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: 11,226

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, 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

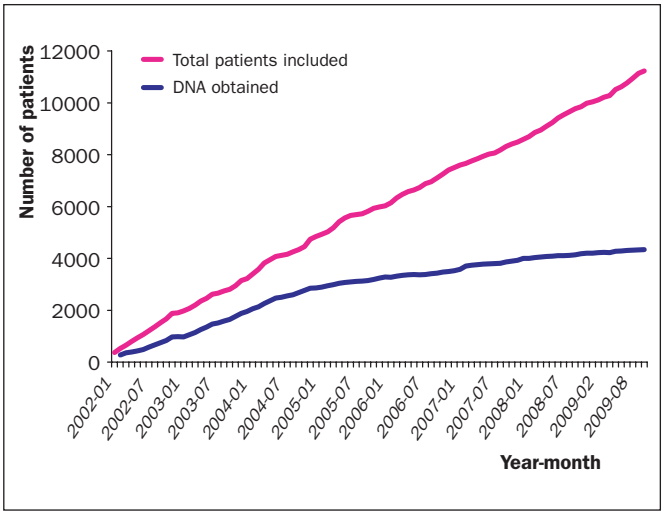

Figure 1. Progress of inclusion.

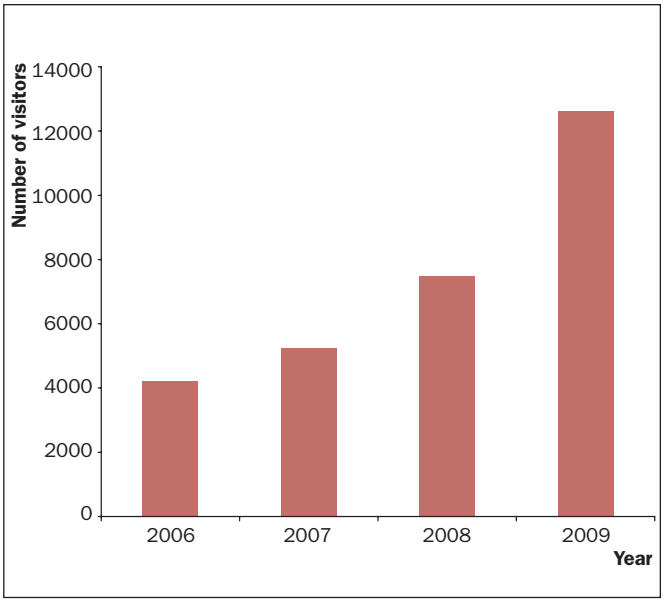

Figure 2. Number of visitors per year on Concor website (www.concor.net).

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

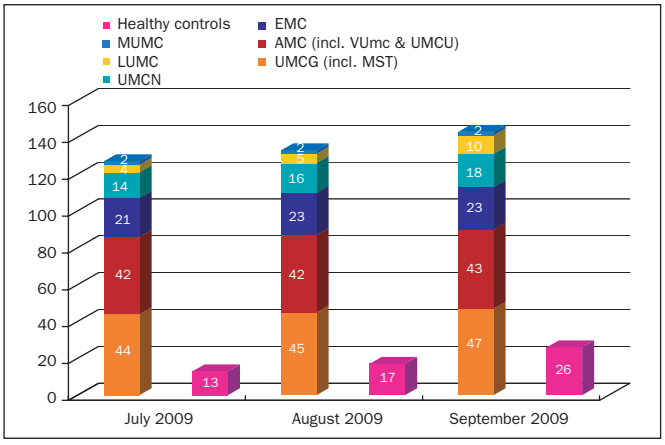

Figure 1. Inclusion of patients and healthy controls in ZAHARA II.

