

PRESS

# RELEASE



## RARE DISEASES: RAISING AWARENESS OF A DOUBLE BURDEN

**Brussels, 28 February 2025** – In Belgium, one in twenty people is affected by a rare disease. But beyond the often complex diagnosis, these patients face a "double burden": the disease itself and the numerous systemic obstacles to accessing care. On the occasion of Rare Disease Day, an open letter signed by Franck Devaux, Ethicist and President of the Ethics Committee at HUDERF, Coordinator of the Rare Diseases Function at H.U.B, and Professor Béatrice Gulbis, Director of the Rare Diseases Function at H.U.B and Co-Coordinator of EuroBloodNet, the European Reference Network for rare hematological diseases, calls for collective awareness and concrete actions to ensure fairer and more inclusive care.

### THE LONG DIAGNOSTIC JOURNEY

The care pathway for patients with rare diseases is often long and fraught with challenges. On average, it takes five years to receive an accurate diagnosis. This wait is exacerbated by several discriminatory factors:

- **Age:** Rare diseases mostly appear in childhood, yet pediatrics remains underfunded and undervalued. The transition to adult healthcare is also a critical phase, often marked by a loss of reference points for young patients.
- **Gender:** Women, in particular, still too often face the minimization of their symptoms, which are dismissed as psychosomatic or hormonal issues. This disparity stems from a medical system historically centered on a male norm.
- **Ethnic and social background:** Patients from disadvantaged backgrounds or minority cultures encounter numerous barriers to accessing healthcare. Technical language, complex administrative procedures, and language barriers all contribute to their sense of exclusion.

Here are some key actions to address this double burden, based on the issues outlined in the open letter:

- Recognizing and supporting multidisciplinary reference centers;
- Improving medical transition when patients move to adult healthcare;
- Enhancing healthcare providers' training to better understand the specificities of rare diseases;
- Providing financial aid and stronger support for research.

### A NECESSARY MOBILIZATION

The story of Layla, a 17-year-old with sickle cell disease, illustrates these challenges. She has experienced a long diagnostic journey and difficulties with the transition to adult healthcare, the invisibility of her pain, and administrative hurdles. Yet behind every diagnosis, there are families, hopes, and struggles. Patients with rare diseases deserve quality care, "without any distinction of any kind" (Belgian Patient Rights Law). Rare, perhaps, but together, we are many and can build a fairer and more inclusive healthcare system.

**Franck Devaux, Ethicist and President of the Ethics Committee at HUDERF, Coordinator of the Rare Diseases Function at H.U.B:** *"The first step in care is creating a space for dialogue where patients' voices are heard."*

**Prof. Béatrice Gulbis, Director of the Rare Diseases Function at H.U.B and Co-Coordinator of EuroBloodNet:** *"Improving equality in access to highly specialized healthcare is a real challenge, but everyone can play a role in making it happen."*

### PRESS CONTACTS

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## ABOUT THE BRUSSELS UNIVERSITY HOSPITAL (H.U.B)

**The H.U.B.**, the academic hospital of ULB, has brought together the Jules Bordet Institute, Erasme Hospital, and the Queen Fabiola Children's University Hospital (HUDERF) since 2021. Located in the heart of Brussels, it provides specialized, oncological, and pediatric care of excellence, combining research and education to train the caregivers of tomorrow. With over 6,000 staff members, the Brussels University Hospital embodies values of solidarity, commitment, inclusivity, innovation, and free inquiry. [www.hubruxelles.be](http://www.hubruxelles.be)

**The Jules Bordet Institute** is the only integrated cancer center in Belgium. Recognized by the OECI, it has been fulfilling a threefold mission for 80 years: patient care, research, and oncology education. Since 2021, the institute has been housed in a state-of-the-art 80,000 m<sup>2</sup> building in Anderlecht, with 250 beds and 43 day hospital places. [www.bordet.be](http://www.bordet.be)

**Erasme Hospital**, on the other hand, is a general hospital with 1,048 beds, admitting up to 30,000 inpatients and handling 400,000 outpatient consultations annually. Its team of 4,000 professionals provides cutting-edge care, complemented by the Lothier Polyclinic and two specialized centers (CTR and CRG). [www.erasme.be](http://www.erasme.be)

Both hospitals are located on the Erasme hospital-university campus, which also includes the Faculty of Medicine, the Faculty of Motor Sciences, and the School of Public Health, with a total of over 6,200 students.

**The Queen Fabiola Children's University Hospital (HUDERF)** is the only hospital in Belgium dedicated exclusively to children and adolescents. Committed to the well-being of its young patients, it empowers them to take an active role in their own development and thrive in society. Located in Laeken, HUDERF has 183 beds, 135,000 consultations, and over 36,000 emergency admissions per year. Its mission is to provide comprehensive and innovative care, combining excellence in treatment, research, and health education. [www.hud erf.be](http://www.hud erf.be)