**Project group**
B.J.M. Mulder, *AMC Amsterdam*
E.T. van der Velde, *LUMC Leiden*
E. Theeuwes, *ICIN*
H.D.M. Murk–Jansen, *ICIN*
J.W.J. Vriend, *ICIN*

**CONCOR**
**National registry and DNA-bank of adults with congenital heart disease**
**www.CONCOR.net**

# Inclusion results -

## 6 January 2003

**Steering committee**
B.J.M. Mulder, chairman, *ICIN*
E.T. van der Velde, *LUMC Leiden*
E.C.M. Mariman, *AZM Maastricht*
J.E. Speksnijder, *Dutch Heart Foundation*
F.J. Meijboom, *EMC Rotterdam*
H.W. Vliegen, *LUMC Leiden*
G. Veen, *VUMC Amsterdam*
P.G. Pieper, *AZG Groningen*
J.H. Kirkels, *UMCU Utrecht*
A. van Dijk, *UMC St. Radboud Nijmegen*
O. Daniëls, *UMC St. Radboud Nijmegen*
J.L.M. Stappers, *AZM Maastricht*
J.G.P. Tijssen, *AMC Amsterdam*

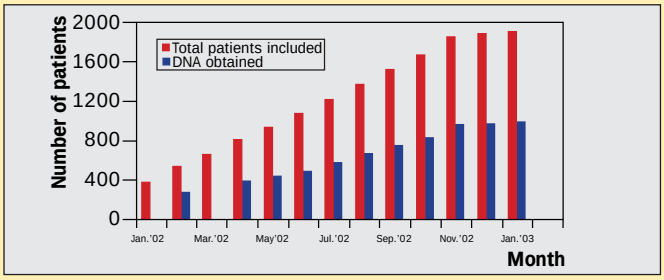


*Figure 1. Progress of inclusion.*

**Table 1.** Patients with affected family members.*

| | | |
|---|---|---|
| **Patients in whom family history was obtained:** | | **896** |
| **Number of patients with positive family history:** | | **190 (21%)** |
| **Patients with positive family history (non Marfan)** | **n = 145** | **/ 845 (17%)** |
| **first degree** | **n=60** | |
| - Parent | | 20 |
| - Child | | 17 |
| - Sibling | | 27 |
| **second degree** | **n=94** | |
| - without 1st degree | | 85 |
| - with 1st degree | | 9 |
| **Patients with Marfan's syndrome with positive family history** | **n=45** | **/ 51 (88%)** |
| **first degree** | **n=45** | |
| - Parent | | 32 |
| - Child | | 14 |
| - Sibling | | 23 |
| **second degree** | **n=12** | |
| - without 1st degree | | 0 |
| - with 1st degree | | 12 |

* One patient may have more than one family member with congenital heart disease.

Marfan syndrome is an autosomal dominant inherited connective tissue disorder. Not surprisingly, almost all patients with Marfan syndrome have affected family members. However a significant number of patients with structural heart disease (without Marfan) have a positive family history as well. Rather striking is the large amount of affected 2nd degree family members.

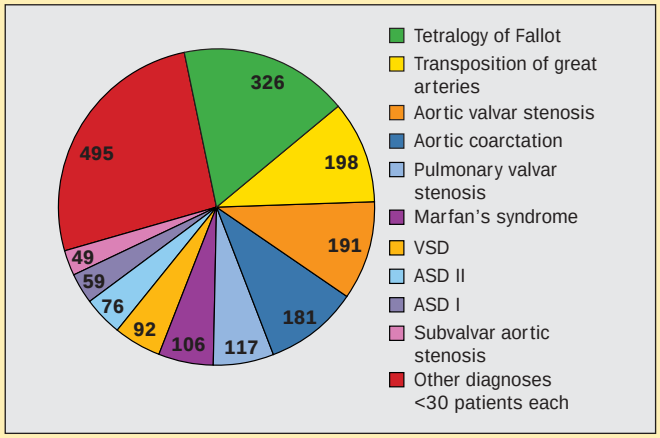


*Figure 2. Most frequent main diagnoses.*

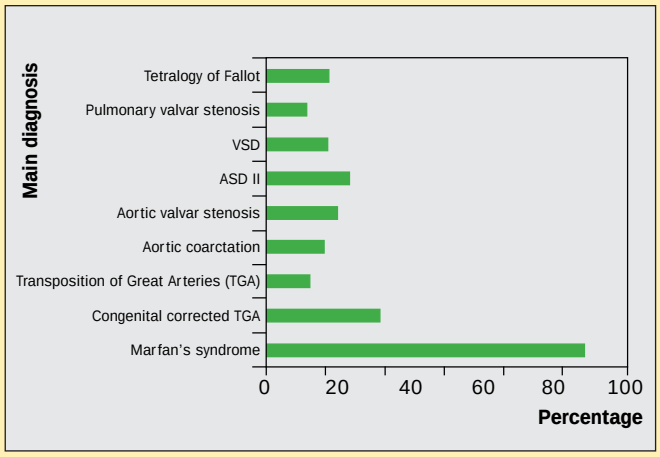


*Figure 3. Patients with affected family members.*