

2nd International Conference on Rare Diseases and Orphan Drugs

“Patient and Family Needs across the Lifespan”

October 25, 2006, Madrid



Anders Olauson

ÅGRENSKA, Chairman, Gothenburg

HSO, Member of the Board, Gothenburg

EURORDIS, Member of the Board, Paris

EPF, President, Brussels

Eesti Agrenska Foundation, Chairman, Estonia

FRIENDS

FAMILY

STYLING

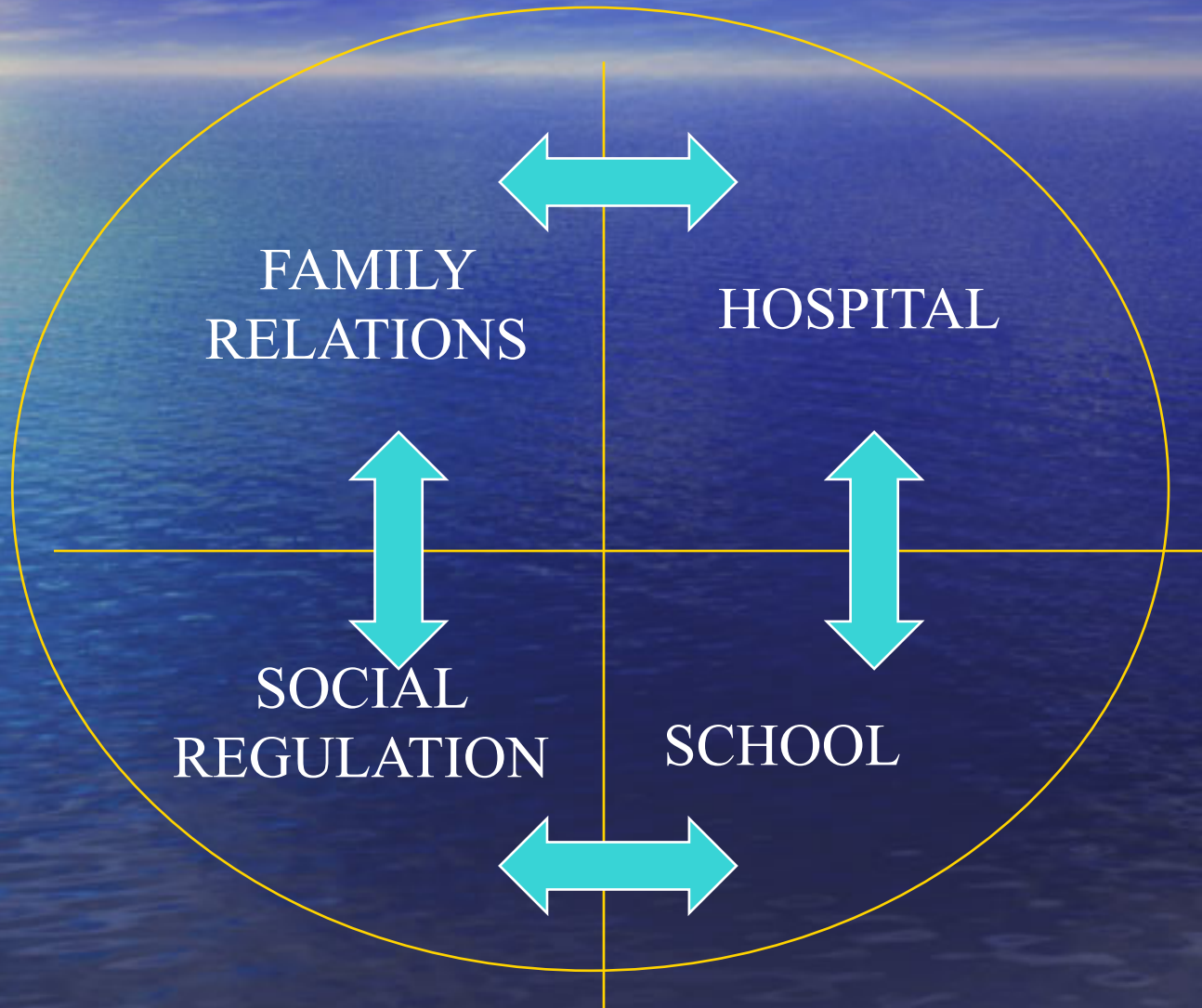
SCHOOL

PARENTS

HOSPITAL



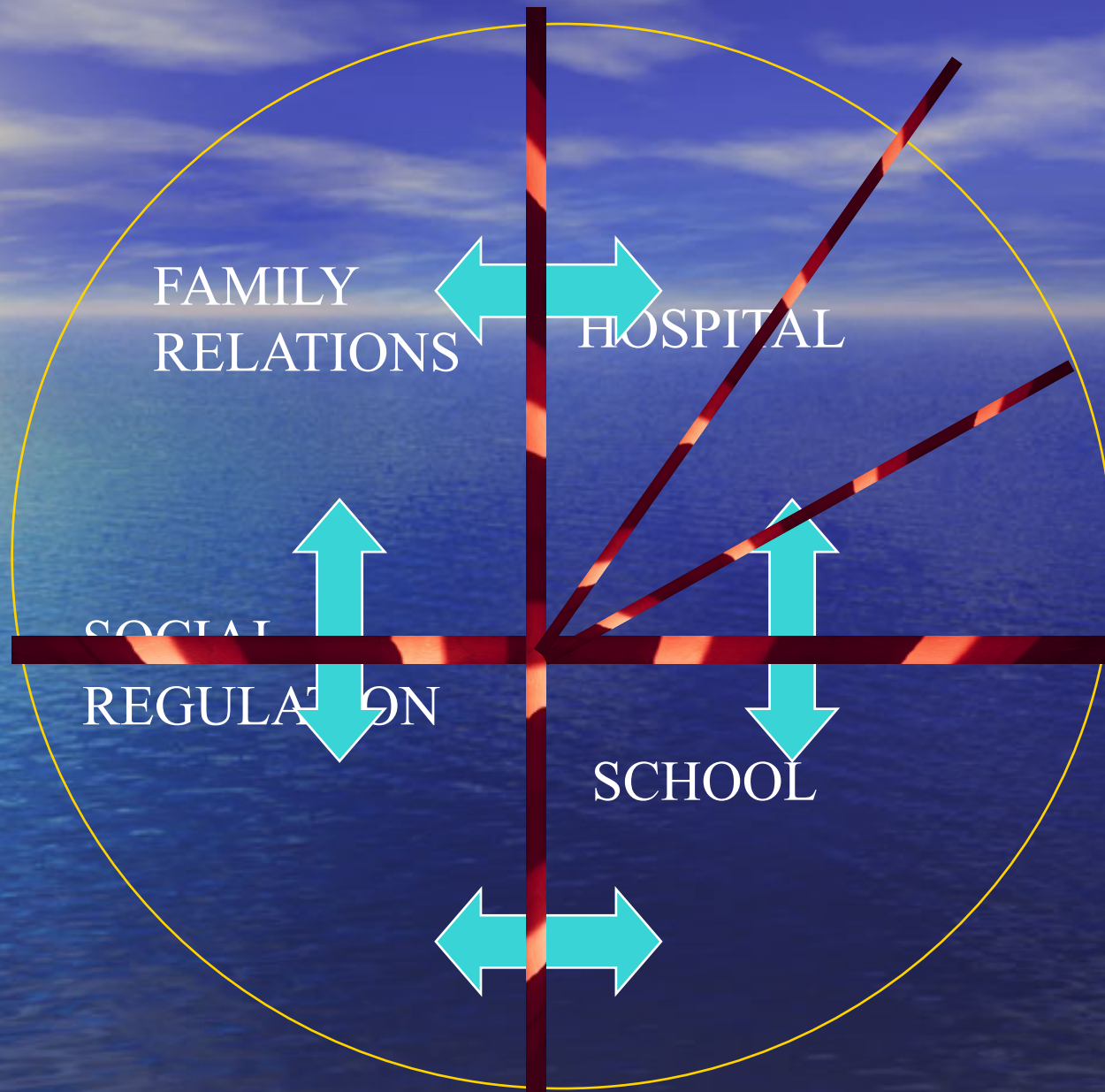
“The life”



