

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

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**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

**Sybille Merz** (UK): Cystic fibrosis multiple? Advancing the interdisciplinary understanding of rare disease in India

**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

**19:00 Dinner**



## Wednesday, 10 May

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**7:30 – 8:45 Breakfast**

Chair: Vivek Neelakantan

**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 Górska (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

**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**

**19:00 Dinner**

## Thursday, 11 May

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**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 & Juan Coca** (Lithuania & Spain): Biosemiotical and sociosemiotical approach to undiagnosed rare diseases

**10:30 Coffee break**

**11:00 Session 8**

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

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

**12:00 Final discussion & WS closing**

**13:00 Lunch**

**Afternoon:** Departure

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

