

Editor's Note



Dear patients, parents, doctors, and friends,

It's been almost a year since corience.org went online. Since then our website has grown significantly and we have received a lot of positive feedback from our community. Today, I am glad to announce the next Corience milestone – our Spanish language version. Being a Spaniard myself, I am proud that Corience is now accessible to even more people.

We will present the new language version during the European Society Cardiology Congress 2009 (ESC), which takes place in Barcelona on August 29 through September 2, 2009. At the same time, we will also launch the redesigned section "Living with a heart defect." It presents content tailored to the needs of specific user groups, making it easier for each user to find the information he or she needs. Special sections for teens, adults, and parents provide structure and make the content more accessible.

As president of the Spanish parent organisation Fundación Menudos Corazones and Corience partner, I have been active in the work for congenital heart defect initiatives for many years. I know that reliable information is crucial for families with a heart child. Our team at Corience works hard to provide comprehensive information on congenital heart defects to those who have to deal with that condition personally and professionally. I want to take this opportunity to thank all those who trusted and supported us in this ambitious project that is already helping a large number of Europeans. We are striving for more, and the Spanish language version is another step forward in our attempt to get closer to all people affected by congenital heart defects.

Enjoy the changes on our website, spread the word about Corience, and please visit us at the ESC Congress in Barcelona. Maybe I'll see you there!

Saludos afectuosos,
Maria Escudero

Living with a heart defect

Drugs and heart defects don't mix well

Whether we like it or not, alcohol, tobacco and, even illegal drugs are a part of life, and many people use them despite the known health risks. For those with a congenital heart defect, the risks are even greater, especially if they smoke. Narcotics not only affect the brain and therefore our vision, hearing, and sensory impressions. They also stress the heart – a possibly fatal risk for those with congenital heart defects. If you are unsure about the specific consequences of your particular heart defect, you should talk to your cardiologist or with a specialist nurse. Confide in someone you trust – and remember that healthcare personnel have your best interests at heart.

On www.corience.org, you will find more information how different drugs affect the heart. *uh*



Living with a heart defect

First love: don't break my heart!

You've never felt like this before. Well, maybe you have felt something similar, but it wasn't quite like this. Maybe the last time you saw each other you said something totally stupid, and now you're embarrassed.

Don't worry – you're not the only one. Chances are, he/she feels just as insecure as you. Why is it so hard to be normal when you're falling in love? Probably because we really want the person we like to like us back – just the way we are. With or without a perfect body. Even with a scar on our chest, a pacemaker, or blue lips.

Accepting each other, isn't that what life and relationships are all about? And mutual trust? So what happens when it's the time to talk to your girlfriend or boyfriend about your heart condition? You should explain that you are just like everybody else, except you just have this heart condition. Only you will know when the time is right, and when you feel confident enough in your relationship.

Read the full article on www.corience.org. *uh*



In this issue

- P 2 Talk to me! – Couples with heart kids
- P 2 Recovering strength
- P 3 European networking activities proliferate
- P 4 Corience now in English and Spanish!
- P 4 Tailored information for teens, adults, and parents

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

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Living with a heart defect

Recovering strength

Why would an employed woman with congenital heart defect need rehabilitation? And why would she choose inpatient rehab instead of individual outpatient therapy?

Eva Niggemeyer has a congenital heart defect and works six hours a day: "I have to be economical with my limited energy reserves. Staying at a rehab clinic with other people with the same condition is worth its weight in gold. Travelling back and forth to an outpatient treatment would be a huge additional strain. I wanted to improve my constitution and build up new power reserves. In rehab I dared to go into the pool for the first time in years when telemetry showed that this was actually possible. My accomplishments also boosted my motivations for life after rehab."

For the full interview and more information about rehabilitation visit www.corience.org *hn*



Living with a heart defect

All you can do is offer good advice

"It is rare for young people or their parents to bring up the topics of education and career when they come to us. I don't believe I've ever seen it happen," says cardiologist Asle Hirth, head of the Heart 13+ youth project at Haukeland University Hospital in Bergen, Norway. "Perhaps they don't view it as a problem. My impression is that young people are highly optimistic," he adds. "When it comes to occupation and education, it is easier to start out with what they cannot do. The list is actually a short one, although certain heart defects can limit the occupational choices somewhat," Asle says.

He emphasises that any guidance offered must be tailored to the individual. "We don't give advice based on the diagnosis, but rather on the individual prognosis. We cannot make the choices for these young people. We can only offer advice." *mh*

Living with a heart defect

Talk to me! – Couples with heart kids

Having a child with a congenital heart disease can put a strain on parents' relationships.

