# NoSCoS general meeting 2023

The meeting will start att 12 pm CET



# Agenda (Wolfram)

- 1) Election of chair, secretary and two adjustors/voice counters for the meeting
- 2) Minutes from the 2022 general meeting (Nora)
- 3) President's report (Wolfram)
- 4) Financial report (Nora)
- 5) Granting discharge for the NoSCoS board (chair)
- 6) Reports from our Professional Networks & Special Interest groups (Randi)
  - Nordic Network of Spinal Cord Injury Nurses
  - NutriNord SCI
  - Pediatric SCI Rehabilitation

- 7) Proposals
  - Proposals for revision of NoSCoS constitution & bylaws (Rikke)
- 8) Membership fee for 2023-2024 (Annette)
- 9) Elections (chair)
  - Elections president, treasurer, vice president and 4 ordinary board members (list of candidates enclosed)
- 10) Applications Special Interest Groups and Professional Networks (Randi)
  - Professional Network Psychologists
  - Special Interest Group Consumer involvement in rehabilitation & research
  - Special Interest Group Neuropathic pain
  - Special Interest Group Spina Bifida
- 11) Presentation of the General Meeting in Helsinki 2024 (Anastasia)
- 12) Any other business (chair)



# Elections of chair, secretary, 2 adjustors/vote counters

#### Suggestions:

- Chair Claes Hultling
- Secretary Annette Halvorsen
- Adjustors Angelica Carlson, Vegard Ström





#### NoSCoS General Assembly, Stockholm, May 6th, 2022

#### 1. Elections of chair, secretary and two adjustors/voice counters

Pall Ingvarsson was elected chair for the meeting

Nora Sandholdt was elected secretary.

Gigja Magnusdottir and Nicolaj Jersild Holm were elected adjustors and voice counters.

#### 2. Minutes from the 2021 digital general assembly

The minutes have been on the home page. The main points were highlighted by Wolfram Antepohl. The GA decided to establish a membership fee and membership procedures. There was a discussion about that a majority of the board should be members coming from highly specialized units as well as the president. That suggestion was declined but will be discussed today. Finally there were elections.

The minutes of meeting were approved by the GA.

#### 3. President's report

Wolfram Antepohl presented the boards work (attachment 1). Main points were a presentation of the board members and the boards meetings, a new webpage and improvements, continued work with constitution & bylaws, NordicSCIR collection of data, Professional network for nurses webinar in November, NASCIR 2.0 improved course and preparations of the 17th NoSCoS scientific meeting in Stockholm.

The president's report was approved by the GA.

#### 4. Financial report

President Wolfram Antepohl presented the financial report of NoSCoS (see attachment 1). A main point was that NoSCoS was established as a non-profit association with Swedish organization number in 2020. NoSCoS has a stable economy. The total expenditure for the past year has been 25 778 SEK for board meeting in Stockholm and web hotel costs.

#### 5. Granting discharge for the NoSCoS board

The NoSCoS board was granted discharge by the GA.

#### 6. Proposals

Proposals for revision of NoSCoS constitution & bylaws

Rikke & Randi presented the boards suggestions of revisions of C&B and the GA voted. See attachment 1.

Suggested amendment to 12 was approved by the GA

Suggested amendment to 15 was approved by the GA

Suggested change to amendment 17. The text in the first sentence needs to be changed to "six-eight elected members". Suggested change to amendment 17 was accepted with the change of sentence.



Suggested change to amendment 18 was presented by Fin Bering Sörensen. Fin explained about that the reason for founding NoSCoS from the beginning was to strive towards centralization. Therefore he finds it important that the president represents a public highly specialized unit. The boards presents that the reason to decline this proposal is that it is excluding consumers and others that wants to be engaged in the society. A discussion arose on what is "a public highly specialized unit". It was proposed that this question needs to be more discussed among the members.

The suggested amendment to 18 was withdrawn.

Suggested amendment to 22 was approved by the GA

Suggested amendment to 24 was approved by the GA

#### 7. Elections of new NoSCoS board members

Election of three ordinary members, which, as far as possible, should be one physiotherapist, one psychologist or social worker and one consumer representative.

The new suggested members Henrik Hagen Poder, PT, Irene Christiansen, psychologist and Cathrine Guldberg, consumer representative presented themselves to the GA.

Henrik Hagen Poder, Irene Christiansen and Cathrine Guldberg were all elected new NoSCoS board members for four years each.

