

and You Have to Decide: where the participants told of having to make a difficult, life-altering decision in a very brief time period; 4) We Didn't Deserve This: in which the participants described experiencing multiple layers of loss while attempting to become mothers; and 5) What If / Which One?: where the participants described the lasting effects of their decision, wondering about ways in which their pregnancy outcomes might have been different or which one of their children might have been reduced.

235S STARTING FROM SCRATCH IN SRI LANKA

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Commitment against obstacles and basic knowledge was vital, but books and journals were a scarcity. This demanded networking with experienced twin researchers. A partnership model for collaboration was used for mutual scientific benefits but not for economically cheaper research in the developing world. Forming a multi-disciplinary team was essential, but for locals twin research was new. Funding was hardest without prior twin research. We were compelled to seek help from commercial establishments but were aware of conflict of interests. Therefore, guidelines were developed on bioethics, consent, data collection, storage and access to the twin database and human biological material, funding, commercial exploitation, international collaboration, and authorship to safe guard the Sri Lankan interests as the moral "rights" and "wrongs" are not absolute but vary with the culture. We initiated a volunteer register launching a competition through media. 4684 multiples registered. Most were less than 30 years. Adaptation and preliminary validation of a zygosity questionnaire was carried out. Using birth records to trace younger twins were feasible, but encountered many problems for older twins. Use of different strategies to establish a population-based registry is possible as evident by feasibility studies. Twins born in the whole island from 1992 are available to us through the Department of Birth Registration. We are now supported by a grant from the Wellcome Trust. Newsletters for twins and researchers are published. Local capacity building is in progress. A Multiple Birth Organisation was formed to represent the interests of multiples and to raise awareness on their issues. It will work with professionals, statutory organisation to initiate service development.

236F THE KOREAN TWIN REGISTRY

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Although twin study can be especially useful to discriminate between genetic and environmental causes of human diseases, most study has been undertaken in Western countries. The Korean Twin Registry is the first nationwide twin study in Korea. It started from the lists and health outcomes of twins gathered through a serial data linkage among nationwide data sources: address code data; Korean National Health Insurance Medical Utilization and Insured Family data; and birth report and death certificate data. Uniform 13-digit ID system, applied to all Koreans from birth registry until death, enabled exact data matching among various sources. The registry totals 156,472, born from 1956. Comparing with the number in birth report data (available since 1982), the registry coverage 1982–1996 was 93.1% (104,237 out of 111,911) ranging from 86.4% (1986) to 99.9% (1996). The registry coverage for twins born between 1979 and 1996 was estimated to be more than 90% (125,779). The list of twins born after 1997 is being updated, and expected to reach as complete level. However, for those born before 1979, completeness drops sharply. Medical utilization data from seven major diseases since 1991 was collected. Individual death certificate data since 1992 was available and case ascertainment of registered twins is being undertaken. The first target diseases were congenital malformations and asthma. Despite some strengths in size, population representativeness, and readiness to ascertain some pediatric diseases, we have not yet conducted surveys on the zygosity and basic risk factors but these are planned. Analyses using disease concordance rate between like-sex and opposite-sex twins are already ongoing.

237S MONOZYGOTIC TWINNING AND ASSISTED REPRODUCTION

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A recent review (Sills et al., *Twin Research* (2000) 3, 217–223) of possible processes which may contribute to and explain the observations of higher rates of monozygotic twinning after ART was inconclusive as to whether ART *per se* has a true role in this apparent phenomena. From early in the development of IVF observations by McDonough and others proposed the first known 'cause' of an increase in monozygotic twinning. Initially this was thought to be as a bi-product of the use

of powerful gonadotrophic regimes. But no exact mechanism was forthcoming. More recently due to advances in, and development of, more invasive ART techniques, specific mechanisms have been proposed as to why MZ twins may be more common. These will be reviewed and will include intracytoplasmic sperm injection (ICSI), extended embryo culture, assisted hatching methods (using acid tyrode and more recently laser techniques.) Also the possible implications of the use of Preimplantation Genetic Diagnosis, which involves the process of embryo biopsy will be discussed.

238P COMPUTER ASSISTED TELEPHONE INTERVIEWS WITH 26,000+ TWINS: A NEW UPDATE OF THE SWEDISH TWIN REGISTRY

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The Swedish Twin Registry comprises in principle all twin births in Sweden since 1886. All living twins in the Swedish Twin Registry born before 1958, are currently contacted for screening of health status. This current update of the registry began in 1996 with a pilot study that included a random sample of twin pairs for each birth year between ages 17 to 85. All twins were contacted for a telephone interview screening for health status. During 1998, the health screening was expanded to a larger scale and by January 2001, more the 26,000 individuals have been contacted. All twins born before 1940 have been contacted and by the end of 2001, all twins born before 1959 will be contacted. Most recent information on last name and address is linked to the telephone company's files to obtain telephone numbers. Introductory letters describing the study are sent to a random sample of approximately 1,000 pairs each month. All data collection is performed with a computer assisted telephone interview by trained interviewers with relevant medical competence. The interview includes a number of items asked to all twins regarding different diseases and symptoms. All administrative data as well as all data collected through screening are entered into an object-oriented database. A series of web-based pages with secured access have been designed to facilitate online administration.

239P GENETIC AND ENVIRONMENTAL CONTRIBUTIONS TO RECURRENT HEADACHE

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Recurrent headache (RH) is a very common health problem in the population. A nationwide population of 55 to 64-year-old twins were interviewed by trained lay personnel on the telephone about common health problems across life span including RH. Items regarding headache symptoms permitted diagnoses in line with consensus criteria of migraine and tension-type headache. Twins were also asked if they themselves thought they had ever had migraine — self-reported migraine. The genetic and environment contributions to liability for different types of headache were computed for 2,053 complete twin pairs. Estimates of the lifetime prevalence and the heritability are listed.

240S HOW FAMILIES COPE WITH PERINATAL LOSS OF A TWIN*

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Western Australia has one of the most comprehensive databases in the world for the study of multiples. The Western Australia Twin Child Health study (WATCH) has compiled data on all multiples born in the state since 1981, including 476 perinatal deaths. Their mortality rate is 4–6 fold that of singletons. Parents with multiples are more likely to experience the joy of a newborn simultaneous with the grief of a death. Little is known, through systematic studies, about the psychological impact of these special losses on families. Woodward (1998) concluded from a study of 200 adult volunteer lone twins, that 81% felt their loss to have a "severe" or "marked" effect on their lives. Segal (1995) using the Grief Experience Inventory (GEI) on subjects over 15 years found twins' grief scores significantly exceeded those of 102 bereaved singletons. But what is the impact on younger surviving twins and three other subsets of the family: mums, dads and siblings? Through interviews with parents and children, this study (currently in progress) aims to:

- Learn how families are impacted by a twin's death
- Generate information to help families cope with the reality of their twin's death
- Provide professionals with information related to what multiple birth families express they need