CONgenital CORvitia

CONCOR

www.CONCOR.net

National registry and DNA-bank of adults with congenital heart disease

Number of participating hospitals: 103
Number of included patients: 11,332

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

Steering committee: BJM Mulder, chairman, ICIN; ET van der Velde, LUMC Leiden; ECM Mariman, AZM Maastricht; FJ Meijboom, UMC Utrecht; 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

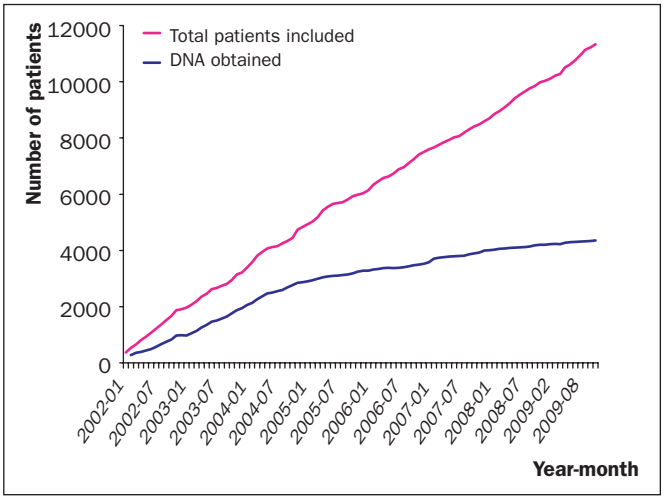

Figure 1. Progress of inclusion.

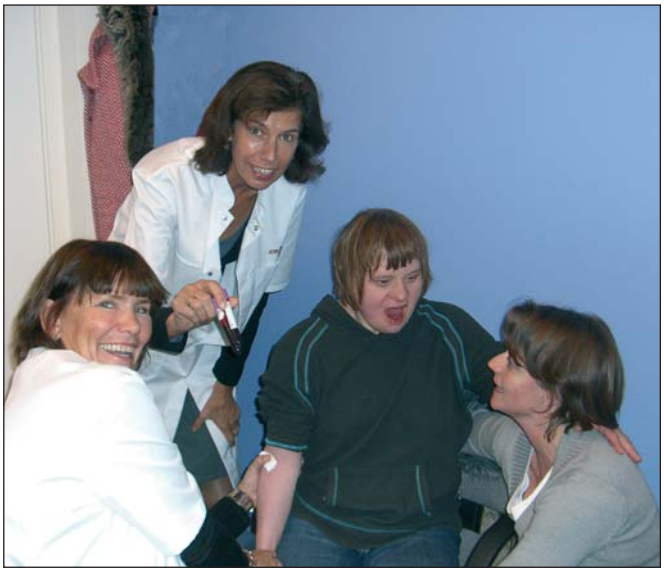

Figure 2. In November 2009 the CONCOR research nurses visited the Medisch Spectrum Twente Hospital in Enschede for a special blood/DNA collection day. Blood from 45 CONCOR patients was obtained.

GENetic CORvitia

GENCOR

National registry for patients and families with a familial heart disease

www.gencor.nl

Number of included patients: 1578
30 October 2009

Project leaders: Y.M. Pinto, ICIN; A.A.M. Wilde, ICIN

Project coordination: J.F. Hermans-van Ast, ICIN

Steering committee: Y.M. Pinto, chairman, ICIN; A.A. Wilde, chairman, ICIN; I. Christiaans, AMC Amsterdam; J.P. van Tintelen, UMC Groningen; D.E. Atsma, LUMC Leiden; Y.H. Arens, MUMC Maastricht; C.L. Marcelis, UMCN Nijmegen; M. Michels, EMC Rotterdam; J.J. van der Smagt, UMC Utrecht; A.C. Houweling, VUMC Amsterdam

In GENCOR patients with familial heart diseases are registered. One of these diseases is the long QT-interval syndrome. This disease is characterised, as the name implies, by prolongation of the QT interval on the ECG. This prolongation results from a delayed repolarisation of cardiac cells. Because repolarisation is generally also less homogeneous, this results in a substrate conducive to (life-threatening) cardiac arrhythmias. The symptoms of LQTS patients are related to these arrhythmias and may range from seizures and/or recurring syncopes to sudden unexpected death. The mode of inheritance is mostly autosomal dominant. In the Netherlands mutations causing long QT-interval syndrome are most frequently identified in the KCNH2 (LQT2) gene (± 50% of genotyped individuals). In GENCOR 108 patients (divided over 26 families) are registered with a mutation in the KCNH2 (LQT2) gene. Five mutations are reported in two or more families. Figure 1 gives an overview of the location of the 19 KCNH2 (LQT2) gene mutations registered in GENCOR.

