INTERNATIONAL FEDERATION FOR SPINA BIFIDA AND HYDROCEPHALUS

50 ans years
Spina-bifida hydrocéphalie Québec
TOUT EST POSSIBLE

31st International Conference on Spina-Bifida and Hydrocephalus

A Lifetime of Experiences: From Preconception to Aging

Programme book

15th – 17th October 2026

CONTENTS

WELCOME FROM THE CONFERENCE ORGANISERS

It is our great pleasure to welcome you to the **31st International Conference on Spina Bifida and Hydrocephalus**, taking place in Montréal from **15–17 October 2026.**

We have prepared an inspiring **three-day** programme that brings together people with lived experience, families, healthcare professionals, researchers, advocates and organisations from around the world. Throughout the conference, we hope you will have opportunities to learn from one another, exchange experiences, engage in meaningful discussions, and connect with colleagues and friends from across the global SBH community.

Our three keynote lectures will explore three important themes: **Hydrocephalus, Transitioning, and Mental Health,** reflecting key aspects of living with Spina Bifida and Hydrocephalus throughout the life course. We hope these discussions will help identify priorities for the future, including strengthening efforts towards a **national NPH campaign** in Canada, and further advancing **global efforts to ensure accessibility for all**.

We are proud to welcome participants from **more than 20 countries**, bringing together a truly international community with diverse experiences and perspectives.

This conference is also an opportunity to celebrate. In 2026, Spina-bifida hydrocéphalie Québec marks **50 years of history,** and we are delighted to celebrate this important milestone together with our global SBH community during the **conference reception**.

We are grateful to our sponsors, partners, and supporters, whose contributions help make this international conference possible.

Welcome to Montréal. We look forward to learning, connecting and sharing these three days with you!

Ms Nadia Dallaire
President Spina-bifida hydrocéphalie Québec
Conference organiser local committee

Dr Sylvia Roozen
Secretary General International Federation for Spina Bifida and Hydrocepahlus
Chair International Scientific Conference

ABOUT SBHQ

Spina Bifida Hydrocephalus Quebec (SBHQ) focuses on mutual support, prevention, information, finding solutions, and providing assistance so that people living with spina bifida and hydrocephalus can lead active lives.

The association was founded in 1976 by parents who felt they lacked the resources and information needed to understand their children's conditions and future, and who wanted better tools to help prepare them for what lay ahead.

Prevention is also one of the association's key priorities. SBHQ raises awareness about the importance for anyone planning to become pregnant to take a folic acid supplement at least three months before conception.

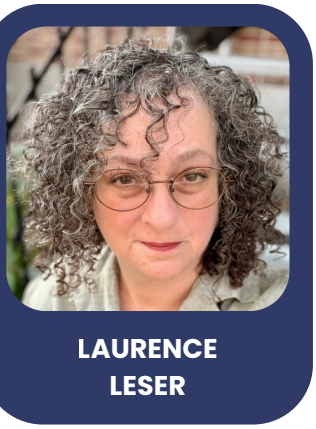
ABOUT IFSBH

The International Federation for Spina Bifida and Hydrocephalus (IFSBH) is the international organisation representing people with Spina Bifida and/or Hydrocephalus and their families worldwide. IF has country members in Africa, the Americas, Asia-Pacific and Europe with unique and expert knowledge on SBH.

The mission of IFSBH is to improve the quality of life of people with SBH and their families and to reduce the prevalence of neural tube defects and hydrocephalus through primary prevention by improving maternal health literacy, raising awareness, political advocacy, research, community building and human rights education.

The vision of IFSBH is to create a society that ensures the human rights of both children and adults with SBH, while also recognising and valuing their contributions. Additionally, IF strives to provide equitable access to maternal health literacy for everyone.

THE LOCAL COMMITTEE



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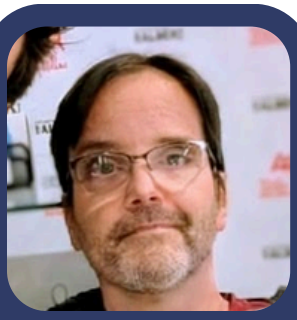

MICHEL
BÉDARD

NADIA
DALLAIRE

STELLA-MARIE
TSELEPI

NATHALIE
BOËLS

SAID
CHRIF

ROY
FU

LAURENCE PERREAULT-
ROUSSEAU

THE SCIENTIFIC COMMITTEE

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DR MATHILDE BARBEAU
CANADA

MS LAURENCE LESER
CANADA

KEYNOTE SPEAKER

DR MARIE-PIERRE FOURNIER-GOSSELIN

HYDROCEPHALUS

Dr. Marie-Pierre Fournier-Gosselin is a neurosurgeon specializing in functional neurosurgery at the Centre Hospitalier de l'Université de Montréal (CHUM). She completed her medical training at Laval University, neurosurgery specialization at the University of Sherbrooke, and additional training in Toronto and Portland, Oregon.

She provides **neuromodulation therapies** for refractory neurological conditions and works closely with neurology teams on **movement disorders, trigeminal neuralgia, and normotensive hydrocephalus.**

Dr. Fournier-Gosselin is a Clinical Associate Professor at the Université de Montréal and **director of the neurosurgery training program**, overseeing the Fellowship in Functional Neurosurgery at CHUM.

She is also involved in research at CR-CHUM, supervising projects on trigeminal neuralgia and pain biomarkers in Parkinson's disease, and co-investigates the **MinPHI initiative on idiopathic normal pressure hydrocephalus.**

KEYNOTE SPEAKER

DR SARA LONG-GAGNÉ
TRANSITIONING

Dr. Long-Gagné completed her medical school at the University of Ottawa and her pediatric residency at the University of British Columbia. She then went to McGill University for a specialization in complex care medicine and a master's degree in epidemiology.

