

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,

It was at the founding meeting of the European Congenital Heart Disease Organisation (ECHDO) in spring 2007 that the idea was born to create a European network on congenital heart disease (CoHD). A network in which patients, parents, doctors, and scientists could cooperate to improve the treatment of CoHD patients across Europe. In the summer of 2007, the European Union agreed to fund the project. In 2008, we launched Corience.

Corience's mission is to provide reliable information about all aspects of congenital heart defects and to foster the dialogue between patients/parents and the scientific community across Europe. It is a platform where all those concerned personally or professionally with CoHD can join forces to promote high-quality research in this area, thus improving the treatment and the quality of life for patients.

As an important step towards this goal, we created a website dedicated to congenital heart defects. After one year of preparation, www.corience.org was launched in September 2008. Valuable input from all CoHD interest groups went into the creation of the site, which provides objective, independent, easy-to-understand information, addressing patients, parents, doctors, and scientists alike. We've already received lots of positive feedback and are looking forward to seeing our website grow. Another milestone towards a strong European CoHD network will be this year's ECHDO/Corience meeting in Berlin. Maybe I'll see you there!

I thank all organisations, doctors, and scientists who contributed to our work so far. For all of you who are not yet involved with Corience: Join us and become part of our community!

Dr. Ulrike Bauer
 Project Coordinator

Corience Heartbeat

Corience – an independent European network on congenital heart defects

Corience is an independent European network dedicated to congenital heart defects (CoHD) sponsored by the European Union. A truly international team of about 15 representatives of self-help organisations and medical professionals currently works for Corience, creating an informative website and coordinating international meetings. Their objective is to inform patients, parents, doctors, and scientists about the different aspects of CoHD, to foster debate and discussions, and to encourage all stakeholders to cooperate more closely.

An important element of Corience is the Corience website. It provides extensive information on diagnostic and treatment methods, CoHD research, and living with a heart defect.

As Maria Escudero, one of the founding Corience members, put it: "It is very important to understand what is going on with your child." Yet the website addresses not only patients and their families, but also doctors, researchers and medical professionals.

All articles are written by journalists and reviewed by leading medical experts. This ensures that they are both easy to understand and scientifically sound. Doctors and scientists can access a database of continually updated information about CoHD research activities. The Corience website is currently available in English, Spanish, German, and Polish versions will follow over the next two years. *wl/ks*

Who we are



Marte Jystad works for the Norwegian association for children with congenital heart disease, FFHB. Her tasks at Corience include writing articles and encouraging more European countries to join the project.



Wiebke Lesch runs a strategic communications and PR consulting firm. Her company's main focus is on life sciences and media. She is responsible for designing and marketing the Corience web portal and for its editorial content.



Maria Escudero is one of the founders of Menudos Corazones, a Spanish non-profit organisation whose primary purpose is to help children born with congenital heart disease and their families. She works as a Corience network researcher.



Ulrike Bauer is the executive manager of the German National Registry for Congenital Heart Defects, the national repository for medical data on patients with congenital heart defects in Germany. She is the Corience coordinator.



Peter Nordqvist is the marketing manager for Hjärtebarnsföreningen, a national Swedish volunteer organisation whose aim it is to improve conditions for children and youths with heart defects and their families. At Corience, he is a network manager.



Hermine Nock is the executive manager of BVHK e. V., the German umbrella organisation for children with congenital heart diseases. At Corience she is responsible for networking with other European patient and parent organisations.

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Events

Corience website launched at the Nordic Meeting in Paediatric Cardiology

On September 26, 2008, the Corience website was officially launched during a lecture at the 38th Nordic Meeting in Paediatric Cardiology in Lund, Sweden. It was the first of several launch events in Nordic- and English-speaking European countries. Peter Nordqvist, one of Corience's founding members, outlined the features, objectives, and scope of the website, and explained the general aims and goals of the European project. His presentation met with acclaim from the paediatric specialists present at the Lund conference. "Impressive. It is an incredibly useful tool, not only for those of us who work with children and youths afflicted by congenital heart defects, but also for patients' families and friends," declared one Norwegian doctor, voicing the opinion of many of his colleagues. Peter Nordqvist and Marte Jystad, who also

