

PRESS

RELEASE

H.U.B



SICKLE CELL DISEASE: THE H.U.B IS CAMPAIGNING FOR RARE BLOOD DONATIONS AND AGAINST RECEIVED IDEAS

Brussels, 15 June 2023 – On the occasion of World Sickle Cell Day on 19 June, the Erasmus Hospital and the HUDERF, national and European reference centres for sickle cell disease within the Brussels University Hospital (H.U.B), are focusing on the disease. Among care staff as well as the general public, received ideas regarding this disease, its symptoms and its complications fuel a series of prejudices resulting in social exclusion as well as difficulty in stimulating the blood donations needed to transfuse these patients. In Belgium almost 90% of sickle cell disease patients require regular blood transfusions.

Sickle cell disease: combating received ideas to encourage access to specialised care

Sickle cell disease is a genetic disease of the blood that affects 1 child for every 2,329 births. Particularly frequent among populations of Caribbean, African and Mediterranean origin, it is the commonest genetic disease in Belgium. It is characterised by a deformation of the red blood cells that results in severe anaemia, a local obstruction in the blood circulation and a reduction in the oxygen supply to several vital organs. A child with sickle cell disease has episodes of extreme pain, periods of acute anaemia and is much more prone to serious infections. Complications of this rare multisystemic disease can affect the brain, heart, lungs, kidneys, bones and eyes. These become established over time, increase in frequency in adulthood and have a major impact on comorbidities and mortality. Since January 2023 sickle cell disease has been one of the diseases detected by the Guthrie test in the Wallonia-Brussels Region, this making it possible to identify and treat patients at an early stage of the disease within a reference centre. Hydroxyurea, chronic transfusion and bone marrow transplants are at present the only treatments available in Belgium that modify the symptoms of the disease to reduce complications and improve the quality of life of patients. The sole curative option is to transplant stem cells (bone marrow) but its applications are limited.

Two reference centres and expert professions within the H.U.B to support the sickle cell patient.

This rare and complex disease requires treatment at specialised centres such as the HUDERF and Erasmus Hospital, both recognised as reference centres for rare diseases of the red blood cell at national and European level since 2017. More than a third of patients on the sickle cell disease register in Belgium are being followed up by the H.U.B for the treatment by multidisciplinary teams of the various aspects of this disease. Our haematologists are central to the clinical biological follow-up, treatment and prevention of complications. The referring nurses, essential links in ensuring awareness and an effective response to a patient's needs, coordinate the care and the professionals who provide it. Our biologists play a major role in screening and boosting awareness of the risk of transmission to children. Finally, our psychologists, dietitians and social workers pay special attention to pain management, emotional support, well-being and diet. For children and adolescents, supporting the child in his or her psychological, social, school and family reality is a central element of care in encouraging the development of autonomy despite the illness as well as adherence to treatment and knowledge of the disease. It is essential to help the child to acquire the awareness and know-how to continue to look after themselves throughout their life, with the solid support of medical teams in an adult environment.

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Rare blood donation and the search for new drugs are the top priorities

Most sickle cell patients will need a blood transfusion at some point. Some of them will need regular transfusions throughout their life. Hence the supply problems. The transfused blood must match as closely as possible that of the sickle cell patients who have blood groups that can be rare in Belgium. At present we regularly face shortages and that is particularly true for the blood groups found predominantly among non-Caucasian populations. Treating sickle cell patients is a daily battle and it is essential to continue research into developing new treatments. A number of clinical trials involving medicines are proposed for both adults and children and especially in the field of cell therapy, with gene therapy a promising avenue for curing rare diseases of the red blood cell.

Make a blood donation

To assist sickle cell patients, a campaign for rare blood donations focusing on sickle cell disease is being launched by our teams within the hospital and on social networks. To give blood, please go to the [Erasmus Hospital Blood Donation Centre](#) or donate via any [Red Cross](#) blood donation centre in Belgium.

Save the date! Festival Drépanocyt'OSE from 17 to 19 June at Tour & Taxis

During the weekend of 17 June 2023, associations active in the field of combating sickle cell disease are organising a festival to increase public awareness of the disease. Experts from the Erasmus Hospital and the Children's Hospital will also be there to represent professionals from the H.U.B.

- Saturday 18 June from 1 pm to 5 pm at our stand at Tour et Taxis
- Monday 19 June, World Sickle Cell Day, during the conference at Tour & Taxis
- For more information: <https://www.festival-drepanocytose.com> launched

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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

ABOUT THE QUEEN FABIOLA UNIVERSITY CHILDREN'S HOSPITAL (HUDERF)

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 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

ABOUT THE H.U.B

The Brussels University Hospital (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