5. The Anthropology of Genetic Science

Convenor:
Angela Procoli, Laboratoire d'Anthropologie Sociale
procoli@ehess.fr

The workshop aims to focus on the contemporary developments in the scientific understanding of genetics and the ways these developments are transforming the possible relations between humans and their natural environnement. Recent advances in the applications of genetic science raise important sociological and ethical issues (patentability of the living, reductionism and biological determinism, social discrimination based on biology) and have significant implications in the way of representing the "living". To what extent does the remarkable progress of biotechnology makes the concept of "personhood" to evolve?
To draw out these issues, contributions will discuss, on the one hand, examples on the making of scientific knowledge (community of geneticists, bio-database programs) and, on the other hand, examples in applied human genetics (genetic testing, antenatal screening, genetic therapy).

The making of knowledge in genomics : a new field for anthropology
Angela Procoli, Laboratoire d'Anthropologie Sociale
procoli@ehess.fr
Anthropology has been drawing closer to the world of genomics as it became concerned with the social, ethical and identity implications of DNA technology. However, it has been given little attention to the building of knowledge in genomics within its scientific laboratories.
The purpose of this paper is to underline the importance of a direct study of the scientific community concerned at the time when media are holding a monopoly over the conveying of scientific knowledge outside the world of laboratories. I will attempt to show that this knowledge is by no means uniform (a good example is the heterogeneous representation of the gene) and it has been built up from an interplay based on the relative strenght of various schools of thought (population genetics, molecular biology, structural and functional genomics). The outcome of these controversies is very often linked to local research politics or traditions.
I will discuss all these issues based on the findings of an ongoing ethnographic survey of the French research community of genetics.

The premature birth of a biobank: Abortion or miscarriage?
Gísli Pálsson, University of Iceland
gpals@hi.is
In 1998, the Icelandic Parliament ratified a bill on a Health Sector Database that would assemble in digital form medical records for the Icelandic population. When combined with genetic and genealogical information, it was argued, such a database would provide a powerful tool for exploring the genetic roots of common diseases. The project immediately became the center of a local and international controversy that focused on the ethics and social implications of the commodification of human genetic and medical information. Later, the company deCode Genetics, which outlined original plans for the Database was granted an exclusive license for constructing the Database in return for a fee. Since then a number of similar biobanks have been planned and prepared in other contexts, including Britain, Estonia, and

Sweden. In the meantime, the Icelandic project has come to a halt. This paper explores the reasons for the "collapse" of Icelandic project, drawing upon interviews with some of the key players as well as public discussions in and beyond Iceland.

Nurturing women and the BRCA genes; emerGent bio-socialities of predictive medicine.

Sahra Gibbon, University College London
s.gibbon@ucl.ac.uk

The relatively rapid translation of the knowledge and technologies associated with inherited 'susceptibility' genes such as BRCA1/2 into clinical practice provide an important if somewhat hidden and subtle context for exploring some of the re-definitions taking place over identity in relation to predictive genetic medicine. Based on ethnographic research carried out in two breast cancer genetic clinics in the UK this paper explores the emergent 'bio-socialities' (Rabinow 1996) presaged by these developments. I show how the figure of the 'distributed' patient and the 'nurturing' woman are not only literal and explicit in this context but necessary to knowledge and care. The importance of sharing information or knowledge about health and risk brings new obligations and responsibilities between kin, such that awareness and involvement in the health of others is as important as individual vigilance. At the same time these new requirements for patienthood are facilitated and enabled by the ubiquity of the value of female nurturance. The incorporation of these social and ethical values raise questions about how genetic knowledge and technologies are being mobilized and to what extent old and new categories of definition and identification are given renewed vitality by these practices. Nevertheless the kind of reductionism at stake here is not easily defined, given the way health awareness, prevention and the valorization of female nurturance have long been part of and are inimical with female identity politics and the growth and visibility of breast cancer activism.

Predispositions: contemporary life in biotechnology and biography

Hannah Landecker, Rice University
hll@rice.edu

Much has been written regarding the understanding of the genome as a text, and DNA as language, speaking to the question of what happens to "life" when it is seen as a book. Here the analysis sets off in the opposite direction, asking what is happening to books, in light of the geneticization of text and writing. This paper considers contemporary autobiographies and biographies which give a determining role to the life of the body in the making of the person, and their relation to biotechnology - in particular to the idea of man-made genomes. Biotechnical narratives of the creation and management of life are manifest not just in changes in the content of these biographies, but in their very form. These mutations in literary form are tied to broader changes in biographical narration that occur when the body becomes differently pertinent to the person, as noted in a variety of anthropological analyses of new forms of biological personhood.