Reference

www.cardiogenetica.nl

Acknowledgement

Thanks to Ahmad Amin from the Academic Medical Center for preparing the figure. ■

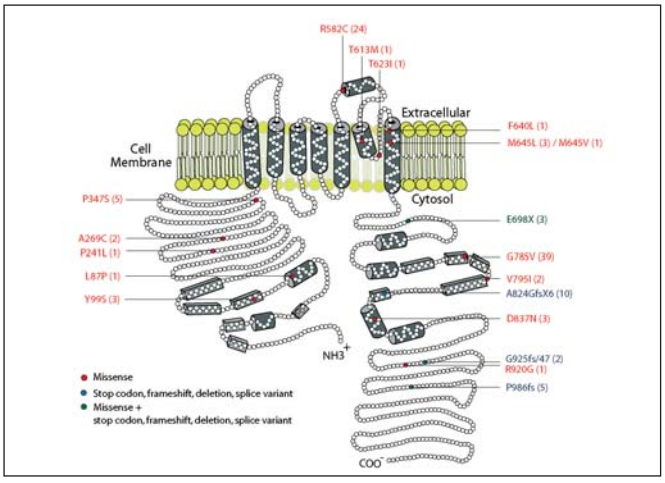

Figure 1. Location of 19 mutation in the KCNH2 (LQT2) gene. In brackets the number of patients reported in GENCOR with the specific mutation.

ZAHARA II

Pregnancy in adult congenital heart disease

A prospective, international multi-centre cohort study to examine the cardio-uterine interaction in pregnancy of women with congenital heart disease (CHD). Women with CHD presenting <20 weeks of pregnancy duration can be included.

Start of study: 1 March 2008
Planned inclusion: 160 pregnant women with CHD, and 60 healthy pregnant women
Number of included patients: 143
Number of included controls: 26
28 September 2009

Study coordination: A Balci, ICIN, Utrecht; Department of Cardiology, UMCG, Groningen, the Netherlands.
Project leaders: PG Pieper, Department of Cardiology, UMCG, Groningen
JG Aarnoudse, Department of Obstetrics & Gynaecology UMCG, Groningen
Principal investigators: The Netherlands: *Department of Cardiology*: PG Pieper, UMCG, Groningen; BJM Mulder, AMC, Amsterdam; JW Roos-Hesselink, Erasmus MC, Rotterdam; APJ van Dijk, UMCN St. Radboud, Nijmegen; HW Vliegen, LUMC, Leiden; E Wajon, MST, Enschede; JLM Stappers, AZM, Maastricht; GJ Sieswerda, UMCU, Utrecht; G Veen, VUMC, Amsterdam. *Department of Obstetrics & Gynaecology*: JG Aarnoudse, KM Sollie, UMCG, Groningen.
Belgium: *Department of Cardiology*: W Budts, UZL, Leuven, *Department of Obstetrics & Gynaecology*: M. Hanssens, UZL, Leuven

For information or inclusion of patients, please contact us at: a.balci@thorax.umcg.nl

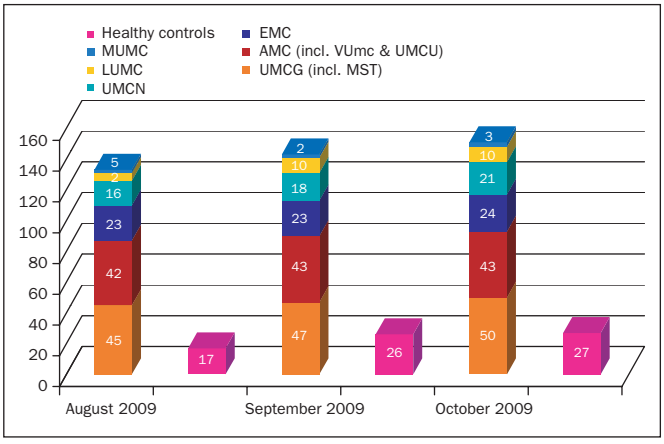

Figure 1. Distribution of included patients and healthy controls in ZAHARA II.

