

NATIONAL MALAYSIAN TWIN REGISTRY - A PERFECT OPPORTUNITY FOR RESEARCHERS TO STUDY NATURE VERSUS NURTURE

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INTRODUCTION

A twin registry is a registry of twin pairs (monozygotic = MZ and Dizygotic = DZ) who are willing to consider participating in health-related research. Twins are able to help researchers study the impact of genetic and environmental factors on health and the treatment and prevention of disease in a special way. Throughout the world, twin registries have been established by the governments via the National Health and Medical Research in order to put researchers in touch with twins who might be willing to take part in particular projects. In Australia, for example, more than 30,000 pairs of twins have joined the registry, making it the largest volunteer registry of its kind in the world. However, in some countries such as Denmark, the first twin registry was born in a medical faculty and it was then expanded to the National Twin Registry of Denmark.

For the very first time in Malaysia, national twin registry is established in University of Kuala Lumpur. This registry is a not-for-profit organization which facilitates scientific research involving participation of twins or their family members in order to answer some of the questions of health and wellbeing relevant to Malaysians. The proposal is approved by Ministry of Health and National Medical Research Registry (NMTR). University Kuala Lumpur has provided the grant for this project.

WHAT ARE THE BENEFITS OF TWIN STUDIES?

Twins are associated with increased in premature birth¹ (singleton rate 28-36 weeks 8.7%, twins 40.2%), increase low birth weight² (singleton rates <2500g 5.8%, twins 50.3%), increased intra uterine growth retardation, increased birth defects, increased birth complications. MZ twins, twin girls, and male twins with low birth weight, seem to be particularly at risk for below average mental and physical growth.³ Twins account for 10-14% of overall neonatal mortality.⁴ The increasing number of twin births is a matter of national concern for two reasons. First the differential rates of preterm delivery and low birth weight among twins compared to singletons; and second, the inordinate contribution of these infants to

overall infant mortality, morbidity, and long term handicap.² Intrauterine death of one foetus in a multiple gestation is associated with significant morbidity and mortality in surviving twin.⁵ Arrival of twins has an economic, social and psychological impact on families of twins.⁶ Vital statistics relevant to twins are needed to plan better services for twin pregnancies and twins.

In efforts to solve the problem on aetiology of disease, twin studies have contributed greatly; since the early days of genetic studies of man.^{7,8} Twin study, may be defined as a "high powered" branch of genetics because when two or more identical siblings are affected by the same disease and external factors have been excluded as the cause, then the disease is most definitely a hereditary one and, as such, it's origin can be traced back in the genealogical tree of that family on either the paternal or maternal side or on both sides.

In genetic epidemiology, twins are of special interest because they offer an "experiment of opportunity". These pairs of individuals of the same age, who share all or, on average, half their genes can be studied from the viewpoint of their similarity in disease state, their similarity in disease determinants or risk factors, difference in their disease state, and exposure to risk factor(s).

Each of these approaches can be used to address questions about disease aetiology. Twins are particularly useful for longitudinal studies, as they generally know they are of special scientific interest and so are usually not averse to being approached more than once.

WHAT TYPE OF STUDY DESIGNS CAN BE USED FOR TWIN STUDIES?

Various study designs can be employed to investigate these questions, including classic twin studies; co-twin control studies, intervention studies, longitudinal studies. Studies addressing twins directly such as clinical and service provision in twin pregnancies; issues re twin pregnancies and deliveries;

problems encountered during breast feeding; learning difficulties; the inheritance of twinning; intra uterine environment of twins (placenta, cord, twin to twin transfusion), infertility, conceiving twins through natural way or ovulation induction, twin disabilities serve as another category of twin studies.

HOW CAN NMTR ASSIST RESEARCHERS TO CONDUCT A STUDY ON TWINS?

NMTR can assist researchers to develop their proposal and give indications of study feasibility and suitability of involving twin registry and provides written approval. This is needed to get ethical approval from relevant grant or ethical bodies. NMTR ethical committee will then formally review applications with the assistance of relevant experts, identifies the modifications if there is any and assist researchers in review process. Researchers are then assisted in preparing draft of ethics submission and provide a letter of support for the study to help expedite ethics approval from National Malaysian Research Registry (NMRR) and or Clinical Research Centre (CRC).

NMTR helps recruit study participants from the available database. Since the database is established recently, if the study sample size is larger than the existing database, support will be provided to recruit twins from general population, hospitals, institutions, etc. NMTR has baseline demographic

of twins collected and is continuing to archive other studies, including bio-specimen collections. Researchers are encouraged to visit our website at www.nmtr.org.my for further information and contact. It is our hope that twin registry of Malaysians can join international counterparts to solve the mystery of unresolved diseases.

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