Individualisation of Women's lives

Bernhard Wieser, Wilhelm Berger and **Sandra Karner,** IFF-TEWI
wieser@ifz.tu-graz.ac.at

Prenatal testing has significantly changed the experience of pregnancy and causes an individualisation of women's lives. Such tests confront women with momentous

decisions. Not only are these decisions between life and death difficult to take, in fact such decisions radically question the individuals who are taking them: Who am I as a mother if I am calling my unborn child's life in question? For this reason prenatal testing endangers the personal identity of effected women (and couples) in a very dramatic way. In the proposed paper the authors want to problematize such processes of individualisation against the backdrop of ethical models that underlie the perception of prenatal testing. As a matter of fact counselling processes as they are required if women undergo prenatal testing are based on ethical principles that presuppose an autonomous individual that is capable of taking such decisions. The aim of genetic counselling is to inform pregnant women in such a way that she is able to take a thoughtful decision for which she can take over responsibility.
Taking individual decisions and being fully responsible for them under circumstances where traditional securities are not given anymore, such conditions are understood to be powerful driving forces of an individualisation process.

The Laboratory in Society. Symbolic discrouse and socio-genetic boundaries in East Asia and European contexts
Margaret Sleeboom, International Institute for Asian Studies
m.sleeboom@let.leidenuniv.nl
Accompanying the development of new genetic technologies, boundaries between species seem to have become more fluid. At the same time, due to the genetic redefinition of existing social, economic and ethnic groups, interhuman group boundaries gained importance.
This latter trend has come about partly as a result of an institutional shift in societies, including the transplantation of laboratory experimentation into a new social context. Thus, antenatal screening and screening for genetically inheritable diseases has become part and parcel of public health care policies.
This shift is accompanied by a discourse in which various publics discuss the consequences of the application of these new technologies in relation to bioethical and social issues. This discourse is embedded in complex of political, legal and religious institutions, whose rhetoric and symbolic values may be central to new socio-genetic identities and conflict among various human groups.
This paper will show how religious and scientific symbols play a part in discussions on antenatal screening in Japanese, Chinese and Dutch contexts. It will become clear that human identities, here defined in terms of their socio-genetic make-up, are closely related to the social and political institutions and policy-making of different nation-states.

The case of the genetic disease: Thalassaemia, in the era of the new genetics
Aglaia Chatjouli, Aegean University
achatjouli@yahoo.com
In the era of the new genetics “conditions” refering to health and illness are re-constructed based on a “genetic reality”; a trend validated by the growing use of genetics in diagnosis, prevention and future (gene) therapies and by the wide celebration of the “gene” and its key position in the “making of us”, in the media, in popular and academic science.
The focus here is how such a trend is informing ideas about “nature”, “human nature”, “normal”, “abnormal”, “health”, “illness” and the conceptualisation of the “self”, particularly concerning people born with a specific genetic disease, *thalassaemia*. These people are categorised according to inherited mutations, and are faced with

genetic testing and future gene therapies, for a “condition” presently monitored via therapy but not cured.
The notion of “relatedness” may also be influenced; new collectivities of inclusion are formed as well as new reasons for excluding; a shared genetic trait, a shared gene mutation may stress a collective identity (sharing a disease), a shared history etc.
This paper will also be dealing with the social discrimination against these people, (with a past in the Greek context), and to what extent and how this empahsis on the “genetic” is underlining a social discrimination based on biology and what kind of biology.

Reflections upon a racialised reprogenetic media event: the birth of ‘black’ twins to a white IVF mother

Katharine Tyler, University of Surrey
katharine.j.tyler@man.ac.uk

This paper examines British newspaper accounts and my research participants’ from Leicester (a city in the East Midlands area of England) reflections upon a much publicised racialised reprogenetic media event that occurred in the UK in July 2002 - the birth of ‘black’ twins to a white IVF mother. The event involved the mistaken mixing and implantation of a white and a black IVF couples’ gametes. I examine the contrasts, complexities and similarities between my co-conversationalists’ Islamic values and ideas on the ethics of the new reproductive technologies and sexual reproduction with those advocated by the British press and jurisprudence. My juxtaposition of these narratives provides an insight into the ways in which ideas of racial and ethnic identity, religious values, biological substance, genetic connection, ideologies of procreation and procreative intent, legal and social relationships are put to work to establish competing claims to motherhood, fatherhood and personhood in English kinship thinking.