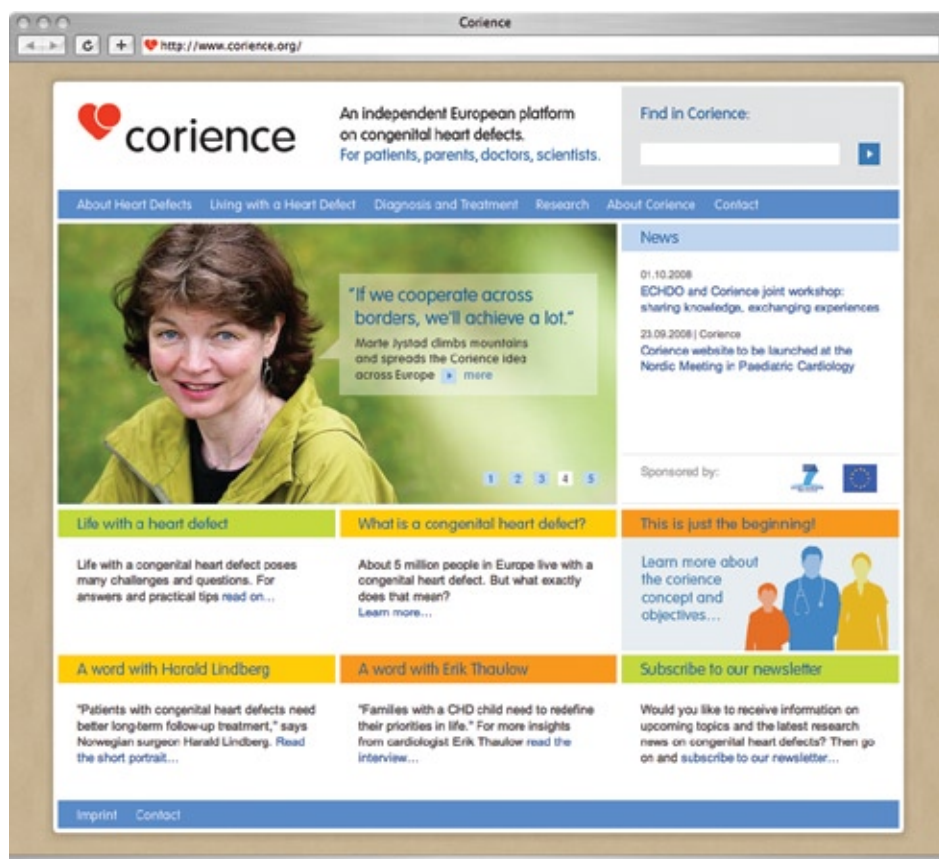
presented Corience and the website at a booth at the conference, were very satisfied with the feedback they received: "The reactions have been extremely positive, both from children's heart surgeons, cardiologists, nurses, and other professionals, and from other interested individuals who visited our booth." Doctors and nurses were particularly impressed by the fact that all articles on Corience are reviewed by relevant specialists. The general opinion was that this reliability and factual correctness made Corience a good and safe source of information for parents, patients, and health professionals alike. As one nurse put it, "there's a jungle of websites on congenital heart defects out there, and it's good to finally know one that is trustworthy and authentic enough to recommend it to patients, parents, and colleagues." *jr*

Events

ECHDO and Corience: sharing knowledge and experience

A joint workshop on November 7 through 8, 2008 in Berlin will bring together the European Congenital Heart Disease Organisation (ECHDO) and Corience to share information and experience and to build a closer network. In the spirit of a CoHD community, the workshop will connect members of parents organisations, self-help groups, doctors, and scientists. Participants will have ample opportunity to network and share success stories as well as best practices; topics will include fundraising, network development, and lobbying. Another strong focus will be on current information about different aspects of medical treatments for congenital heart defects, including drug safety, clinical trials, quality control, etc.

The coordinators hope that this workshop will strengthen the ties between organisations, advance the cause of a European network of CoHD organisations, and serve as a stepping stone for future activities in a strong European CoHD community. *jr*



More Events

07.11.2008 – 08.11.2008
 ECHDO/Corience joint workshop
 Berlin, Germany

08.11.2008 – 09.11.2008
 Corazón y Vida:
 Congenital Heart Disease Conference
 Seville, Spain

10.12.2008 – 13.12.2008
 EuroEcho 2008
 Lyon, France

22.03.2009 - 25.03.2009
 7th International Workshop on
 Interventional Pediatric Cardiology
 Milano, Italy

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Living with a heart defect

Sports is important – especially for people with congenital heart disease

Physical activity keeps your body fit and increases your general sense of wellbeing. In short, it improves your quality of life. This is also true for children and youths with congenital heart defects (CoHD). For fear of negative effects or lack of information, many parents, teachers, and even some doctors try to slow down these kids' natural urge to move, run, and jump. Thus begins a vicious circle involving reduced motor activity, motor deficits and psychosocial adaptation issues, such as low self esteem and further social isolation. The limited amount of action that derives could in turn further reduce physical activity. The vicious circle remains closed and hard to break.

The proportion of CoHD children whose doctors advise them not to partake in sports or physical activity varies widely from one European country to another. Whereas patients with congenital heart disease are sometimes

even forbidden to move in southern European countries, most are allowed to practise nearly any type of sport in northern European countries.

