



# The National Endometriosis Clinical and Scientific Trial (NECST) Network MRFF Grant

## *Progress Report*

Prepared for the National Endometriosis Action Plan Implementation Committee

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## The NECST Network

### Project Outline

The aim of this project is to build a national research platform that underpins a comprehensive national program of clinical, basic science and translational research relevant to the needs of Australian endometriosis sufferers, consistent with the research objectives in the draft National Action Plan for Endometriosis (NAPE). Specific achievements will include:

- (i) Development of a national Clinical Trials Network (CTN) that co-ordinates support for research organisations and conducts clinical trials for endometriosis treatments and services.
- (ii) Development of an Australian Endometriosis Collaborative Research Framework to support co-ordinated patient recruitment, consistent data collection and a national database and bio-repository developed from clinical trials and research projects for national and international research projects specific to endometriosis.
- (iii) Formation of a National Collaborative Network capable of responding to a targeted call for integrated endometriosis research focused on translational outcomes.

### Key outcomes attributable to the project

By the end of the four-year period covered by this Grant, we anticipate that the project will have achieved:

- (i) A national endometriosis clinical trials network encompassing the research communities in hospitals, universities and research institutes with skills and resources relevant to endometriosis across all sub-disciplines
- (ii) Nationally co-ordinated patient databases, and clinical sample repository to support existing and future trials in endometriosis
- (iii) Prevalence data, direct economic cost of endometriosis, health seeking characteristics by analysing the Australian Longitudinal Study on Women's Health
- (iv) International recognition of the NECST Network for commercially sponsored trials relevant to endometriosis, with specific trials either underway or under negotiation
- (v) A network of research-active clinicians with expertise in endometriosis, who are supported by research support staff in the collection of data and samples through this Grant such that they are able to collaborate in the conduct of large-scale, multi-site clinical trials for international impact
- (vi) A strategic development of scientific support fellowships to commence the analysis of biological samples accumulated through the national database and sample collection to facilitate a potential pathway for emerging basic scientists in this field.
- (vii) The leverage of philanthropic and industry support to conduct trials in endometriosis.

## Achievements to date

### *Establishment of the NECST Strategic Governance Committee:*

The NECST Strategic Governance Committee will ensure the MRFF endometriosis funding is managed and acquitted in accordance with MRFF Funding Principles and with research governance best practice. They will also review and approve funding decisions on allocation of funding to specific activities, in light of the grant's project plan and MRFF funding principles. The Committee will meet 4-6 times per year.

The Committee will convene in November, setting the terms of reference and agreeing upon the process for distribution of grant funding. The Chair is Prof Kate Leslie AO FAHMS, a Specialist Anaesthetist and Head of Research at the Department of Anaesthesia and Pain Management, Royal Melbourne Hospital. She is also an honorary professional fellow in the Centre for Integrated Critical Care, Melbourne Medical School, and Department of Pharmacology and Therapeutics, University of Melbourne. She is also an Adjunct Professor at the School of Public Health and Preventative Medicine, Monash University. She is a director of the Australian Medical Council and chairs its Specialist Education Accreditation Committee. Prof Leslie's research interests include depth of anaesthesia and awareness, sedation for gastrointestinal endoscopy and large trials in perioperative medicine. She was the recipient of the AMA Woman in Medicine Award for 2014 and received an honorary doctorate from the University of Melbourne in 2017. Prof Leslie was made an Officer of the Order of Australia in 2016 for her distinguished services in medicine for anaesthesia and pain management practice and research.

Other Committee Members:

### **Associate Prof M. Louise Hull BSc MBChB, PhD, FRANZCOG, CREI**

Research Program Leader, Endometriosis Research Group, Discipline of Obstetrics and Gynaecology, Robinson Research Institute, AHMS Building,

Staff specialist in reproductive endocrinology and infertility specialist, Women & Children's Hospital

Fertility Specialist, O&G

### **Melissa Parker RN RM MNurs(Research)**

Endometriosis Coordinator and Researcher, Canberra Endometriosis Centre, Centenary Hospital for Women and Children

### **RANZCOG nominee**

### **Australian Government Department of Health nominee**

### **Two Patient Community Representatives**

#### **Mr David Lloyd**

CEO, Jean Hailes for Women's Health

#### **Dr Rachel Mudge**

Head of Research Partnerships, Jean Hailes for Women's Health

*Appointment of the NECST Clinical Trials Manager:*

Dr Cecilia HM Ng has been appointed as the NECST Clinical Trials Manager. Cecilia is responsible for setting up and managing the National Endometriosis Science and Clinical Trials (NESCT) Network.

Prior to joining Jean Hailes for Women's Health, Cecilia worked in clinical coding of medical records at Royal North Shore Hospital, scientific and clinical research within the Department of Radiation Oncology and Department of Obstetrics, Gynaecology and Neonatology at Royal Prince Alfred Hospital and The University of Sydney and as a Medical Science Liaison at Vifor Pharma.

Her qualifications include a Bachelor of Science, with majors in biochemistry and physiology and a Masters in Health Information Management. She completed her PhD and a post-doctoral fellowship with the Department of Obstetrics, Gynaecology and Neonatology at The University of Sydney and Royal Prince Alfred Hospital, characterising molecular pathways involved in the pathophysiology of endometriosis.

Cecilia has published in the areas of endometriosis and women's health. She continues to maintain a strong interest in developing research that will help educate and improve the health of women.

*Funding Allocation – Identification of baseline data on burden of disease*

Professor Gita Mishra is the Head of the Epidemiology and Biostatistics Division and Professor of Life Course Epidemiology at the School of Public Health, University of Queensland (UQ). She is also Director of the Australian Longitudinal Study of Women's Health (ALSWH).

Prof Mishra will perform a detailed analysis of existing databases from the Australian Longitudinal Study on Women's Health (ALSWH). This will achieve the following:

- a. To estimate the prevalence and incidence of endometriosis in the Australian population
- b. Linkage with health administrative databases to determine the direct cost of disease
- c. Costs of lost work productivity in weekly hours in paid work will also be calculated from employment status, total monthly workplace hours missed and valued using average Australian wages
- d. Quantify the relationships between endometriosis and future health for precise targeting of interventions
- e. Describe the current health seeking behaviour of women with endometriosis.

## Summary

The NECST Network progress is well aligned with projected Milestones. Progress in Quarter 3 and the start of Quarter 4 has been achieved in the areas of Project Governance, Project Management and ALSWH analysis as described in the Project Management Outline.