

Brocher Foundation workshop

Rare Diseases, Global Health, and Social Sciences: Counterbalancing Biomedical Reductionism

May 9-11, 2023, Hermance, Switzerland
organized by Małgorzata Rajtar & Eva-Maria Knoll

Tuesday, 9 May

7:30 – 8:45 Breakfast

Chair: Małgorzata Rajtar

9:00 Welcome and opening

9:30 Session 1

Joyce M. Olenja (Kenya): Rare diseases and the question of neglect: Perspectives from the African Region

Waleska Aureliano (Brasil): A family matter: The limits of biotechnologies in the construction of kinship among families affected by rare genetic diseases in Brazil

Ilaria E. Lesmo (Italy): Anthropology, biomedicine, and rare diseases: Limits and potential for a complex knowledge.

11:00 Coffee break

11:30 Session 2

Stefan Reinsch (Germany): Immigrants to health: Tinkering with therapy, visibility of illness, and belonging in Cystic fibrosis

Pauline McCormack (UK): The genomic dream: Promissory technologies and rare disease

12:30 Lunch

14:00 Session 3

Adrienne Lagman (US): Stressed to death: Counterbalancing biomedical reductionism in experiences of Cushing's Syndrome and Disease

William Lucas (US): Norming practices in caring for rare diseases: Evaluating transverse myelitis within spinal cord injury rehabilitation practice

Nancy J. Burke (US): A case study in structural racism and urbanism: The neglect of Valley Fever

15:30 Coffee break

16:00 – 17:00 Comments and general discussion

18:30 Dinner

Wednesday, 10 May

7:30 – 8:45 Breakfast

Chair: Małgorzata Rajtar & Eva-Maria Knoll

9:00 Session 4

Rebecca Dimond (UK): The politicised patient: Power and vulnerability of rare disease communities

Jacquelyne Luce (US): Expert mobility: Transnationalizing mitochondrial disease research, care, and organizing

Eva-Maria Knoll (Austria): Remote sickle cell biosociality and a children's book in the making

10:30 Coffee break

11:00 Session 5

Sangeeta Chattoo (UK): Precarity of the poor, public health policy and imagined communities: (Re)classifying sickle cell as a rare disease in India

Giorgio Brocco (Austria): Powers of belonging: The limits of biosociality and multiple enmeshments of Albinism in contemporary Tanzania

Magdalena Góralaska (Poland): Nonspecific Lyme: Controversial diseases in the digital age

12:30 Lunch

14:00 Session 6

Rajesh Kalarivayil (India): Dynamics of international collaboration in rare cancers research in India: What are the lessons for larger institutional collaboration framework?

Kristin Bright (USA): Activism otherwise: At the edge of description and relation in precision medicine for rare cancers

Claudia Egger, Susan van Hees and Wouter Boon (Netherlands): Values and incentives in the development of an intelligent ecosystem to improve the governance, the sharing and the re-use of health data for rare cancers

15:30 Coffee break

16:00 – 17:00 Comments and general discussion

17:15 *Excursion: Walk through medieval Hermance*

18:30 *Dinner*

20:15 *Complementary: Wine tasting Vineyard Domaine des Champs-Lingot*

Thursday, 11 May

7:30 – 8:45 Breakfast

Chair: Eva-Maria Knoll

9:00 Session 7

~~**Paul Just** (Austria): Governing rare diseases through the EU Regulation on Health Technology Assessment (HTA): “Quality of life” measurements as governmental practices~~

Koichi Mikami (Japan): United we stand, divided we fall? Lessons from the history of rare diseases policy in Japan

~~**Tomas Kačerauskas and Juan Coca** (Lithuania & Spain): Biosemiotic and sociosemiotic approach to undiagnosed rare diseases~~

Małgorzata Rajtar (Poland): The vulnerability of “small” data: Counterbalancing health policy on rare diseases with anthropology

11:00 Coffee break

11:30 Final discussion & WS closing

13:00 Lunch

Afternoon Departure

This workshop is supported by the Brocher Foundation, Hermance, Switzerland.

