**An Anthropology of Rare Diseases: A Study of the Baltic Sea Region.**

Rare diseases make up a large group of diseases (7,000-8,000) that are characterized by a low prevalence in populations (≤5: 10,000 in Europe). However, they affect 6%-8% of the population during their lifetime. It is estimated that the total number of people affected by rare diseases in the EU is between 27 and 36 million. Heightened medical and genetical attention to rare diseases has focused on their "frequency", "prevalence," and "treatment." Rare diseases have also been given special attention by political bodies, such as the Council of the European Union (EU). Emphasizing their "low prevalence" and the high total number of those affected, the Council, however, has focused on mortality prevention as well as the development of new diagnostics and treatments. It also urged member states to prepare and adopt a national plan or strategy for rare diseases by the end of 2013 at the latest. National Plans for Rare Diseases have been implemented in Finland (along with most EU countries), but have not been implemented in Poland and Sweden yet.

Anthropological and social science knowledge concerning ways that those afflicted with rare diseases cope in their daily lives that would allow for going beyond biomedical and healthcare policy approaches is still underdeveloped. Further, medical anthropology scholarship on rare disorders is rather dispersed and seldom ethnographically comparative. Additionally, despite the importance of dietary regimen, diet, and biomedical technologies (i.e. feeding tubes) in many rare diseases, this scholarship has devoted little attention to these issues.

The project focuses on rare metabolic disorders, in particular, fatty acid oxidation disorders (FAODs) and organic acid disorders (OADs) in three countries around the Baltic Sea region: Finland. Poland, and Sweden. FAODs are among the most common inborn errors of metabolism. Like in the case of other rare diseases, there currently are no drugs available that would "cure" patients with rare metabolic disorders. Treatment itself is clinically challenging and it subjects patients (often children) and their family members to a dietary regimen for the rest of their lives. Moreover, this dietary treatment significantly differs from "traditional" nutritional recommendations for "normal" children and often leads to overweight and obesity. Additionally, feeding problems that often occur in children and adolescents with rare metabolic disorders necessitate tube feeding.

By utilizing ethnographic methods (such as participant observation and in-depth and biographical interviews), the proposed project aims at attending to the daily experiences of people living with rare metabolic disorders and their family members, paying special attention to dietary treatment and biomedical technologies as well as practices and actors of care. Moreover, it aims at examining the relationship between disability and rare diseases as well as state and transnational policies regarding rare disorders and orphan drugs with a special focus on the production of scientific knowledge in this domain and its implementation in different countries. By facilitating a constructive dialog about chronic disorders such as rare diseases that afflict a small number of people in their singularity, but millions of patients in total, the project launches an "anthropology of rare diseases" and intends to establish a center for medical anthropologists and other scholars interested in examining rare disorders in Europe, especially around the Baltic Sea Region. This will facilitate a better understanding of rare disorders within anthropology and social sciences.