Subsequently, she joined the Montreal Children's Hospital (MCH) as a pediatrician with a particular interest in **advancing care for children with complex health conditions.**

She is one of the **leaders of the new Intermediate Complexity Coordination and Navigation Service** (CONCI) **and co-director of the Spina Bifida service at the MCH.**

She is also involved in research and medical education projects aimed at improving health services for children with chronic diseases.

KEYNOTE SPEAKER

PROF DR ALEXANDER VON GONTARD

MENTAL HEALTH

Alexander von Gontard is a child and adolescent psychiatrist, psychotherapist, and pediatrician. He has published widely on **incontinence, chronic medical conditions, disabilities, and mental health in children and adolescents.**

He is affiliated with the **Governor Kremers Centre** in Maastricht, contributing to interdisciplinary research and policy discussions, and serves as an **advisor to the International Federation for Spina Bifida and Hydrocephalus**, supporting mental health, psychosocial care, and rights-based approaches.

His work promotes an **integrative approach to child and adolescent mental health**, combining biological, developmental, and psychosocial perspectives.

DANNY LAMB

MUSICIAN. AUTHOR. ADVOCATE. STORYTELLER.

Bringing energy and new perspectives to the main stage

Danny is a musician, author and advocate who brings a unique perspective shaped by his lived experience of spina bifida. Through his music, writing and advocacy, he uses his voice to challenge perceptions, share his experiences and inspire others.

At the conference, Danny will co-lead the Youth Forum with Ina Åkerberg, creating a space for young people with SBH to connect, share experiences and make their voices heard.

CONFERENCE AGENDA

DAY 1 - THURSDAY, 15 OCTOBER, 2026

Understanding SBH: Hydrocephalus, Care Systems & Prevention

TIME	PLENARY ROOM	ROOM 1	ROOM 2	ROOM 3
08:00 AM - 09:30 AM	Registration & Welcome Coffee			
09:30 AM - 09:40 AM	**Welcome & Opening of the Conference**			
09:40 AM - 10:45 AM	• The Global SBH Community: Vision, Challenges & Opportunities • Lived experience perspective • Introduction to the Conference Programme			
10:45 AM - 11:15 AM	Coffee Break & Poster Viewing			
11:15 AM - 12:00 PM	**Keynote Speaker on Hydrocephalus** by Dr Marie-Pierre Fournier-Gosselin			
12:00 PM - 12:20 PM	**Special guest Danny Lamb**			
12:20 PM - 01:00 PM	**Roundtable Hydrocephalus 360°** (51)			
01:00 PM - 02:00 PM	Lunch & Poster Viewing			
02:00 PM - 03:00 PM	Parallel Session 1 **Transition & Life Course Care** • Speakers (Abstract No.): ◦ Laurence Veilleux (5) ◦ Melissa Goktogan (17) ◦ Abby Varghese (33) ◦ Yakob Seman Ahmed (40)	Parallel Session 2 **Research, Innovation & Clinical Care** • Speakers (Abstract No.): ◦ Richard Finnell (37) ◦ Sahrish Masood (31) ◦ Jeffrey Blount (21) ◦ Elizabeth Zimmermann (46)	Video **The Spirates: a maritime adventure uniting the SBH community in France and beyond**	
03:00 PM - 03:30 PM	Coffee Break & Poster Presentations Session A			
03:30 PM - 04:30 PM	Parallel Session 3 **Prevention & Public Health** • Speakers (Abstract No.): ◦ Mathilde Barbeau (6) ◦ Ann Paal (34) ◦ Maman You Espérance Broalet (12) ◦ Vijaya Kancherla (19) ◦ Eduardo Tizzano (43)	Parallel Session 4 **Rehabilitation & Functional Recovery** • Speakers (Abstract No.): ◦ Priya Sayal (29) ◦ Anne Jougit (36) ◦ Chris Toelle (7) ◦ Sandra Sanchez (4) ◦ Kate Steele (3)	Panel **Designing Mind Friendly Environments for People Living with Hydrocephalus — Enhancing Accessibility and Well-Being** Stella-Marie Tselepi (20)	
04:30 PM - 05:30 PM	**Formal Opening Ceremony**			

Networking | **Keynote** | **Plenary Session** | **Parallel Session** | **Engagement Session** | **Sponsored session**