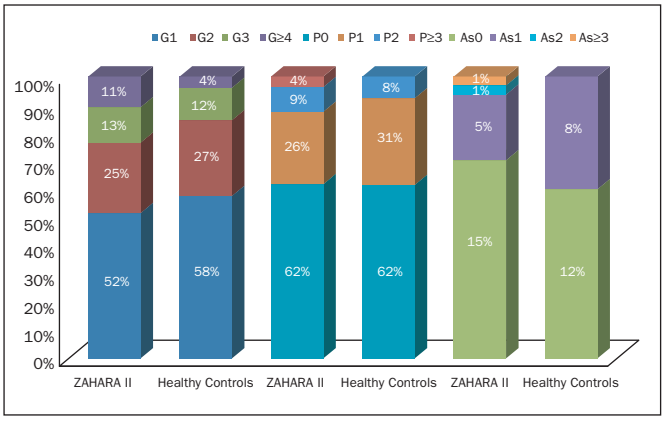

Figure 2. Distribution of gravidity (G), parity (P), spontaneous abortion (As) and offspring from previous pregnancies (children alive) in the ZAHARA II population compared with healthy controls from ZAHARA II.

RACE 3

Planned start inclusion:
1 June 2009

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

Steering committee: Isabelle C. Van Gelder, UMC Groningen; Marco W. Alings, Amphia Hospital Breda; Harry J.G.M. Crijns, Maastricht UMC; Raymond Tukkie, Kennemer Gasthuis Haarlem; Johan Brügemann, UMC Groningen; Joep R.L.M. Smeets, UMC Nijmegen; Charles J.H.J. Kirchhof, Rijnland Hospital, Leiderdorp; Hans L. Hillege, UMC Groningen; Jan G.P. Tijssen, AMC Amsterdam; Dirk J. Van Veldhuisen, UMC Groningen, Robert G. Tieleman, Martini Hospital Groningen
Study coordination: Marcelle D. Smit, UMC Groningen
PhD Student: Ismaël D. Achekar, UMC Groningen

Counselling in the Race 3 study

Patients randomised to the upstream rhythm control arm in the Race 3 study will receive counselling visits by a heart failure/ rhythm nurse as part of the upstream therapy beside medical treatment and cardiac rehabilitation. The main goals of these counselling visits are to stimulate patients' compliance and to motivate them to improve their lifestyle. The visits start one week after inclusion and will be repeated every six weeks until the end of follow-up. During the counselling visits patients receive advice concerning diet (i.e. salt and fluid restriction, caloric intake), alcohol and caffeine intake, and attention is paid to adherence to medical therapy. Furthermore, patients are stimulated to be physically active, and to stay physically active even after the cardiac rehabilitation programme ends. ■

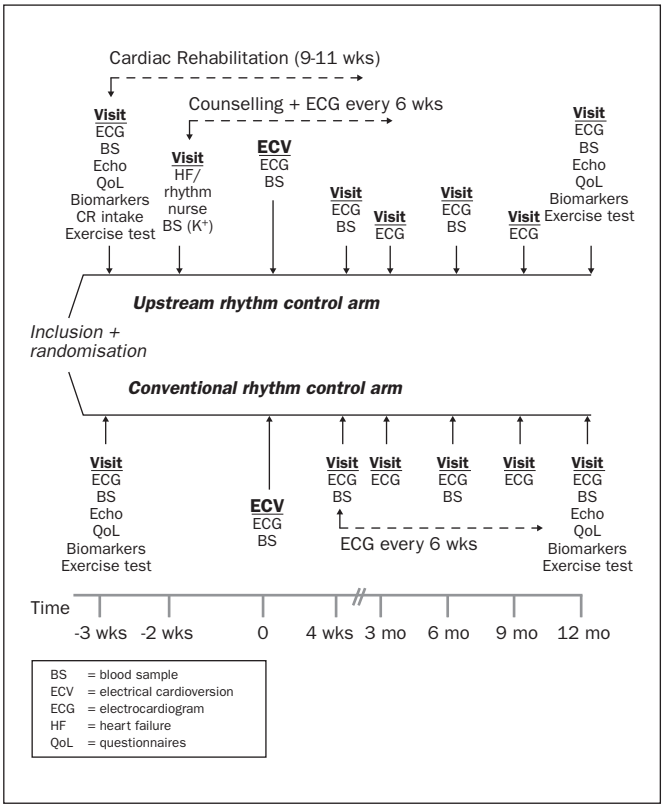

Figure 1. Flowchart of the Race 3 study.