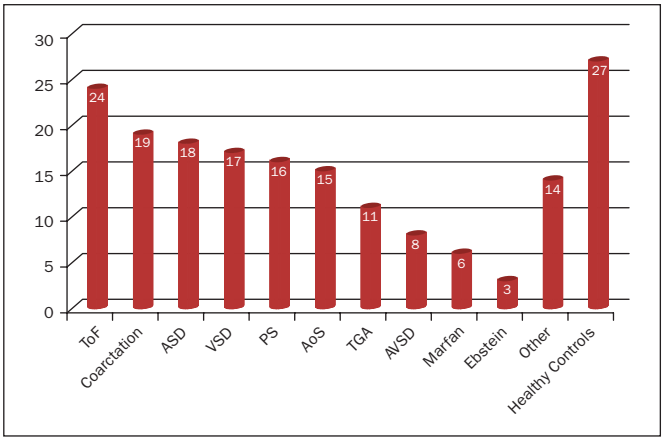

Figure 2. Distribution of main CHD-diagnoses in ZAHARA II.

ESC/AEPC

In cooperation with the ESC and the AEPC

Total inclusion Europe: 617
Total inclusion Netherlands: 85
October 2009

International Expert Committee: Jörg Stein, Austria; Roger Hall, UK; Jolien Roos-Hesselink, the Netherlands
National coordinators for the Netherlands: Jolien Roos-Hesselink, Department of Cardiology, ErasmusMC, Rotterdam; Els Pieper, Department of Cardiology, UMCG, Groningen

Study summary

Heart disease is a major cause of mortality in pregnant women. The most common causes of mortality are aortic pathology, cardiomyopathy and ischaemic heart disease.

This registry will focus on complications during pregnancy, method of delivery and medication (anticoagulation) during pregnancy. All patients with structural heart disease who gave birth after 1 January 2007 can be included in this electronic, web-based registry.

Inclusion

- All patients with structural heart disease (valvular, congenital, or ischaemic heart disease, disease of the aorta or cardiomyopathy) who were pregnant and/or gave birth after 1 January 2007.

Exclusion

- Non-structural heart disease, e.g. arrhythmias occurring in the context of a normal heart
- Inclusion in the ZAHARA II study (see page 49)
- Miscarriage / abortion <20 weeks of gestation

Please join the Registry!

Contact the EuroHeartSurvey: ehs@escardio.org or contact us at: j.roos@erasmusmc.nl or p.g.pieper@thorax.umcg.nl ■

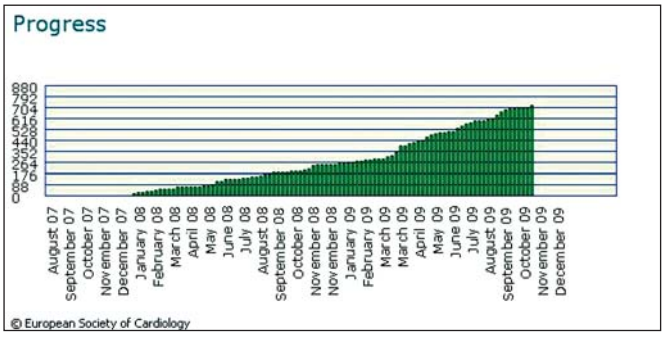

Figure 1. Inclusion worldwide.