CONFERENCE AGENDA

DAY 2 – FRIDAY, 16 OCTOBER, 2026

Living with SBH: Transition, Rights & Independence

TIME	PLENARY ROOM	ROOM 1	ROOM 2	ROOM 3
09:00 AM - 09:30 AM	Welcome Coffee & Networking			
09:30 AM - 10:15 AM	**Keynote Speaker on Transitioning** by Dr Sara Long-Gagné			
10:15 AM - 10:45 AM	Coffee Break & Poster Viewing			
10:45 AM - 12:00 PM	Parallel Session 5 **Bladder, Bowel & Continence Care** • Speakers (Abstract No.): ◦ Kate Steele (2) ◦ Nebiyat Tesfaye (16) ◦ Sneha Sawant (11) ◦ Sandhya Maurya (32) ◦ Brad E Dicianno (14) ◦ Sonia Thakur (25)	Parallel Session 6 **Inequalities & Human Rights** • Speakers (Abstract No.): ◦ Lyudmil Ninov (15) ◦ Julie Fontaine (13) ◦ Kelani Aminath Bariath Phuong-Tam (10) ◦ Swara Madav (8) ◦ Marine Gailhard (44)	Parallel Session 7 **Surgical & Clinical Interventions** • Speakers (Abstract No.): ◦ Alina Korsak (37) ◦ Volodymyr Likhodiievsky (39) ◦ Gabrielle Gour-Provençal (18) ◦ Agnieszka Pastuszka (1)	
12:00 PM - 01:00 PM	Lunch & Poster Viewing		Sponsored session by invitation only	
01:00 PM - 02:00 PM	**Country Updates I** Canada, Nigeria, Estonia, India, US, France, Colombia, Senegal, Montenegro			
02:00 PM - 03:00 PM	Sponsored Session **Advancing neurogenic bowel care with transanal irrigation** Coloplast	Sponsored Session **From Prevention to Lifelong Outcome: Food Fortification and Folic Acid** GAIN	Workshop **Fetal Surgery** Agnieszka Pastuszka (45)	
03:00 PM - 03:30 PM	Coffee Break & Poster Presentations Session B			
03:30 PM - 05:00 PM	Roundtable 1 **Human Rights** Vanessa-Anne Paré & Laurence Leser (26)	Roundtable 2 **SBH & Employment** Laurence Perreault-Rousseau (41)	**Ping Pong Session: Genetics** Richard Finnell & Eduardo Tizzano (49)	**Youth Forum** Danny Lamb & Ina Åkerberg (48)
05:00 PM - 05:30 PM	**Plenary Discussion & Closing Remarks: Day 2**			

Networking | **Keynote** | **Plenary Session** | **Parallel Session** | **Engagement Session** | **Sponsored session**

CONFERENCE AGENDA

DAY 3 – SATURDAY, 17 OCTOBER, 2026

Thriving with SBH: Wellbeing, Function & Future Directions

TIME	PLENARY ROOM	ROOM 1	ROOM 2	ROOM 3
09:00 AM - 09:30 AM	Welcome Coffee & Networking			
09:30 AM - 10:15 AM	**Keynote Speaker on Mental Health** by Prof. Dr. Alexander von Gontard			
10:15 AM - 10:30 AM	Coffee Break & Poster Viewing			
10:30 AM - 11:30 AM	Parallel Session 8 **Hydrocephalus** • Speakers (Abstract No.): ◦ Diana Gray (22) ◦ Ali El Jamal (9) ◦ Amy Huang (30) ◦ Marc-Antoine Gobeil (24)	Parallel Session 9 **Quality of Life, Obesity & Lifestyle** • Speakers (Abstract No.): ◦ Charlotta Levén Andréasson (42) ◦ Jennifer Tudor (23) ◦ Sandhya Maurya (38) ◦ Carylyn Lim (28) ◦ Namita Singh (35)	Workshop **Mental Health for Parents & Caregivers** Roy Fu (50)	
11:30 AM - 12:30 PM	**Country Updates II** Canada, Norway, Luxemburg, UK, Ethiopia, Malaysia, Germany, Slovakia			
12:30 PM - 01:30 PM	Lunch & Poster Viewing			
01:30 PM - 02:30 PM	**Closing Plenary: The Future of SBH – From Care to Inclusion**			
02:30 PM - 03:00 PM	**Final Conference Closing Remarks**			
06:30 PM - onwards	**Reception & Award Ceremony**			

Networking | **Keynote** | **Plenary Session** | **Parallel Session** | **Engagement Session** | **Sponsored session**

PARALLEL SESSIONS DETAILS

Parallel Session 1 - Transition & Life Course Care

Abstract no	Title & Authors
5	Understanding the needs of youth living with spina bifida during transition to adult care **Laurence Veilleux,** Nadine Korah, Kimberly Anganu, Sara Long-Gagné
17	Empowering early journeys: a co-designed developmental and peer support pilot for families of children with spinal bifida **Melissa Goktogan,** Corrine Browne
33	Virtual Multidisciplinary Transition Clinic Improves Outcomes for Pediatric Urology Patients Transitioning to Adult Care Sharon Fishberg, **Abby Varghese,** Michael Chua, Eyal Podolsky, Sarah Neu, Sender Herschorn, Rano Matta
40	Unmet Assistive Devices Needs among Children with Spina Bifida in Ethiopia: A Cross-Sectional Study **Yakob Seman Ahmed**

Parallel Session 2 - Research, Innovation & Clinical Care

Abstract no	Title & Authors
37	Innovative treatment modalities for Spina Bifida repair surgery using a large animal model **Richard Finnell,** Mehmet Kizilaslan, Hasan Khatib, Bruna Corradetti, Bermans Iskandar
31	Early urologic outcomes after prenatal vs postnatal myelomeningocele repair: A single-centre retrospective study **Sahrish Masood,** Usman Kahloon, Abby Varghese, Joana Dos Santos, Michael Chua
21	Transition Readiness and Self-Management in Spina Bifida: Comparing Pediatric and Adult Clinic Populations Using the TRAQ-SB **Jeffrey P. Blount MD MPH,** Betsy D Hopson PhD, Daniel Harmon MD, Danielle Powell MD MPH
46	Bone health in youth with spina bifida and hydrocephalus before and after exercise training **Elizabeth Zimmermann**, Camille Costa

