

Living with Spina Bifida myelomeningocele as adults

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LEARNING OBJECTIVES

- Increase the insight into specific challenges that people with SBM experience during adulthood
- How research can contribute to improve everyday life for persons with SBM
- How to structure a good follow-up routine for persons with SBM

Adults with Spina Bifida Myelomeningocele (SBM) often have characteristic challenges that affect everyday life. Although, they have much in common with people with Spinal cord injury (SCI), they are often neglected when it comes to systematic multidisciplinary care and follow-up routines. Why?

The aim of this workshop is to listen to the voices of adults with SBM regarding their needs, and to discuss recent research in this field.

The workshop will, in dialogue, explore the themes below.

- Representatives of persons with SBM and their organizations will give their picture of their challenges in everyday life as well as their expectations on the healthcare system and society.
- Recent research from Resource Center for Rare Disorders (TRS), Sunnaas Rehabilitation Hospital, and the Spinalis Clinic in the field of adults with SBM – short oral presentations
- Brief overview of the follow-up in the Nordic countries.
- How can research facilitate and improve systematic multidisciplinary care and follow-up routines? How can this impact everyday life? How can we work together? What needs to be done? Group discussion.

CONTRIBUTORS

Anders Andrae, founder of Skogstur (a Swedish organization of disabled persons organizing excursions into nature)
Erica Barrdahl, writer, will be present online
Rasmus Isaksson, SpinOff (a Swedish organization of adults with SB)
Lena Lindbo, Reg. Nurse, Urotherapist, Spinaliskliniken, SBM-team, Aleris Rehab Station, Stockholm
Carl Norrman, Skogstur (a Swedish organization of disabled persons organizing excursions into nature)