

Media Information

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Ulrika Jonsson backs launch of heart defect website

Celebrity Big Brother winner, Ulrika Jonsson, who has a child with a heart defect, is backing Corience, a European web platform that provides information about congenital heart disease, being launched in the UK today at the Science Museum in London by the Children's Heart Federation.

Ulrika says, "Having a child with a heart defect puts everything else into perspective. As a parent, you are desperate for information that will help them get the best treatment and care, when they are born and as they grow. You look for ways of helping their brothers and sisters too. This is why I welcome the launch of Corience. It has information available in a clearly understandable way. I naturally know of the strengths of the British and Swedish health systems. To be able to see what works well right across Europe is a great benefit because sharing knowledge will help improve things for heart children in every country."

Corience is an independent European network dedicated to congenital heart defects (CoHD) sponsored by the European Union. Its aim is to provide accessible and authoritative information to patients, parents, doctors and scientists on good practice in the diagnosis, treatment and support of people with CoHD. The UK version of the website launched today will be followed in the autumn by versions in Spanish and German and later in Polish.

The Keynote speaker at the Launch, John Bowis OBE, Conservative Member of the European Parliament for London and the Conservative spokesman on the Environment, Health and Food Safety in the European Parliament highlights Corience's role in enabling the five million people in Europe with CoHD to make informed decisions about their own health and to press for excellence of treatment and care. He quotes Louis Pasteur, saying, "Science recognises no borders because knowledge belongs to humanity and is the torch which illuminates the world."

Dr David Low, National Clinical Lead for NHS Connecting for Health (Paediatric and Child Health) observes, "At the moment, the Corience website is targeted at adults – the right place to start in its early stages. And I'm impressed with the way it presents information accessibly, so that parents, who bear the task of reassurance and explanation about CoHD for the 99% of the time a healthcare professional is not around, can absorb factual information and then 'translate it' to a form and deliver it at a pace uniquely suited to their child's age and stage. The next stage, which I look forward to, will be to develop part of the Corience website with a child-friendly design and contents."

Anne Keatley-Clarke, the Chief Executive of Children's Heart Federation, comments, "If you have CoHD in the UK, you are likely to get very good medical treatment and follow-up. Being part of Corience has highlighted is the work that remains in this

country to ensure our psycho-social care is on a par with the best in Europe. Family support and emotional care is under-developed in the UK compared with other countries in Europe. Corience gives us an insight into what works well elsewhere and is also a powerful signposting tool, referring heart-families to their local support organisations for advice, information and practical help.”

Visit Corience at www.corience.org and Children’s Heart Federation at www.childrens-heart-fed.org.uk.

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Notes for editors:

Congenital heart conditions are the most common birth defect in the UK, and a leading cause of birth-defect related deaths world-wide. One in every 133 babies in the UK is born with a heart condition (approximately 5000 children each year, with a further 1000 developing a serious heart problem after birth).

The Children’s Heart Federation is an umbrella organisation with 22 member organisations dedicated to helping children with congenital or acquired heart disease and their families in the UK and Ireland.

CHF provides information and support through its freephone helpline open Monday to Friday on 0808 808 5000 and its website www.chfed.org.uk

Ulrika Jonsson’s daughter, Bo, now eight, was born with a major heart defect.

Speakers at the Corience Launch also include:

- Jenny-Lee Spencer, Senior European Manager, NHS European Office.
- Dr Ulrike Bauer, German National Registry for Congenital Heart Defects
- Thomas Pickardt, German National Registry for Congenital Heart Defects
- Harry Spurling aged 13 who has CoHD and his father, Julian
- Julie Wootton, Chairperson, Children’s Heart Federation

CHF can provide detailed notes of the content of each talk and provide photographs from the event.