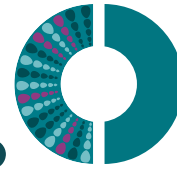


KOLKATA GYNAECOLOGICAL ONCOLOGY TRIALS & TRANSLATIONAL RESEARCH GROUP

Kolkata, India



GLOBAL
OVARIAN
CANCER
CHARTER
a World Ovarian Cancer
Coalition initiative

KolGOTrg welcomes the Global Ovarian Cancer Charter because of its ability to highlight the challenges of progress for women with ovarian cancer in low and middle-income countries such as India where we are based and the need to close the gap with more affluent settings. We hope that the work we have undertaken to establish a patient focused clinical research group within a tertiary cancer centre in such a setting, will encourage others down this hard but rewarding path to driving much closer and fruitful engagement with patients and improvements in survival.

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CHAMPION

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BEST POSSIBLE CARE

Overcoming cost & toxicity issues to bring new treatments to lower income countries

CHAMPION PROJECT: OVERCOMING COST & TOXICITY ISSUES TO BRING NEW TREATMENTS TO LOWER INCOME COUNTRIES

Ovarian cancer is the third commonest, costliest and most lethal women's cancer in India. Whilst PARP inhibitors (PARPi) are now revolutionising the treatment for a considerable number of women in higher income settings, providing a significant prolongation of life, they remain unaffordable for most women and healthcare providers in low and middle-income countries, costing some £5000 to £7000 a month in India (5-7 lakh INR).

The current recommended scheduling for the tablet treatment is daily, based on a maximally tolerated but not necessarily biologically optimal dosing. In addition, many women in India have a lower body-weight and pre-existing anaemia, which means that PARPi related haematological toxicities will be challenging for many.

Pre-clinical work by Newcastle University (UK) and current ongoing work in collaboration with KolGOTrg has shown that a single dose of PARPi (rucaparib) once a week was as effective as the daily dose, so the key clinical question they now aim to answer through a proof of concept study is do shorter or alternative maintenance treatment schedules provide similar or better outcomes with less toxicity and therefore be more affordable to the Government in India and other low middle income countries. This project named IPIROC (intermittent PARP inhibitor in recurrent ovarian cancer) has already received seed funding from CRUK-DBT affordable cancer challenges call.

They will examine which PARP inhibitor is most effective in the reduced dose (non-inferior) and more tolerable and cost effective. They also plan to develop a low-cost bio-marker (functional HRD assay) to define which patients are most suitable for this type of therapy. At first this will be trialled in women who have BRCA mutations that have relapsed ovarian cancer. Initial work has already involved their newly formed patient-public involvement group who have provided invaluable input into the dilemmas such treatments in their current forms place on women and their families.

The Coalition chose to showcase this programme because it tackles a very fundamental question about affordability in low income settings and how the toxicity of drugs may affect women differently in different countries. KolGOTrg's aim to find the optimal dosage at an affordable cost could transform access to such important therapies not only in India, but in many other low and middle-income settings.

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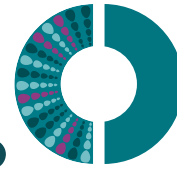


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FAMILY HISTORY

Family History
Clinics

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CHAMPION PROJECT: FAMILY HISTORY CLINICS

Breast and ovarian cancers are the highest and most lethal form of women's cancer in India, respectively, with a significant proportion of them having a hereditary background. The blueprint of genetic clinics in developed countries is currently not implementable in low-middle income countries where there is a lack of an adequately trained workforce. While there is a very small number of centres in India, their community outreach is poor in terms of family history clinics. This means hereditary cancers are often missed due to lack of awareness of symptoms and the familial links, social stigma and a lack of national cancer registries.

Having piloted a programme to train a research nurse in clinics in India and the UK (UKIERI grant), KolGOTrg has shown that acceptability of nurse led counselling was remarkably high, and led to more patients identifying their risks and seeking testing. However, uptake of testing by family members was still low. The group are now proposing a new programme for 2021, NuGenA (nurse led genetic counselling clinic and awareness), to train further nurses and medical social workers to develop a community-based programme for health education, cancer awareness and genetic counselling and referral services in Eastern India and Nepal. They will be linked to the tertiary cancer centre which also runs the population-based registry of the state and the virtual genetic clinic India through telemedicine support, thereby enabling them to identify patients getting treatment for breast or ovarian cancer. Through KolGOTrg's organised patient-public initiative, Sarbojaya,

people with a family connection or cancer themselves will be involved in identifying locations for temporary Genetic Clinic Camps, and assist local nurses and health workers in providing information on a wide range of topics relating to hereditary cancers, and identifying those with significant family histories who might undergo testing and counselling.

The Coalition chose to showcase this programme because it shows a concerted effort to establish an important service in a country where little has so far been achieved in terms of managing families with a history of inherited cancers. It directly involves families affected in reaching out more widely and in its efforts to overcome significant stigma in order to promote best possible care for patients who have or who may develop cancer. It will complement their forthcoming programme to ascertain if parp inhibitors, being used to treat BRCA related ovarian cancers in higher income countries, can, by adapting dosage and frequency be made more affordable in the Indian setting.

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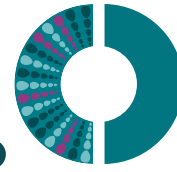


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BEST POSSIBLE CARE

Creating KolGOTrg
– meeting the needs of
patients and opening up
access to clinical trials in
Kolkata, India

CHAMPION PROJECT: CREATING KOLGOTRG – MEETING THE NEEDS OF PATIENTS AND OPENING UP ACCESS TO CLINICAL TRIALS IN KOLKATA, INDIA

When compared to high income countries, the survival of women with ovarian cancer in India is much more challenging. Whilst a small number of organisations undertake research in the country, it is very hard to initiate, regulate and maintain cancer research. A tertiary cancer centre seems an obvious setting, but even so, the lack of knowledge about research meant an intensive search for the right people to train. Setting up KolGOTrg in 2017, the group began by identifying a small number of nurses, and a medical social worker and worked with them on research skills, genetic counselling and procedures specific to gynaecological cancer. The team has grown considerably and are moving towards first major studies – the trial of targeted HIPEC (HR-HIPEC) and intermittent PARP inhibitors (IPIROC) in low income settings. This has already led to involvement with the Gynae-Cancer Inter Group (GCIG) who lead a number of important international collaborations.

The nurses and medical social workers work closely with the women, enabling long term follow up, better and early access to palliative care, consideration of patient needs and a building of trust around clinical trials. The women have been central to the development of the studies, providing an understanding of what is important to them, particularly when personal finance is limited. But the women have given so much more, helping establish a survivorship programme, raising awareness, helping establish cervical screening camps and raising funds in their communities, and widening the volunteer pool through relatives wishing to give something back. They, supported by their nurses, now exist as a group in their own right called 'Sarbojaya', the name of the most worshipped Hindu female deity, Goddess Durga, meaning one who always wins. They have a cultural programme, survivorship initiatives and seven women, with KolGOTrg, are working on a formal patient and public involvement (PPI) group in relation to the trials.

The Coalition chose to showcase this programme because it demonstrates the journey of establishing such a group in a challenging setting, and in addition to enabling new trials to be brought to the area, shows the remarkable and wide benefits of clinicians working directly with patients.

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