

# International perspective on Pharmacogenetics

October 19, 2005 Rome

“Impacts on human health and health care systems”

**Anders Olauson** Gothenburg

**EURORDIS**, Member of the board, Paris

**European Patients Forum**, President, Brussels

**Eesti Agrenska Foundation**

**ÅGRENSKA**, Chairman, Gothenburg

**HSO**, Member of the board, Chairman, Estonia



I don't claim that I hold the Truth.

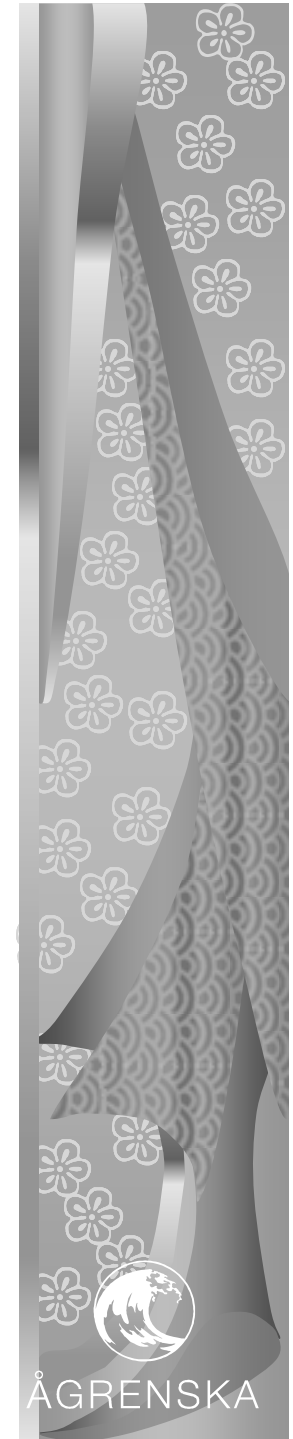
The views expressed in this presentation are patients view.

EURORDIS

EPF

AGRENSKA ACADEMY

EESTI AGRENSKA



# What about pharmacogenetics?

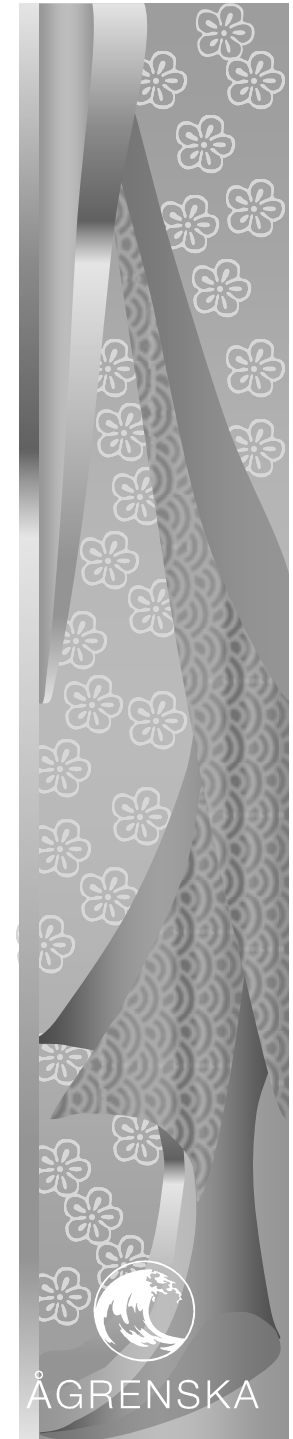
YES – We think this is great

YES – We feel comfortable to have medicine that is for “my body”

YES – We are used to be tested

YES – We would like to get the best drug wherever I live and whenever I need it

YES – to Pharmacogenetics!



# BUT

- There are some implications!

