

# KolGOTrg 3<sup>rd</sup> Annual Meeting 2021

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**Venue: Hotel Hindustan International**

**Minutes of the Session: Launch of the NUGENA (nurse led genetic counselling and awareness for hereditary women's cancer) study**

## **Brief discussion of the study**

A brief was given to the delegates about the NUGENA study, how the nurse genetic counsellor will work in the institute, the background work behind it, about the funding body OVARCOME in USA, the testing centre MedGenome, and the immense support they are providing us for the study. We also elaborated about the outreach plan and the training program which will be supported academically by ELNEC and Sister HanifeMacGamwell. We also had a discussion regarding the KolGOTrg Patient Public involvement group and how it is functioning in the study. In addition, several doctors and nurses from Nepal joined the virtual meeting and supported the launch of NuGenA study in Nepal. We also had representatives from the World Ovarian Cancer Coalition and officials from the British Council India and Department of Science and Technology, India.



## **Talk with Sister HanifeMacGamwell**

Sister Hanife is the lead trainer of ELNEC India, a subgroup of End-Of Life Nursing Education Consortium (ELNEC) by the American Nurses Association. She has trained various nurses for the ELNEC Palliative Care Train the Trainer Program. She has previously trained the Genetic Nurse, Dona in Train-the Trainer Palliative program and along with her has trained 5 more nurses in palliative care.



*(In pictures: Left to right- Dona, Twinkle, Barnali, Papiya, Dr. Asima, Sona, Sister Hanife, Madhurima. Dona and Barnali are the Trainers of ELNEC Program: West Bengal Chapter, and have trained the other nurses in palliative care. Missing in frame: Priya)*

She gave a small speech about the NUGENA study and she is excited to participate in the outreach programs and the nurse training program. She informed that she will assist in developing training modules on behalf of ELNEC and the training will be done in collaboration with the ELNEC Palliative care training workshops.

#### **Discussion with Patient Public Involvement Group**

The Patient Public Involvement Group was represented by Mandira Chakraborty and Susmita Pal. They were very enthusiastic about the study and described it as an 'innovative idea' and 'need of the hour in the Indian scenario'. Mandira stated, "I myself have been tested to be Lynch positive and I know how it feels to know what risks of cancer I have and what risk my siblings and children have. I now know what to look for and how to handle a risk rather than wait for another mishap happen to me or my family. I know the importance of getting tested. It was possible because of you and your team. It feels wonderful to be a part of a study where you identify such risks and help them benefit from testing." Susmita stated, "It is important to know about hereditary cancers, especially because we know we can prevent it in many generations of the family. I have faced cancer and I know how worse the journey is. I would never want any of my family members to go through the same thing. If there is something which helps you identify whether your family members have a chance to get cancer, I think they should absolutely go for it. We are immensely thankful to OVARCOME and the funders for supporting this novel initiative." Delegates from the Manisha Nandy Foundation (NGO developed in the memory of Manisha Nandy, a young energetic lady who died due to ovarian cancer) at Siliguri, North Bengal supported the launch of the NUGENA study in Siliguri on 24<sup>th</sup> and 25<sup>th</sup> of February 2021.



*(In pictures: Left- Susmita Pal, Right- Mandira (left) and Sister Sathi(right), Nursing Superintendent, CNCI,Kolkata)*

### **Discussion with the Nursing team at Chittaranjan National Cancer Institute**

A small discussion was done with nursing superintendents of CNCI,Kolkata. Sister Sathi Ghosal said,It is a very new concept for us. We have read about hereditary breast and ovarian cancer in our syllabus but haven't received any formal training about genetic counseling and pedigree analysis. It is essential for us to get trained so that we are able to identify potential patients and refer them for testing. Moreover the concept of nurse-to-nurse referral is very new and innovative and I feel it will enhance our role in the healthcare profession even more. It is so exciting to know that nurses will be leading in camps and clinics in India which is basically a concept in developed countries!"



### **Conclusion and End of discussion**

The meeting was very informative and successful. Everyone appreciated the cause and believes it will bring massive change in the healthcare delivery system if implemented on a national level after completion of the study period. Everyone appreciated the sponsors and mentioned that it would not have been successful without cooperation from them. The MOU between Medgenome and KolGOTrg was signed and the program was concluded with a group picture.

The PI of the study, Dr. Asima Mukhopadhyay said, “this effort would not have materialised without the support from OVARCOME. We are immensely grateful to all funders who have contributed to this effort. This is only the beginning. We hope that with continuing support and sponsorship, we can expand this program in other areas of Bengal, India and neighbouring countries like Bangladesh, Nepal and Bhutan and this study becomes a template for other LMICs as well.”

The lead nurse and Co Investigator of the study, Dona Chakraborty said, “Thank you OVARCOME. Your gesture will support education and training of nurses in low middle income countries in genetic counselling and hopefully one day development of genetic counselling courses.”



**KolGO Trg** **OVARCOME** **MEDGENOME**

**A LARGE NUMBER OF WOMEN'S CANCER CAN BE PREVENTED BY GENETIC TESTING**

Pedigree analysis of hereditary cancer | Cheaper genetic test

Parent 1 | Altered cancer gene | Parent 2

Child 1 | Altered gene passed down | Child 2

If you or any member of your family had cancer

You will be eligible for participation in the NUGENA study  
(Nurse led genetic counselling in improving awareness and implementation of screening services for hereditary women's cancer)

Several types of women's cancer which have hereditary background i.e., ovarian, breast and endometrial cancer, benefit from genetic counselling and testing. At risk healthy family members who are at an increased risk of developing cancers in the future can be identified and support counselling advice on preventive measures can be offered. Genetic testing also helps in planning for treatment and chemotherapy options.

Genetic counselling | Cancer preventive strategies

For more details please contact the GYNAE ONCOLOGY OPD of Chittaranjan National Cancer Institute or call 62896 24961

**KolGO Trg** **OVARCOME** **MEDGENOME**

**KOLGOTrg** in association with **MEDGENOME** and **OVARCOME** is supporting the launch of the study **NUGENA**

*Nurse led Genetic counselling in improving Awareness and implementation of screening services for hereditary women's cancer*

(Images: Poster and banner for NUGENA at the KolGO Trg 3<sup>rd</sup> Annual Meeting, 2021)