

## Better support in Sweden for people with rare diseases and their families



**Thanks to greater competence and exchange of experience, people with rare diseases will get better and faster help from the community. This will hopefully be the outcome of the National Board of Health and Welfare's new National Function for rare diseases, that will be entrusted to 'Ågrenska' outside Gothenburg.**

On 24th July 2010, the National Board of Health and Welfare was commissioned by the Swedish government to establish a coordination and information dissemination programme in the field of rare diseases. A disease is characterized as rare if it affects one person per 10 000 inhabitants, or a maximum of 900 people in Sweden. Rare diseases are often syndromes, or a combination of multiple symptoms and impairments. They usually lead to diverse and changing long-term needs.

There is scarce knowledge from a holistic perspective on the needs of people with rare diseases regarding their health care, rehabilitation services, educational opportunities, social services, social insurance, employment and other social facilities to ensure their quality of life. The rarer the condition the more challenging this becomes.

Ågrenska outside Gothenburg won the National Board of Health and Welfare's procurement on a nation-wide rare diseases programme that will start 1st January 2012.

The agreement with the Swedish government includes;

- promoting the coherence and coordination of health care resources for people with rare diseases, and increased coordination with the social insurance, employment services, social services, NGOs and other actors
- contributing to the dissemination of knowledge and information
- contributing to the exchange of good practice and experiences, also at international level
- developing an inventory of available resources for people with rare diseases.

In his reaction to the news, Anders Olauson, Chairman of Ågrenska AB said:

“Mostly I think of the relief that families who have a child with a rare diagnosis will feel about the government's decision to set up this unique programme. A decision to put the holistic view first. I am proud that we have won this tender and feel honored that Ågrenska now have the opportunity to develop and manage this work in collaboration with others, “

### **For more information, please contact:**

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Ågrenska activities, work from a holistic perspective for children, adolescents and adults with disabilities, their families and professionals. Ågrenska is a creative and stimulating meeting place to address real needs, enhance knowledge and increase people's ability to cope with their daily lives and live as good and as independent lives as possible. Ågrenska was founded in 1914 as a convalescent home for children with contemporary long-term illnesses.

HM Queen Silvia is Ågrenska's patron.