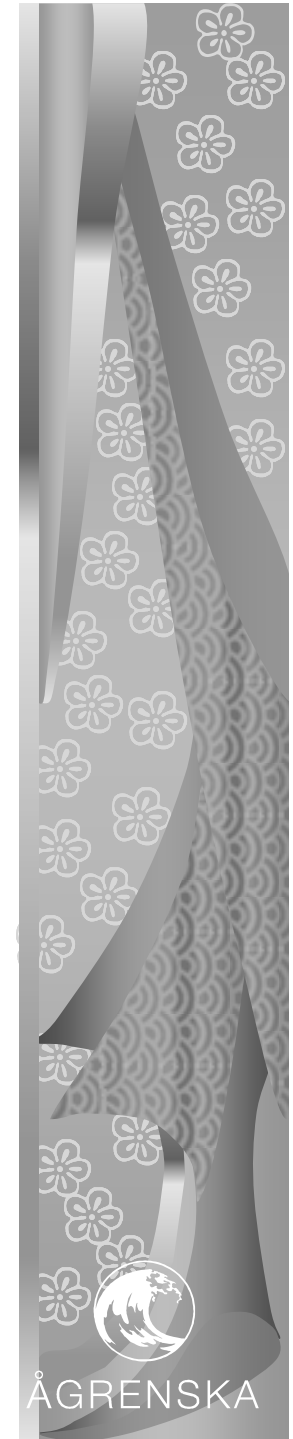


Short time benefits  
Longtime regret



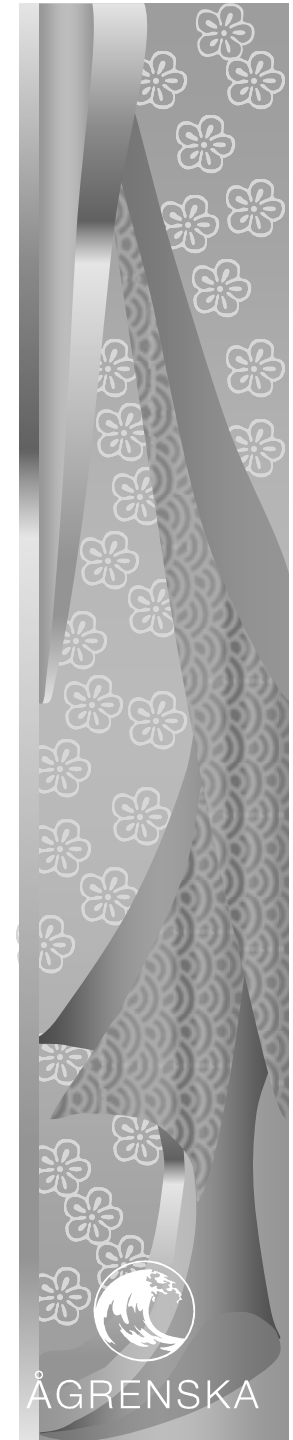
# Implications –

- Discrimination
- Insurance
- Employment
- Adopting a child
- Anti terrorist
- Others.....



# Implications....

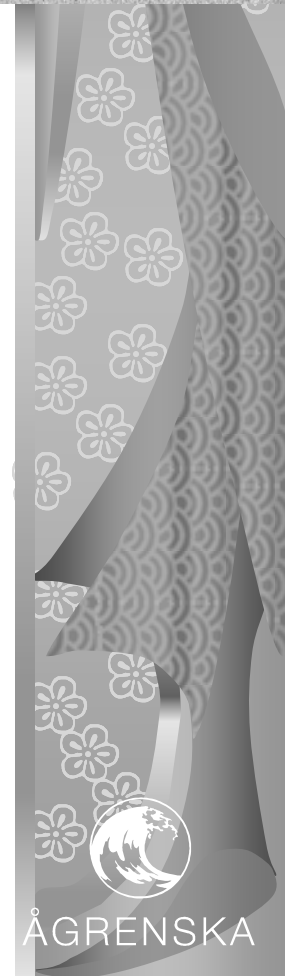
- Storage of DNA samples
- Informal consent
- New perspective
- Education





