics were explored for 2021 They include clinical trials, MRD testing, Health Tree demonstrations, somatic coaching, ASH update, nutrition and supplements and patient/caregiver split.

It was decided to set programs quarter by quarter rather than aiming for a 12 month schedule. The programs will attempt to balance topics to focus on medical topics, healthy living topics and psycho/social support.

Maddie will contact Brian McMahon to schedule a Sparks Cure confirmation for the January meeting. Kate will contact Dr. Vogl to check his availability for ASH update in February. Christina will work with the committee to decide the best format for Patient/Caregiver split in March.

Finance Report

Phil reported no changes in the account balances since last meeting.

PMMNG Account	\$2131
IMF/PMMNG	\$7637

Phil will contact Ilana Kenville at the IMF on the status of the Miles for Myeloma 2021 race. Based on information he receives the committee will decide on the extent of the steering committee involvement in the event.

Richard asked about the status of the group's insurance policy that we needed to secure based on our meetings at the University of the Sciences. Phil will try contacting Dave Deardon again to see if we can suspend the policy and if we would be entitled to any rebate. It is assumed we will not be using their facilities in the near future due to Covid 19 concerns, but continue to see our presence there in the future.

It was decided that our Post Office box at the annual cost of \$110 will be maintained.

Communications

Joel presented a new web domain to enhance and make less cumbersome the communication and data sharing between the steering committee and our members.

Aptly named : **MIDAS**

M (myeloma)

I (interactive)

D (data)

A (access)

S (system)

The system is currently operational and is being beta tested by Maddie, Mike and Phil. The committee expressed their gratitude for all Joel's work.

Outreach Letter Process

Since our meeting format has been virtual the process for the lovely outreach letter sent by Sharon needs to be reworked. The new MIDAS system will allow us to run a report on new members. And as Sharon recovers from her wrist injury, she'll be assisted by Barbara and Marilyn with getting the outreach letters sent with updated resources. Christina suggested Mingtoy may all be helpful.

Sustainability

Maddie reminded the group of the effort to share responsibility for leading the meetings. This will require members to become more familiar and competent with Zoom

components. As Maddie will not be present for the October meeting, Kate will assist the chatbox with Christina. Marilyn will host the meeting. It was decided that members should look to assist in the future so meetings won't depend on just a couple of people.

RN Social Worker Partnership

Christina shared with the group that Colleen Erb NP with many years of oncological experience, mostly recently at HUP, is willing to share a consultant role for our group with Christina. This announcement was enthusiastically received. She will be a valuable resource for us. Maddie will reach out to Colleen and welcome her officially.

Celgene Update

Richard shared that Celgene, who had reneged on their original offer, is now prepared to make a 34 million dollar settlement. This concerns the out of pocket expenses patients paid for Revlimid. The specifics of the news and what a patient should do will be posted by Cynthia on our FB page. Mike will update our website when he is able. Richard felt this information was very important to share as soon as possible.

Diversity Outreach Committee

Kate reported that the group had met twice. Margie Fishman was compiling a master list of contacts from national cancer organizations, Black churches, hospital systems and health care providers, politicians and media. These contacts have been provided by committee members, who will focus on where we can have the greatest impact in addressing health disparity in the myeloma community. The new brochure was shared with the group.

Next Steering Committee Meeting: January 2021