

## EDITORIAL

### Towards a research culture in Sri Lanka

Although the Sri Lankan academic community displays intellectual richness and variety, it is clear that its capacity is insufficient for the scale of research efforts needed today. Therefore it is essential to achieve a paradigm shift in thinking and actions of the scientific community, to create a new strategic alliance among academics, scholars, professionals and the public, so that the intellectual contributions of individuals and institutions will be optimised and the power of science technology and knowledge could be mobilised to address the problems of the society based on an evidence-based approach. This new research culture will redress the impact of global divide of science and technology that undermine our indigenous knowledge and heritage. In this culture the public will respect, acknowledge and will be willing to be influenced by the decisions based on this synthesised knowledge.

The research culture we propose is one that the concept of research and research and further research is the slogan of the day. The whole nation should be engulfed in this thinking

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## Efforts Continue for a Bio-Ethics Framework

The draft guidelines formulated by the NTR for an ethical framework for twin research in particular and all research in general, from a developing world perspective has now being discussed extensively. We have had comments from national, regional and international academics and organisations who have a special interest and expertise in research ethics in the developing world.

Our proposed bio-ethical guidelines for the developing world are based on the following fundamental principles.

1. International collaborations should be for mutually beneficial research based on an agenda set by the developing world, but not for easy and cheap research.
2. Capacity building in the developing world is essential
3. Third party (ombudsman) to ensure freely given informed consent
4. Protect the national ownership and prevent undue commercial exploitation
5. Statutory framework robust enough to protect public interest but balanced enough to allow new developments

The detailed guidelines are to be published shortly.

### MSc Success

Dr. Enoka Suraweera a mother of twins was successful at her MSc dissertation titled "Some selected problems associated with growth and development of twins aged 0-3 years in the MOH areas of Kaduwela and Homagama" and it was submitted in partial fulfillment of the requirement for the degree of Master of Science (Community Medicine) to the Post Graduate Institute of Medicine, University of Colombo in January 2002. NTR supported her project.

### NATIONAL TWIN REGISTRY WEB SITE

Maintained by Mr. Keerthi Abeywickrama, Managing Director, Jobnet (Pvt) Ltd, Battaramulla

[www:http://infolanka.com/org/twin-registry](http://infolanka.com/org/twin-registry)

so that at every stage of any activity, individuals, groups, institutions and the nation will be asking 'why are we doing this, is it rational to do it and is it rational to continue doing it, does it need any change in the current practice, or is there a better way of doing it'. etc. In such a research culture, capacity building at individual, group, institutional and at national level will be encouraged. The concept of evidence based informed decision-making would be cultivated.

Although the twin and family studies methodology is one of the most advanced research tools, we feel the need to advance beyond twin research to achieve the above vision. Clearly there is a need for a forum for research and development with a multi disciplinary approach.

## PUBLICATIONS...

1. Sumathipala A, Fernando DJS, Siribaddana SH, Abeyasingha MRN, Jayasekare RW, Dissanayake VHW, De Silva N. Establishing a twin register in Sri Lanka. *Twin Research* 2000; 3: 202-205
2. Sumathipala A, De Silva N, Siribaddana SH, Abeyasinghe MRN, Fernando DJS. Cross cultural adaptation and preliminary validation of a zygosity determination questionnaire for twins in Sri Lanka. *Twin Research* 2000; 3: 205-212.
3. Sumathipala A, De Silva N, S. Sivayogam, Siribaddana SH, Abeyasinghe MRN, Fernando DJS. Feasibility of Using Different Approaches for Recruiting Younger Twins to Establish A Population Based Twin Register in Sri Lanka. *Twin Research* 2001; 4:459-463

## A Proposal to Develop Capacity in Bio-Ethics in Sri Lanka

The field of bio-ethics is at an early stage of development in Sri Lanka.

Our hypothesis is that increasing awareness and capacity building on bio-ethics will lead to higher ethical standards in health research in Sri Lanka. Therefore our objectives are to ensure higher ethical standards in research, through increasing awareness within the scientific community and the public through capacity building at an individual, institutional and national level.

The proposed project aims to develop a comprehensive curriculum in bio-ethics, sensitive to local socio-cultural needs. Primary focus will be on the ethical, legal and social principles guiding the responsible conduct of research in developing countries, particularly on scientific integrity and the protection of the interest of research participants.

Accordingly general emphasis will be on research ethics. However medical ethics and research methodology will be the other main components included. Our intention is to train a critical mass young faculty by offering them a Masters level training in UK or any other centre of excellence to take-up expert role and leadership to advance bio-ethics.