Parallel Session 3 - Prevention & Public Health

Abstract no	Title & Authors
6	How Can We Support Gynecological Health of Women Living with Spina Bifida? **Mathilde Barbeau**
34	Chromosomal 22q11.2 microdeletion confers substantial meningomyelocele risk: a case report **Ann Paal,** Tiit Nikopensius, Karmo Tali, Elvira Kurvinen, Laura Zirel
12	Knowledges and practices of perinatal healthcare professionals regarding folic acid and neural tube defects **Maman You Espérance Broalet,** Raïssa Diaby, Sié Jacques Karidioula, Jean Baptiste Kéké, Mohamed Vakaramoko Koné, William Panan Bamba, Prisca Yapi
19	Mortality Through 2021 Among Persons Born With Spina Bifida in Metropolitan Atlanta, 1981-2018 **Vijaya Kancherla,** Victoria Konrad Markwalter, Janet Cragan, Elizabeth B. Gray, Catharine Riley, Jennita Reefhuis
43	Preventing neural tube defects in Latin America: a regional call to action on folic acid fortification and surveillance Roozen, S., Rodas-Moya, S., Benavides-Lara, A., Congionti, J., Groisman, B., Genoway, J., Montgomery, S., Farris, M., Sandoval, V., Wertelecki, W., **Tizzano, E.F.**

PARALLEL SESSIONS DETAILS

Parallel Session 4 - Rehabilitation & Functional Recovery

Abstract no	Title & Authors
29	Development and Implementation of an After Visit Summary in an Interdisciplinary Spina Bifida/Spinal Cord Injury Outpatient Clinic Priya Sayal, Sahrish Masood, **Jenna Doig**
36	Perineal rehabilitation in pediatrics (ages 0-18) with a focus on spina bifida, lessons learned from our new clinic **Anne Jougit,** Emilie Croteau
7	Clinical outcomes of a powered knee-ankle-foot orthosis in children with flexed-knee gait **Chris Toelle**, Kathleen Carroll, Adrianne Parker, Dwiesha England, Tom Dibello, Shane Wurdeman
4	Clinical decision-making in orthoses, gait alignment, and mobility optimization in pediatric spina bifida **Sandra Sanchez pht, Camille Costa MD**
3	Transcutaneous Spinal Stimulation (tSCS) using the NISE-Stim Protocol in Paediatric Spina Bifida Physiotherapy **Kate Steele**

Parallel Session 5 - Bladder, Bowel & Continence Care

Abstract no	Title & Authors
33	Strengthening continence care workforce to transform outcomes for individuals with Spina Bifida in Nigeria Afolabi Fajemilo, **Kate Steele**
16	Clean intermittent catheterization practices among myelomeningocele patients in Addis Ababa: role of caregiver awareness **Nebiyat Tesfaye,** Cherinet Abuye, Bethelehem Yesehak Worku, Mihretab Ermias, Silante Mulud
11	Urinary incontinence and health-related quality of life in children with spina bifida: preoperative versus postoperative assessment after continence surgery **Sneha Sawant,** Sonia Thakur, Sandhya Maurya, Srishti Shinde, Santosh Karmarkar
32	Bladder surgery is essential yet underperformed for social continence in neurogenic bladder **Sandhya Maurya**, Sonia Thakur, Sneha Sawant, Srishti Shinde, Santosh Karmarkar
14	Cystatin C provides stable kidney function estimates across lesion levels in adults with spina bifida **Brad E Dicianno,** Stephen Kisty, Sarah A Korth, Blaise W Abramovitz, Oluwasanmi Adenaiye, Paul Rusilko
25	Restoring independence with continent catheterizable channels in neurogenic bladder **Sonia Thakur,** Sandhya Maurya, Srishti Shinde, Sneha sawant, Santosh Karmarkar

Parallel Session 6 - Inequalities & Human Rights

Abstract no	Title & Authors
15	Health equity gaps in spina bifida and hydrocephalus: insights beyond global disability frameworks **Lyudmil Ninov,** Egidia Pichon, Jessica Congionti, Victoria Sandoval, Sylvia Roozen
13	Universal Accessibility to Voting — Measures Implemented in Quebec **Julie Fontaine, Anne Claire Pelletier**
10	Anxiety and depression in parents of children with spina bifida and hydrocephalus in Niger **Kelani Aminath Bariath Phuong-Tam,** Zika Ousseyni Oumou, Sikidou Ramatou D Seyni, Lawali Issa Housseina, Hamissou Moussa Maman Roufai, Catala Martin
8	Employment Experiences and Barriers among individuals with SBH in Asia : Perspectives from India and Malaysia **Swara Madav**
44	Social Integration Through Sport and the Outdoors in Youth Living with Spina Bifida **Marine Gailhard**

PARALLEL SESSIONS DETAILS

Parallel Session 7 - Surgical & Clinical Interventions

Abstract no	Title & Authors
37	Neurosurgical focus on the multidisciplinary management of patients with mild forms of closed spinal dysraphism **Alina Korsak,** Volodymyr Likhodiievskyi, Serhii Olefir, Nazar Holubnych, Yan Tytarenko, Andrii Akymov, Vladyslav Myronov, Andrii Iskov, Andrii Harkusha, Pavlo Andrieiev
39	Challenges of TMS in children under 9 for tethered cord syndrome diagnostics: need for multicenter collaboration **Volodymyr Likhodiievskyi,** Alina Korsak, Oleksandr Solonovych, Serhii Ziablitsev, Yulia Perepelytsya, Iryna Holovatiuk, Myroslava Marushchenko, Maksym Hroma, Daria Yehorova, Andrii Akymov
18	Measuring hemi cord symmetry in split cord malformation to help predict lower limbs sensory-motor outcomes Antoine Welniarz, **Gabrielle Gour-Provençal**, Timothée De Saint-Denis, Pauline Lallemant-Dudek
1	Prenatal Repair of Spina Bifida: An option for Treatment or an Opportunity to Improve Quality of Life? **Agnieszka Pastuszka**

