

First KolGo Trg PPI Activity

Minutes of the meeting

Date: 13.05.2020

Participants of the meeting:

Dr. Asima Mukhopadhyay- Project Lead

Dona Chakraborty- Clinical Nurse Specialist

Aparajita Bhattacharya- Medical Social Worker

Deepti Chandra

Kumari Anju Sinha

Mandira Chakraborty

Manjula Maitra

Susmita Pal

Introduction to the meeting: Formal introduction of the participants were done, their health status was identified. Brief knowledge was given regarding the CRUK team and PPI activities, the purpose of PPI and how will they be involved.

Brief idea about upcoming studies- Knowledge level of the participants regarding causes of cancer, genetic tests, PARP inhibitors, and surgeries were assessed. Brief introduction regarding:

1. IPIROC- Intermittent PARP Inhibitors in Recurrent Ovarian Cancers
2. BIODIVERSITY-BRCAness In Breast and Ovarian Cancer: Impact of Diverse Arsenic Exposure in India in causation and Prevention strategy
3. NuGenA-Nurse led GENetic counselling and Awareness for women's cancer
4. HIPEC-HR- HIPEC in Homologous Recombination stratified ovarian cancer

were given to them. Participants expressed their views regarding **money value versus chances of survival** for IPIROC study. They expressed their interest regarding all the studies. Manjula asks whether they can be involved both in PPI activities as well as participate in the trial. She has shown interest in IPIROC. The rest were interested in all the studies and have expressed their interest to help and participate in research.

Discussion about willingness to pay for studies: Payment for the drugs (PARP inhibitors) used in upcoming studies were discussed. Participants had doubts regarding participation of patients in trial and whether the patients have to bear the cost of the drugs used in the study. Dr. Mukhopadhyay

clarified that participants in the study do not have to pay any charges for the PARP medications and will be sponsored by the trial team.

Other doubts: Dr. Mukhopadhyay discussed about the studies and how the PPI team will be helping in the research. Aparajita and Dona would be the primary point of contact for future upcoming meetings and would be setting up the PPI team with the CRUK team. The participants were asked to give a written consent, either digitally through whatsapp or through mail. They were asked to give feedback following the meeting

Summary and end of discussion: After the end of the discussion, the patients were individually asked whether they understood the topics and whether they have any specific query. They were asked regarding their health status and how they feel regarding participation in the PPI. All of them expressed excitement to participate and are eager to join the upcoming meetings.

Feedbacks: All the patients are very eager to join the PPI group. Manjula says she feels very glad to be considered for the patient participation and hopes that the Government pitches in to make it possible on a national level. Deepti has expressed that she is thankful to be a part of the group and for sharing the research ideology.