

Online and free of charge!
The times are Stockholm times (CET)

Spina Bifida-dagarna 2024

Thursday, September 12
Clinic and practice

To sign up, go to:

https://docs.google.com/forms/d/e/1FAIpQLSfvKI0kXXIWDYku35cNgBO5Ic_MOH_Dah8gWd7fZCj6YHgCUg/viewform?usp=pp_url

09.00-09.15 – **Welcome and introduction (svenska/norska)**

09:15-10.00 – **Basic information on spina bifida and an update on Orphanet codes and classifications (English)** Petra Aden

10.00-10:15 **Paus/Break**

10:15-10:45 – **Uppföljningsprogrammet för ryggmärgsbråck i Sverige – MMCUP (svenska)** Annika Lundkvist Josenby

10:45-11:15 - **Sommarläger för barn med ryggmärgsbråck (svenska)** Annette Hill, Anna-Karin Undrén och Linda Sandström

11:15-11.30- **NOSCOS update (English)** (Elisabeth Fagereng)

11.30-12.30- **Lunch**

12.30-12:55 – **Hva er Studio 99? (norska)** Studio 99

13:00-13:45 - **Multidisciplinary prevention and follow up of pressure ulcer at Sunnaas rehabilitation hospital (English)** Ingebjorg Irgens m.fl.

SB-dagarna 2024
Friday, September 13
Research/International focus

9:00-9:30 – **Mental health in parents of children with SB** (*English*) Melinda Rocchi

9:30-10:30 – **“And what about me?” The situation of siblings of chronically ill children** (*English*) Laura Inhestern

10:30-10:45 **Break**

10:45-11.10 – **Pain in spina bifida** – (*English*) May Phyu Sin

11:15-12.00 – Planned session on tethered cord (*English*) (not confirmed)

12:00-12:45 **Lunch**

12:45-13:15 – **MMCUP – the Swedish Combined Follow-Up Program and National Registry for Individuals with Spina Bifida**
(*English*) Annika Lundkvist Josenby

13:20-14.00 – **Update on spina bifida in Ethiopia** (*English*) Yakob Ahmed

14.05-14.40 – **Update from the Spina Bifida Association in the United States**
(*English*) Judy Thibadeau

14.40-14.50 **Break**

14:50 -15:30- **The role of the caregivers in Postural care management: a case study from Argentina** (*English*) Silvana Contepomi

Welcome!