

INTRODUCTION RARE DISEASES

- a web-based course for professionals who meet people with rare diseases and their families

Ågrenska has developed a web-based introduction about rare diseases that, from a holistic perspective, intends to provide basic knowledge in the field.

Background

PLWRD and their families need support from many parts of society. Surveys show that knowledge of rare diseases is generally low among the actors you need support from. Collaboration between the actors is often also inadequate. It makes life difficult for PLWRD and their families throughout their lives.

The aim and purpose

The aim of the course is to increase the knowledge about rare diseases among professionals, primarily within rehab units, schools, the Swedish Social Insurance Agency and personal assistance so that they can contribute to create better conditions for PLWRD and their families.

The purpose is also to increase interest in learning more about different areas related to rare diseases.

Raise the level of knowledge

Gives basic knowledge of rare diseases and insight into the challenges in the field.

The course is free of charge and gives an insight into the challenges associated with life with rare diseases and important areas to think about as a professional, e.g. collaborating with PLWRD and with other professionals.

Help to professionals

Recommendations on how to work, where to look for information and where to turn with questions.

In the course, the participant gets recommendations on how to work, where to seek more information and where to get help when there is a need to know more. In addition, the course contains reflection questions that can be discussed at workplaces.

In-depth knowledge

Recommendations in-depth training provided by Ågrenska.

Ågrenska arranges seminars, courses, and conferences for professionals who meet children and adults with rare diseases.

Certificate

Certificate is available after passing a knowledge test and answering questions about the course.

In order to get the participants to complete the course, and to acquire basic knowledge about rare diagnoses, the participants have the opportunity to obtain a certificate when they have completed the whole course, tested their knowledge and answered questions about the course. The course takes about one hour to complete.

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Introduction rare diseases is produced by staff at Ågrenska in collaboration with several people, among others, Rare Disease Sweden, Centres for Rare Diseases, The National Agency for Special Needs Education and Schools, and The Swedish Social Insurance Agency.

The course was launched on Rare Disease day, February 29th 2020. The course can be adapted for use in other countries.



Scan me for more information and register. English subtitles available.



ÅGRENKA

Ågrenska is a national centre of competence in Sweden, providing programs for children and adults with disabilities, their families and for professionals supporting the family.