

Corience is an independent European network on congenital heart defects for patients, parents, doctors, and scientists.

Visit our website. Enjoy it!
www.corience.org

Editor's Note



Dear patients, parents, colleagues and friends,

With the words 'We have lift off,' Corience was officially launched in the UK and Ireland by the Children's Heart Federation, a Corience partner, on January 30, 2009. Attending the launch at the London Science Museum were parents and patient representatives, as well as doctors and politicians from the UK and Ireland. Many more launch events are currently being held in Sweden, Norway, Lithuania and Italy, and news of the creation of Corience is spreading throughout the whole of Europe.

For a long time now, doctors, scientists, parents and self-help associations have been calling attention to a lack of reliable information about congenital heart defects (CoHD). It was for this reason that five European parent umbrella organisations for CoHD joined forces with the German National Registry for Congenital Heart Defects to create Corience, a real European website. Our goal is to build a network of experience and expertise and to provide information for people from all over Europe who work towards easing the suffering of those living with a heart defect. To this end, we provide countless articles that address both medical topics and everyday issues related to living with a heart defect, which would otherwise receive too little attention. We know from the reports and personal experience of our editors just how much knowledge can contribute to dealing adequately with the illness, or even saving lives.

Most of the articles provide space for your comments. Please share your opinions with us and tell us about your own personal experiences. You will be helping us to help others not lose hope. I hope that the news of our new website will spread quickly throughout the whole of Europe. Let's join forces in spreading the Corience news.

Yours,
 Wiebke Lesch
 Editor in chief, Corience

Events

"We have lift off!"

Corience, the European congenital heart defect (CoHD) web platform is now officially live in the UK where it was launched by the Children's Heart Federation on Friday 30 January 2009 at the Science Museum in London. The 65 delegates represented all of the web platform's key target audiences: people with CoHD, their families, members of patient support groups, nurses, CoHD clinicians and healthcare policy makers.

Keynote speaker, John Bowis OBE, who is Conservative Member of the European Parliament (MEP) for London and the Conservative spokesman on Health in the European Parliament, reminded us that behind the statistics - five million people in Europe living with CoHD

- there are individuals coping with extensive medical treatment, loss and stresses. Mr Bowis declared, "When a child is born with a heart defect, your life will change, but it need not be devastated. Parents and sisters and brothers and grandparents will have to adapt, and they need to know how; they need to see the options. To have a web network available means that, at the touch of a button, you are able to share and explore experience and expertise across your own country and reach out to people across our continent. It means contact between patient or parent and professionals and scientists. Finding and sharing best practice is at the heart of European Health policy, and it will be the gift of Corience." cy



Julian Spurling (Harry's father), Anne Keatley-Clarke (Children's Heart Federation (CHF)), Dr Thomas Pickardt (Competence Network CoHD), Jenny-Lee Spencer (NHS), Harry Spurling (patient), Dr Ulrike Bauer (Competence Network CoHD), Julie Wootton (CHF), John Bowis OBE (European Parliament), Dr David Low (NHS)

Corience Heartbeat

More European languages

The Corience website is currently available in English only, however more European languages will be available over the coming years. Spanish, German and Polish versions of the website will be launched in summer and late autumn 2009. We hope to be able to launch many more European languages in the future. ks

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Corience Heartbeat

Corience ambassador in Cyprus

One of Corience's most important aims is to foster networks between European patient and parent organisations for children and young people with congenital heart disease. In January 2009 Marte A. Jystad, Corience networker from Norwegian organisation FFHB, visited Pediheart in Cyprus. Pediheart is the Cypriot parent organisation for congenital heart disease. The reason for the visit was, among other things, to launch a Norwegian-Cypriot fund for voluntary organisations and to introduce Corience to the Cypriot public. The launch was attended by more than 200 people. Pediheart, which has 1,000 member families, is now in the process of preparing an application for funding from the fund. It is difficult to imagine that this could have been possible without Corience. Pediheart has just two employees, Stella and Christina, who undertake varied work for both children and young people affected by congenital heart disease.

Pediheart is an active organisation, and sees great possibilities in working with Corience, not least of which is the chance to create a cross-European network. After all, children and young people with heart defects have the same needs whether they live in Cyprus or Norway, and through Corience their needs can be better met. *mj*



Dr Antonis P. Jossif (Pediatric cardiologist), Stella Eletheriadou (Director of Pediheart) and Marte Jystad (FFHB and Corience)

Corience Heartbeat

First Lithuanian organisation for congenital heart diseases founded

The first organisation for children with congenital heart diseases was founded in Lithuania on November 22, 2008. The organisation owes its existence to Daiva Jonauskiene, mother of a two-year-old girl with a congenital heart defect.

After participating in the ECHDO and Corience joint workshop in Berlin in November Daiva felt inspired and encouraged to take the first step towards establishing an independent organisation in Lithuania. She began inviting parents to join and form such an organisation on her return journey from Berlin, and it took her only two weeks until her idea became reality: the organisation "Padek vaiko sirdelei" ("help children's hearts") currently has 21 members; Daiva was elected first chairwoman. Among the most important tasks of the new project is the establishment of a website that communicates the organisation's goals and progress.

"Padek vaiko sirdelei" wants to cooperate with other organisations in Europe. As a first step towards that goal, they have joined ECHDO.

