

Stiftelsen Sällsyntafonden

The Rare Disease Research Foundation

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Summary

The goal of the Rare Disease Research Foundation at Ågrenska "Sällsyntafonden" is to promote rare disease research to facilitate the lives of individuals with rare diseases of all ages by developing better diagnostics, tailor-made treatments and an improved overall holistic care.

Donations to Sällsyntafonden will primarily be directed to research on rare diseases in general, but targeted funds for specific purposes and specific diagnoses or diagnostic groups will be accepted. However, in addition to administrative costs, 10% of the donated sum will always go to the fund's common pot.

Sällsyntafonden has a medical and a multidisciplinary scientific advisory board with cutting edge competence. Patient advocates are actively involved in all boards. Sällsyntafonden will make general calls in all areas of rare diseases. In addition, the foundation will have specific targeted calls within these diagnostic groups:

- ✓ Rare endocrine conditions
- ✓ Rare gastrointestinal diagnoses
- ✓ Rare hematological diseases
- ✓ Rare immune deficiency and immunological diseases
- ✓ Rare vascular diseases
- ✓ Rare hepatological diseases
- ✓ Rare respiratory diseases
- ✓ Rare congenital metabolic diseases
- ✓ Rare congenital urogenital diagnoses
- ✓ Rare neuromuscular diseases
- ✓ Rare kidney diseases
- ✓ Rare skeletal diseases
- ✓ Rare congenital malformations with or without intellectual disability / autism
- ✓ Rare cancer predisposition syndromes
- ✓ Rare epilepsies
- ✓ Rare neurological diseases
- ✓ Rare skin disorders
- ✓ Rare eye diseases
- ✓ Rare heart diseases
- ✓ Rare connective tissue and musculoskeletal diseases
- ✓ Rare ear, nose and throat (ENT) disorders

Rare diseases present a public health challenge and imply a great economic burden. Rare disease research can contribute to identify, develop and suggest strategies to minimize costs and at the same time improve healthcare, social services, schools, insurances and labor for individuals living with rare diseases and their families. In addition, advanced knowledge about rare diseases will pave the way towards better understanding and care for patients with common diseases.

Conclusions

By donating to Sällsyntafonden you contribute to research so that more individuals with rare diseases can get an improved holistic care and receive;

- ✓ An explanation for the disease through an accurate diagnosis
- ✓ Information about the natural course of the disease
- ✓ Improved supportive care and prevention strategies
- ✓ Precision medicine with available targeted therapeutics
- ✓ Possibilities to develop new and to re-purposing of already existing drug therapies
- ✓ Tailored psychological and pedagogical tools
- ✓ Tools to improve everyday life
- ✓ Better diagnostic and therapeutic devices

Donate to improve lives for individuals with rare diseases and their families!



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Today, we support Swedish researchers but our plan is to become an international rare disease research foundation in the near future.

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