Continuous, honest, and open communication between couples helps avoid misunderstandings and maintain a loving relationship. And that improves the emotional health of the entire family.

There are some potentially stress-inducing factors that might cause distance and resentments, especially at the very beginning, when parents receive the news that their child has a congenital heart defect.

To avoid emotional distance, couples can boost communication and understanding by being honest, finding the right moment to talk, listening without judging, showing respect, trust, and empathy, and being patient.

Read the full article on www.corience.org *mm*



Research News

Folic acid in flour prevents congenital cardiac defects

Since 1998 it has been mandatory in Canada to add folic acid to flour and pasta. A study published in May 2009 shows that since the beginning of this practice there had been a significant reduction in the occurrence of congenital heart defects. The results of the study indicate that an increase in folic acid intake may prevent congenital cardiac defects, particularly if the mother-to-be consumes a sufficient amount of folic acid prior to conception, and not just after the pregnancy has been established. Enhancing basic foodstuffs with folic acid means that it is possible to reach women who become pregnant unexpectedly. Folic acid is a vitamin found in wholegrain products, greens, tomatoes, egg yolk, and nuts. The recommended daily intake is 600µg. Read the full article on www.corience.org *sw*

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Events

European networking activities proliferate

European networking through the European congenital heart disease organisation (ECHDO) and Corience has spawned several new organisations for children and adults with congenital heart defects. Furthermore, ECHDO bylaws were established at a Rare!Together network workshop in Barcelona on June 19th.

Since the first meeting in 2007, the number of countries participating in ECHDO has increased from 13 to 22. Since the last meeting in Berlin in November 2008, four new member organisations have joined the network. One new member is the Italian GUCH Association AICCA. The Italian psychologist Edward Callus was so inspired by the idea of ECHDO/Corience that he started a whole new organisation that was founded in April this year.

"I attended the meeting in Bruges last year, and it was so inspiring," Callus recalls. "Together with my colleagues I searched everywhere for a patient or parents' organisation in Italy to cooperate with, but we could not find one. Thus, we took the initiative because there was no one else to do it – but we want this organisation to be run by the patients themselves. To make it work, we need to cooperate, like in ECHDO/Corience, and we

need better communication between doctors and other professionals and patients." The meeting also included a compelling session on medical presentations.

Prof. Dr. Hess from the German Heart Center in Munich talked about the Melody valve, a new procedure to replace a pulmonary valve without the need for open-heart surgery. Ines Hartwig-Zaidan from MTBASA in Berlin talked about self-management of anticoagulation for children and adults on blood thinning drugs.

Although new members are joining, Hermine Nock and ECHDO continue to reach out. "We are trying to find groups supporting patients and families affected by CoHD in Latvia, Malta, Portugal, Slovakia and the former Yugoslavian countries. Please contact us!" says Hermine Nock, spokesperson for ECHDO.

"I am so excited because I met so many people like me, who share my goals," Malgotzata Pawlowska from Luxembourg exclaimed. "It is wonderful! I am a multi-national, I was born in Poland and my children were born in France. We need to cooperate throughout Europe. This meeting offered everything I expected, and we want and need more meetings like this!". mh



22 member organisations were represented at the ECHDO/Corience meeting in Barcelona

Events

Corience at the PCCS Congress in Cairns

Corience was present at the "5th World Congress of Pediatric Cardiology and Cardiac Surgery" held in Cairns, the tropical capital of the Australian province Queensland, June 21 through 26, 2009. Researchers and health professionals involved in the care for heart disease patients of all age groups – from fetuses to adults – met to discuss the latest developments in their rapidly evolving field. With more than 4,000 participants from all over the world, the conference provided ample opportunities to network, exchange viewpoints, and share experiences.

Corience's own Marte Jystad outlined the European project's objectives and successes in a poster presentation. Together with her colleague Peter Nordqvist, she took the opportunity to discuss the need for reliable information on congenital heart defects with their audience of international health professionals. Drawing from their everyday experience, all attendants agreed that comprehensible information helps patients deal with their affliction.

