

## Symposium

### **New Biosciences/ New Society?: Socio-cultural, bioethical and political implications of developments in the biosciences**

Supported by the Brocher Foundation Programme, Geneva

**Date: April 28/29 2008**

Location: Brocher Foundation, Geneva, Switzerland



## Introduction

The Brocher Foundation's primary focus on ELSI issues related to the new biosciences provides an excellent forum through which members of SATSU's former Marie Curie European training programme can consolidate their work as well as engage in dialogue with others working in the field.

The Symposium is organised around three themes:

- The changing boundaries of human, animal and society
- The new forms of governance engaged in the social regulation of these boundary shifts
- The new social and cultural relations that are made possible by these changes

The main questions we shall explore in each theme are outlined below:

### *Changing boundaries of human, animal and society*

As a result of the play of genetics, informatics and tissue engineering, the boundaries of the human body become more permeable and more plastic. As Waldby (2000) emphasises, biomedicine itself depends on this 'malleability' of the body in order to accommodate the vast range of biomedical interventions that medics deploy. This malleability is extended through the increasing use of chimeras in stem cells research, the deposition of body tissue/DNA in genetic databases and tissue-banks and the global movement of biological tissue (such as embryonic stem cell lines) via international research and commercial networks. How far do these changing boundaries create new challenges for our understanding of our bodies, ownership of tissue, and rights and obligations as patients and citizens?

### *The new forms of governance engaged in the social regulation of these boundary shifts*

How is governance at the level of formal regulation by state actors and agencies being complemented and in some contexts in tensions with new forms of governance found in non-statutory areas; three are increasingly prominent and need examination: the family which has to handle the 'risky relations' of the new genetics and the promise and challenge of new reproductive technologies and clinical application of tissue engineering (in areas such as Alzheimer's disease; the consumer market wherein the genetics and regenerative technologies are being packaged as objects of consumption by commercial companies (as in cord blood banking); and finally the reframing of governance as a matter of choice rather than regulation at the level of the individual. What bioethical, political and cultural implications for the social management of biosciences emerge from these changes, and with what lessons for policy?

Within formal regulatory arenas, genetic diagnostics, in numerous forms and applications (including pre-implantation and pre-natal screening, diagnostics for the detection of late-onset adult disorders, etc) is increasingly changing peoples' health and reproductive experience. In turn, these applications present policy makers and healthcare providers with the difficult challenges of responsible social management. At stake are the sometimes fraught relationships between different stakeholders including patients, clinical specialisms, disability groups, government and industry.

### *The new social relations that are made possible by these changes*

How far do the changes noted above bring about new types of social relationship? For example, the increasing availability of eggs for donation for IVF or embryonic tissue for stem cells research as well as the commercialisation of both (especially in the US) create tensions between the gift relationship underpinning donation and the exploitation of tissue as private property. At the same time, aspirations associated with the long-term therapeutic use of regenerative medicine may – as in banking cord blood from a baby to derive autologous stem cells for future use creates new types of familial expectations and responsibilities that may bring new pressures on families in the decades ahead, and problems for health services where family breakdown occurs.

Moreover, as tissue becomes a more mobile object in time and space, new questions about traceability and safety will arise that need to be understood today.

### **Outline format for the Symposium**

Papers presented at the symposium will be work-in-progress short papers prepared by the network members and invited speakers. These will be circulated to all participants in advance of the meeting, and thus it will be expected that all participants read all papers prior to the start of the symposium in order to maximise discussion time. A number of delegates will be invited to act as discussants for each of the papers.

The analytical and practical implications of the results for the European context will be integrated into the discussion throughout the meeting. One session at the end of the symposium will be devoted to identifying areas for future international collaboration.

These work-in-progress papers will then be refined as a result of discussion at the meeting and prepared for publication. Improvements to the papers can be realised through discussions about experiences in other countries and regions, allowing culturally and policy-specific issues to be more clearly identified.

