

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

Date: 9-11 May 2023

Venue: Brocher Foundation, Hermance, Switzerland

Organizers: **Małgorzata Rajtar** (Institute of Philosophy and Sociology, Polish Academy of Sciences)
& **Eva-Maria Knoll** (Institute for Social Anthropology, Austrian Academy of Sciences)

The last two decades have witnessed the growing importance of the “Rare Disease” (RD) category in the context of national health policies and Global Health. Lacking a universal definition, RDs are defined as conditions that affect no more than 1 in 2000 people in the EU and Australia; they affect fewer than 200,000 and 50,000 in the US and Japan respectively. It is estimated that some 30 million people in the EU and 263-446 million globally live with one of the over 6000 described RDs. In a 2021 resolution, the United Nations presented the complex nature of the challenges people living with a RD and their families face as being intrinsically linked to both human rights and to the Sustainable Development Goals. The 2021 report issued by the global alliance Rare Disease International identified ten common challenges and needs that impact diagnosis, care, and treatment of the RD population globally. A significant proportion of the listed challenges and needs lies beyond the realm of biomedicine and life sciences.

The workshop *Rare Diseases, Global Health, and Social Sciences: Counterbalancing Biomedical Reductionism* aims to bring together, enhance and further develop social science and medical humanities approaches to the globalizing RD field by addressing these challenges and concerns that include social acceptance, equality, inclusion, political recognition, empowerment, and geographical and cultural considerations. In particular, the workshop proposes to address three thematic areas that have a significant and long-term impact on both the individual lives of people with a RD as well as on society, health policies, economies, and politics on national and global levels. These include (a) vulnerabilities of people with RDs, (2) the patient transition to adulthood and aging, and (3) the judicialization of health within the field of RDs. The workshop will also critically engage RD initiatives that originate in and are promoted by the Western world, much like Global Health initiatives, which have recently received ample criticism for being driven by biomedical reductionism. We invite contributions from scholars in anthropology, sociology, the medical humanities, bioethics, law, and related disciplines as well as patient organization representatives that address the social, political, and economic consequences of biomedical reductionism in the field of RDs, including the above-mentioned topics.

The workshop will gather an interdisciplinary group of scholars and experts who are involved in research, publication, and advocacy in RDs and Global Health. Confirmed speakers include Waleska Aureliano (Rio de Janeiro State University, Brasil), Giorgio Brocco (University of Vienna, Austria), Nancy J. Burke (UC Merced, USA), Sangeeta Chattoo (University of York, UK), Pauline McCormack (Newcastle University, UK), and Samuel Agyei Wiafe (Rare Disease Ghana Initiative).

The workshop is planned as an in-person event. There is no workshop fee, however, the costs of travel and accommodations cannot be covered by the organizers.

To apply, please send an abstract (300 words max.) and a short bio to Małgorzata Rajtar mrjatar@ifispan.edu.pl and Eva-Maria Knoll eva-maria.knoll@oeaw.ac.at by September 30, 2022.