HEBE III

A prospective, randomised, clinical study to examine the effects of a single bolus of erythropoietin on left ventricular function in patients with a myocardial infarction

Number of included patients: 529
1 June 2009

Funded by the Netherlands Heart Foundation

Study coordination: A. Belonje, UMC Groningen

Principal investigators: A.A. Voors, F. Zijlstra, D.J. van Veldhuisen, UMC Groningen

Participating centres: University Medical Center Groningen, University Medical Center Leiden, Medical Centre Alkmaar, Isala Clinics Zwolle, Amphia Hospital Breda, Academic Medical Center Amsterdam, St. Antonius Hospital Nieuwegein

Primary endpoint

The primary endpoint of the HEBE III trial is left ventricular ejection fraction (LVEF), measured six weeks after myocardial infarction. Initially, the LVEF was only measured by planar radionuclide ventriculography (MUGA). During the course of the trial, it was decided that LVEF could also be measured by MIBI scan. This decision was based on the fact that some participating centres perform a MIBI scan postmyocardial infarction as part of a postinfarction protocol. This LVEF assessment method uses 600 MBq Tc-99m tetrofosmin for assessing left ventricular volumes, regional wall motions and LVEF (figure 1).

Furthermore, it was decided that all MUGA and/or MIBI scans that are performed within 4 to 16 weeks postinfarction will be included for the evaluation of the primary endpoint. Secondary analysis will include the evaluation of all patients who underwent a MUGA or MIBI scan between 4-8 weeks and the evaluation of only those who underwent a MUGA scan at 4-8 weeks. ■

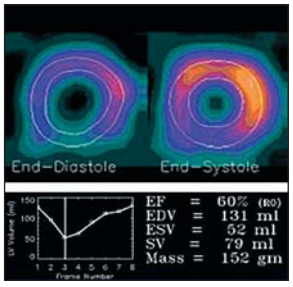

Figure 1.

RACE 3

Number of included patients: 15
1 November 2009

This study is supported by: Biotronik, Boehringer Ingelheim, Boston Scientific, Medtronic, Sanofi Aventis, St. Jude Medical and Astra Zeneca.

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Study coordination: Marcelle D. Smit, UMC Groningen
PhD Student: Ismaël D. Achekar, UMC Groningen

As of 1 November 2009, the Oosterschelde Hospital Goes, Amphia Hospital Breda, Rijnstate Hospital Arnhem/Velp and the University Medical Center Groningen have been initiated to start the inclusion of patients for the RACE 3 study. Other hospitals will follow soon. On 1 November 2009 a total of 15 patients had been included in the trial. ■

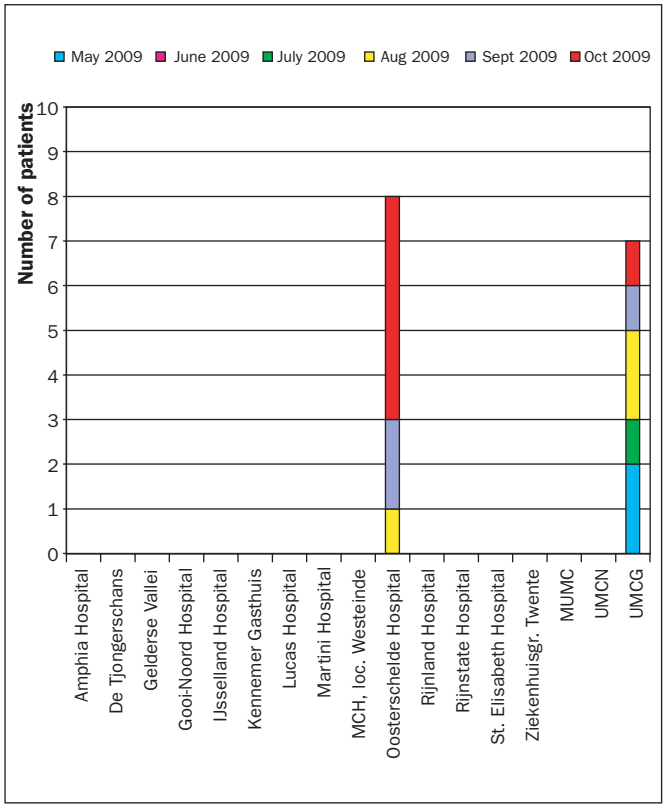

Figure 1. Flowchart of the Race 3 study.