



Significant Achievement for Capacity Building

Study on Common Mental Disorders, Suicidal Thoughts & Alcohol Abuse in Colombo District

No Genetic Material out of the Country!

Genetic Lab with a Sequencing Machine in Colombo

“Every international collaboration should ensure a significant contribution to the capacity building locally”. This is one of the firm stands taken by us, along with the progressive international research community that defend ethical research in the developing world. In keeping with this, the most significant contribution of this project for capacity building in terms of infrastructure is the establishment of the genetic laboratory.(see page 4)

Unprecedented Ethical Review and Approval

We have received ethical clearance from :

1. Secretariat Committee on Research involving Human subjects (SCRIHS) of World Health Organisation, Geneva.
 2. Ethical Review Committee of the Medical Faculty, Sri Jayawardene - pura University.
 3. Ethical Review Committee of the
-(see page 2)

A large study is underway to investigate several public health priorities in Sri Lanka: alcohol abuse, suicidal ideations, depression, anxiety and somatisation. This is a large community based twin & singleton study with 4000 twins and 1000 sing

-letons. Study will take a comprehensive look at these complex health problems from a Sri Lankan perspective taking into account the wider aetiological factors, such as psychological, socio-economic, developmental and genetic. In addition

(see page 4)

Funded by The Wellcome Trust



This study is funded by Wellcome Trust (UK). It is a non-commercial public charity supporting medical research all over the world. According to the World Health Organiza

-tion (WHO) Wellcome Trust is the 2nd largest organization in the world helping medical research after USA government.



World Health Organization Signs a Collaborative Agreement for the Project

Dr. Robert Beaglehole, Director Health Promotion, Surveillance Prevention & Management of Non-communicable Diseases and Dr. Victor Bonlyjenkov, responsible officer, Human Genetics Programme sign

-ed the agreement to provide advice & collaboration. Dr. Athula Sumathipala, Director Sri Lankan Twin Registry signed on behalf of the SLTR. WHO will provide advice and collaboration for the project.



Institute of Psychiatry – London The Main Collaborative Partner

The Institute of Psychiatry, Kings College, London is a centre of excellence and a leader in the world in the field of mental health research and training. The Institute

and its world renowned researchers are providing the crucial collaborative support needed for the programme.

www.infolanka.com/org/twin-registry

SRI LANKAN TWIN REGISTRY WEBSITE

Pioneering Non-invasive Zygosity Testing

Dr D.A.R.K Dayaratne, Consultant Physician, General Hospital Badulla, with expertise in molecular biology was trained at the Social Genetic Developmental Psychiatry Centre in the Institute of Psychiatry to carry out non-invasive zygosity testing. It is based on the DNA in mucosal cells, obtained by rolling out cotton buds inside the cheeks. Twelve micro satellite markers are used for this.

TRAINING TRAINERS

a sustainable contribution to local capacity building

**WHO ExpertTrains
Sri Lankan Researchers**

Use of standardised research instruments is essential to study human behaviours.

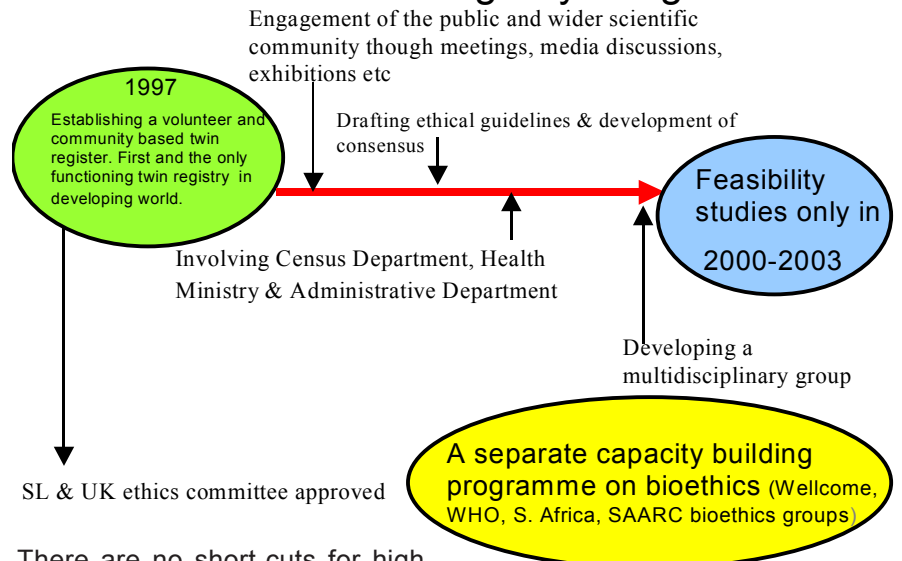
Another benefit arising from this project was the training offered to 14 Sri Lankan psychiatrists, community physicians, and laypersons. They will be resource persons for training research assistants not only for this project but anyone in the field of mental health.

