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Corience: A website dedicated to congenital heart defects

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Congenital heart defects are the most common congenital disease affecting 1 in 100 children. This amounts to about 5 million people in Europe alone. To most families, the diagnosis “congenital heart disease” is a strong blow. They are suddenly faced with numerous questions: How can this disease be treated? Will my child be able to lead a normal life? Will there be restrictions? The website www.corience.org provides answers to these and many other questions. It comprises a knowledge base providing practical advice and background information for patients, families, and health professionals.

For a long time now, patients, parents, and health professionals have been calling attention to a lack of reliable information about congenital heart defects. It was for this reason that five European parent umbrella organizations for congenital heart defects and the German National Registry for congenital heart defects joined forces and created Corience in 2008. The project is currently funded by the European Union.

Prof. Szatmári, former president of the Association for European Paediatric Cardiology (AEPC) and member of the Corience Advisory Board, actively supports the project and emphasises the value and significance of the information and networking opportunities Corience offers.

Corience provides a wide spectrum of information

Articles about sports, nutrition, quality of life, employment and sexuality are as integral a part of the platform as detailed explanations of the different types of heart defects, diagnosis, and treatment methods. Lists of web links, updates on the latest research, interviews with specialists, and personal stories of patients and their families complete the site, which is unparalleled in its information bandwidth. All articles are written by international journalists and reviewed by leading medical experts. This ensures that they are both easy to understand and scientifically sound. Most of the articles provide space for comments. All users are invited to share their opinions and personal experiences - thereby helping others not lose hope.

Knowledge helps patients deal with their affliction

Health professionals in particular know that reliable information is a substantial part of good treatment. A well-informed patient can handle his illness better and knows how to avoid unnecessary health risks. Many doctors and other health professional throughout Europe already use the information provided on Corience in their consultations because it is highly accessible and quality-assured. They also recommend the website as a trustworthy knowledge base for patients to use at home.

Continuously updated information for health professionals

Corience not only satisfies the information needs of patients and their families, but addresses doctors and other medical professionals as well. Doctors and scientists can access an easy-to-use database containing up-to-date information about recent research activities related to congenital heart defects. This database is based on and aligned with clinicaltrials.gov – a registry of publicly and privately funded clinical studies conducted around the world.

Strengthening science and research for congenital heart defects

Corience contributes to a strong European network on congenital heart disease by creating horizontal and vertical cross-links between patients, parents, physicians, scientists, medical organisations, etc. Worldwide there is a lack of information concerning the long-term outlook for patients with congenital heart defects. Only by working together on an international level, scientists can collect a sufficient number of cases to conduct high quality research. “I would like to see a closer cooperation between doctors and researchers throughout Europe. Together, we can achieve a lot,” says Dr. Ulrike Bauer, project coordinator of Corience.

A truly European website

Corience is currently offered in English with further language versions to follow. The Spanish version of Corience was launched during the ESC Congress 2009 in Barcelona, Spain. The German version of the website followed in autumn 2009.

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