



About 6000 children with heart defects are born in Germany every year.

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## Action for data

There are currently around 300,000 children, young people and adults with heart defects living in Germany. But generally valid research findings on the long-term progress of these patients are still lacking. Up to now, the small patient numbers included in trials carried out at the individual heart centres in Germany prevented meaningful results from being obtained. This gap is to be closed by the Competence Network by means of a patient database. In the "National Register for Congenital Heart Defects" the data of patients with congenital heart defects is being collected and evaluated. In the case of the 17,000 patients who are already registered, the course of the disease, life expectancy, quality of life and situation regarding care are being examined. The data from the register will make valuable long-term trials possible for the first time.

Please give us your support! Join those on the register. Should you have any questions, don't hesitate to ask and we will be glad to assist you.

Is there anything you would like to ask?  
Do you need assistance?

You can reach us on:

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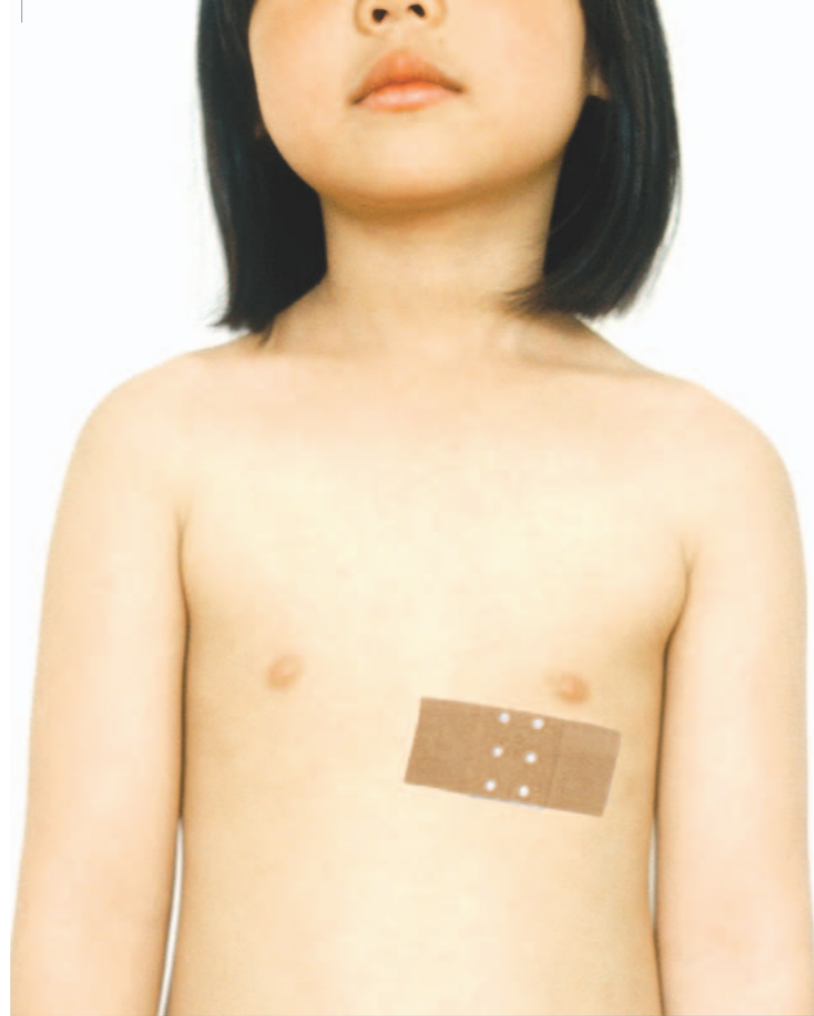
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## Congenital heart defects

Congenital heart defects are the most frequent congenital illness. They arise as a result of developmental disturbances during the first three months of pregnancy. There are many sorts of different congenital heart defects. They range from minor defects, which scarcely affect the functioning of the cardio-vascular system, to very serious heart defects which, if not treated, lead to death.

## Research safeguards survival

Without an operation, approximately 70 % of patients die whilst still children. Thanks to improved procedures in pediatric cardiology, heart surgery and anesthesia, more than 90% of these children today reach adulthood. But the majority of those affected remain chronically ill throughout their lives. Secondary problems often arise, which can lead to impairment in the patients' quality of life, reduction of fitness and ability to work and even to life-threatening situations.



## Research for people

In the Competence Network for Congenital Heart Defects, doctors, scientists, parent associations and self-help groups are working hand-in-hand nationwide. The common aim is to raise the quality of life and the care of those affected. Long-term side-effects following operations are to be investigated and new methods for diagnosis and treatment developed. At the heart of the network's activities are trials examining the therapy and prevention of functional disorders involving the right heart. Guidelines for the treatment of congenital heart defects and the further and on-going training of doctors are designed to produce lasting benefits in improved patient care. At the Competence Network, knowledge regarding congenital heart defects is compiled, extended and transmitted rapidly to the patient. The Patron of the Competence Network is Friede Springer.

Survival rate children with CHD