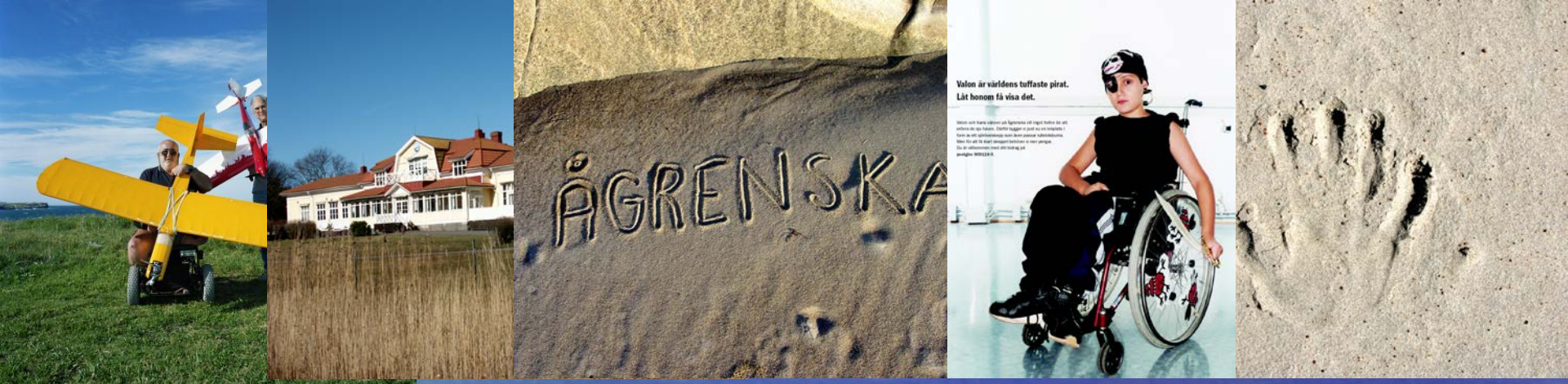
Excluded

instead of

Included



“The life”



- “In order to understand how it is to be a parent to a disabled child – you have to be a parent to a disabled child yourself!”

Åke Martinsson, Sweden

What is Ågrenska?



The Board

- **Programs:**
 - Family program
 - Adult program
 - Respite and summer service
 - Educations
 - ADHD counselor
 - Family support unit
 - Training program to get a job
 - Staff who has a disability
 - Eesti Agrenska
 - Agrenska Friends
 - Agrenska Virtual Academy

Ågrenska is a International Centre of Knowledge



Queen Silvia inaugurates "the Queen Silvia Auditorium" at Ågrenska Academy in 2001.



Ågrenska Family Program



- Rare disorder
- The whole family + family related staff
- Increase coping
- Part of the (Re)hability process
- 4 parallel program:
 - The child with the diagnose
 - Parents
 - Siblings
 - Family related Professionals
- 20 stays per year
- From whole of Sweden
- More than 120 different diagnosis since the start in 1989

Ågrenska 1990 - 2005

- 180 different forms of diagnoses
- From all part of Sweden
- More than 2 400 visiting families
- More than 3 300 visiting parents
- More than 2 500 visiting children/adolescents who have a rare diagnose
- Nearly 3 000 visiting siblings



Effects – families tell:

- Parents feel "normal" for the first time
- The family feel empowered, by meeting other in the same situation
- Parents get new knowledge, to take better care of their own life
- Children with the disorder meet other in the same situation
- Siblings meet other siblings



Educational implications in RD

- Rare Diseases have a specific implication on all aspects of life.
- Educational tools are also part of the treatment!

Methods

- Using a controlled and validated observations material which is approved by the University of Gothenburg
- Systematic observations of the children is performed in our school activities, during the family program
- Lectures of the syndrome to parents and the children's accompanying professionals
- To report back and connect to the children's local teachers at home

Structured observation

- Motor ability
- Perception
- Social behavior
- Speech and communication
- Learning strategies
- Writing, reading and mathematic

Diagnosis in our database



Diagnose	N=	Diagnose	N=
Fragile X syndrome	30	Galaktosemi	4
Klinefleters syndrome	6	Marphans syndrome	11
Möbius syndrome	2	Neurofibromatoses	11
Noonans syndrome	9	OI	2
Prader Willie	13	Rubenstein Tabi	8
Silver Russel	6	Sotos	11
Sturge Weber	4	Tourettes syndrome	20
Treacher Collins	2	Tuberös Scleros	14
Williams syndrome	17	Acondroplasi	12
Albinism	9	Angelmans syndrome	12
Aperts syndrome	1	Aspergers syndrome	33
Beckers muscheldystrofi	7	22q11/catch 22	20
CDG	7	Charge syndrome	5
Cornelia de Lange	6	Crouzon syndrome	7
Dystrofica Myotonika	14	Ehlers Danlos syndrome	10
PKU/Fenylketonuri	9	LMBB	9
Cri du Chat syndrome	7	Turners syndrome	10

HDK + Ågrenska = true!



