



SVENSKA  
**MPS**  
FÖRENINGEN

**August 2<sup>nd</sup> – 6<sup>th</sup> 2023, Viskadalen, Sweden.**

Dear SSIEM,

On behalf of the Swedish MPS association, I am writing to you to express our heartfelt gratitude for your support – our family conference would not have been so successful without it!

MPS is short for Mucopolysaccharidoses, and is a group of lysosomal storage diseases. There are six different kinds and while they all affect all cells in the body, they express themselves in different ways. It is an ultra-rare disease, affecting less than 1 in 100,000 newborn children. There is no cure, though there are treatments for some of the variants that can reduce the progress of the disease.

Your contribution made it possible all families of the MPS association to participate in one or all of the days. They were able to listen to highly qualified lecturers, participate in round table discussions. We organized various activities also for children, playing games and doing crafts, as well as group discussions with an experienced psychologist for healthy siblings of patients.

It is my desire to convey our deepest gratitude for your financial support that made it possible for us to host this biannual family conference during the wonderful Swedish summer with our patients, their families and health professionals.

List of speakers and scientific panel:

Marizela Kljajic, Psychologist, Sweden

Marion Brands, Doctor, The Netherlands

Evelien Tump, Nurse, The Netherlands

Anna Hallgren, Sociologist, Sweden

Lina Håkansson, Occupational Therapist, Sweden

Stewart Rust, Paediatric Neuropsychologist, United Kingdom