

CATCH 22

The 22q11 Deletion Syndrome Society of Sweden

a. The society was founded on 6 May 2000 on the initiative of 20 parents in collaboration with Sólveig Óskarsdóttir, Senior consultant in Paediatrics at The Queen Silvia Children's Hospital, Göteborg. It is a nation-wide society based in Göteborg. The number of members is currently (April 2004) circa 90 families, of which some are sustaining members.

b. The aims of the society are to:

- Provide advice, information and help to all the society's members and their families.
- Spread awareness of and information about 22q11 Deletion Syndrome to health services, social services, schools, school welfare officers and to any person who has to deal with, examine, treat or advise people with 22q11 Deletion Syndrome.
- Make sure that decision-making bodies are aware of the special problems of children and young people with the syndrome.
- Collaborate with and support active research into 22q11 Deletion Syndrome.
- Collaborate with other 22q11 Deletion Syndrome groups in other countries in order to exchange information.

c. Challenges of the national association: A large country with a widespread population.

d. The structure of the board of the national association is a mixed one, with lay members and one professional. The president is RoseMarie Larsson.

e. Contact person of the national association:

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f. Link to the website: www.catch22.nu