Annastasia Schulga replaces Claes Hultling as chair of organizing committee of the next NoSCoS conference 2024 in Helsinki

#### 8. Presentation of the General Meeting in Helsinki 2024

The 18th NoSCoS meeting will be in Helsinki 22-24 May at Scandic Marina Congress. Helsinki.fi/

#### 9. Any other business

No other business were discussed.

#### 10. Closing of meeting

The meeting was closed by chair Pall Inguarsson

Pall Ingvarsson, chair	Nora Sandholdt, secretary
Giaia Maanusdottir, adiustor	Nicolai Jersild Holm. adjustor

# Presidents report (Wolfram)



# The Team: Executive Committee

Wolfram Antepohl MD (2021-2023), President Dep of Rehabilitation Medicine, University Hospital, Linköping, Sweden

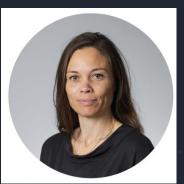
Randi Steensgaard RN (2019-2023)
Specialhospitalet for Polio og Ulykkespatienter, Denmark

Annette Halvorsen MD (2021-2023), Treasurer
St Olavs Hospital, Trondheim, Norway

Nora Sandholdt MA (2021-2025), Secretary, Dep of Rehabilitation Medicine, University Hospital, Linköping, Sweden

Anastasia Shulga, MD (2022-2024), NoSCoS 2024 OC chair Helsinki University Hospital, Finland











#### **Board Members:**

Hanne Björg Slettahjell, Dietician, (2019-2023), Sunnaas Rehabilitation Hospital, Norway

**Irene Christiansen**, Psychologist (2022-2026), Bodil-Eskesen-Centret, Copenhagen, Denmark

<u>Cathrine Guldberg</u>, Consumer (2022-2026), RYK, Ryggmarvsskadede i Danmark, Denmark

<u>Henrik Hagen Poder</u>, PT (2022-2026), Bodil-Eskesen-Centret, Copenhagen, Denmark

Rikke Middelhede Hansen, MD (2019-2023), Special-hospitalet for Polio og Ulykkespatienter, Denmark

Marie Thodén, MD (2019-2023), Helsinki University Hospital, Helsinki, Finland

Ingibjörg Tómasdóttir, RN (member 2019-2023), Landspitali, Reykjavík, Iceland

Johanna Wangdell, OT (member 2021-2023), Sahlgrenska Universitets-sjukhuset, Gothenburg, Sweden

















### **Activities**

- Four online board meetings, one board-meeting IRL (in Stockholm) March 2023. Four additional EC-meetings (three virtual, one IRL in Vancouver)
- Continued working group on Constitution & Bylaws, Membership & Financing
- New membership structure for individual membership in place since March. Membership registry, mailing list (Angelica, Tina, see separate slide)
- Interaction with ISCoS: Stand at Vancouver meeting with information on ISCoS and upcoming conferences. Acitive participation in "Affiliated Societies". Stephen Muldoon (ISCoS consultant on collaboration, Head Educational Committee) to take part in board meeting in Stockholm.



### Activities continued

- Continuous update and improvement of homepage, new graphic profile (Nora, Angelica, Anna)
- Professional bank account with appropariate acces to and control over all financial resourses.
- 17th NoSCoS Scientific Meeting in Stockholm with a positive revenue (50% to NoSCoS) thanks to great work from local organizing and scientific committee



### Activities continued

- NordicSCIR collection of data for 2022 and preparations for annual report.
- NASCIR 2.0 started April 2022, concept evolved and further improved based on feedback. 38 participants in 9 teams from 5 countries.
   Finished in November 2023.
- Special Interest Groups and Professional Networks (see separate slide)
- Continued preparation of NoSCoS 2024 in Helsinki and NoSCoS 2025 (joint meeting with ISCoS)



