

Identifying and Meeting Patient and Family Needs Across the Lifespan

September 14-15, 2007, Brussels

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FRIENDS

FAMILY

HOSPITAL

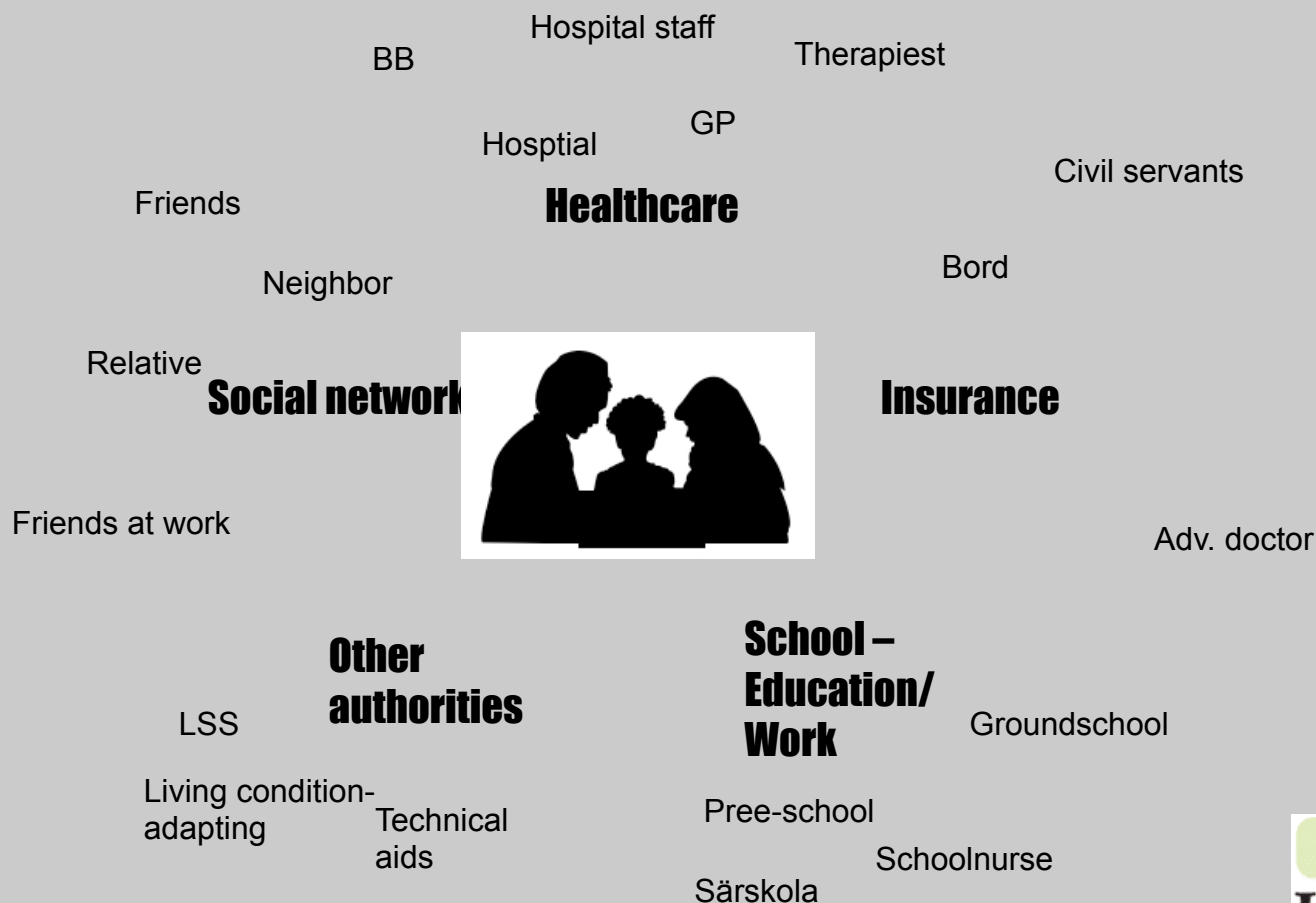
SIBLING

PARENTS

SCHOOL



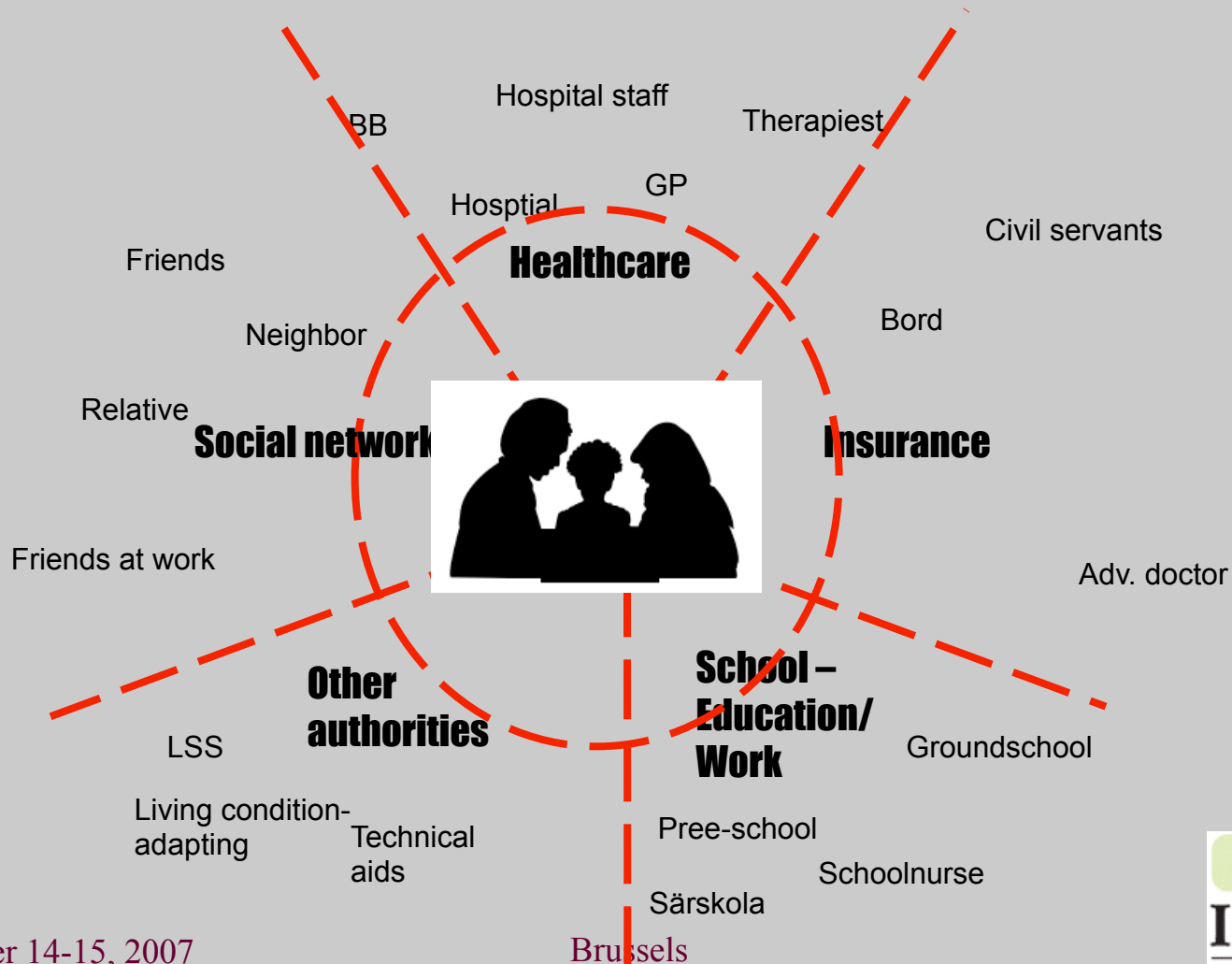
Background – reality for the family



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Background – reality for the family > 40 contacts



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Experience from family- and adult programs



- To few among different professionals have appropriate knowledge about RD
- Services from society don't coordinate for persons who have a RD
- There is a need to discuss possibilities rather than obstacles
- Describe themselves as "outsiders"
- They always have to explain and defend their condition because of it's rareness
- They need in different phase of live receive knowledge and meet other who also have the same RD

Present time!

