

# CONgenital CORvitia

## Project group

BJM Mulder, AMC Amsterdam  
 ET van der Velde, LUMC Leiden  
 J Vis, ICIN  
 CJM Engelfriet-Rijk, ICIN  
 I Harms, ICIN  
 S Mantels, ICIN



National registry and DNA-bank of adults  
 with congenital heart disease  
[www.CONCOR.net](http://www.CONCOR.net)



## Steering committee

BJM Mulder, chairman, ICIN  
 ET van der Velde, LUMC Leiden  
 ECM Mariman, AZM Maastricht  
 FJ Meijboom, Radboud UMC Nijmegen  
 HW Vliegen, LUMC Leiden  
 G Veen, VUMC Amsterdam  
 PG Pieper, UMC Groningen  
 HWM Plokker, St Antonius Hospital Nieuwegein  
 APJ van Dijk, Radboud UMC Nijmegen  
 JLM Stappers, AZM Maastricht  
 JW Roos-Hesselink, EMC Rotterdam  
 JGP Tijssen, AMC Amsterdam  
 RMF Berger, UMC Groningen  
 GJ Sieswerda, UMC Utrecht

Number of participating hospitals: **103**  
 Number of included patients:  
**9410**

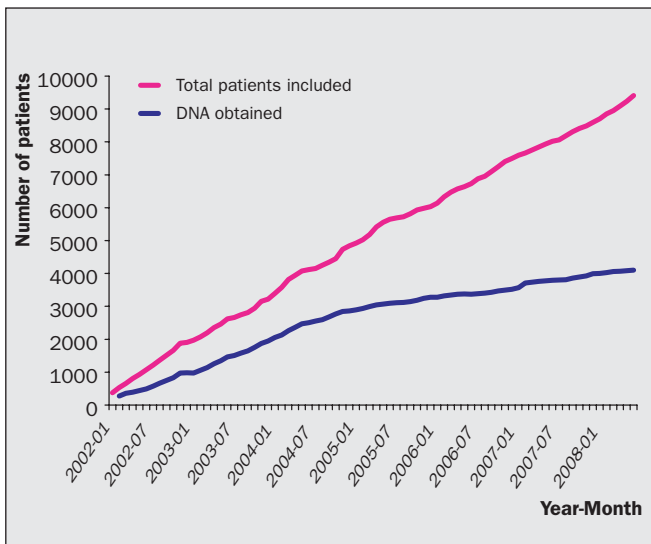


Figure 1. Progress of inclusion.

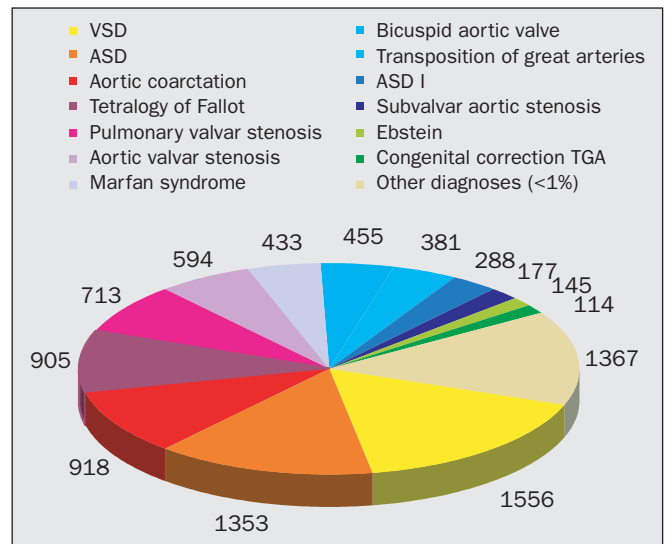


Figure 2. Most frequent main diagnoses.

Genetic causes play a substantial role in congenital heart disease (table 1 and figure 3).

Syndrome	Number of patients
Marfan syndrome	435
Trisomy 21 - Down's syndrome	258
22q11 microdeletion - CATCH 22	22
Noonan syndrome	56
45X0 - Turner's syndrome	55
Williams syndrome	
(infantile hypercalcaemia)	31
Foetal rubella syndrome	3
Alagille's syndrome: arteriohepatic dysplasia	3

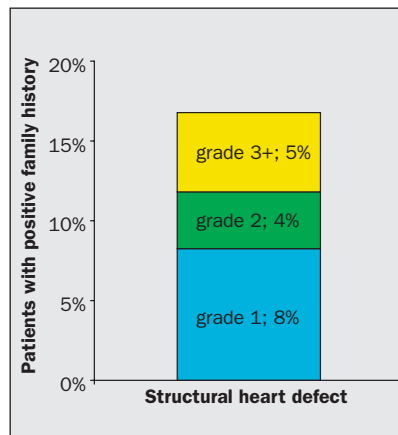


Figure 3. Percentage of patients with structural heart defect and positive family history



In June 2008, CONCOR research nurses visited the Zorghoosam Hospital in Terneuzen to include patients in the CONCOR registry.