

PRESS

# RELEASE

H.U.B



## RARE DISEASE WEEK : LET'S HOIST OUR COLOURS TOGETHER!

Brussel, 27 February 2023 - **More than 300 million people worldwide suffer from a rare disease. Then there are all the families and friends who are also affected by the illness. United in supporting them across the globe are the hospitals, professionals, nurses and volunteers. The Brussels University Hospital (H.U.B.), consisting of the Erasmus Hospital, the Queen Fabiola Children's University Hospital and the Jules Bordet Institute, is committed to arriving at a better understanding of these diseases, to effectively combating them and to improving the quality of life of patients. To support them and the RadiOrg campaign symbolised by colours during this world week to boost awareness of rare diseases, the H.U.B. is also hoisting its colours!**



### *Rare diseases that are not as rare as that...*

It is estimated that between 6% and 8% of the population, that is between 660,000 and 880,000 people, suffer from a rare disease in Belgium. They are known as "rare" because each of these diseases affects fewer than 1 in 2,000 people, that is between 1 and a maximum of 6,000 people<sup>1</sup> in Belgium. There are estimated to be more than 6,000 rare diseases. This means that the expertise is pleomorphic and access to affordable, qualified and adapted treatment difficult. It takes an average of 4.9 years to obtain a correct diagnosis for a rare disease. It is in childhood that 70% of these diseases first appear and 72% are of genetic origin. At present fewer than 6% of patients receive effective treatment. Rare cancers alone account for more than 20% of all cancers diagnosed in Belgium every year. With RadiOrg (*Rare Diseases Organisation Belgium*) and the support of its hospital network, the Brussels University Hospital is participating in the "Share your colours" campaign as a means of echoing the voices of all persons living with a rare disease and their demands, expectations, needs and hopes. A call and a responsibility that are proudly embraced by the Brussels University Hospital and the three institutions of which it is composed that concentrate comprehensive and highly specialised care in diagnosing and accompanying patients with rare diseases. **We are all rare, together!**

### *Networking to boost expertise*

Treating rare diseases, including rare cancers, is a particular strength of the Brussels University Hospital and its hospital network. On one hand, bringing together the expertise of the three institutions of renown that constitute the H.U.B. means we can count on almost 100 clinical and scientific specialities and close to 5,000 care staff. On the other hand, national collaborations strengthen this expertise. The ULB hospital network includes almost 20 institutions in Belgium that mobilise to support our patients and their family and loved ones.

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Treating a rare disease does not only take place within a single institution but in cooperation with national institutions or even institutions worldwide. The Brussels University Hospital is a part of this dynamic in offering each patient the very best quality care and the very best chances of recovery.

## *Committed to providing the best possible care*

At the H.U.B we therefore strive every day to develop recognised expertise, optimal access to treatment and innovative medicines, better cooperation between care staff, and adapted and coordinated care and support. Every day we work on highlighting the demands formulated in the various rare disease plans and promote clinical excellence, research and teaching. Finally, we are present on a day-to-day basis alongside our patients, their families and associations to ensure that the right of access to quality and accessible care is recognised:

- In all the dimensions of global care;
- From the bedside to policy-making;
- At national and international level;
- In the teaching and continuous training of our teams;
- In research and the dissemination of new treatments;
- In developing, sharing and implementing new directives and care resources;
- In personalised care pathways that are continuously adapted to the needs of our patients, their families and their respective developments;
- In patient partnerships that are rich in meaning and opportunities to provide an ever better response to the multiple and individual realities of illness.

To conclude: rarity is more than statistics alone. When it comes to our patients suffering from a rare disease and their families and loved ones, 100% are concerned by the disease. It is therefore also 100% of their carers who are at their side in sharing and hoisting their colours!

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## **ABOUT THE ERASMUS HOSPITAL**

The Erasmus Hospital is located on the Erasmus hospital-faculty campus, which includes the Faculty of Medicine (about 3500 students), the Faculty of Motor Sciences (about 1100 students) and the School of Public Health (about 600 students). Opened in 1977 and with a capacity of 1,048 beds, the hospital receives 25,000 to 30,000 inpatients annually and has 350,000 to 400,000 consultations.