# Proposal NoSCoS Award

- Why? The NoSCoS Society would like to acknowledge persons and/or organizations who have contributed to the mission of NoSCoS: to improve the well-being of persons with spinal cord injury and disease and their close ones in the Nordic countries throughout life. The NoSCoS Award consists of a diploma.
- Who? Persons, clinics, colleagues, healthcare professionals, societies, persons with lived experience can nominate the persons or organizations. Persons or organization cannot nominate themselves.
- <u>Eligibility</u> Persons or organizations who through their work and/or actions have contributed substantially to the mission of NoSCoS are eligible. The work or contribution can be ex. interventions or projects which make a difference to the well-being of persons with spinal cord injury/dysfunction. In this context well-being is defined as a broader term and must have been registered in a broader group of persons not just one person or a few individuals.
- The person/or a representative for the organization should be willing to give a talk at the NoSCoS sConference.
- How? If persons, clinics, colleagues, healthcare professionals, societies or persons with lived experience would like to nominate a person or organization for the "NoSCoS Award" it should be done by stating how the person or organization have contributed to the mission of NoSCoS. The NoSCoS Board will choose between the nominated persons/organizations.
- When? At the 18<sup>th</sup> Meeting of NoSCoS in Helsinki the first NoSCoS Award winner will be presented.













# Financial report 2022-2023

(Nora)

- Finally managed to open a NoSCoS bank account June 2022
- Transfered money from, and closed old Gothenburg account
- Swedish tax declaration for the first time!

- Currently looking over the accounting system for NoSCoS
- Suggestion: accouting year NoSCoS = calendar year
- Budget proposal at general meeting
- Internal auditor looks over accounting prior to general meeting



# Finances since May 2022

- + 32 008 SEK Incoming balance from Gothenburg account
- 8 532 SEK NoSCoS booth at ISCoS
- 1 350 SEK Costs bank account
- 720 SEK Webhotel costs
- + 72 426,5 SEK Surplus NoSCoS meeting Stockholm 2022
- 10 792 SEK Board meetings (travels, accomoation, food)
- 4 219 Membership Registry set up
- = 78 823 SEK Outgoing balance

Big thanks to the Spinalis Foundation & our employers!



# Granting discharge for the NoSCoS board (chair)





## Reports from our PN & SIGs (Randi)

 Templates created for reports and applications for professional networks and special interest groups



#### SPECIAL INTEREST GROUP ANNUAL REPORT



#### NORDIC NETWORK OF SPINAL CORD INJURY NURSES

# How many meetings have you had the last year?

E.g. Where, how many, digital/in person?

No meetings, but activity on Facebook





Topics on Facebook

Information about

- different educational activities e.g., SCIMOOC
- NoSCoS
- various relevant conferences
- Wellspect study grant.

# Action plans for the next year?

#### We hope to work on:

- more activity on Facebook
- some small webinars e.g. sharing knowledge, work with cases
- start preparing the workshop at NoSCoS in Helsinki





Malin Nordin malinordin@gmail.com

Maria Moschovou moschovoum@gmail.com

Line Trine Dalsgaard Ltd@specialhospitalet.dk

Philip Bilberg <u>uxbiph@sunnaas.no</u>

Charlotte Gervø charlotte.gervoe@regionh.dk

# NutriNord



#### SPECIAL INTEREST GROUP ANNUAL REPORT



NUTRI NORD\_SCI

# How many meetings have you had the last year?

E.g. Where, how many, digital/in person?

About 6 digital meetings, plus physical meetings during NoSCos 2022, Stockholm, Sweden.



#### Main topics for discussion?

- Preparing for Nutri Nord workshop
- •New materials, eg. Guidelines for health personnel working with SCI rehabilitation
- Collaboration with Coloplast

# Action plans for the next year?

- •Plan potential collaboration with Coloplast (distribution of brochure, develop more information on nutrition and neurogenic bowel ++)
- •Prepare workshop for NoSCos meeting 2024, Helsinki, Finland



#### Any changes or comments?

#### Core group:

Line Trine Dalsgaard (nurse, Denmark) chair

Hanne Bjørg Slettahjell (dietitian, Norway) chair

Charlotte Gervø (nurse, Denmark) joined the core group in 2022 (new core member)

Anna-Carin Lagerstrøm (physical therapist and lifestyle coach, Sweden)

Anna Wahl (dietitian, Sweden)

Nicolaj Jerslid Holm (physical therapist, Denmark) left the group

## Pediatric SCI rehabilitation



# Proposals

Proposed changed to constitution & bylaws (Rikke)



# Definition and Mission of the society

Current text	Suggested changes and amendment	Remarks
<b>4.</b> NoSCoS is an association of individuals and institutions in the Nordic countries with special interest in spinal cord injury and dysfunction.	Change to 4:  NoSCoS is an association of individuals in the Nordic countries with special interest in spinal cord injury and dysfunction.	Suggestion by the NoSCoS board Motivation: For now we only have individual membership, because of clear voting rules



## The Vision of NoSCoS is

Current text	Suggested changes and amendment	Remarks
5. To organize scientific meetings and educational activities for professionals working with people affected by spinal cord injury and dysfunction	Change to 5: To organize scientific meetings and educational activities for individuals who are actively involved in the management, representation, rehabilitation of or research about persons with spinal cord injuries and dysfunctions	Suggestion by the NoSCoS board Motivation: Broader involvement of member and due to definition of ordinary member.