“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





Ågrenska of today was inaugurated  
1989



**Queen Silvia is the Protector of Ågrenska**



# What is Ågrenska?



## ■ 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



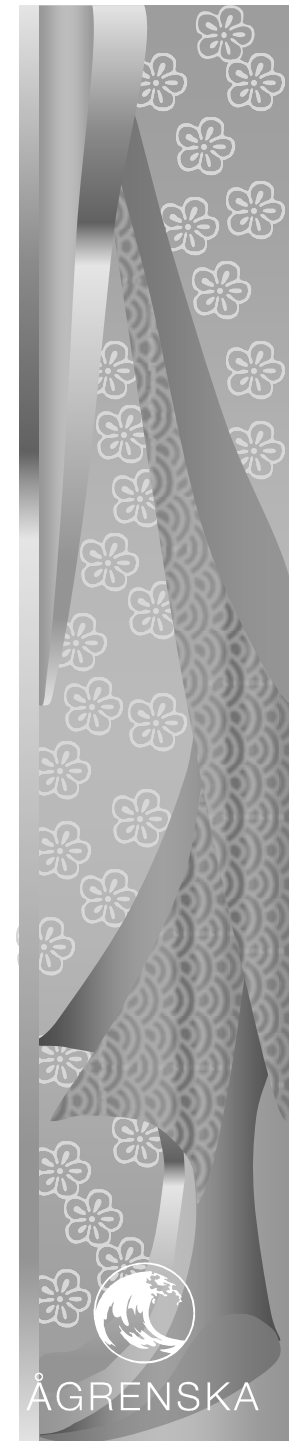
# Where is Ågrenska located?



# 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**



## Effects – families tell

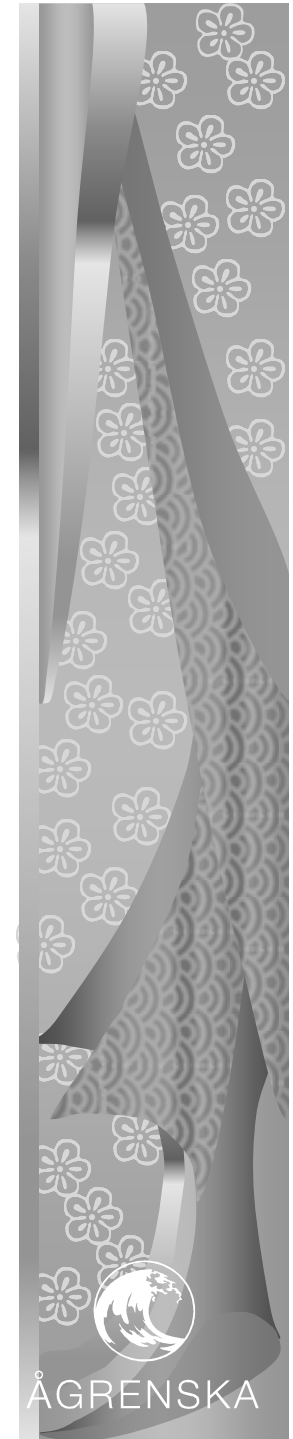
- Parents feel "normal" for the first time
- The family feel empowered, by meeting other in the same situation
- Parents get new knowledge, to take better care of their own life
- Children with the disorder meet other in the same situation
- Siblings meet other siblings



# Effects – scientific proof:

- **Reduced costs for healthcare**
- Attended family program - consumed medical care for 13.000 SEK/ year
- Attended ordinary program – consumed for 35.000 SEK/year

**45 Billions €**



# 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



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## 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



The **Scientific Council** of AiA consists of representatives mainly from the academic field in areas such as psychology, socioeconomic, neuropsychiatry and paediatric medicine. There are also representative from important field which affect the persons who have a rare disease. The role of the Council is to evaluate the scientific out-put and to advise in new developments and external collaborations.

General secretary **Gunilla Ekvall**, HSO Sweden

Professor **Christopher Gillberg**, University of Gothenburg, Department of Child and Adolescent Psychiatry

Professor **Ola Hjalmarsson**, The Queen Silvia Children Hospital

Professor **Erland Hjelmquist**, University of Gothenburg Department of Psychology

Chairman **Anders Olauson**, Ågrenska



So the question is how can patients become more informed about medicines to learn of possibilities and other critical details? ;

- All information, should be communicated in a way that the patient understands so that he/she can take responsibility.
- Adjust the local legislations to better protect the integrity for the patients, national as well as international.
- We need new and secure possibility for storage the DNA samples. – The numbers is supposed to increase enormously
- The State/Regulatory – by creating opportunities to improve the flow of accurate, reliable and balanced information from various stakeholders.
- Patient's org. like EURORDIS, European Patient's Forum (EPF), and Agrenska – they can educate patients, disseminate information and enhance patient dialogue among various stakeholders
- The different companies who deliver the services, e.g. a pharmaceutical industry, should improve their cooperation and dialogue to patients organisations



# Towards the future!