More than 4,000 members of staff, in 80 different professions, contribute on a daily basis to providing care under the sign of ambition, excellence and well-being. The Lothier Polyclinic and 2 external centres (the Traumatology and Rehabilitation Centre - CTR and the Geriatric Revalidation Centre - CRG) complete the care offer.

[www.erasme.ulb.ac.be](http://www.erasme.ulb.ac.be)

## **ABOUT THE JULES BORDET INSTITUTE**

An integrated multidisciplinary centre, the only one of its kind in Belgium, the Jules Bordet Institute is an autonomous hospital dedicated exclusively to cancerous diseases.

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During the past 80 years the Jules Bordet Institute has been offering its patients diagnostic and treatment strategies at the leading edge of progress to prevent, detect and actively fight cancer. The Institute pursues three missions: care, research and teaching. The Institute's international reputation attracts leading experts in the field of cancer. Its spirit of innovation has enabled it to participate in the development and discovery of new methods of diagnosis and major treatment innovations, with the aim of translating the results into improved patient care as rapidly as possible.

In May 2028, the Jules Border Institute was officially awarded, for the second time, OECl (Organisation of European Cancer Institutes) accreditation as a "Comprehensive Cancer Center", a quality label reserved for multidisciplinary cancer care institutions that combine research and training. The Jules Bordet Institute is the only Comprehensive Cancer Centre with OECl accreditation in Belgium.

On 28 November 2021, the Jules Bordet Institute opened its new building on the ULB university campus in Anderlecht with 80,000 m<sup>2</sup> fully dedicated to leading edge cancer care, research and training, as well as a patient well-being centre. It offers 250 hospitalisation beds and 43 day hospitalisation beds.

The Jules Bordet Institute is also part of the H.U.B., the University Hospital of Brussels, which includes the Erasmus Hospital, the Jules Bordet Institute and the Queen Fabiola Children's Hospital. Thanks to new investments, this internationally renowned university hospital group is able to guarantee high quality care accessible to all combined with excellence in research and training.

[www.bordet.be](http://www.bordet.be)

## ABOUT THE CHILDREN'S HOSPITAL

The Queen Fabiola University Children's Hospital is the only Belgian hospital exclusively dedicated to children and adolescents. By doing everything possible for the well-being of children, our hospital contributes to their being actors of their own development and to their blossoming in society.

The hospital's mission is to

- To care for and support children, adolescents and their families through comprehensive, multidisciplinary, humanistic and excellent care.
- To provide high-level teaching and research through a continuous process of innovation and development of knowledge.
- To contribute actively to health education.

The Children's Hospital in figures: 183 beds, nearly 135,000 consultations, more than 36,000 emergency admissions and more than 41,000 days of hospitalisation per year. More than 3,700 operations are performed in the operating area each year. More than 1,000 people work there today, representing 750 FTEs (full-time equivalents), including 170 FTE doctors (52.5 post-graduate FTEs) and 440 FTE nurses and paramedics.

[www.hudorf.be](http://www.hudorf.be)

## ABOUT THE H.U.B

The Hôpital Universitaire de Bruxelles (H.U.B) is the academic hospital of the Université Libre de Bruxelles (ULB), which unites the Jules Bordet institute, the Erasme Hospital and the Queen Fabiola Children's University Hospital (HUDERF) since 2021. As an international reference center, located in the heart of the Brussels Region, the H.U.B offers high quality general, oncological and pediatric care. This excellent care, accessible to all, is enriched and sustained by a dual approach of scientific research and teaching for the caregivers of tomorrow.

In 2022, the H.U.B. is composed of more than 6,000 employees who share the following values: Interest of the patient, Respect, Commitment, Solidarity, Diversity and Inclusion, and the principle of Free enquiry.

[www.hubruelles.be](http://www.hubruelles.be)