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**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/1FAIpQLSfvKl0kXXIWDYku35cNgBO5lc\\_MOH\\_Dah8gWd7fZCj6YHgCUg/viewform?usp=pp\\_url](https://docs.google.com/forms/d/e/1FAIpQLSfvKl0kXXIWDYku35cNgBO5lc_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 – **Uppfölningsprogrammet for ryggmärgsbräck i Sverige – MMCUP**  
(svenska) Annika Lundkvist Josenby

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

11:15-11.30- **NoSCoS update (English)** (Elisabeth Fagereng)  
(NoSCoS (Nordic Spinal Cord Society) er det nordiske ryggmargsskadenettverket. Det har nylig blitt opprettet en interessegruppe for ryggmargsbrokk (SIG-SB))

11.30-12.30- **Lunch**

12.30-12:55 – **Hva er Studio 99? (norska)** Studio 99.  
(Studio 99 bedriver arbete med vuxna med SB)

13:00-13:45 - **Tethered cord (English)** (Magnus Tisell)

**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**

10:45-11.25 – **Update on spina bifida in Ethiopia** (*English*) Yakob Ahmed

11:30-12.15 – **Multidisciplinary follow-up and prevention of pressure ulcer** (*English*) Ingebjorg Irgens et al.

12:15-13:00 **Lunch**

13:00-13:30 – **MMCUP – the Swedish Combined Follow-Up Program and National Registry for Individuals with Spina Bifida** (*English*) Annika Lundkvist Josenby

13:30-13.55 – **Pain in spina bifida** – (*English*) May Phyu Sin

14.00-14.40 – **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!**