# Membership

Current text	Suggested changes and amendment	Remarks
7. Institutions that are actively involved in the management, representation, rehabilitation or research of persons with spinal cord injuries and dysfunctions can apply for membership of the Society.	Change to 7:	Suggestion by the NoSCoS board Motivation: Institutions, associations and companies can apply to receive news about NoSCoS on the home page, but can not be individual members for now.



# Meetings

Current text	Suggested changes and amendment	Remarks
10. The Annual General Meeting shall consist of:  a) A business part, in which reports and accounts shall be considered and discharge for the board be granted or not granted. Furthermore, the Officers and Members of the Society shall be elected.	Change to 10:  a) A business part, in which reports and accounts shall be considered and discharge for the board be granted or not granted. Furthermore, members of the executive committee and the board, shall be elected.	Suggestion by the NoSCoS board Motivation: We only elect board and executive committee members



# Meetings

Current text	Suggested changes and amendment	Remarks
12. All Ordinary Members of NoSCoS and all present at the General Meeting are alleged to vote at the Annual General Meeting.	Change to 12:  All Members of NoSCoS  at the General Meeting  are allowed to vote at the Annual General Meeting.	Suggestion by the NoSCoS board Motivation: We only have one type of membership, and you need to be present to vote



# Meetings

Current text	Suggested changes and amendment	Remarks
10b) A scientific part, in which opportunities shall be given to Members to exchange and share scientific results, ideas and experiences from practice.  Members shall forward to the Secretary the titles of communications to be presented at the Meeting by a date agreed by the Board in collaboration with the Organizing Committee of the respective meeting.	Amendment to 10 b: Organizing Committee of the respective meeting.  In case the biannual scientific meeting yields a profit, 50 percent shall be assigned to the NoSCoS society.	Suggestion by the NoSCoS board Motivation: NoSCoS provides brand, organization and engaged members that contribute to the scientific meeting and needs coverage for the expences.



# Membership fee NoSCoS for 2023-2024 (Annette)

- Working group on membership has considered several possibilities (presented during general meetings before).
- The purpose of having a register at NOSCOS is to meet the requirements from the Swedish tax authorities. Since NOSCOS is a society with a bank account the Swedish Tax Authorities demands a membership register.
- The time and money spent by administering a membership fee are costly.
- Therefore is the proposal that the personal membership is free of charge for 2023-2024.

Nordic Spinal Cord Society

## Elections

#### **Executive committee members for election:**

President: Wolfram Antepohl MD (2017-2023), re-election

Vice President: Randi Steensgaard, RN (2019-2023) re-election

Treasurer: Annette Halvorsen (2017-2023), re-election

#### Other NoSCoS board members for election:

Hanne Björg Slettahjell, dietician (2019-2023) re-election Rikke Middelhede Hansen, MD (2019-2023) re-election Ingibjörg Tómasdóttir, RN (2019-2023) re-election Marie Thodén, MD (2019-2023) re-election



#### **Board members that continue:**

Representative NoSCoS 2024 organising committee: Anastasia Shulga

Secretary: Nora Sandholdt (2021-2025)

Irene Christiansen, psychologist (2022-2026)

Henrik Hagen Poder, physio therapist (2022-2026)

Cathrine Guldberg, consumer representative (2022-2026)

#### **Resigning candidates:**

Johanna Wangdell, occupational therapist (2019-2023)



### **New Candidates**

Lisa Holmlund, OT, assistant professor, Stockholm, Sweden
I am a reg. occupational therapist with a PhD in medical sciences. My clinical background is at the Spinalis SCI Unit in Stockholm from 2003-2019. Today I work as an assistant professor at Karolinska Institutet. I am involved in research and development concerning people with spinal cord injuries and am active in Rehab Station Stockholm's R&D unit.

