Maartje Meier

Project title: Incidence and prevalence of fibrous dysplasia/McCune-Albright syndrome – a nationwide registry-based study in Denmark

Duration	2.5 months
Short Bio	I am a medical doctor, working at the Center for Bone Quality of the LUMC, a collaboration of the Department of Orthopedic Surgery and the Department of Endocrinology (among others). Here I did a PhD trajectory with several studies on fibrous dysplasia and the McCune-Albright syndrome. After my PhD, I started to specialize for orthopedic surgery.
Home Institution	Leiden University Medical Center, the Netherlands
Host institution	Aarhus University, Denmark
Project description	My project was conducted with researchers from the Department of Endocrinology of Aarhus University Hospital, Department of Endocrinology of Leiden University Medical Center, and Department of Clinical Epidemiology of Aarhus University. We studied the epidemiology of fibrous dysplasia/McCune-Albright syndrome, a rare and debilitating bone disease, of which incidence and prevalence were previously unknown. By using the Danish national health care registry, we calculated incidence and prevalence stratified for sex, age interval, calendar interval and diagnosis type. The epidemiology of FD/MAS is expected to be similar across counties, since the disease is genetic, and occurs randomly. Furthermore, the Danish health care system is similar to the Dutch system, and demographics of both populations are similar as well. For these reasons, we can safely assume that incidence and prevalence in Denmark will also apply to the home country, the Netherlands, and to many other counties. This knowledge may be useful for estimating the distribution and burden of FD/MAS in a population, for health care planning, counselling of patients, and research.

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Personal statement	I have gained knowledge on how a nation-wide registry is designed, used, and implemented in research. Such large registries do not (yet) exist in the Netherlands, so this experience was valuable and interesting to learn. I have also gained knowledge on how to calculate and interpret incidence and prevalence. I have learned to address limitations of registry studies and reasons for increasing/decreasing epidemiology measures. Besides scientific knowledge, I have learned to adapt to another culture, and learned about differences between health care systems and cultures in general, not only by getting in touch with Danish residents, but also with researched from abroad who were also residing in Denmark for research.

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