Parallel Session 8 - Hydrocephalus

Abstract no	Title & Authors
22	Quality of Life, Obesity & Lifestyle **Diana Gray**
9	DTI-ALPS as a prognostic biomarker of glymphatic function in idiopathic normal pressure hydrocephalus **Ali El Jamal,** Arash Sarshoghi, Albert Guillemette, Marc-Antoine Gobeil, Sami Obaid, Pierre Blanchet, Marie-Pierre Fournier-Gosselin
30	Bio-inspired self-cleaning catheter material and design **Amy Huang,** Haritosh Patel, Duygu Dengiz, Mariya Pravdivtseva, Olav Jansen, Eckhard Quandt, Ariel Jiyoung Lee, Jack Alveranga, Jia Liu, Joanna Aizenberg
24	Video-based kinematic gait analysis to predict shunt response in idiopathic normal pressure hydrocephalus **Marc-Antoine Gobeil,** Tristan Martin, Albert Guillemette, Pierre-Luc Lévesque, Ali El Jamal, Laurie Flynn, Laurence Charbonneau, Pierre Blanchet, Marie-Pierre Fournier-Gosselin

Parallel Session 9 - Quality of Life, Obesity & Lifestyle

Abstract no	Title & Authors
42	Health-related quality of life in children with spina bifida: a review of quantitative HRQoL studies **Charlotta Levén Andréasson,** Michaela Dellenmark-Blom, Marie Andersson, Sofia Sjöström, Giovanni Mosiello, Sylvia Roozen[3], Christian Radmayr, Rien Nijman, Jean-Marie Jouannic, Kate Abrahamsson
23	Inconsistent weight management strategies for individuals with Spina Bifida utilized by healthcare providers **Jennifer C. Tudor**
38	Nutritional and psychological status in individuals with spina bifida in India **Sandhya Maurya,** Sonia Thakur, Arshiya Kadri, Sneha Sawant, Srishti Shinde, Santosh Karmarkar
28	Sleep-disordered breathing in infants with myelomeningocele and Chiari II malformation: evaluating current diagnostic pathways **Dr Carylyn Lim,** Melissa Goktogan, Dr Natalie Gentin, Dr Tobias Hunt, Dr Ruth Mitchell
35	Unrecognized sleep problems in children with spina bifida: A simple screening approach Sonia Thakur, **Namita Singh,** Sandhya Maurya, Srishti Shinde, Sneha Sawant, Santosh Karmarkar

50TH ANNIVERSARY

In 2026, **Spina-bifida hydrocéphalie Québec celebrates its 50th anniversary.**

For fifty years, we have informed, supported, advocated for rights, and brought together people living with spina bifida and/or hydrocephalus, their families and loved ones. For fifty years, we have worked alongside healthcare professionals, researchers, partners, and all those who contribute to improving the quality of life and social participation of the people we serve.

Since 1976, much has changed. Knowledge has advanced, care has evolved, and life expectancy has improved considerably. The children we once supported have grown into adults, parents, members of the workforce and, today, in some cases, older adults. With these advances have come new needs and new challenges.

Our history is, above all, the story of the people who built it: parents who came together to break isolation and advocate for better services; people living with spina bifida or hydrocephalus who made their voices heard; and the volunteers, board members, professionals and partners who believed in our mission and helped it grow.

Celebrating this milestone during the **31st International Conference on Spina Bifida and Hydrocephalus** holds very special meaning. Under the theme "**A Life of Experiences, from Preconception to Aging,**" the conference reflects how far we have come while also reminding us of the work that still lies ahead.

And now, it is time to celebrate!

We warmly invite you to join us for our 50th Anniversary Reception, an evening to celebrate five decades of commitment, progress and community. It will be an opportunity to reconnect, share memories, honour those who have contributed to our journey, and celebrate together the people who have made these 50 years possible.

We look forward to celebrating this milestone with you and to writing the next chapter together.

Laurence Leser
Spina-bifida hydrocéphalie Québec Executive director

50TH ANNIVERSARY

Join us to **celebrate the 50th anniversary of Spina-bifida hydrocéphalie Québec Association** at a festive evening following the conference.

This event will be an opportunity to come together, share experiences, learn, and recognize the progress made over the past five decades.

We've prepared a **festive evening full of surprises for you**.
On the program: a cocktail dinner, a mixologist, entertainment, dancing, and many more surprises! Don't miss it!

Practical information :

Theme of the evening and dress code:
- Theme: Turquoise and Gold
- Dress code: Smart casual

Registration includes: the meal (in the form of a cocktail dinner) and a drink voucher. Beyond that, drinks will be at the participants' expense.

Address: Grande Bibliothèque de BAnQ - 475 Boul. de Maisonneuve E, Montréal, QC H2L 5C4

Schedule:
- 17 October 2026
- Doors open 6pm
- Evening starts 6:30pm
- Evening ends 10:30pm

Link to register: Click here to register

KEYNOTE ABSTRACTS

TALK 1 | Hydrocephalus

Dr. Marie-Pierre Fournier-Gosselin
Centre Hospitalier de l'Université de Montréal (CHUM), Canada

Background: Since the 1950's, major advances in the surgical management of hydrocephalus were achieved. The condition of Normal Pressure Hydrocephalus (NPH) was intimately link to those historical developments. With aging population, NPH is becoming a definite public health issue. Recent regain interest in clinical and fundamental research on NPH offer new hope for patients, caregivers and health care providers .

