

# The PAN Study: The First Step into the Future

## Die PAN-Studie – der erste Schritt in die Zukunft

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Lindinger et al. published in this issue of *Klinische Pädiatrie* the data of a new nationwide registry for newborns with congenital heart defects [3]. The so called PAN-study needs to be mentioned from different views as it is important not only for pediatric cardiologists but for all physicians involved in the care of pediatric patients with congenital heart defects and to build up an interdisciplinary network [2]. Furthermore it provides for the first time epidemiological data on the prevalence of congenital heart defects from a nationwide approach. This registry will substantiate the data from previous registries applying different methods [1,5]. In the era of transthoracic echocardiography being readily available in Germany for almost every newborn with a suspected congenital heart defect, the prevalence of congenital heart defects was 1.08% which is higher at the extent of the mild forms [4].

Probably the prevalence for congenital heart diseases may increase furthermore if a highly efficient nationwide postnatal screening program will be introduced. For example Tautz et al. report in this issue on non-invasive peripheral oxygen saturation assessment in 3364 term neonates, carried out at 6–36 h of age. They detected 9 congenital heart defects that had not been recognized prenatally by routine echocardiography [6]. Only half of these children were found to have other anomalies at the clinical examination. Otherwise, one neonate with coarctation of the aorta and one with pulmonary stenosis were missed in the screening program, with pulse oximetry saturation levels >95%. In addition neonatal infections have been detected by this screening in 7 newborns.

The methods applied in this nationwide PAN-study are state-of-the-art avoiding duplicate registration in at least 97.5% of severe and >95% of moderate types of congenital heart defects. The following years will show, how underreporting will be excluded; >90% of newborns with congenital heart defects born during the study period should be enrolled.

It is of note that only 12.1% of all congenital heart defects had been detected by fetal echocardiography while the prenatal detection rate was highest for severe lesions as univentricular hearts and Ebstein's anomaly. Facing the fact, that detailed

ultrasonographic screening is offered in every pregnancy, these data should alert physicians and health care providers in order to improve the quality of prenatal diagnostics.

Several limitations need to be addressed that, however, do not impair the strength of the study. The PAN study probably underestimates the true prevalence of heart defects as embryos and fetuses with a lethal defect that precluded birth are not included due to the study design. The same is true for pregnancies which were terminated for a severe cardiac defect of the fetus. On the other end of the spectrum, subclinical defects such as bicuspid aortic valve have most probably not been included into the registry.

This is the report from the first year of data acquisition and it is to be expected that the ongoing PAN study will confirm the data and that it will provide a basis for future studies. Follow-up data for example on outcome are, therefore, not available.

Finally, besides the authors of this report, all pediatricians and pediatric cardiologists involved in the care of babies with congenital heart defects in our country should be acknowledged for their tremendous efforts to realize this first nationwide registry which may serve as a benchmark for other countries when the structure of the care of pediatric heart patients is discussed.

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