



Press release: Congenital Heart Defects | Personalia | Research Award

Julia Remmele awarded research prize

DGPR and German Heart Foundation honor registry study

Berlin, July 26, 2022 - With support from the National Registry, Julia Remmele conducted research on sequelae in patients between the ages of 15 and 25 with congenital heart defects. The results show how risky the patchy use of specialized care is. In June, the German Society for Prevention and Rehabilitation of Cardiovascular Diseases (DGPR) and the German Heart Foundation awarded her the Science Prize of the Kurt and Erika Palm Foundation 2022.



Julia Remmele works and conducts research at the German Heart Center Munich. Foto: © privat

One in one hundred children is born with a congenital heart defect. The diagnosis is still a shock. But thanks to medical progress, congenital heart defects have lost much of their horror. Today, well over 90 percent of those affected reach adulthood. In Germany alone, there are now around 300,000 adults living with congenital heart defects. And the number is growing. Around 350 cardiologists and pediatric cardiologists with additional qualifications in adults with congenital heart defects (ACHD) care for this growing group of patients in German ACHD centers, ACHD specialist clinics, and ACHD specialist practices.

PRESS RELEASE



Physician Visits are Limited to the Family Doctor

The only problem is that many adults do not arrive at the specialized care center. In fact, more than one-third (36 percent) of 18- to 70-year-olds with highly complex heart defects still limit their visits to the general practitioner's office, according to the results of a published last year (<https://t1p.de/KNAHFStudieNachsorge>) by the Competence Network for Congenital Heart Defects. Especially in the transition between the 15th and 25th year of life, many drop out of appropriate further medical treatment.

High Risk Negligence

This is risky, regardless of the type of congenital heart defect. Complications such as cardiac arrhythmias, arterial hypertension, and pulmonary hypertension can trigger serious cardiac events, including sudden cardiac death, even at a young age. They are not always noticed or cause symptoms immediately. In addition, over a lifetime, the risks for other cardiovascular diseases, as well as non-cardiac diseases, increase. "These have different and often much more severe effects in a patient with a congenital heart defect than in a patient with a "normally" healthy heart. Pregnancy is also different in women with congenital heart defects", says Ulrike Bauer, executive director of the Competence Network for Congenital Heart Defects and the National Registry for Congenital Heart Defects. Adults with congenital heart defects therefore definitively belong in the hands of specialists.

Up to Four Cardiac Sequelae and Seven Other Diagnoses

The secondary diseases and other conditions diagnosed in the transitional phase between the ages of 15 and 25 are shown by the registry study at the Competence Network for Congenital Heart Defects, for which scientist Julia Remmele of the German Heart Center Munich was recently awarded the Science Prize of the Kurt and Erika Palm Foundation 2022. Her analysis of the medical data of a total of 8,834 participants in the National Registry between the ages of 15 and 25 showed that around a quarter (25.5 percent) of young female patients suffer from cardiac arrhythmias. Pulmonary hypertension is the second most common secondary condition diagnosed in this age group with 4.5 percent, followed by arterial hypertension (3.6 percent). There are often additional diagnoses of neurological (7.3 percent), musculoskeletal (6.9 percent), and mental health conditions (5.6 percent). "Overall, we have already identified up to four cardiac sequelae and seven non-cardiac conditions per patient between the ages of 15 and 25," says Julia Remmele. She considers the award from the DGPR and the German



Heart Foundation a great honor. The researcher hopes that the work will also help raise patients' awareness of the urgency of seamless follow-up treatment by specialized physicians.

Julia Remmele, born in 1982, is responsible for various research projects on congenital heart defects as a research associate at the German Heart Center Munich. The qualified physiotherapist completed her Bachelor of Science in Physiotherapy at Dresden International University. For her Master of Science in 2017 at the Technical University of Munich (TUM), Julia Remmele conducted research on motor performance and health-related quality of life in children and adolescents with congenital heart defects. Currently, she is doing her doctorate on "Neurocognitive developmental status and health-related quality of life in patients with congenital heart defects" at the Technical University of Munich. Since 2018, she has been a Junior Member of the Association of European Pediatric and Congenital Cardiology (AEPC).

For Your Research

The results of the study were published under the title "Endangered patients with congenital heart defect during transition-Germany-wide evaluation of medical data from National Register for Congenital Heart Defects (NRCHD)" in "Cardiovascular Diagnosis and Therapy": <https://pubmed.ncbi.nlm.nih.gov/35070798/>.

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