Methods: The presentation will review the treatment state of the art in hydrocephalus, will then precise the particularities in NPH, presents the NPH situation in Canada and reviews the main research efforts and developments in this field.

Findings: Hydrocephalus studies across all ages and conditions are, in the end, intimately link. Development of safer surgical strategies approaches and devices can offer greater benefit and lower the risks for all patients with hydrocephalus conditions.

Discussion: Deeper understanding on hydrocephalus mecanisms and pathophysiology (namely the glymphatic system) could allow identification of radiological, biological and dynamic biomarkers to support the clinical decision-making in the aging and frail population with NPH.

TALK 2 | Bridging the gap: Lessons learned from transitioning youth with spina bifida to adult care

Dr. Sara Long-Gagné
Montreal Children's Hospital, McGill University Health Centre, Canada

Background: Transition from pediatric to adult healthcare is a critical milestone for youth with spina bifida and is often associated with poorer health outcomes and loss to follow-up. Navigating this transition can be challenging for youth, families, and providers alike.

Approach: This presentation draws on the experience of the Montreal Children's Hospital Spina Bifida Clinic, a tertiary interdisciplinary program with more than 50 years of experience caring for children and youth with spina bifida. Clinical program development, collaboration with adult healthcare providers, and evaluation of transition practices informed the identification of key challenges, lessons learned, and successful strategies.

Findings: Common challenges reported in the literature and reflected in our experience include fragmented care, difficulty accessing adult healthcare services, and supporting youth to become active participants in their care. Youth surveyed in our clinic identified navigating adult healthcare services and accessing available supports as the areas for which they felt least prepared.

Discussion: The Spina Bifida Clinic at the Montreal Children's Hospital has a longstanding partnerships with adult rehabilitation services supporting transition through joint transfer visits, early adult physiatry assessment, and access to care coordination. Over the past five years, the clinic has implemented standardized transition practices to improve preparation, including early attachment to a primary care provider, annual transition readiness assessments, goal setting to foster autonomy and self-management, and access to further supports through the hospital's pediatric-adult transition hub. Despite these advances, psychosocial well-being, sexuality, and mental health remain areas requiring greater attention, highlighting the need to address the less visible challenges that influence healthy development and independence in young adulthood.

TALK 3 | Mental Health Across the Lifespan in Individuals with Spina Bifida and Hydrocephalus

Prof. Dr. Alexander von Gontard
Governor Kremers Centre, Department of Urology, Maastricht University Medical Centre, Maastricht, The Netherlands

Background: Advances in medical and multidisciplinary care have transformed the lives of individuals with spina bifida and hydrocephalus, with increasing numbers reaching adulthood and older age. However, mental health has received far less attention than physical health, despite its major influence on education, participation, independence and quality of life. In addition, mental health problems and disorders can be assessed and treated effectively, thereby reducing incapacitating and distressing symptoms.

Presentation: This keynote lecture is based on a systematic review of the literature, examining mental health across the lifespan in individuals with SBH. Typical problem areas and disorders were identified, including cognition, neuropsychological functioning, attention-deficit/hyperactivity disorder (ADHD), anxiety, depression and other mental health conditions.

The aim is to give an overview on these different problems and disorders in a practical way, highlighting key diagnostic features, modes of assessment and effective treatment options.

The evidence demonstrates that mental health challenges are common throughout life. Children and adolescents are at increased risk of cognitive, neuropsychological difficulties and ADHD, while anxiety and depressive disorders are prevalent in adulthood.

Mental health outcomes are closely linked to educational achievement, social participation, employment and independent living. Nevertheless, mental health assessment and psychological support remain inconsistently integrated into routine SBH care.

Conclusions: Mental health should be recognized as a core component of comprehensive, lifelong SB care. This keynote will discuss the current evidence, highlight knowledge gaps, and explore how multidisciplinary teams can better integrate mental health into clinical practice, research and policy to improve outcomes and quality of life for people living with SBH.

SESSIONS ABSTRACTS

Nº1 | Prenatal Repair of Spina Bifida: An option for Treatment or an Opportunity to Improve Quality of Life?

Agnieszka Pastuszka
Medical University of Silesia, Poland

Background: Spina bifida is the second most common congenital malformation after heart defects and the most common developmental defect of the nervous system. Its incidence varies from 0.3 to 5 per 1,000 live births. The defect develops early in fetal life and has a multifactorial origin, with folic acid deficiency before and during pregnancy being an important risk factor. The treatment of spina bifida has developed over time, including the possibility of prenatal surgical repair.

Method: Prenatal surgery for spina bifida has been performed for 28 years in the United States and for more than 21 years in Poland, the first country in Europe to introduce this procedure. This presentation draws on the Polish experience and discusses the development of prenatal repair and the experience gained over more than two decades. Prenatal and postnatal surgery are compared, with particular attention to hydrocephalus, motor function, urinary and digestive function, and quality of life.

Findings: Comparative analyses indicate that children who undergo prenatal repair are less than twice as likely to require ventriculoperitoneal shunt placement for hydrocephalus. Prenatal myelomeningocele surgery reduces the duration of exposure of the spinal cord and nerves to toxic amniotic fluid and mechanical trauma. This may contribute to improved motor function and better function of the urinary and digestive systems. Studies have also demonstrated a statistically significant improvement in quality of life following prenatal repair.

Discussion: Prenatal repair of spina bifida represents an important development in the treatment of this condition. By reducing exposure of the developing spinal cord to damaging factors before birth, it may improve neurological and functional outcomes and, ultimately, quality of life. Prenatal surgery should therefore be considered not only as an option for treatment, but also as an opportunity to improve the long-term quality of life of children with spina bifida.