Lamprini Lili, candidature withdrawn for now



# Applications from new proffessional networks & Special Interest groups (Randi)

- PN Psychologists
- SIG Consumer involvement in rehabilitation & research
- SIG Neuropathic pain
- SIG Spina Bifida



# PN - Psychologists

Proposed Name of	Nordic Network of Spinal Cord Injury Psychologists	
<b>Professional Network</b>		
Contact details of	Irene Christiansen, Psychologist, member of the NoSCoS Board	
<b>Professional Network</b>		
Main Purpose, Interest or		
Theme of Network	The main purpose of the professional network is to share and exchange knowledge (both theoretical and practical) about psychological aspects of living with SCI and how to offer people with SCI the best possible psychological treatment and rehabilitation.	
Core members of the		
Professional Network, and	Anders Orup Aaby, Naja Bøje Casupei, Irene Christiansen, etc. (to be discussed further at our next meeting in order	
their Designations	to secure representation from the different Nordic countries).	
Focus area for your		
<b>Professional Network over</b>	1. Sharing and exchanging knowledge (see the above main purpose). The context is virtual meetings which take	
the next 2 years	place two to three times a year.	
	2. Contributing to the coming conference in Helsinki 2024 by means of a workshop/a session for psychologists	
Who can be a member of	Psychologists who work professionally with people with SCI. Psychologists who have relatives with SCI or live with SCI	
the Professional Network?	themselves.	

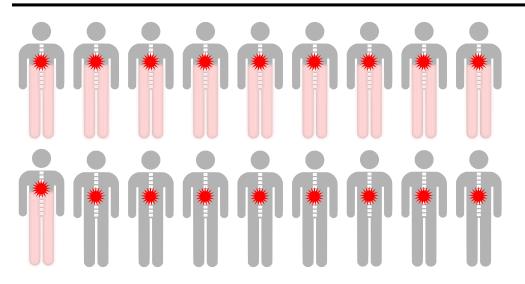
# SIG – Consumer involvement in rehabilitation & research

Proposed Name of	Consumer involvement in rehabilitation & research	
Special Interest Group		
Main Purpose, Interest	To create a network for people interested in strengthening the involvement of persons with lived experience of SCI, in	
or Theme of Special	rehabilitation and care as well as research and development. This should cover the entire process from design to	
Interest Group	implementation and continuous activity. This group's main goal is to raise the involvement of consumers in research and	
	development.	
	We are suggesting that the consumer representative on the NoSCoS board should be the contact person for this group	
	to ensure continuity for the SIG but also to strengthen the consumer perspective of NoSCoS.	
Core members of the	Cathrine Guldberg, contact person, consumer representative NoSCoS board	
Special Interest Group,	Nora Sandholdt, project coordinator Dep Rehabilitation Medicine, Linköping university hospital, secretary NoSCoS	
and their designations	board	
	Marrku Poikela, Akson, member scientific committee NoSCoS 2024	
Focus areas for your	To raise the involvement of persons with lived experience in research focused on SCI and development of rehabilitation	
Special Interest Group	and care, during the entire process from design to implementation and continuous activity.	
over the next 2 years	To organize a workshop focused on consumer involvement at each NoSCos scientific meeting.	
Who can be a member	Anyone interested in the group's main purpose.	
of the Special Interest		
2		

# SIG – Neuropathic Pain

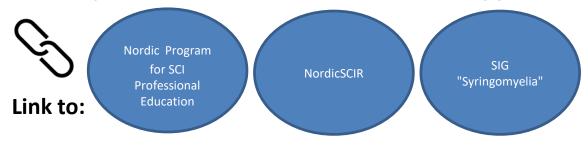
Contact details of	Jan Rosner, MD
Special Interest Group	Danish Pain Research Center, Aarhus University
Name / E-mail	
Main Purpose, Interest	The main purpose of this SIG is to advance the diagnosis and management of neuropathic pain following spinal cord injury from a
or Theme of Special	biopsychosocial and interdisciplinary standpoint by, among others, improving our understanding of the underlying
Interest Group	pathophysiological mechanisms and implementing standardized and evidence-based diagnostic and treatment approaches across the Nordic countries.
Core members of the	Jan Rosner, MD, Neurologist and Postdoctoral Research Fellow, Tiina Rekand, MD, PhD, Senior Consultant and Professor, Nanna B.
Special Interest Group,	Finnerup, MD, DrMedSc, Professor and Director, Rikke M. Hansen, MD, Consultant, Sophie Lykkegaard Ravn, PhD, Psychologist and
and their Designations	Head of Research, Anastasia Shulga, MD, PhD, Head of Department, Ivan Sunara, MD, Pain Medicine Resident
Focus areas for your	Facilitate information sharing and experience exchange on assessment and treatment of neuropathic pain across Nordic countries,
Special Interest Group	including the exchange with existing SIGs such as the "Syringomyelia" SIG.
	Establish standardized bedside assessment protocols to identify and monitor signs and symptoms associated with neuropathic pain, which can be used in clinical practice and for clinical trials.
	Increase outreach efforts through educational initiatives and research dissemination such as collaborating with the "Joint Nordic
	Program for SCI Professional Education," organizing workshops and symposia at national and international SCI or pain conferences.
Who can be a member	Our aim is to encourage participation and collaboration among professionals with different backgrounds and expertise in this area.
of the Special Interest	For this reason, we welcome applications from a diverse range of specialties, including for example physicians, nurses,
Group?	psychologists, physiotherapists, occupational therapists, and translational scientists, who are interested in the diagnosis,
	pathophysiology, and interdisciplinary management of neuropathic pain in individuals with spinal cord injuries.

