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| **Meeting summary for PMMNG Meeting (10/05/2024)** |

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| **Quick recap** |
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| The meeting focused on the importance of clinical trials in the development of new treatments for multiple myeloma, with panelists sharing their personal experiences and the role of the Institutional Review Board (IRB) in ensuring patient safety. The discussion also covered the importance of understanding the phase of a clinical trial, the potential side effects, and the resources available for patients considering trials.  |
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| **Next steps** |
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| Barbara/Michael to distribute survey to group members this Monday.  |
| * Group members to complete survey by October 15th.
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| Group members to register for MMRF walk on October 19th if interested. Next meeting November 9th, 130-3pm Insurance and Financial Annual Update* Cancer Support Community will host a webinar Tuesday October 29, 2024 at 630pm called “The seasons are changing…and so is Medicare” with Christina Bach and Aimee Hoch, oncology social workers and financial specialists. This webinar is free and will focus on the 2025 changes to Medicare part D, in particular the $2000 maximum out of pocket and the Medicare Prescription Payment Plan (also called “M3P” or “the smoothing.”
* Register for this webinar here: <https://bit.ly/3BzbiXm>
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| **Meeting Summary** |
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| **Accessibility Feature Proposal and Clinical Trials** |
| Julie discussed her personal experience with clinical trials, highlighting the challenges and importance of trusting her doctor. She shared her decision-making process and experience with bispecific antibody treatments achieving remission. Julia Fuhrer explained the phases of clinical trials  |
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| **Clinical Trials: Phases, Implications, and Patient Safety** |
| Julia discussed the phases of a clinical trial and their implications for drug release and patient safety. She emphasized that clinical trials are not a last resort and should be considered as another viable option for early access to medications. Julia also clarified that placebos are not used in cancer clinical trials due to ethical considerations. She highlighted the importance of informed consent, patient rights, and the role of the Institutional Review Board (IRB) in ensuring patient safety. Julia also discussed the potential risks and benefits of early-phase clinical trials, the importance of understanding the trial's design, and the availability of supportive care during the process. She reassured participants that they can come off a clinical trial at any time without fear of retaliation and that they will still receive long-term follow-up care.  |
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| **Clinical Trials for Faster Drug Development** |
| Julia emphasized the importance of participating in clinical trials for faster drug development and advances in myeloma care. She encouraged the team to use clinical trials as an additional tool, not as a last resort, to gain early access to drugs. Mike then took over, discussing his participation in clinical trials and his role as a member of Memorial Sloan Kettering's Institutional Review Board (IRB). He explained the purpose of the IRB, which is to ensure the protection of human rights and welfare in research. Mike also shared tips for finding and considering clinical trials, including consulting with oncologists, using online tools, and talking with other patients. He stressed the importance of understanding why a specific trial might be beneficial and knowing the trial's phase.  |
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| **Understanding Clinical Trials and Patient Rights** |
| Mike discussed the importance of understanding the phase of a clinical trial and the patient's role in it. He emphasized the need to ask about the trial's progress, the number of patients involved, and the potential side effects. Jackie, a licensed clinical social worker, shared her experience working in clinical trials and offered resources for patients considering trials. She highlighted the importance of understanding one's rights as a patient, the difference between standard of care and research costs, and the need to consider travel and transportation costs. Jackie also provided resources for financial assistance, lodging, and flight programs.  |
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| **Disappointing Clinical Trial Experience and CAR T-Cell Therapy** |
| Grace shared her disappointing experience with a clinical trial recommended by her doctor at Penn. She experienced worsening eyesight as a side effect, leading to skipped treatments and prolonged recovery. Grace mentioned trying nine treatments, with CAR T-cell therapy being the most effective.  |
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| **Clinical Trials Resources and Supportive Care** |
| Christina shared several resources for searching clinical trials, including OncoLink's Emerging Med and [clinicaltrials.gov](http://clinicaltrials.gov). She highlighted the importance of supportive care trials, such as those examining the effects of yoga on nerve pain caused by chemotherapy. Christina also mentioned Spark Cures, which will be discussed further in the March meeting, and the Leukemia and Lymphoma Society's clinical trial nurse navigator service. Mike clarified that every clinical trial must be listed on [clinicaltrials.gov](http://clinicaltrials.gov), which serves as the master database.  |
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| **Multiple Myeloma Clinical Trials and Treatment Options** |
| The meeting focused on the experiences of individuals with multiple myeloma, particularly those undergoing clinical trials. Julie shared her experiences with clinical trials, highlighting the importance of monitoring and the potential for continued treatment if a drug is effective. She also discussed the possibility of returning to a trial if her condition worsens. Mike emphasized the advancements in treatment options for multiple myeloma, noting that there are more tools available now than in the past. The team also discussed the differences between expanded access and compassionate use, with Julia explaining that expanded access allows for continued treatment if there's demonstrated clinical benefit, while compassionate use is typically reserved for patients with severe conditions who have exhausted other options. The conversation ended with an appreciation for the organization and speakers.  |
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| **Support Network and Future Program Ideas** |
| Christina expressed her gratitude to Julie Cohen for organizing the session and to all panelists for sharing their experiences. She emphasized the importance of the support network and her excitement to continue discussing more topics with the group. Christina announced that a survey would be sent out to gather feedback on the group's performance and future program ideas. The next meeting was scheduled for November 9th, after the US election, and some topics might be influenced by the election results. Barb reminded everyone about the MMRF walk on October 19th and the registration process. Julie thanked Christina for organizing the panel and the guest speakers for their time. Christina also mentioned that she would try to make the AI transcript available for the meeting. The conversation ended with Mike taking a group photo. |