N°2 Strengthening continence care workforce to transform outcomes for individuals with Spina Bifida in Nigeria

Afolabi Fajemilo, **Kate Steele**
Festus Fajemilo Foundation, Nigeria

Background: Children and young adults with Spina Bifida in Nigeria face major barriers to receiving safe and consistent continence care. Workforce shortages, limited specialist training, and lack of integrated services lead to preventable infections, poor continence management, school exclusion, and social stigma.

Methods: A multi-layered workforce development model was implemented, combining online and in-person clinical training, case-study-based learning, and on-site practical demonstrations. Leadership and governance training were delivered to selected nurses to increase local ownership and quality assurance. Outreach workers were recruited from local communities to extend care into homes and schools, improving equity and early intervention.

Findings: At its core, the model strengthens clinical capacity of more than 120 nurses and outreach workers who completed online and face-to-face training in continence care, assessment, disability-inclusive practice, and early detection of complications to provide care and improve the well-being of more than 300 babies, children and young adults with spina bifida. A development programme in leadership and governance equipped 5 lead nurses to act as programme champions, aiding in cascading a sustainable, quality-assured training structure, across public health facilities. Trained outreach workers conducted over 130 home and school visits, extending clinical care into daily environments, identifying complications early, and serving as a vital conduit between families and clinical services. A multidisciplinary peer network of 61 health workers supports ongoing case discussions, shared problem-solving, and continuous learning across regions. While a nationwide campaign reached 11.5 million people to reduce stigma, encouraging early intervention, and promoting folic acid awareness.

Discussion: SLIF has produced a scalable blueprint to transform national continence care in low-resource settings, demonstrating how coordinated action and gaining commitment from key partners can reshape outcomes and create equitable pathways for children and young people living with spina and offering a replicable model for countries seeking to build sustainable continence care.

N°3 Transcutaneous Spinal Stimulation (tSCS) using the NISE-Stim Protocol in Paediatric Spina Bifida Physiotherapy

Kate Steele
SHINE: Spina bifida - Hydrocephalus - Information - Networking – Equality, United Kingdom

Background: Physiotherapy in spina bifida has traditionally aimed to compensate for functional loss and prevent complications. In spinal cord injury, there's strong evidence supporting the use of tSCS neuromodulation therapy to improve functional outcomes. The published evidence for this neurorehabilitative therapy in spina bifida is more limited but shows promise.
Since 2022, Shine has provided a tSCS service to Shine members, predominantly children but also some adults with spina bifida.

Methods: Service delivery is via pop-up clinics across the UK and remote support. The service uses the NISE-Stim protocol developed for spina bifida by Gerti Motavalli and Dr Gad Alon. Portable stimulation units with adhesive electrodes are used to provide targeted electrical stimulation over the spine and peripheral muscles. Parameters are personalised according to the child's baseline physiology and therapeutic goals.
We screen potential service users for practical and medical suitability. Following preassessment, most will engage in long-term, consistent therapy.

Findings: We have found the service to be safe: there have been no serious adverse effects attributable to NISE-stim, including in those with programmable ventriculoperitoneal shunt valves. Any side effects tend to be mild and temporary, such as skin irritation or discomfort. We perform clinical assessments at the start of therapy and at 6-monthly intervals, with remote support available in -between appointments. Our assessments show multiple functional domains improve in the treated children, the majority within 3 months of starting therapy. We see gains in strength and movement quality, progression in milestones and skill development, and increased participation and activity. There's also evidence of improvement in posture, sensation, circulation, and bowel management.

Discussion: NISE-Stim is a promising new treatment for people with spina bifida. Further clinical trials are needed to build quantitative evidence of efficacy, and basic research is needed to explore the mechanisms underlying the therapeutic benefits.

N°4 | Clinical decision-making in orthoses, gait alignment, and mobility optimization in pediatric spina bifida

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Background: Children with spina bifida present with evolving musculoskeletal and gait impairments that affect alignment, mobility, and long-term joint health. Rehabilitation focuses on minimizing secondary deformities and supporting efficient, functional mobility throughout growth.

Methods: This presentation will review common gait patterns observed in children with spina bifida, based on findings from instrumented gait analysis, including standard gait laboratory assessments and the GRAIL (Gait Real-time Analysis Interactive Lab) system. Associated gait deviations will be described, along with their impact on alignment, energy cost, and endurance.

Findings: We will outline our clinical approach to orthotic management, which is based on longitudinal observation of gait and function. Clinical examination, gait analysis data, and functional goals are integrated to guide orthotic prescription and decisions regarding the introduction of mobility aids.

Discussion: Clinical cases will be used to illustrate how gait analysis, functional assessment (including stability and endurance), and individualized goals inform orthotic design, alignment strategies, and mobility training. In this presentation, we provide a structured, clinically applicable framework for assessing gait and guiding bracing in children with spina bifida, with the aim of supporting efficient mobility and participation.

N°5 | Understanding the needs of youth living with spina bifida during transition to adult care

Laurence Veilleux[1], Nadine Korah[2], Kimberly Anganu[3], Sara Long-Gagné[2]
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Background: Spina bifida is a complex congenital disorder that can lead to lifelong sequalae. Transition to adult care for this population is associated with declining health outcomes, struggles with self-management and poor social participation. This project aims to determine areas of need related to the transition practices of youth with spina bifida and identify priorities for future quality improvement initiatives.

