

I. BACKGROUND AND OBJECTIVES FOR DELHI EXPERT ROUNDTABLE:

Objectives of the roundtable:

The expert roundtable is co-organised by the Centre for Bionetworking (University of Sussex), Research and Information System for Developing Countries (RIS), New Delhi and the Department of East Asian Studies (Delhi University), Delhi. This event is specifically aimed at engaging the wider public on these issues and, further to this, informing policymaking on questions relating to biomedical innovation, regulation of new medical technologies and patient needs in India. The experts include both individuals with scientific and technical expertise such as policymakers, scientists and medical practitioners but also, importantly, panellists who can contribute insights on the day-to-day experience of patients (such as patient organisation representatives and patients themselves).

The expert roundtable builds upon a workshop co-organised by the Centre for Bionetworking in October, 2013 on the same topic ('Patient needs and stem cell research in India) held in Bangalore. Brought together a group of 14 individuals with expertise in the area of stem cell research, patient needs and/or biomedical innovation, the Bangalore workshop sought to stimulate discussion and ideas for novel solutions on how best to address patient needs, particularly for individuals living with terminal and incurable conditions such as spinal cord injury, muscular dystrophy, diabetes and cardiovascular disease. The two events seek to raise attention to how biomedical innovation can best address the needs of Indian patients and capture new insights in academic articles, policy briefings and public discussions.

About Research and Information System for Developing Countries (RIS):

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About Department of East Asian Studies, University of Delhi:

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About the Centre for Bionetworking:

The Centre for Bionetworking is a group of researchers based in the Department of Anthropology at the University of Sussex focusing on formal and informal collaborations in the life sciences in Asia. Our team brings together scholars with diverse regional and disciplinary expertise to investigate how innovations in the life sciences, in particular stem cell science, are conducted and organised in Asia and Europe. Through our work, we look for ways to overcome existing challenges to collaborative life science research as well as how best to promote safe, just and mutually profitable international exchanges.

II. CONCEPT NOTE AND AGENDA

Proposal for roundtable on 'Patient Needs and Regenerative Medicine in India: regulatory and policy issues' to be held on 2nd July 2014, proposed venue: India International Centre, Lodhi Road, New Delhi. Time: 2.30pm – 5.00pm

Question:

In addressing the needs of patients in India with terminal or incurable conditions, should funding regenerative medicine (stem cell research) be considered a priority?

Concept note:

Patients of terminal and incurable conditions have diverse medical and non-medical needs. These range from everyday requirements around care-giving, quality healthcare and emotional support to more specialised needs such as genetic testing, disabled-friendly buildings and access to information about treatment options. In addition to fulfilling these everyday needs, many people living with terminal or incurable conditions are anxious for a breakthrough in biomedical research which will lead to a treatment to improve their quality of life. For many conditions, stem cell therapy is seen to have significant potential and, despite the fact that it remains unproven, is actively sought after by many patients.

In this roundtable, panellists will be asked to address the importance of stem cell research in the specific context of Indian patients living with terminal conditions such as muscular dystrophy, spinal cord injury, diabetes and cardiovascular disease. With the realm of biomedical research, basic research is being conducted across the country in government-funded research institutes as well as in many private sector institutes. Significant clinical research is also taking place in India—however, this is largely conducted by international pharmaceutical companies for drugs which are not necessarily aimed at the Indian population. Panellists will be asked to present their views on whether, given these factors, investing in stem cell research should be considered an important priority for the government, patient organisations and industry.

I. FORMAT:**Topic:**

Patient Needs and Governance of Regenerative Medicine in India

Date and Time:

2nd July 2014, 14:30 – 17.00 hr

Venue:

India International Centre Annexe, Lodhi Road, New Delhi

Welcome address: Prof. Sachin Chaturvedi, RIS, New Delhi, 7 min

Introducing the Guest: Prof. Srimati Chakravarti (Chairperson of the Session), Department of East Asian Studies, University of Delhi, Delhi, 8 min

Presentation of the theme of the Roundtable Discussion: Dr. Carolyn Heitmeyer / Dr. Prasanna Kumar Patra, University of Sussex, UK, 10 min

Presentation by Invited Panellists: to be moderated by Dr. Ravi Srinivas, RIS, 60 min.

Discussant: Dr. Ravi Srinivas, RIS, 10 min

Open discussion with the Audience: to be moderated Dr. P.K.Patra, University of Sussex, UK, 45 min.

Concluding remarks: Dr. P.K.Patra, University of Sussex, UK, 5 min

Vote of Thanks: Dr. Nabin Panda, DU, 5 min

III.LIST OF PANELLISTS:

1. Dr.Roop Gursahani, P.D.Hinduja National Hospital, Mumbai
2. Mr. Rabindra Mahapatra, a spinal cord injury patient, Rourkela
3. Prof. P.B. Seshagiri, Indian Institute of Science, Bangalore
4. Mr. B.M. Manohar, CEO, Stempeutics Research Pvt. Ltd., Bangalore
5. Dr. Vasantha Muthuswamy, former Director General of ICMR
6. Mr. Louise, Executive Director, Muscular Dystrophy Foundation of India, Madurai
7. Dr. Nandini Gokulchandran, DyDirector, Neurogen, Mumbai