- RD – needs both geographically and occupationally cross border cooperation
- Insufficient activities from the Healthcare system because of lack of proper knowledge about RD
- Oftentimes wrong or severe delayed diagnose
- Parents stay home from work unnecessary because of insufficient knowledge
- They know to little about the diagnose and where to seek knowledge of proper support
- To little cross border cooperation between different centre within the system



The conference will be opened by
HER MAJESTY QUEEN SILVIA of Sweden.
The Ågrenska Centre is operating under
the patronage of the Queen.



orders.

The family perspective is also given to all topics at the conference, in order to enhance understanding among all involved persons. After the opening ceremony, **MRS. BERIT ANDNOR, Minister for Children and Families**, from the Department of Social Affairs in Sweden, will present the Swedish approach.

In every section of the conference internet participants are invited to address the speakers with questions, which will be answered during the conference.

On our website you will find the program and a registration form.

Welcome

THE ÅGRENSKA ACADEMY

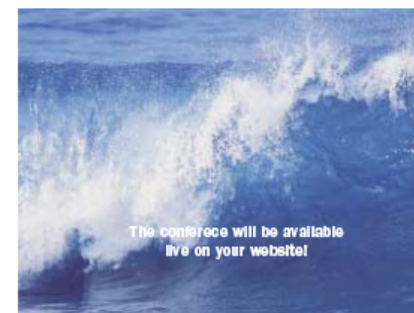
Anders Olsson

Tuesday 21 October

- 12.00 - 13.00** Buffet lunch
- 13.00 - 13.10** Opening of Conference
Anders Olsson, Ågrenska Academy
- 13.10 - 13.20** Opening Ceremony
H. M. Queen Silvia of Sweden
- 13.20 - 13.40** The Swedish approach -
To have a child with a disability
Berit Andnor, Minister for Children and
Families, Department of Social Affairs, Sweden
- 13.40 - 14.20** The Family perspective on rare disorders
* From birth to adult life
* Mom and Dad, different reactions
* The family of today, implications
* Questions from Internet participants
Elisabeth Wallenius, Sällsynta Diagnoser
Carina Hvalstedt, Ågrenska
Lotta Delive, Gothenburg University
Jan Andersson-Norlander, Mun-H-Center,
Orofacial centre in Sweden
- 14.20 - 15.00** Childhood and beyond
* Educational implications of rare disorders
* Play, design and new possibilities
* Making friends
* Questions from Internet participants
Gry Hammer Neander, NORDSPES, Norway
Ann-Catrin Röjwik, Ågrenska
Bo-Erik Gyberg, Gothenburg University
Centre for Design and Culture.
- 15.00 - 15.30** The Major Ågrenska Award 2003
Prize Award Ceremony
H. M. Queen Silvia of Sweden
- Coffee with musical entertainment
The Church choir Omaticantus, Halland
- 15.30 - 16.20** An international view
* Access to knowledge
* Access to treatment - new network for centres
of excellence
* Access to contacts - "Perspectives in European
Collaboration - the role of EURORDIS" (European
Organisation for Rare Disabilities)
* Questions from Internet participants
James Hansen, NIH (National Institute
of Health) USA
Stephen Groft, NH, USA
Arrigo Schieppati, Mario Negri Institute, Italy
Terkel Andersen, EURORDIS, Denmark
- 16.20 - 16.50** Surprise!
- 16.50 - 17.00** End of day - summary
Anders Olsson
- 17.00 - 20.00** Dinner and musical entertainment
The Church choir Omaticantus, Halland