Doctors should base their evaluation of whether a CoHD child is fit to participate in sports on the post-operative findings, not the severity of the heart defect. For more information on why CoHD children can and should play sports, visit www.corience.org. *es*



Living with a heart defect

Going abroad? Useful travel tips

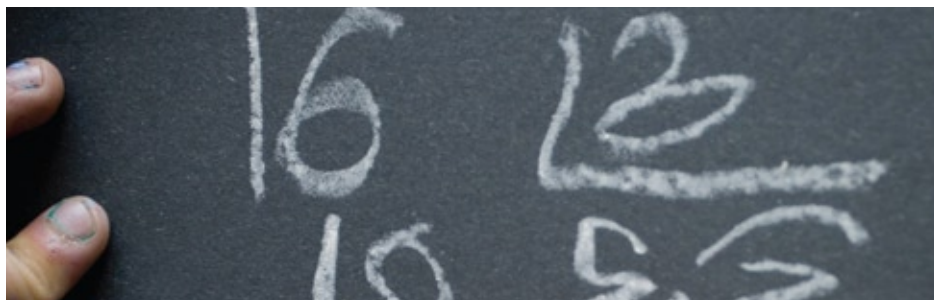
Travelling with a congenital heart defect is, in principle, not a problem. Just make sure that you are well prepared in case you require medical care abroad. Be sure to bring all relevant information about your or your child's heart defect with you. This includes the type of diagnosis as well as your doctor's name and contact details. Individuals with a complicated heart defect may experience difficulties changing planes – better book a connecting flight that takes off several hours after your arrival. Choosing the right destination also involves some considerations. If you have trouble with your blood pressure, avoid high-altitude destinations like the Andes. If you're easily hydrated, don't travel to hot climates. EU citizens travelling with the EU and Switzerland need to bring their European Health Insurance card. Please notice that this card does not replace your ordinary insurance. More travel tips on www.corience.org. *uh*

Living with a heart defect

In school with a congenital heart defect

Absenteeism, discrimination and difficulties with social integration – these are some of the main school problems that children with a congenital heart defect (CoHD) have to face. With some understanding and the right attitude, parents, doctors, and teachers can help to soften the impact of these problems. Belén Tarrat, a Spanish psychologist who works with CoHD children, talks about some of these issues.

For Belén Tarrat, the main problem children with CoHD face in school are long absences due to hospital stays. Absenteeism is a difficult situation for parents and teachers, which needs to be handled carefully to minimise the harmful effect on the child. To deal with this situation, the child needs support both from the school and from the hospital-based school. Read the full interview on www.corience.org. *mm*



Research News

Heart valve replacement without surgery

Patients with congenital heart disease can now have their pulmonary heart-valve replaced without open heart surgery. Since 2000, more than 650 patients in Europe underwent this new catheter procedure. Some doctors call it a revolution, claiming that the procedure will permanently change the way in which we treat people with heart diseases. Others are more sceptical, warning that the evidence collected so far doesn't suffice and that the procedure only postpones open heart surgery. Tissue valves (implanted surgically or by catheters) are seldom permanent. Nevertheless, some of the patients who underwent this procedure have now been walking around with the same transcatheter pulmonary valves for 5 years, and the valves are still working fine. However, it is too early to tell what the situation will be in 10, 15 or even 20 years. Read the full article on www.corience.org. *mh*

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Living with a heart defect

What is quality of life? – an interview with Philip Moons

Why do adults with congenital heart diseases (CoHD) tend to have a better quality of life than the average population? What is the best way to measure quality of life? Why is it so hard to define? Quality of life is a complex issue. Corience explores it in an interview with the Belgian scientist Philip Moons. Moons has done a lot of research on quality of life and CoHD. He says that researchers do not agree on a common concept of quality of life, as we all have different ways to approach the term. For the full interview, more information about

quality of life for patients with CoHD, and the latest studies in this area, visit www.corience.org. *mh*



Diagnosis and treatment

Olivia: answers to questions and fears

Olivia was born with a severe heart defect. Her parents knew that at some point Olivia would need to have a Ross procedure. The information they found on the Internet did not answer their many agonising questions. Will Olivia be in a lot of pain? What will we do if she dies? Together with Olivia, they visited a heart surgery information session at the clinic. It gave them answers to the worries that had been plaguing them for weeks. They took a look at the intensive care unit and found that up close, it all looked a lot less frightening. They received a copy of “Anna’s Heart Diary”, looked at the pictures of the operation again and again and talked about it. The surgery went well and Olivia recovered fast – after only 9 days she was released from the hospital. Her parents are very proud of her and feel privileged to have such a courageous daughter. *hn*



Research

Database for clinical studies

Corience offers an easy-to-use database containing up-to-date information about recent research activities related to congenital heart defects (CoHD). This database is based on and aligned with clinicaltrials.gov – a registry of publicly and privately funded clinical studies conducted around the world.

To find continually updated information on CoHD-related studies, simply enter a search term for a specific CoHD condition. You may narrow your search by selecting a country and/or trial status. Search results are presented in list form. For more details, click on a study title. *ks*

Search term

Country

Status

[▶ Start Search](#)

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