Dr. Nick Glozier, Consultant Psychiatrist from Institute of Psychiatry, University of London trained Sri Lankan researchers during March 9th to 12th at Trans Asia Hotel in a workshop organised by Sri Lankan Twin Registry.

He trained them on a Composite International Diagnostic Interview (CIDI), a tool to detect status of mental health in the community. This tool was developed by WHO and was used in more than 70 countries in the world.



Sri Lankan Twin Registry Programme



There are no short-cuts for high quality, sustainable and ethical research programme. This diagram highlights the 7 years of ground work to bring in all the essential

components of an ethical research programme, before we embarked on this specific project.

Prestigious Journal “Nature Genetics”

Comment on Sri Lankan Twin Registry (SLTR)

“Nature Review” Journal in its November 2002, (Volume 2002 page 872-882) issue published a review on “Classical Twin Studies & Beyond”.

This invited review was written by Dorret Boomsma, Andreas Busjahn & Leena Peltonen, three famous twin researchers from Amsterdam,

Berlin and Helsinki.

According to them, “.....The existing or emerging population based registers, such as those in Scandinavia, Italy, Korea and Sri Lanka, are of extreme value for epidemiological research owing to the lack of ascertainment bias.....”

“Twin Research” Journal Express Hope on SLTR

Twin Research Journal devoted its 2002 October issue (Volume 5 Number 5) to twin registers around the globe. We from Sri Lankan Twin Registry described our work in that journal.

Writing a guest editorial Dr. Andreas Busjahn has special comments about Sri Lankan Twin Registry.

“.....Our particular hope is for the newly emerging twin registers in countries such as Sri Lanka, China and Korea to become an integral part of the twin research community.....”

Twin Research is the official Journal of the International Society for Twin Studies.

(from page 1) **Unprecedented Ethical approval**

Institute of Psychiatry, Kings College, University of London. The Academic Committee of the Government Medical Association (GMOA) also approved the project.

Twin Registry Committee Members Trained in UK



From Left, Dr. DARK Dayaratne, Dr. A Sumathipala, Dr. Matthew Hotopf (Reader, Dept. of Psychological Medicine, Institute of Psychiatry, King's College, London), Prof. Peter McGuffin (Director of Social Genetic & Developmental Psychiatry Research Centre & Prof. of Psychiatry Genetics, Institute of Psychiatry, King's College, London) and Dr. Deepthi De Silva (Senior Lecturer, Medical Geneticist, Psychology Dept, Kelaniya University).



From Left, Dr. DARK Dayaratne, Prof. Pak Sham (Prof. of Statistical Genetics, Social genetic & Developmental Psychiatry Research Centre, King's College, London), Dr. Matthew Hotopf, Prof. Peter McGuffin, and Dr. Sisira Siribaddana.

SLTR Team Invited for Guest Lecture at Denmark

SLTR Team is Invited for guest lecture and presentations at the 11th International Congress on Twin Studies. This is the second such ISTS meeting, that SLTR was invited.

1. Use of key informants and a community survey to compile a population based twin register.
2. Intensive course on bioethics; an evaluation.
3. Using school curriculum to popularize twin research.

Research Ethics Reviewed by “Twin Research”



Susan Treloar, PhD. Genetics epidemiology laboratory, Queensland institute of medical research reviewed the is “Research Ethics from a Developing world perspective” in the prestigious “Twin Research” Journal.