Wednesday 22 October

- 08.45 - 09.00** Summary of day 1
Anders Olsson
- 09.00 - 09.15** Living and Growing -
"Adapting to the changing needs
of patients with a rare disease"
Lesley Green, CLIMB, England
- 09.15 - 10.15** The need of new perspectives
* Childhood and beyond
* The Ågrenska program
* Cross border cooperation - examples
* Socioeconomic facts
* Genetic knowledge - for the future
* Design for all needs
* Questions from Internet participants
Christopher Gillberg, Gothenburg University,
William Gunnarsson, Orphan Europe, France
Person to be confirmed, Business School of Gothenburg
Jan Wahlström, Sahlgrenska University Hospital
Stefan Johansson, Funke HU, Sweden
- 10.15 - 10.45** Coffee
- 10.45 - 11.45** Parallel workshops
Chair, to be confirmed
- 11.45 - 12.15** Feedback from workshops
Considerations:
* The Family perspective
* Childhood and beyond
* An international view
* The need of new perspectives
Plans and projects for next year
Topic 1
Topic 2
Topic 3
Chair Anders Olsson
- 12.15 - 13.00** Closing statement and Buffet lunch



The conference will be available
live on your website!

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ICORD
International Conference on
Rare Diseases & Orphan Drugs

Other comments and needs..

- Assure easier reliable access to information
- How to go from a problem pathology perception to a potential family oriented perspective?
- How can we, authorities, and the medical profession, patient organizations in different countries get in closer contact to increase knowledge, spread ideas, and assess best treatment/therapies?
- What will life be like for my child as an adult and how can I influence that when the child is young?

- How to change attitude towards disability more positive and acceptable in the professionals, families and the society?
- How can we speed up the diagnosis and how can the information about the disease to the family be better and more understandable?
- Educational perspective!
- How will services be accessible for minority groups in our society?
- The economic perspective, income and costs from an individual perspective.
(Investment rather than costs!)

International activities

- Norway
- Sweden
- Finland
- Estonia
- Spain
- France
- USA
- Argentina
- Australia
- New Zealand
- ?

Suggested activities

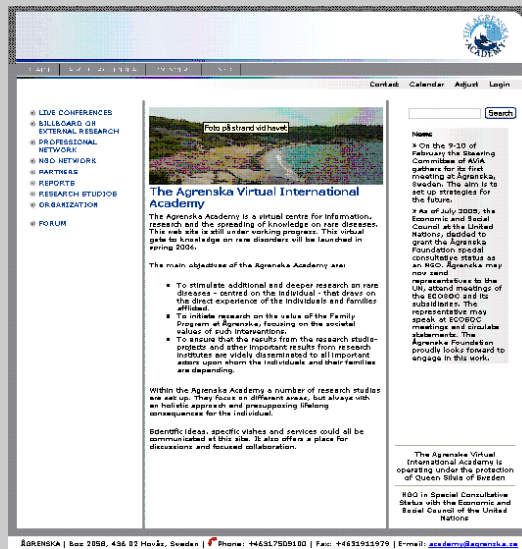
- Start a workgroup who should...
- Set up a network among present and planned centre
- Make a global survey about which and where there are centre working



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The Agrenska Virtual International Academy

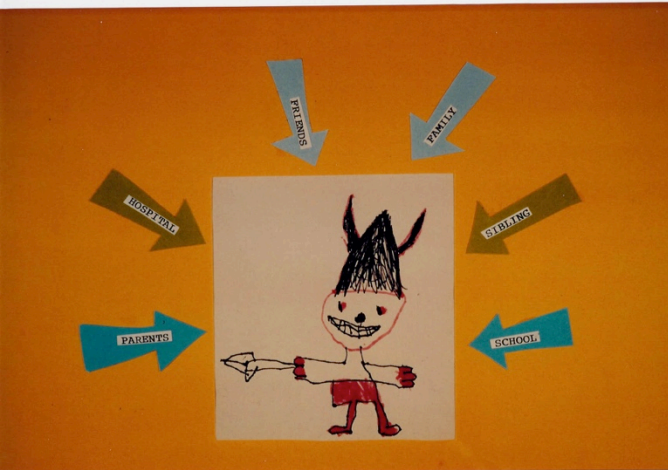


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- Virtual centre for research
- Stimulate further and deeper research regarding rare diseases
- Based upon experiences from Agrenska programs
- Holistic perspective
- International cross boarder cooperation's
- Scientific council
- Appointed “NGO in Special Consultative Status with ECOSOC





“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

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