

International Workshop: The Establishment of Genetic Counseling in the Second Half of the 20th Century

Berlin, February 2-3, 2016

Deadline: January 26, 2016

The rapid development of molecular genetics in the 1950s not only led to the establishment of human genetics as a separate discipline, it also fundamentally changed the thinking about disease and health. Genetics became indispensable for studying the causation, formation, and development of diseases. Yet, because of the low potential for an actual cure of genetic diseases, genetic counseling received special significance as "the most immediate and practical service that genetics can render in medicine and surgery," according to the WHO Expert Committee on Human Genetics in 1964. Genetic counseling centers were set up throughout the world, although unevenly distributed. The reasons for why people sought counseling varied considerably – from evaluating the risk of having a child with Down's Syndrome to detecting the sickle cell gene.

The aim of the workshop is to bring together researchers in the history of medicine or science, in disability studies, cultural anthropology and other related fields in order to analyze global, national, and local factors that influenced the establishment of genetic counseling and shaped its further development.

Location:

Institute of the History of Medicine and Ethics in Medicine

Charité-Universitätsmedizin

Thielallee 71

14195 Berlin

Germany

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Program



Tuesday, 2nd of February 2016

8:45-9:00

Come together

9:00 -9:15

Welcome

Volker Hess (Director of the Institute of the History of Medicine) and Susanne Doetz

Genetic Counseling in Europe and the USA: International Case Studies

9:15 – 10:15

Panel I: Genetic Counseling in the Mediterranean Area

Chair:

Jenny Bangham

Luc Berlivet:

Genetic Counseling as a Eugenic Device. The “Fight Against
Thalassemia” in 1950s Italy and Afterwards

Alexandra Barmpouti:

Genetic Counseling for Mediterranean Anemia in Post-War Greece
(1950-1980)

10:15-10:30

Coffee break

10:30-13:00

Panel II: Country Case Studies

Chair

Ulrike Klöppel

Maria Björkman/Anna Tunlid:

Development of Genetic Counseling in Sweden 1950-1980

Joris Vandenriessche:

Genetic Counseling in Belgian Academic Hospitals, 1960-1980

Katja Geiger/Thomas Mayer:

The Establishment of Human Genetic Counseling in Austria during the
1970s in between the Formation of Human Genetics and the Eugenic
Indication of Abortion

Heike Petermann:

Genetic Counseling in the United States of America and the Federal
Republic of Germany (1945 to 1974). A Comparative Perspective

13:00-14:00

Lunch

14:00-16:30	<p>Panel III: Shaping the Development of Genetic Counseling in the US: Crosscurrents of Professionalization, Uncertainty, and Disability</p> <p><i>Chair: Petra Fuchs</i></p> <p>Robert Resta: Colleagues, Conflicts, and Conciliations: Genetic Counsellors, Medical Geneticists, and the Historical Arc of The Genetic Counseling Profession</p> <p>Marion Schmidt: From Preventing Defect to Serving a Disadvantaged Minority: Genetic Counseling for Deaf People</p> <p>Andrew J. Hogan: Managing a Marginal Diagnosis: Genetic Counseling and the Expansion of Prenatal Testing</p> <p>Adam Turner: Genetic Counselors and Parent Advocates on Abortion and Disability, 1950-1990</p>
16:30-17:00	Coffee break
17:00-18:00	<p>Panel IV: Genetic Counseling behind the Iron Curtain</p> <p><i>Chair: Jenny Bangham</i></p> <p>Michal Simunek: Genetic Counseling in the CSSR</p> <p>Susanne Doetz: "The Happiness of the Individual is of Primary Importance" - Genetic Counseling in the GDR</p>
18:00-18:30	<p>Comment:</p> <p>Jean Paul Gaudillière</p>
20:30	Dinner

Wednesday 3rd of February 2016

Genetic Counseling: Actors, Practice, and Methods

9:30-12:00

Panel I: Actors

Chair:

Susanne Doetz

Yechiel Michael Barilan/Margherita Brusa: Expanded Newborn Screening: Genetic Counseling at the Level of Public Health through the Prism of three Historical Case Studies

Mauro Capocci:

Catholic Counseling. Medical Genetics and the Church Approach

Birgit Nemeč:

Risk, Prevention and Counseling in Human Genetic Screenings - Western Germany 1945-1980

and

Gabriele Moser:

Abortion and Sterilisation in Mecklenburg after WWII: Family Planning between Social Needs and Eugenics

Jörg Pittelkow:

Herbert Bach (1926 – 1996) – A Pioneer of Human Genetics in East Germany (GDR)

12:00-13:00

Lunch

13:00-14:50

Panel II: Practice and Methods

Chair:

Florian Bruns

Ana Barahona:

Karyotyping and Genetic Counseling in Mexico in the 1960s

Shachar Zuckerman:

Challenging the Feminist Criticism of Genetic Counseling

Angus John Clarke:

Evolving Ideas around 'non-directiveness' in Genetic Counseling

14:50-15:15

Coffee break

15:15-15:45

Final Comment:

Alexander von Schwerin

15:45-16:00 Uhr

Final Discussion

This workshop is kindly supported by the *Deutsche Forschungsgemeinschaft*.