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

Electrocardiography

ECGs were collected at different time points during the course of the study. The ECG registration at baseline was performed on admission to hospital (figure 1). Therefore, some of these ECGs were taken in the ambulance and others on the coronary care unit prior to PCI and some were even done at the beginning of the procedure. The second ECG was taken when patients returned to the coronary care unit after the PCI procedure (figure 2).

All ECGs will be analysed as pairs and are graded for ST-segment resolution by an investigator who is unaware of the clinical data. The sum of ST-segment elevation and deviation in all 12 leads is measured. The second ECGs are classified by comparison of the ST segments with those on the first ECGs. Normalised ST segment was defined as no residual ST-segment elevation of ≥0.1 mV in any of the 12 leads; improved ST segment was defined as ST-segment elevation <70% of that on the first ECG; unchanged ST segment was defined as a residual ST-segment elevation of ≥70% of that on the first ECG. ■

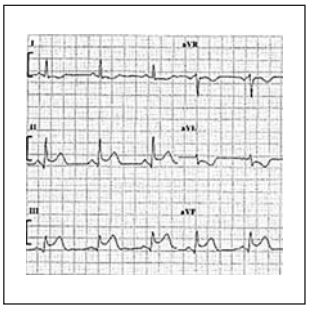

Figure 1.

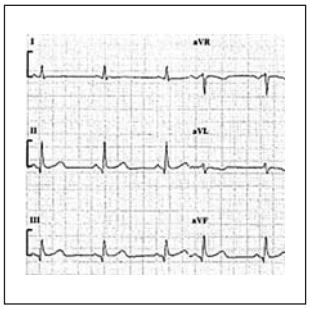

Figure 2.

GENetic CORvitia

National registry for patients and families with a familial heart disease

www.gencor.nl

Number of included patients: 1571
30 September 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

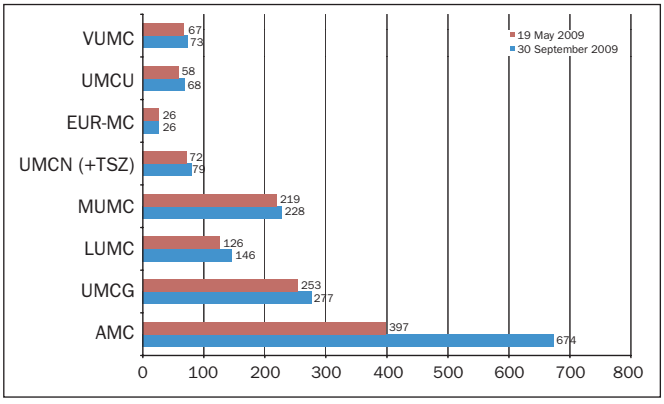

Figure 1. Number of patients included on 19 May 2009 (red bar) and on 30 September 2009 (blue bar) per academic centre. On 19 May 2009 the total number of included patients was 1218. On 30 September 2009, 1571 patients were included in total.

Table 1. In total 66 patients are registered in GENCOR with a mutation in the LQT1-gene causing long QT-syndrome. Only two mutations are reported in two or more families and 16 mutations each occur in just one family.

Protein	Base pair	Number of patients	Number of families
p.Q367H	c.1101G>T	5	1
p.R259C		1	1
p.Arg380Gly	c.1138A>G	1	1
p.I374fsX44	c.1124_1127delTTCA	2	1
p.Ala344Val	c.1031C>T	10	1
p.Arg562Met		1	1
p.Arg243Cys	c.727C>T	15	1
p.Arg397Trp	c.1189C>T	5	1
p.Gly189Glu	c.566G>A	1	1
p.Thr153Thr	c.459G>A	1	1
p.R259C		3	1
p.R190Q		1	1
p.K557E		2	1
p.Arg190Gln	c.569G>A	2	1
p.Arg533Trp	c.1597C>T	1	1
p.Tyr184Ser	c.551A>C	3	1
p.Gln356X	c.1066C>T	8	2
p.Gly292Arg	c.875G>A	4	3
	Total	66	21