Corience was also invited to a meeting with the "Global Organization for Pediatric and Congenital Heart Disease" in Cairns. Their mission is to promote quality of life for all patients with pediatric and/or congenital heart disease. Chairman Dr. Christo Tchervenkov emphasized the significance of Corience's lobbying work, which supports the Global Organization's mission. mj/ks

More Events

30.09.2009 – 03.10.2009
European Echocardiography Course
Rotterdam, Netherlands

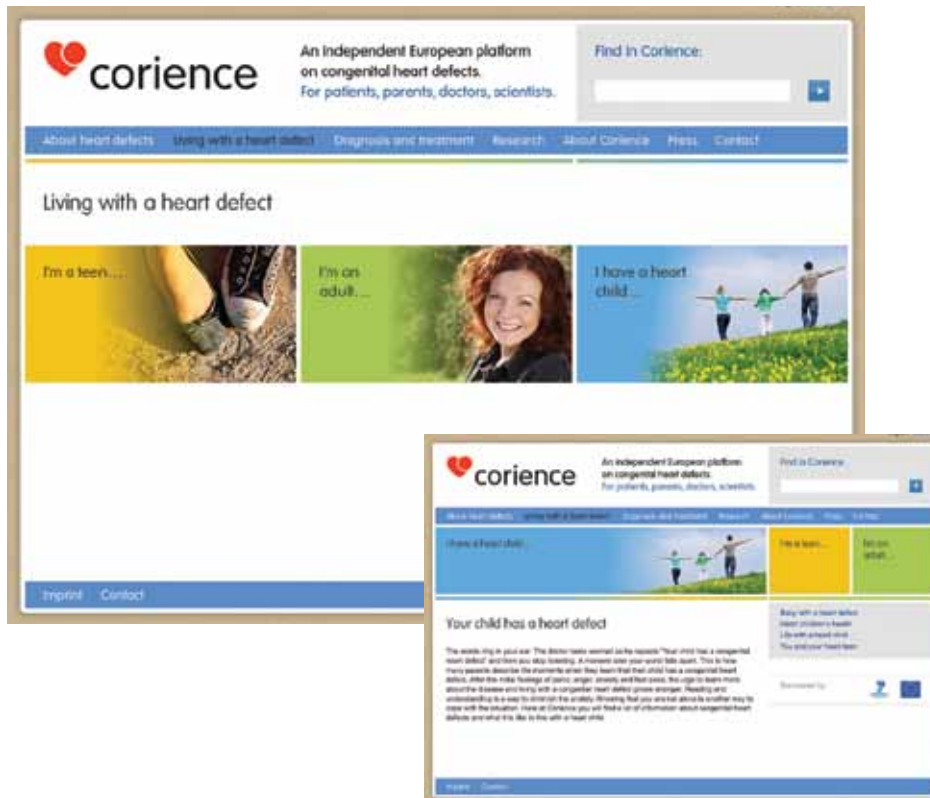
03.10.2009 – 06.10.2009
Annual Meeting of the German Society of Paediatric Cardiology/German launch of Corience
Weimar, Germany

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Corience Heartbeat

Tailored information for teens, adults, and parents



Corience's section "Living with a heart defect" has been relaunched with a new face and structure. The tailored content will make it easier for each user to find the information he or she is looking for.

Are you a mom of a heart child? Go to "I have a heart child," and you will find what you are looking for, whether you are expecting a baby with a heart defect or have a heart teen. We have collected a number of topics that you might be interested in.

Are you a teen with a heart condition? Click "I'm a teen" for lots of information on burning issues like love, sex, and friendships. Soon you will find more topics dealing with body, health, family, school, jobs, and many more. There is also a section especially designed for adults with a congenital heart defect. Go to "I'm an adult" to find comprehensive information on heart matters, body and soul, as well as career and lifestyle.

Content includes interviews with experts, personal stories, recent research, and much more. Most of the articles allow you to leave comments. We would be happy if you shared your thoughts with us! ks

Events

ESC 2009: Corience now in English and Spanish!

Corience will present its work during the European Society of Cardiology (ESC) Congress from August 29 to September 2, 2009 in Barcelona, Spain. The ESC is Europe's largest congress for cardiology and a great opportunity to learn about news from the scientific and medical community.

The Corience team will present several www.corience.org features, which serve as useful tools for health professionals. Cardiologists

from all over Europe will be invited to join the Corience community and build a strong European network on congenital heart defects. The conference will also see the premiere of Corience's Spanish-language version, which will be launched during the ESC. Now bilingual with English and Spanish versions, www.corience.org will reach even more people throughout Europe and worldwide.

Come visit us at the ESC, Booth A 83! ks

About Corience

Stay informed with our Corience e-mail 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!