

Programme

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 (Department of Medical Ethics and History of Medicine,
University Medical Center Göttingen, DE)
Barbara Prainsack (Department of Sociology and Communications, Brunel
University London, GB)

In cooperation with:

Josef Quitterer (Department of Philosophy, Theological Faculty, 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

**Conference desk at lecture hall opens on Thursday, October 27, 2011,
8:15 a.m.**

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Thursday, October 27, 2011

8:45 am Welcome and introductory remarks

9:00 – 12:30 am, Session 1: Messages from the genome – state-of-the art, ethical and epistemological aspects

9:00 **Florian Kronenberg**, Division of Genetic Epidemiology, Medical University of Innsbruck (AT); *Finding genes for complex diseases: the systematic search in a haystack*

9:40 **Johannes Zschocke**, Division for Human Genetics, Medical University of Innsbruck (AT); *Predictive genetic testing: concepts, challenges and clinical practice*

10:20 **Coffee break**

10:45 **Tamar Sharon**, STS Program Maastricht University (NL); *Choice, expertise and critique: freedom and the meta-discussion on personal genomics*

11:05 **Lucca Chiapperino, Giuseppe Schiavone**, SEMM – European School of Molecular Medicine, Milan (IT); *Informed consumption of genetics: the role of professional expertise*

11:25 **Samantha Leonard, Alexandra Soulier, Anne Cambon-Thomsen**, Inserm, Unit 1027, team 4: Genomics, Biotherapy and Public Health, Toulouse, and Université Paul Sabatier, Toulouse (FR); *No man is an island – a look at the wider implications of direct-to-consumer genome sequencing*

11:45 **Charles Dupras**, Bioethics Programme, Medical Faculty, University of Montreal (CA); *Philosophical, ethical and sociological aspects highlighted by improved knowledge in epigenetics: the impact of redefined biological identity on public health management*

12:05 **General discussion**

Chair: **Gabriele Werner-Felmayer** (Medical University of Innsbruck, AT)

12:30 – 2:00 pm Lunch break

2:00 – 5:40 pm, Session 2: Interplay of genetics, culture and new media – global and cross-cultural impacts

2:00 **Gísli Pálsson**, Department of Anthropology, University of Reykjavik (IS); *Laboring life: tournaments of biosocial value*

2:40 **Jennifer Fishman**, Biomedical Ethics Unit, McGill University, Montreal (CA); *Where boutique medicine meets risk assessment: personalized medicine in the clinic and on the web*

3:20 **Coffee break**

3:50 **Aviad Raz**, Department of Sociology and Anthropology, Ben Gurion University of the Negev, Beer-Sheva (IL); *Making life plans – patients and lay people attitudes towards the use of genetic testing for late-occurring diseases*

4:30 **Pascal Ducournau, Claire Beaudevin**, Inserm, Unit 558, LISST – Le Mirail University, Toulouse, and Cermes3 (CNRS UMR 8211 – Inserm, Unit 8211), Paris (FR); *Confiscating biopolitics in a paradoxical way? An anthropological study of direct-to-consumer genetic test users' motives and perceptions*

4:50 **Heidi Carmen Howard, Pascal Borry**, Institute of Bio- and Medical Ethics, University of Basel (CH), Centre for Biomedical Ethics and Law, KU Leuven (BE), and EMGO Institute for Health and Care Research, VU University, Amsterdam (NL); *A qualitative analysis of European clinical geneticists' views of direct-to-consumer genetic testing*

5:10 **General discussion**

Chair: **Barbara Prainsack** (Brunel University London, GB)

