

Malaysian Twin Registry

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The National Malaysian Twin Registry was established in Royal College of Medicine, Perak, University Kuala Lumpur (UniKL) in June 2008 through a grant provided by UniKL. The general objective is to facilitate scientific research involving participation of twins and their family members in order to answer questions of health and wellbeing relevant to Malaysians. Recruitment is done via mass media, poster, and pamphlets. We now have 266 adult and 204 children twins registered. Several research projects including reproductive health study of twins and the role of co-bedding on growth and development of children are carried out. Registry holds annual activities for twins and seeks to provide health-related information for twins. We seek international collaboration.

■ **Keywords:** Malaysia, reproductive health, twin, registry

Research Background

The Malaysian Twin Registry started with a reproductive health study that captured many aspects of reproductive health and reproductive behavior of adult twins. Publications of the study focused on age of menarche, premenstrual syndrome, menstrual characteristics, and reproductive health of opposite sex twins (Jahanfar, 2012a, 2012b; Jahanfar et al., 2011, 2012).

General Objectives

The aims of the Malaysian Twin registry are:

- to establish a research foundation, that can bring researchers together to carry out research activities.
- to provide a bridge between researchers and twins and public as a whole, who will ultimately benefit from the result of these studies.
- to collect, preserve, and communicate information about twins and other multiples.
- to convey information of interest to twins and educate twins regarding health issues.
- to establish a community for twins of all types, ages, and ethnicities in order to provide educational, emotional, and social support through construction of a social network.
- to encourage funding for medical and social research relating to multiple births.
- to build services to cater to twins' needs by working with researchers, professionals, NGOs, and governmental bodies.

- to support families of young twins in order to ease the problems with raising twins or higher order multiples.

Recruitment Strategy

To recruit twins a poster and a pamphlet were published inviting all twins to register. These materials were sent to all public and private hospitals, clinics, secondary schools and high schools, colleges and universities, ministries, public offices, and shopping centers. The information was disseminated through mass media such as radio and newspapers. A website was created to maintain the recruitment process as other sources of advertisement proved to be costly. The recruitment process is slow but ongoing. We will translate the website to other languages (Malay, Chinese, and Tamil) to involve more twins. Advertisements in health section of local newspapers have shown to be efficient and will be continued.

Zygosity Determination

Twin zygosity is determined from twins' or their parents' responses to a zygosity questionnaire that included questions about physical similarities and frequency of confusion of

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TABLE 1
Frequency of Socio-Demographic Characteristics of Twins in Malaysian Twin Registry (n = 266)

Variable	Frequency	Percentage
Race		
Malay	147	54.9
Chinese	66	24.8
Indian	28	10.5
Others	26	9.8
Gender		
Male	73	27.4
Female	193	72.6
Education		
Illiterate	15	5.6
Primary school	42	15.8
Secondary school	74	27.8
High school	62	23.3
University degree	73	27.4
Occupation		
Student	32	24.6
Unemployed	66	50.8
Government employee	20	15.4
Private employee	12	9.2
Marital status		
Single	94	35.3
Married	172	64.7

the twins by family members and friends. Accuracy of this method has been estimated around 90% as compared with DNA analyses (Rietveld et al., 2000).

Sample Characteristics

Adult twins: Altogether there are 266 individual or 133 twin pairs inclusive of 78 monozygotic (MZ) twins ($n = 156$) and 55 dizygotic (DZ) twin pairs ($n = 110$). The majority are female (72.6%), married (64.7%), unemployed (42.1%), and about 50% had secondary school education or lower (Table 1). The mean age of our twins is 30.47 ± 10.14 , minimum of 15.

Twin children: The registry has 204 twin children registered. Fifty-eight twin pairs ($n = 116$) are MZ and 44 pairs ($n = 88$) are DZ. The total number of males is 88 (43.1%) and 116 are female (56.9%). Of MZ twins, 23 pairs are of male-male gender, 34 pairs are female-female, and 1 pair is of opposite gender, while of non-identical twins, 14 pairs are male-male, 17 pairs are female-female, and 13 pairs are male-female. The majority of twins are Malay (68.6%), while 18.6% are Chinese and 11.8% are Indian. The remaining 0.1% belonged to other races. Their age ranges between 1 and 17 years of age with the mean of 8.15 ± 4.6 , and median 8.00.

Accomplishments

An electronic newsletter is published every 3 months to inform twins and researchers about activities of the twin registry. The twin registry also holds ceremonies, activities, and public forums for twins, such as the Family Campaign, where families with twins inclusive of parents and children participate to become familiar with the twin registry,

and to support mothers pregnant with twins. Members of the registry have participated in national and international congresses to advertise for the registry. Several studies have been published in scientific journals such as the *Family Medical Journal*, *Twin Research and Human Genetics*, *Shiraz E-Medical Journal*, and the *Indian Journal of Genetic Studies* (Jahanfar, 2012a, 2012b; Jahanfar et al., 2011, 2012). The results of reproductive health studies were also presented at several scientific gatherings (Jahanfar, 2010a, 2010b, 2011a, 2011b, 2011c). Local newspapers have published reports about the registry. A twin festival was held in June 2010 in Kuala Lumpur. The registry has collaborated with the Iran Twin Registry and is looking forward to communicate with other registries.

Future Directions

We are planning to apply for research grants and involve more NGOs to hold twin festivals and recruit more subjects. We welcome international collaborations.

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