

Obtaining health-related genomic information is no longer restricted to the clinical realm. Genome-wide analyses to identify genetic predispositions for a range of conditions, including rare diseases as well as common, multi-factorial diseases like cancer, diabetes, or heart disease, can now be purchased online. Similarly, tests for genetic ancestry, paternity, or “recreational traits” such as athletic propensities, can be obtained direct-to-consumer (DTC) from commercial companies. Social networking tools are used by individuals not only to share their individual genetic profiles, but also to actively participate in disease research, thereby complicating some of the core categories that the organisation of disease research and health care rests upon: experts and lay persons, gate-keepers and specialists, and producers and recipients/consumers of knowledge.

The ethical and legal debate about such developments has just started. This symposium will explore the mutual relationship between genetics, markets and societies in this field. Our aim is to facilitate an interdisciplinary debate on whether and how socio-cultural factors influence attitudes towards the usage of, and the belief in, *genetics2.0*. Furthermore, we seek to explore how individual and collective identities are challenged by cultural meanings of genetics.

The event will include explorations of the meanings of genetics at the interface of science and arts in cooperation with Priska Gisler, Institute for Transdisciplinarity, Bern University of the Arts, CH. In addition, the artwork *Con'Sequences* will be presented.

Symposium participation is free of charge. For organizational reasons, we kindly ask you to register until 7 October 2011. Please e-mail the registration form found at: http://www.i-med.ac.at/ethucation/Events/conference_2011.html to ethucation@i-med.ac.at. Should you be unable to attend despite registration please let us know.

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For a detailed schedule, programme updates and further information check at: <http://www.i-med.ac.at/ethucation/>



Interdisciplinary Symposium

“Genetics as Culture in a Consumerist Age”

Organized by:

Gabriele Werner-Felmayer (Division of Biological Chemistry, Biocenter, and Bioethics Network Ethucation, Medical University of Innsbruck, AT)

Silke Schicktanz (Culture and Ethics of Biomedicine, University Medical Center, University of Göttingen, DE)

Barbara Prainsack (Department of Sociology and Communications, Brunel University London, GB)

In cooperation with:

Josef Quitterer (Department of Philosophy, Faculty of Theology, University of Innsbruck, AT)

Siegfried Walch (International Health Care Management, Management Center Innsbruck, AT)

Date and Venue:
October 27 – 29, 2011

Hotel Grauer Bär, Innsbruck,
Universitätsstraße 5
Innsbruck, Austria

Thursday, October 27, 2011

8:45 Welcome

9:00 – 12:30, Session 1: Messages from the genome

Finding genes for complex diseases: the systematic search in a haystack
(Florian Kronenberg, AT)

Predictive genetic testing: concepts, challenges and clinical practice
(Johannes Zschocke, AT)

Choice, expertise and critique: freedom and the meta-discussion on personal genomics
(Tamar Sharon, NL)

Informed consumption of genetics: the role of professional expertise
(Lucca Chiapperino, Giuseppe Schiavone, IT)

No man is an island – a look at the wider implications of DTC genome sequencing
(Samantha Leonard, Alexandra Soulier, Anne Cambon-Thomsen, FR)

Philosophical, ethical and sociological aspects highlighted by the development in epigenetics (Charles Dupras, CA)

2:00 – 5:40, Session 2: The interplay of genetics, culture and new media

Laboring life: tournaments of biosocial value
(Gisli Palsson, IS)

Where boutique medicine meets risk assessment: personalized medicine in the clinic and on the web (Jennifer Fishman, CA)

Making life plans – patients and lay people attitudes towards the use of genetic testing for late-occurring diseases
(Aviad Raz, IL)

Confiscating biopolitics in a paradoxical way? An anthropological study of DTC genetic test users' motives and perceptions
(Pascal Ducournau, Claire Beaudevin, FR)

A qualitative analysis of European clinical geneticists' views of DTC genetic testing
(Heidi C. Howard, Pascal Borry, CH, BE, NL)

Friday, October 28, 2011

9:00 – 12:30, Session 3: The ethics of genetics – revisited in the light of consumerism, choice and collective identities

Re-thinking responsibility – autonomy, control and genetic knowledge
(Silke Schicktanz, DE)

The ethics of patenting in genetics
(Sigrid Sterckx, BE)

The changing self – philosophical concepts of self, personhood and the individual in a post-clinical age of genetics
(Josef Quitterer, AT)

Genome and identity. On the fingerprints of self, behaviour and free will
(Natascha Gruber, AT)

The gift of spit: a critical exploration of how consumers of online genetic testing services are participating in research
(Anna Harris, Sally Wyatt, Susan Kelly, GB)

2:00 – 3:00, Session 4: Genetics, notions of identity, practical aspects

If to tell children born as a result of advanced infertility treatment, about the identity of their father or mother?
(Edna Katzenelson, IL)

Between lineage and choice: genetics and reproductive medicine
(Andreas Exenberger, AT)

The transparent patient
(Claudia Paganini, AT)

3:00 – 6:00, Session 5: Ancestry and identity – between knowledge and imaginations

Ancestry Testing via DNA: The molecular inscription of identity and putative kinship
(Troy Duster, US)

My mother – the enigma, ancestry tracing: artistically revisited, a video essay as research report

(Mo Diener, CH)

Il Nonno, video installation
(Luzia Hürzeler, CH)

7:00 Evening performance

Consequences, multidisciplinary improvisation (sounds, dance, words & installation on genetics and identity)
(Nadia Braitto, Federica Sposito, Saverio Monti, IT; Helene Keller, AT)

In cooperation with the University Center of Italian Studies, displayed at "Kunst im Gang", Karl-Rahner-Platz 1, 1st floor

Saturday, October 29, 2011

9:00 – 1:00, Session 6: Governance of genetics/markets in a global and virtual world

Characteristics of online genetic tests users: implications and recommendations
(Colleen McBride, US)

Governing DTC genetics - in a global and/or virtual world?
(Barbara Prainsack, GB)

Constructing responsible innovation in DTC genetic susceptibility testing
(Christopher Groves, Adam Hedgecoe, Richard Tutton, GB)

Personal Genomics and the law: a US perspective, a global challenge
(Daniel Vorhaus, US)

Legislation on DTC genetic testing in seven European countries
(Pascal Borry, Rachel E. van Hellemond, Dominique Sprumont et al., BE)

1:00 end of symposium