

The use of social media to create a foundation and drive research on rare diseases



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STAR** foundation, SallaResearch.org*

Introduction – S.T.A.R

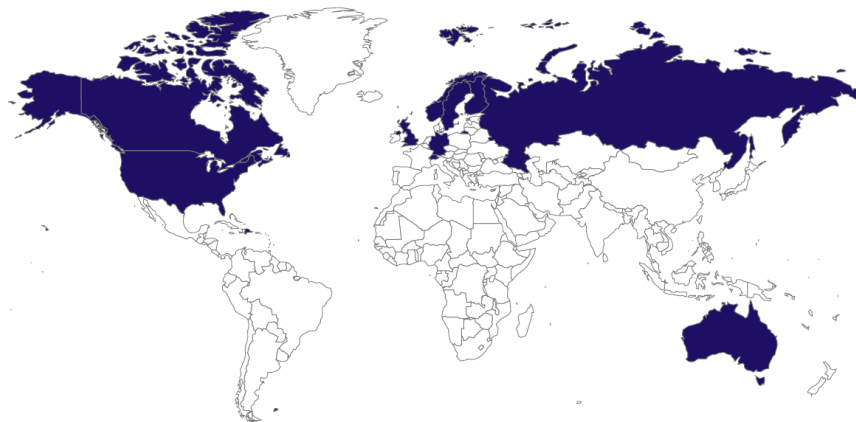
S.T.A.R - Salla Treatment and Research Foundation (S.T.A.R) was established by the Foglio family in New York in 2018 to promote research, treatments, awareness, and family networks for Salla disease. S.T.A.R is driven by an unwavering belief that with sufficient support, a small team of committed researchers, families, supporters, and advocates can create meaningful solutions for those impacted by the disease.

Salla disease

Salla disease, intermediate severe Salla disease, and infantile free sialic acid storage disease (ISSD) are neurodegenerative disorders resulting from increased lysosomal storage of free sialic acid. Salla disease has been reported in approximately 200 individuals in the world, mainly from Finland and Sweden.

Social media to unite families from all over the world

Through social media, STAR has managed to connect about 30 families in 13 countries around the world.



A network for parents has been created where they can support each other, share knowledge and experience on how to further develop their child.

Funding through Social media

- Private funding initiatives using social media such as Facebook
- An international walk held in 5 countries arranged and informed mostly through social media.
- Auctions, concerts, and gala
- In less than two year these initiatives have been able to raise funding for at least 2 years of research at NIH, US.

Research and SASD consortium

In 2018 a Think Tank was held where scientists and families came together. The SASD* consortium was established and below are just a few examples on research conducted by SASD consortium with the support from S.T.A.R**;

- A knockout mouse model of Salla Disease established.
- A new Salla disease knockin mouse model is being generated at NIH, US.
- SLC17A5/Sialin mutation analysis allowing for research confirmation of diagnosis has been established at NIH, US.
- The Salla disease intracellular phenotype is being characterized at NIH, US for use in drug screening/testing.

* SASD – Sialic Acid Storage Disease Research

** S.T.A.R – Salla Treatment and Research