#### SIG Application "Neuropathic Pain"



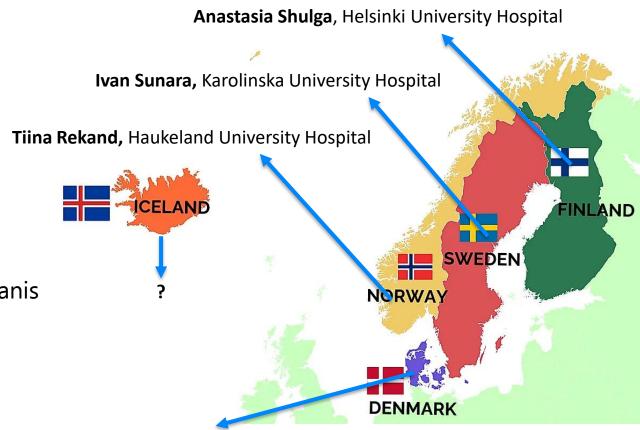
#### **Unmet Clinical Need**

- > 50% of traumatic SCI patients
- Advance the diagnosis and management
- Improve understanding of pathophysiological mechanis
- Standardize diagnosis
- Implement evidence-based treatment approaches



Contact: jan.rosner@clin.au.dk

#### **Interdisciplinary & Multiprofessional Team**



Jan Rosner, Danish Pain Research CenterNanna B. Finnerup, Danish Pain Research CenterSophie Lykkegaard Ravn, Specialized Hospital for Polio and Accident VictimsRikke M. Hansen, Specialized Hospital for Polio and Accident Victims

# SIG – Spina Bifida

Contact details of Special Interest Group	Hanna Gabrielsson, PhD, registered nurse, senior lecturer. Swedish Red Cross University

Main Purpose, Interest or Theme of Special Persons with Spina Bifida (SB) have a congenital spinal cord disorder (injury), often involving cognitive impairments, which puts special demands on the healthcare. The aim of this special **Interest Group** interest group (SIG) is to highlight the concerns of persons with SB within NoSCos, by gathering and disseminating information and research with the goal to develop adequate follow up guidelines and improved care and quality of life for persons with SB.

Core members of the Special Interest Group, Martina Bendt, PhD, Physiotherapist Hanna Gabrielsson, PhD, Registered nurse, Dorothee Riedel, MSc, Occupational therapist, Kerstin Lundberg Larsen, Physiotherapist, MSc. Ingeborg **Lidal, PhD Medical doctor, PhD, Anders Andrae**, founder of Skogstur, **Carl Norrman**, Skogstur Jonas Gripenland, PhD, MD, et al

collaborations within research and development in the clinical work, between the Nordic

Rasmus Isaksson, Spinoff, Cato Lie, Alette.halvor.jensen@regionh.dk, Occupational Therapist, Focus areas for the first two years of SIG-SB is to establish contact and identify possible

SIG-SB. Who can be a member of the Special Interest This SIG is for all healthcare professionals as well as for persons with SB, and their organizations,

countries. Equally important is to involve persons living with spina bifida and their organizations in

who's voices are of great importance.

Form filled in by:

and their Designations

over the next 2 years

Focus areas for your Special Interest Group

Hanna Gabrielsson

Group?

# Presentation of the General Meeting in Helsinki 2024 (Anastasia)

www.helsinki.fi/noscos2024



# Any other business?

