



Lessons Learned from Research on Rare Diseases: Ethical and Legal Challenges

Guest Editors:

Dr. Sabina Gainotti

Dr. Giovanna Florida

Dr. Carlo M. Petrini

Prof. Dr. Deborah Mascalonzi

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Message from the Guest Editors

Dear Colleagues,

This Special Issue will focus on two main levels: the data-driven research stimulated by open access in the last few years and the clinical research interwoven with aspects that include diagnosis and early treatments of rare diseases (RDs).

RDs represent a public health problem as they are often debilitating and require expensive therapies and long-term care at considerable financial and social costs for patients, their families and the entire healthcare system.

Most RDs are genetic—they are typically hereditary and are more rarely caused by de novo mutations. Study of them is of particular interest for understanding the role of genes in the functioning of common diseases.

Decisions about the use of data and samples in research and decisions about diagnosis and treatment are rarely made by the patients themselves as RDs usually affect children. Difficult choices are thus made by parents, which do not necessarily reflect the wishes of young RD patients.

The aim of this Special Issue is to collect different insights and ethical views on the ethical, legal and social (ELSI) challenges, opportunities and solutions in the research of RDs.





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Editor-in-Chief

Prof. Dr. Paul B. Tchounwou

RCMI Center for Urban Health
Disparities Research and
Innovation, Richard Dixon
Research Center, Morgan State
University, 1700 E. Cold Spring
Lane, Baltimore, MD 21251, USA

Message from the Editor-in-Chief

Addressing the environmental and public health challenges requires engagement and collaboration among clinicians and public health researchers. Discovery and advances in this research field play a critical role in providing a scientific basis for decision-making toward control and prevention of human diseases, especially the illnesses that are induced from environmental exposure to health hazards. *IJERPH* provides a forum for discussion of discoveries and knowledge in these multidisciplinary fields. Please consider publishing your research in this high quality, peer-reviewed, open access journal.

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MDPI, St. Alban-Anlage 66
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