According to **Dr. Treloar**

“.....This slim volume marks a very significant milestone for Sri Lanka – first, for the development of the country’s human research and, second, for the impetus and legitimacy it will provide for developing countries like Sri Lanka to formulate their own research ethics. The book announces to the world that the Sri Lankan Twin Registry (SLTR) aims to establish a centre of excellence for twin, family and genetic studies.

The authors see twin research as uniting diverse disciplines and research methods. The aim is to develop a population-based register ...”

“.....The book has chapters, each quite brief and including its own list of reference. The chapters raise various issues for further discussion. Many, such as informed consent, data issues and the collection, storage and access to human-

samples, will be familiar to researchers in developed countries. Others may be less familiar, such as a proposed role for an independent third party (ombudsman) in assisting in the informed consent process. The authors suggest this through concern that the esteem in which clinicians are held in Sri Lanka might compromise patients’ ability to refuse participation in research.....”

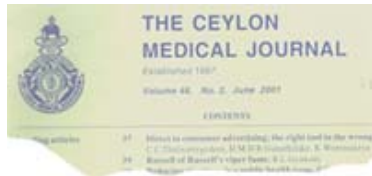
“.....This concise book succeeds in creating an excellent basis for moving ethical research in developing countries forward. As a pioneering discussion document it will be of use not only in Sri Lanka but also to international research programs in general.....”

Twins to Study Twins!

Public engagement and community participation is a part of ethical research. Keeping in line with this current thinking, we will employ twins as research assistants for this project. Though this initiative, we will encourage twins to study problems specific to twins: medical, psychological, social, and many other aspects of being twins.

FLASH

Sri Lankan Twin Registry is incorporated as a professional organization & now is a legal entity. We thank Mr. Jayantha Dolawatte, Senior Lawyer for helping us in this endeavour.



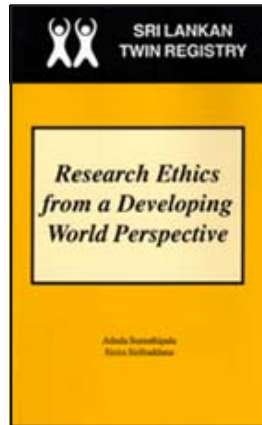
Prof. Valentine Basnayake
Commends Ethical
Guidelines in
Ceylon Medical Journal
September 2003, Volume 48,
Page 101



Prof. Carlo Fonseka
Commends Ethical
Guidelines in
Daily News
October 08, 2003, Daily News

Sri Lankan Twin Registry Publishes

First Ever Ethical Guidelines for Research in Sri Lanka



Launching ceremony of the book titled 'Research Ethics from a Developing World Perspective' was held on the 08th March 2003 at National Library Services

Board auditorium, Colombo. Prof. Harendra de Silva, Professor of Paediatrics, University of Kelaniya and Chairman of Child Protection Authority was the chief guest. Special guest lecture was delivered by Dr. Robert Simpson, Anthropologist, University of Durham, UK. Title of the guest lecture was 'Bridging the Divide: Some Reflections on the North-South Dialogue in Bioethics'. Researchers and public were invited for this event. Prof. Priyani Soysa, Prof. Susirith Mendis, Prof. Narada Warnasuriya and Dr. Anula Wijesundara also participated.

(from page 1) Significant Achievement for Capacity Building

the study will bring many other benefits to enhance research capacity at individual, institutional and national level.

It will be a model on how, high quality research can be carried out while adhering to the highest ethical stand

-ards while bringing back wider benefits to the society. Therefore, this is not a circumscribed project but a part of a long-term programme.

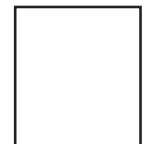
(from page 1) No Genetic Material out of the Country!

Therefore, it is a milestone for the beginning of an end to export of human biological material for research. We are grateful to our reviewers and the funders who supported our view. However, the genetic component of this study is limited to zygosity determination.

Neither the genetic material is stored nor any other genetic studies will be carried out with the material collected. This fact is clearly stated in the information leaflets provided to the research participants. Our aim is to make this laboratory avail-

-able for high quality research, and to develop a sustainable, and nationally important genetic research, and service development programme. We have had successful discussions with the Ministry of Health who will be an active collaborator on this initiative.

Twin News



To :

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Mulleriyawa New Town
Sri Lanka