MasterLab

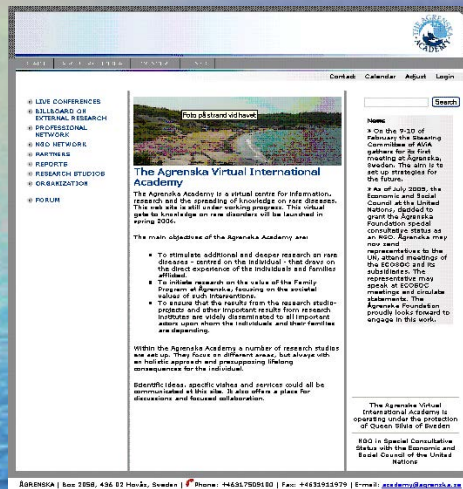
The purpose of MasterLab is to create a platform where different actors can meet and;

- Exchange their knowledge
- Create and develop new products and/or services
- Research

Design as a force of change in society.

- Fight segregation
- Create accessibility
- Broadening the view of me as a person
- Influence other areas of research e.g.;
 - Architecture
 - Travel
 - Leisure time
 - Work

The Agrenska Virtual International Academy



- Virtual centre for research
- Stimulate further and deeper research regarding rare diseases
- Based upon experiences from Agrenska programs
- Holistic perspective
- International cross boarder cooperation's
- Scientific council

- [LIVE CONFERENCES](#)
- [BILLBOARD ON EXTERNAL RESEARCH](#)
- [NETWORK](#)
- [REFERENCES](#)
- [REPORTS](#)
- [RESEARCH STUDIOS](#)



The Agrenska Academy

The Agrenska Academy is a virtual centre for information, research and the spreading of knowledge on rare diseases. This web site is still under working progress.

The main objectives of the Agrenska Academy are:

- To stimulate additional and deeper research on rare diseases - centred on the individual - that draws on the direct experience of the individuals and families afflicted.
- To initiate research on the value of the Family Program at Agrenska, focusing on the societal values of such interventions.
- To ensure that the results from the research studio-projects and other important results from research institutes are widely disseminated to all important actors upon whom the individuals and their families are depending.

Within the Agrenska Academy a number of research studios are set up. They focus on different areas, but always with an holistic approach and presupposing lifelong consequences for the individual.

Scientific ideas, specific wishes and services could all be communicated at this site, as well as discussions and focused collaboration.

News

» Newstext will be here

» Newstext will be here



The Agrenska Academy is operating under the protection of Queen Silvia of Sweden

United Nations Nations Unies



NGO SECTION, DESA
1 UN Plaza, Room DC1-1477, New York, NY 10017
tel: (212) 963-8652 / fax: (212) 963-9248
www.un.org/esa/coordination/ngo
e-mail: desangosection@un.org

011081



21 July 2005

Dear sir/madam:

We would like to inform you that the Economic and Social Council, at its substantive session on July 2005, decided to grant Special consultative status to the organization "Agrenska Foundation (Grosshandlare Axel H. Agrens Donationsfond)".

The organization may now designate official representatives to the United Nations – to the United Nations Headquarters in New York and the United Nations offices in Geneva and Vienna using the form on our web site: www.un.org/esa/coordination/ngo. Designated representatives must pick up their passes in person at the designated site. Needless to say, the regular presence of your organization will allow your organization to implement effectively and fruitfully the provisions for this consultative relationship.

Please note, in particular, Parts II, IV, V and VII and the Council Resolution 1996/31, describing the procedures for carrying out your consultative relationship with the Council. Also, kindly note Part IX, paragraph 61c which requests that organizations in General and Special consultative status submit quadrennial reports on their activities for the four-year period in 2005-2008 to the Committee in 2009. You will be advised of the modalities for completing your report in due course. Meanwhile, we suggest that you maintain detailed records of your activities.

The United Nations issues a calendar of meetings and conferences, which can be obtained by your representatives at the United Nations sites. Every year, you will receive from this office the "Calendar of United Nations meetings open to participation by or of special interest to NGOs in consultative status". The latest copy of the calendar and other NGO-related information can also be found on the NGO Section's homepage.

Finally, should you wish to indicate your status with the United Nations on your letterhead, please use the following wording: *"NGO in Special Consultative Status with the Economic and Social Council of the United Nations"*. The United Nations emblem may not be used, unless expressed approval has been granted by the Legal Office of the United Nations. This is neither granted for stationery use, nor for any printed materials describing your organization.

We look forward to a productive relationship with your organization and its representatives.

Sincerely yours,

Hanifa Mezoui, Chief
NGO Section / DESA

Agrenska Foundation (Grosshandlare Axel H. Agrens Donationsfond)

Box 2058
SE-436 Hovas
Sweden
FAX: 46-31-911979

2V FACSR

October 25, 2006

Estland – Eesti Agrenska



Tammistu

Conclusions

- The patient of the twenty-first century
 - Difference from the past
 - Similarities with the past
 - Needs for today
 - Needs for tomorrow

The Swedish Vikings where the first Entrepreneur and the patients are today's

