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, 2\textsuperscript{nd} 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:  

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  
**Panel III: Shaping the Development of Genetic Counseling in the US: Crosscurrents of Professionalization, Uncertainty, and Disability**  
*Chair:* Petra Fuchs  
Robert Resta: Colleagues, Conflicts, and Conciliations: Genetic Counsellors, Medical Geneticists, and the Historical Arc of The Genetic Counseling Profession  
Marion Schmidt: From Preventing Defect to Serving a Disadvantaged Minority: Genetic Counseling for Deaf People  
Andrew J. Hogan: Managing a Marginal Diagnosis: Genetic Counseling and the Expansion of Prenatal Testing  
Adam Turner: Genetic Counselors and Parent Advocates on Abortion and Disability, 1950-1990  

16:30-17:00  
Coffee break  

17:00-18:00  
**Panel IV: Genetic Counseling behind the Iron Curtain**  
*Chair:* Jenny Bangham  
Michal Simunek: Genetic Counseling in the CSSR  
Susanne Doetz: “The Happiness of the Individual is of Primary Importance” - Genetic Counseling in the GDR  

18:00-18:30  
*Comment:* Jean Paul Gaudilliére  

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 Nemec: 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.