7:30 Conference dinner

Friday, October 28, 2011

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

- 9:00 **Silke Schicktanz**, Department of Medical Ethics and History of Medicine, University Medical Center Göttingen (DE), *Genetic responsibility revisited – the anticipation of late on-set diseases in the light of multiple responsibilities*
- 9:40 **Sigrid Sterckx**, Bioethics Institute, University of Gent (BE); *The ethics of patenting in genetics*
- 10:20 **Coffee break**
- 10:45 **Josef Quitterer**, Department of Philosophy, Faculty of Theology, University of Innsbruck (AT), *The changing self – philosophical concepts of self, personhood and the individual in a post-clinical age of genetics*
- 11:25 **Natascha Gruber**, Department of Philosophy, University of Vienna (AT), OHST, University of California, Berkeley (US); *Genome and identity. On the fingerprints of self, behaviour and free will*
- 11:45 **Anna Harris, Sally Wyatt, Susan Kelly**, Department of Technology & Society Studies, and Maastricht Virtual Knowledge Studio, Maastricht University, e-Humanities Group, Royal Netherlands Academy of Arts & Sciences, Amsterdam (NL), ESRC Centre for Genomics in Society, University of Exeter (GB); *The gift of spit (and the obligation to return it): a critical exploration of how consumers of online genetic testing services are participating in research*
- 12:05 **General discussion**

Chair: **Aviad Raz** (Ben Gurion University of the Negev, IL)

12:30 – 2:00 pm Lunch break

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

- 2:00 **Edna Katzenelson**, Department of Psychology and Dep. of Medical Education, Sackler Faculty of Medicine, University Tel Aviv (IL); *If to tell children born as a result of advanced infertility treatment, about the identity of their father or mother?*
- 2:20 **Andreas Exenberger**, Department of Economic Theory, Policy and History, University of Innsbruck (AT); *Between lineage and choice: genetics and reproductive medicine*
- 2:40 **Claudia Paganini**, Department of Philosophy, Faculty of Theology, University of Innsbruck (AT); *The transparent patient*

Chair: **Josef Quitterer** (University of Innsbruck, AT)

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

- 3:00 **Troy Duster**, Department of Sociology, New York University (USA); *Ancestry testing via DNA: The molecular inscription of identity and putative kinship*
- 3:40 **Coffee break**
- 4:10 **Mo Diener**, artist, Zürich (CH); *My mother – the enigma, ancestry tracing: artistically revisited, a video essay as research report*
- 4:50 **Luzia Hürzeler**, artist, University of the Arts, Bern (CH); *Il Nonno, video installation*
- 5:30 **General discussion**

Chair: **Priska Gisler**, University of the Arts (FSp Intermediality), Bern/ETH Zürich Collegium Helveticum (CH)

- 7:00 **Evening performance at “Kunst im Gang”, Karl-Rahner-Platz 1, 1st floor** (opposite the hotel), **in cooperation with the Innsbruck University Center of Italian Studies:** **Nadia Braitto**, vocalist (IT), **Federica Esposito**, dancer (IT), **Saverio Monti**, sound designer (IT), **Gabriele Werner-Felmayer** (AT) and **Helene Keller**, artist (AT), *Con’sequences, multidisciplinary improvisation (sounds, dance, words & installation on genetics and identity in the context of consumerism)*
Buffet after the performance

Saturday, October 29, 2011

9:00 – 1:10 pm, Session 5: Governance of genetics/markets in a global and virtual world

9:00 **Colleen McBride**, Public Health Genomics Section, National Human Genome Research Center, National Institutes of Health, Bethesda (US); *Characteristics of online genetic tests users: implications and recommendations*

9:40 **Barbara Prainsack**, Department of Sociology and Communications, Brunel University, London (GB), *Governing direct-to-consumer genetics - in a global and/or virtual world?*

10:20 **Christopher Groves, Adam Hedgecoe, Richard Tutton**, ESRC Centre for Social and Economic aspects of genetics (Cesagen), Cardiff University (GB); *Constructing responsible innovation in direct-to-consumer genetic susceptibility testing*

10:40 **Coffee break**

11:10 **Daniel Vorhaus**, Robinson, Bradshaw & Hinson P.A., North Carolina (US), *Personal Genomics and the law: a US perspective, a global challenge*

12:00 **Pascal Borry, Rachel E. van Hellemond, Dominique Sprumont et al.**, Centre for Biomedical Ethics and Law, Katholieke Universiteit Leuven (BE); *Legislation on direct-to-consumer genetic testing in seven European countries*

12:20 **General discussion**

Chair: **Silke Schicktanz**, University of Göttingen (DE)

12:50 Closing remarks and end of symposium

13:00 Lunch

Cooperations and financial support by:

