

## **ERN GUARD-Heart Exchange Programme: A Week of Learning, Collaboration and Inspiration at Copenhagen University Hospital**

As part of the ERN GUARD-Heart Exchange Programme, I had the opportunity to spend one week at the *Inherited Cardiac Condition Clinic* at Copenhagen University Hospital, Rigshospitalet. The visit provided fascinating insights into clinical practice, research and multidisciplinary care, complemented by open discussions and a highly engaging exchange with colleagues from across the department.

The programme focused on the organisation and workflow of a high-volume inherited cardiac disease centre, including referral pathways, multidisciplinary decision-making, genetic counselling and family cascade screening. It also allowed comparison of different approaches to patient care, prevention strategies and research infrastructure between Denmark and Germany, while further strengthening collaboration within the European Reference Network.

From the very first day, I was introduced to the structure of the department, the Danish healthcare system and the nationwide registries that underpin both clinical care and research. It became clear how closely clinical practice and data-driven research are integrated, and how the registry infrastructure supports both patient management and scientific work. Learning about the ATS Registry Project was a particular highlight in terms of understanding the scale and complexity of registry-based research, including the methodological and organisational challenges involved in its development. In addition, an exchange with a forensic researcher provided fascinating insights into how genetic analyses and DNA methylation patterns are increasingly used not only in clinical genetics but also in forensic applications and phenotype prediction.

Over the following days, I gained insight into patient care across a range of clinical settings. During ward rounds on the cardiac arrest unit, I followed the management of patients with diverse inherited and acquired cardiac conditions. What stood out most was the time devoted to each patient and their family. Clinical findings, imaging results and treatment options were discussed thoroughly, with complex medical information explained in a remarkably clear and compassionate way. Equally notable was the close interdisciplinary collaboration between physicians and specialised nursing staff, with shared responsibility in clinical decision-making and patient follow-up.

Accompanying the inherited cardiac disease outpatient clinic offered an excellent overview of the clinical pathway for patients and their families. I attended both face-to-face and telephone consultations, family screening appointments and genetic counselling sessions. It was fascinating to observe how complex topics such as variants of uncertain significance, pathogenic variants and their clinical implications were communicated in a way that patients and relatives could easily understand. Challenging cases were frequently discussed within the multidisciplinary team before decisions were made, highlighting the importance of shared expertise in the management of inherited cardiac diseases. Where appropriate, patients were also introduced to ongoing research projects and invited to contribute through additional blood sampling. Another aspect that caught my attention was the seamless real-time documentation system, allowing patients immediate access to consultation notes through a dedicated digital platform.

After expressing my interest in cardiovascular pathology, I was able to spend a day at the Department of Pathology and Forensic Medicine, although this had not originally been part of the planned programme. I greatly appreciated that my hosts arranged this at short notice. Following the morning case conference, I observed an autopsy with a focus on findings relevant

to inherited cardiac diseases, accompanied by detailed explanations throughout the examination. As my last experience with autopsy teaching had been during medical school, it was particularly valuable to revisit this field in such a structured and well-guided setting.

My final day was spent in the pacemaker and ICD clinic, where I observed another example of highly efficient multidisciplinary collaboration. Routine device interrogations were performed by specialised technicians, while physicians joined consultations whenever more complex findings required clinical interpretation or therapeutic decisions. Despite the high level of efficiency, patient interactions remained unhurried, personalised and clearly focused on individual needs.

Beyond the well-structured programme, many of the most meaningful impressions came from informal discussions with clinicians, researchers, PhD students and nursing staff. Colleagues were exceptionally welcoming and generous with their time, openly sharing their clinical and academic work while also expressing a genuine interest in our practice in Germany. These exchanges fostered a strong sense of mutual learning and contributed significantly to the overall experience.

The exchange provided valuable insights into multidisciplinary care, genetic counselling, family cascade screening, prevention strategies and the interpretation of complex genetic findings. It also offered perspectives on national differences in legislation, ethics and data sharing in genetic cardiology. Importantly, it generated several ideas that may be useful for the further development of patient pathways and genetic testing processes at our own institution, and laid the groundwork for future collaborative research within the ERN network.

Finally, I would like to express my sincere thanks to my host Jacob for his outstanding organisation, flexibility and support throughout the week. My particular gratitude also goes to Bo for his time, guidance and key contributions throughout the clinical programme, and to Priya for her dedicated support, explanations and invaluable input across different parts of the visit. I am equally grateful to Stine, Tobias, Isabelle and all other colleagues who contributed to this exchange in many different ways. Whether through formal teaching, clinical discussions or informal conversations, every interaction was characterised by openness, enthusiasm and a genuine commitment to sharing knowledge.

Finally, I would like to thank the ERN GUARD-Heart Exchange Programme for making this visit possible. It is an outstanding initiative that connects colleagues across Europe, fosters lasting collaboration and ultimately contributes to improving the care of patients with inherited cardiac diseases. I would strongly encourage participation in this programme to anyone working in the field.