



PPA Webinar Series

# Rare Diseases: Good Words Make Good Science

Communication, media, ethics

Wednesday, 25 January 2023; 12 Eastern/18 Central

Ethical, legal, and social issues (ELSI) inform many aspects of the scientific workflow, from data collection to data dissemination. Their role in shaping all parts of the osteological research is crucial, ranging from the potentials and limits of destructive analyses on human tissues to the weight of colonial interpretative frameworks on historical narratives and the display of osteoarchaeological specimens in collections or museums.

This symposium is intended as a platform to discuss how traditional as well as next-generation communication tools are shaping paleopathological research, and, particularly, the research on ancient rare diseases.

Because rare diseases are generally perceived as a particularly narrow topic, paleopathology still has large potential for building new research avenues and developing a wider outreach. Yet, ethical aspects of osteological research on ancient rare diseases need to be discussed interactively with concerned parties to shape a research agenda which includes societal issues and potential controversies from the beginning. Apart from others, sensitive topics like sampling and treating skeletons with rare diseases (e.g. overexploiting), storing and archiving them in museums and collections (biobanks, genetic archives), and making research data available will be reviewed. The aim of the symposium is to outline ethical guidelines, by building up a contextual approach to the historic realities of rare diseases, expressed through a multilayered yet integrative language. Such language, aware of the specific ELSI concerning ancient rare diseases, must match the semiotic dynamics required by last-generation communication tools, widening outreach and tearing down stereotypic identities.

## **The importance of language when discussing paleopathological conditions**

Anne Titelbaum

The University of Arizona College of Medicine-Phoenix

## **Rare diseases in identified individuals: opportunities and responsibilities**

Ana Luisa Santos

Department of Life Sciences CIAS - University of Coimbra

## **Ancient DNA and rare disease**

Dan Bradley

Smurfit Institute of Genetics, Trinity College Dublin