"It is a big advantage for a new organisation such as ours to be a part of a bigger community in Europe," says Davia. "There's a lot we need to learn, and a lot we can share with others." *mj*



Daiva Jonauskiene (President of "Padek vaiko sirdelei")

Events

Launch in Lithuania

Corience was recently launched in Lithuania. Daiva Jonauskiene, who is the president of the Lithuanian Paediatric Heart Association, invited parents and healthcare personnel to the launch meeting at the University Hospital in Vilnius. Marte A. Jystad and Peter Nordqvist presented the concept behind Corience, and provided the audience with a thorough review of the various topics that are available at www.corience.org. The response was extremely positive.

"There is a tremendous need for information about congenital heart defects in Lithuania," says Daiva. "We have produced our own information to a limited extent, and the fact that we are now able to have access to Corience is enormous important to us," she says. Paediatric heart surgeon Virgilijus Tarutis said that he was glad that a separate such organisation had now been established in Lithuania. He was impressed with the Corience Project, and is especially happy to see that all the articles presented via Corience have been quality-assured.

Network-building in Europe in general and in Eastern Europe in particular is an important part of the work that Corience does. The patient organisations in these countries are often weak and modest in scope compared with those in, for instance, the Scandinavian countries, which have long been aware of the importance of strong patient organisations. *mj*

More Events

15.05.2009 – 17.05.2009

GUCH national conference: How to deal with conflicts – family, work, social
 Arbanasi, Bulgaria

21.06.2009 – 26.06.2009

5th World Congress of Pediatric Cardiology and Cardiac Surgery
 Cairns, Australia

19.06.2009 – 20.06.2009

ECHDO/Corience Meeting
 Barcelona, Spain

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Living with a heart defect

Jessica and Mikael wanted children

Jessica's heart defect led cardiologists to advise her to not get pregnant; instead she chose to adopt. She has a severe heart defect and at the age of 10 she got her first pacemaker. She had always wanted a child, so for Jessica the decision to adopt was obvious. However, it wasn't so obvious to the adoption bureau. Jessica and her partner Mikael were assigned a case manager who had concerns about whether Jessica's congenital heart defect would affect her ability to be a suitable mother.

The case manager began to do some research, investigating whether people with heart defects could conceivably become adoptive parents. A year later they were assigned a new, more positive case manager and things started to move ahead. Today Jessica and Mikael have two adopted girls. One of the most important things for Jessica to achieve before becoming a mother was to get a clean bill of health. Read the whole story on www.corience.org. *uh*



Living with a heart defect

Checklist for choosing a career

Having a congenital heart defect can raise a lot of questions about education and possible career opportunities. What are the important factors to consider? Avoid heavy physical jobs and work that is highly stressful. Discuss your plan with your cardiologist! Proper medical and career counselling is very important if you want to succeed at work.

Your cardiologist knows a great deal about the careers you should avoid. Learning as much as you can about your own heart defect will also improve your quality of life and prognosis, including in your working life. At the Corience webpage there is a comprehensive section on education and employment. This is information that is hard to get elsewhere. *mh*

Things you should know about pregnancy and contraception

Heart defects and pregnancy, few things awake more thoughts. Smaller heart defects seldom causes trouble, whereas if you have a severe defect, the cardiologist might tell you that getting pregnant is unwise. There are also different aspects on contraceptives that you have to bear in mind if you have a heart disease. Read the full article on www.corience.org. *uh*



Living with a heart defect

Help! My child won't eat!



It's not unusual for children born with a heart defect to refuse to eat, whether because they are too tired or are suffering the effects of tube feeding. Speech therapists like Ingalill Ek are there to give help and support.

"When a child is born with a life threatening disorder, the focus naturally should be on the medical and surgical treatments," she says. It is important to remember that not all children with congenital heart disease have the same feeding problems. "One child might be hypersensitive, while for another eating has become an emotional problem."

Ingalill's tips for addressing the issue include exploring the texture and taste of different foods together with the child. "As a parent you aim to solve the eating problems right away, but you have to let it take time. You will get there." Read the full interview on www.corience.org *uh*

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Living with a heart defect

Siblings: The forgotten members of the family

The brothers and sisters of a child or adolescent with a congenital heart disease are often the forgotten members of the family. Recognising the difficulties that siblings face when the family goes through the changes caused by a child's heart defect is an important step towards helping the siblings adapt to the situation and respond in a positive way.

What can parents do to minimise negative reactions in siblings, such as changes in behaviour? Children need information, communication and contact. Involving siblings helps them to accept the situation and visits help to dissipate fears. Read the full article on www.corience.org. *mm*



Research News

New GUCH guidelines

A task force drawn from the American College of Cardiology (ACC) and the American Heart Association (AHA) recently published "Guidelines for the Management of Adults with Congenital Heart Disease". The guidelines are intended to improve patient care and include:

- descriptions of approaches to the diagnosis, management and prevention of specific diseases or conditions
- recommendations for personnel and services for regional GUCH centres
- recommendations for transition of care and definitions of surgical procedures. *wl*

What's new on Corience

Please share your opinions with us

Do you want to tell us about your experiences? We invite you to leave comments on our articles. With your help we want to initiate debate in

order to improve the treatment of congenital heart defects Europe-wide. Please go to www.corience.org and discuss with us.

About Corience

Find local support throughout Europe

Are you looking for advice or a contact close to you? Corience provides a list of patient and parent organisations from across Europe.

The list contains detailed information about the organisations' goals as well as their contact details. If you are a member of an organisation that is not yet listed, please send us your contact details. To find local support in your country visit www.corience.org *ks*

Subscribe to our newsletter

Would you like to stay updated on upcoming topics and the latest research news on congenital heart defects? Just subscribe to our free e-mail newsletter on www.corience.org!

My comment: *

First name * (will be published)

Last name * (will be published)

Country * (will be published)

E-Mail * (needed, not to be published)

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