

## Research Project

# Bioethics and Rare Diseases: An Empirical Examination in the United Arab Emirates

### **Project funded by own resources**

**Project title** Bioethics and Rare Diseases: An Empirical Examination in the United Arab Emirates

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**Organisation / Research unit**

Ethik / Bio- und Medizinethik (Elger)

**Project Website** <https://ibmb.unibas.ch/research/bioethics-and-rare-diseases/>

**Project start** 01.09.2015

**Probable end** 31.08.2018

**Status** Completed

#### Introduction

In the United Arab Emirates (UAE) there are 60,000 patients who suffer from a rare disease. Conditions with a prevalence of less than 5 in 10,000 are generally classified as rare diseases (report CAGS 2015). Orphan drugs are medicinal products that are developed for the diagnosis, prevention or treatment of rare diseases. They are referred as “orphan” due to the lack of interest on the part of the pharmaceutical industry to “adopt” the research needed to develop drugs for diseases that affect so few people. Patients affected by rare diseases face many problems related to the delay of diagnosis, difficulty in obtaining access to appropriate services and care, inconsistent medications, financial problems, social isolation, reduced educational and professional opportunities and stigmatization. In the UAE the incidence of rare diseases is on the rise due to the high rate of consanguineous marriage and the large size of families.

#### Research aims

The first aim of the research project is to explore the availability and accessibility of orphan drugs in the UAE. Health authorities and policy makers in the Middle East have largely ignored rare diseases. Resources and technology in the area of health care are directed towards common diseases. This has created important market availability issues. Further, as the number of patients with rare diseases grows, insurance companies have become more and more sensitive to costs. This in turn has led to differences in access to orphan drugs: patients with a high income might be able to pay for the drugs through private health insurance, but those with a lower income may have to rely on charity (or even forego treatment). The second aim of the project is to examine the quality of special services provided to patients suffering from rare diseases. Despite the high qualification of physicians in UAE, they lack adequate knowledge of rare disease. This is worrisome given the high incidence rate of rare diseases in UAE.

The study is exploratory in nature and possibly the first of its kind in the UAE.

#### **Financed by**

Other funds

**Add publication**

**Add documents**

**Specify cooperation partners**