In summary, outputs of the symposium will include:

- Improved synthesis papers for publication in relevant books and journals
- Learning by all participants to be included in own research and practice
- Outline of research proposals for future grant submission

### **Participants**

Participants will be made up of the following, with a total number of approximately 25-30

SATSU members (Director plus 2/3 colleagues)

Former members of the European Marie Curie Training Programme in Genetics and Society

Colleagues from the University of Lausanne

Invited guest speakers

## Programme

### Day 1

- 9.30 – 9.45 Andrew Webster (SATSU, University of York) Introduction to the Symposium: core themes in the social analysis of the biosciences
- 9.45 – 12.15 *Theme 1 Changing boundaries of human, animal and society*
- 9.45 – 10.15 Opening plenary: Nik Brown (SATSU) Transpecies identities and regulation: the chimeric body  
Discussant: Erich Griessler, (HIS [Institute für Höhere Studien]).Vienna
- 10.25 – 12.15 Work in progress papers:
- 10.25 – 10.50 Coffee break
- 10.50 –11.10 Sakari Tamminen (University of Helsinki): Chronotope(s) of genetic autonomy: Genetic resources and the reordering of (natural) boundaries of nationhood
- 11.10- 11.30 Tora Holmberg, (University of Uppsala): Tail tales: Handling transgenic dilemmas in practice
- 11.30- 11.40 Discussant: Andrew Webster
- 11.40- 12.15 Open Discussion session  
Chair: Ragna Zeiss (University of Maastricht)
- 12.15-1.15 Lunch

### Theme 1 (continued)

- 13.15- 13.40 Klaus Hoyer, (University of Copenhagen): Almost human? Bones and prostheses between humanness and thingness
- 13.40- 14.00 Bettina Bock v. Wülffingen (University of Bremen) Changing methodology and the understanding of (epi-)genetic action in reproductive genetics
- 14.00- 14.10 Discussant: Pablo Santoro (University of Madrid)
- 14.10-14.30 Coffee break
- 14.30 – 17.00 *Theme 2 The new forms of governance engaged in the social regulation of these boundary shifts*
- 14.30- 15.00 Opening plenary: Katie Featherstone (University of Cardiff)
- 15.00-15.10 Discussant: Conor Douglas (PFGS)
- 15.10 - 15.30 Aaro Tupasela (University of Helsinki): Governing Hereditary Disease in the Age of Autonomy
- 15.30 – 15.50 Martin Rémondet (INRA-Transformations sociales et politiques liées au vivant) Regulating Cloned Animal Products: Expertise in the making in France, Europe and the United States

- 15.50- 16.10 Open Discussion  
Chair; Conor Douglas
- 16.10 – 16.30 Janus Hansen (Copenhagen Business School): Political Cultures of Public Engagement
- 16.30- 17.00 Ingrid Metzler (University of Vienna): Tissue banks and governance regimes
- 17.00 – 17.10 Break
- 17.10 - 17.30 Closing Guest paper: Lazare Benaroyo (Interface Sciences-société, University of Laussane, Switzerland) Vulnerability and its significance for medical ethics
- 17.30 - 17.50 Closing Discussion Day 1: Chair, Nik Brown

**Day 2: Theme 3: *The new social and economic relations that are made possible by these changes***

- 10.00- 10.30 Opening Plenary: Paul Martin (University of Nottingham): Innovation and the Market for Tissue engineering
- 10.30 – 10.40 Discussant: Graham Lewis (SATSU)
- 11.00 – 11.20 Ine Van Hoyweghen (University of Maastricht) Insurance in the molecular age. Towards new forms of solidarity?
- 11.20 – 11.45 Coffee break
- 11.45 – 12.05 Gyula Kasza (University of Corvinus, Hungary): The Mist Curtain in a former Iron Curtain Country
- 12.05 – 12.25 Antoinette Rouvroy (University of Namur, Belgium): Genetic privacy and discrimination in the context of neoliberal governance?
- 12.25 – 12.45 Open Discussion
- 12.45 – 13.45 Lunch
- 13.45 – 16.00 *Open session on the organisation and dynamics of contemporary bioscience*
- 13.45 – 14.15 Niki Vermeulen (University of Maastricht) Supersizing Science; On building large-scale research projects in biology
- 14.15 – 14.25 Discussion
- 14.25 – 14.50 Guest paper: Lena Eriksson (SATSU) Pluripotent promises – characterising human embryonic stem cells
14. 50 – 15.30 Roundtable: future research agendas, projects Chair: Andrew Webster
- 15.30- 16.00 Close: publication of symposium proceedings, Chair: Andrew Webster