We plan to offer several courses on bio-ethics, in Sri Lanka. They are, a short basic course on research ethics and research methodology, an advanced course on research ethics and a short course on research ethics for lay people and non-medical professionals. A model curriculum will also be developed for undergraduates and postgraduates. All the above course material will be made available in the web. We will also establish a resource support center on bio-ethics and promote research and education in bio-ethics.

The proposed project will be an international collaboration between Kings College London, UK and several academic and research institutions/ groups in Sri Lanka.

Once an adequate faculty is available in Sri Lanka, this Masters programme will be continued here on a non fee paying basis.

We wish to increase awareness among general public through mass media and to influence ethics related policies. Developing strategic partnerships with other organizations, lobbying and increasing awareness among policy makers and opinion leaders about ethical perspectives of research in vulnerable populations will be targeted.

**Finally we will campaign to establish a statutory framework robust enough to protect the public interest but balanced enough to allow new developments.**



## Registration of NTR as an Independent Research Organisation

As suggested by the National Science Foundation of Sri Lanka we have now applied to be registered as a non profit charitable organisation like other professional organisations in Sri Lanka.

## National Science Foundation of Sri Lanka on Twin Registry Project and its Bio-ethics Guidelines

National Science Foundation of Sri Lanka forwarded us the following encouraging comment and some other important points in the letter dated 24.12.2001.

*"The project has been well thought of and is one, which will enable cross institution and multidisciplinary research. The objective of establishing a nationwide population based twin registry is indeed commendable."*

### Invitation...

Are you a twin doctor? Or Are you a doctor having twin children? If yes to either of these queries, please contact us. You are kindly invited to join us.

## Members of the Supervisory Committee of the NTR

Dr. Athula Sumathipala  
Prof. Devaka Fernando  
Dr. Sisira Siribaddana  
Dr. Nihal Abeysinghe  
Prof. Narada Warnasooriya  
Dr. D.A.R.K. Dayaratna  
Dr. Deepthi De Silva

## An Eventful Year of international recognition for NTR

NTR made its presence at the 10<sup>th</sup> International Congress of Twin Studies (ISTS) 2001 in London. Dr. Athula Sumathipala, Dr. Sisira Siribaddana and Ms Nimali de Silva (research assistant) represented the NTR.



Dr. Siribaddana & Sumathipala with Prof. Nick Martin (Founder of Australian Twin Registry and editor of Twin Research)



Dr. Athula Sumathipala delivering his guest speech at the ISTS 2001 meeting

3<sup>rd</sup> Global Forum on Bio-ethics held in South Africa in which Dr. Sumathipala represented NTR as an invited delegate sponsored by the Medical Research Council of UK.



Bioethics workshop in Canada hosted by Prof. Peter A. Singer University of Toronto Joint Centre for Bioethics. This was sponsored by Fogarty International Centre (National Institute of Health - USA) & NTR was invited.



Dr. Elizabeth Bryan (out going president) with new joint presidents (twins) Dr. Keith Louis and Dr. Donald Louis at ISTS 2001

We acknowledge the support offered by the following leading international research charities

1. Wellcome Trust, UK
2. Fogarty International Centre (National Institute of Health, USA)
3. Medical Research Council, UK



# NEWS

## Multiple Birth Foundation (MBF) Madurawala Branch

Madurawala Twin Society, one of the most active branches, has been successful in getting financial aid worth rupees 50,000 for five low income families with twins from Dept. of Probation and Child Care Services. They also organised a ceremony to distribute educational equipments for twins attached to their society during April 2002 with NTR contribution.

### Join us

We invite any interested academic/ researcher to join us or to collaborate on research projects

## Help MBF to Help Twin & Multiple Children of Low Income Families

The revised Declaration of Helsinki emphasises that "the research is justified only if the population to be studied stand to benefit"

Therefore NTR encouraged twins and their families to form the **Multiple Birth Foundation** to organise multiples and their families in to a separate organisation of their own. Its objectives are to raise awareness of unique issues faced by multiples and their families, and to build services to cater to their needs by working with professionals, statutory services and policy makers. They will also represent the interests of twins and observe ethical issues related to twin studies.

MBF has now initiated a project to help educational and health needs of twin & multiple children of low-income families because of the requests received from parents of twins.

If you are interested to help we can link you with the MBF or its branches.

### NTR is affiliated to the International Society for Twin Studies(ISTS).

The ISTS is an international, non-political, multi-disciplinary scientific organisation. Its purpose is to further research and public education in all fields related to twins (and higher multiple births) and twin studies, for the mutual benefit of twins and their families and scientific research in general. Its 1<sup>st</sup> congress on twin studies was held in Rome in 1974.

This newsletter is supported by a grant from The Wellcome Trust UK

# TWIN NEWS

To:-

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### From:

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Faculty of Medical Sciences  
University of Sri Jayawardenapura  
Gangodawila, Nugegoda