



Parent support group on del 22q11.2
(Belgium; Flemish speaking group)

a. History

Founded in May 1996 after several meetings with parents of children with del22q11 and the multidisciplinary del22q11 team of University Hospital Gasthuisberg Leuven

Currently more than 150 families in the association

b. Aims of the association.

- Improve the quality of life and social integration for all people with del22q11 syndrome and their families.
- Improve the physical and mental well-being, socially as well as occupationally, of all persons with VCFS/del22q11 syndrome.

by:

- giving information on del22q11
- supporting parents and families
- educating parents and professionals
- collaborate with and support active research into 22q11 deletion syndrome

c. Challenges of the association

- All genetic services bring del22q11 families in contact through Vecarfa
- Improve the collaboration between the different parent associations in Belgium (Flemish-French-German speaking groups)

d. Structure of the board

President: Paul Van Wingham

The lay-member board consists of 5 other parents.

Advisory and consulting board: del22q11 experts (professionals)

e. Contact person of the association

Paul Van Wingham: vecarfa@skynet.be

f. Link to the website

<http://users.pandora.be/vcfs/vecarfa.html>