Methods: A condition-specific Transition Readiness Assessment Questionnaire (TRAQ) was completed by 28 patients (ages 14-18) followed in the spina bifida clinic at the Montreal Children's Hospital between October 2023 and January 2026. This questionnaire uses a 4-part response set (no help needed, some help needed, substantial help needed, non-applicable) within 5 categories (Knowing my Health, Using Healthcare, Lifestyle/Social Supports, Becoming Independent and Self-Advocacy). The average score in each category is used to determine the areas requiring additional support and education.

Findings: The TRAQ was completed by 28 individuals with a mean age of 14.9 years (SD 1.3); 14 males (50%) and 14 females (50%). Using Healthcare and Becoming Independent were the categories in which a majority of patients demonstrated poor transition readiness (82.0% and 57.1%) as opposed to Knowing my Health (29%), Lifestyle/Social Supports (4%), and Self-Advocacy (39%).

Discussion: Our results suggest that youth living with spina bifida may benefit from additional support developing competencies in using the healthcare system and developing their independence. The creation of short, engaging, and informative videos aimed at empowering youth in these areas may be considered as a second part of this study.

N°6 | How Can We Support Gynecological Health of Women Living with Spina Bifida?

Mathilde Barbeau
Family physician in CISSS-CA and MaClinique des Ponts, Lévis, Canada

Background: We know that access to gynecological examinations may be more difficult for women with paraplegia or mobility impairments. In addition, during medical appointments, women with spina bifida often have many health-related issues to discuss, leaving less time to address gynecological health and related preventive care.

Methods: We will present Quebec recommendations for cervix cancer screening in women, applied to women with spina bifida. We will also present general recommendations regarding prevention of sexually transmitted infections and unplanned pregnancies that are relevant to women with spina bifida.

Findings: We will present the barriers that women with spina bifida may encounter in accessing cervix cancer screening and examine how lack of information may negatively affect pregnancy planning and the prevention of sexually transmitted infections.

Discussion: We will discuss different approaches to cervix cancer screening, including a new self-sampling method available in Chaudière-Appalaches and in some other regions of Quebec. We will also discuss fertility in women with spina bifida, different contraceptive options that can support pregnancy planning and help prevent sexually transmitted diseases, and folic acid recommendations for women with spina bifida or for women who have a parent or sexual partner living with a neural tube defect.

N°7 Clinical outcomes of a powered knee-ankle-foot orthosis in children with flexed-knee gait

Chris Toelle, Kathleen Carroll, Adrianne Parker, Dwiesha England, Tom Dibello, Shane Wurdeman
Hanger Institute for Clinical Research and Education, USA

Background: Flexed-knee gait is common in children with neuromuscular and orthopedic conditions such as cerebral palsy and spina bifida and can significantly limit mobility. Conventional orthoses often improve stability but have limitations. Microprocessor-controlled powered knee-ankle-foot orthoses (MPKAFO-P) offer dynamic assistance; however, evidence regarding real-world functional outcomes remains limited. This study aimed to evaluate the effectiveness of MPKAFO-P use on gait, mobility, and quality of life in pediatric populations.

Methods: A prospective clinical study was conducted with 16 children (mean age 10.5 ± 2.5 years; 8 males) presenting with flexed-knee gait. Participants completed a three-hour training session followed by three months of home and community use of the MPKAFO-P. Outcome measures included EQ-5D-Y-3L, Neuro-QoL Pediatric Lower Extremity, Observational Gait Scale (OGS), Timed Up and Go (TUG), and 2-Minute Walk Test (2MWT). Secondary outcomes included frequency of trips/falls and foot drag. Pre- and post-intervention measures were compared using dependent t-tests ($\alpha = 0.05$).

Findings: Significant improvements were observed in EQ-5D-Y-3L (0.825 ± 0.14 to 0.898 ± 0.09; $p = 0.030$) and OGS scores (8.1 ± 3.3 to 10.6 ± 5.7; $p < 0.001$). Neuro-QoL scores increased but were not statistically significant ($p = 0.23$). No significant improvements were observed in performance-based measures (TUG, $p = 0.90$; 2MWT showed a decrease, $p = 0.02$). Notably, trips or falls decreased from 69% to 15%, and foot drag from 85% to 31%.

Discussion: MPKAFO-P use was associated with improved gait quality, health-related quality of life, and safety in real-world settings. Despite limited changes in performance-based metrics, reductions in falls and gait deviations highlight meaningful functional benefits. These findings support the clinical potential of powered orthotic technology in enhancing health related quality of life for children with flexed-knee gait.

N°8 | Employment Experiences and Barriers among individuals with SBH in Asia : Perspectives from India and Malaysia

Swara Madav
Spina Bifida Foundation India, India

Background: Employment is a key determinant of independence, psychosocial wellbeing, and quality of life for individuals with Spina Bifida. Despite this, limited evidence exists on employment experiences in Asian contexts, where systemic, social, and infrastructural barriers may differ significantly from high-income regions. This regional update aimed to explore employment challenges, enabling factors, and support needs among individuals with Spina Bifida in India and Malaysia.

Methods: A qualitative regional update approach was used, drawing on structured stakeholder inputs from individuals with Spina Bifida and advocacy networks across India and Malaysia. Data were synthesised using thematic analysis to identify shared and context-specific employment experiences, perceived barriers, and enabling supports.

Findings: Three key themes emerged: (1) structural barriers, including inaccessible workplaces, transportation challenges, and limited workplace accommodations; (2) social and attitudinal barriers, such as stigma, low employer awareness, and reduced confidence during job-seeking; and (3) enabling factors, including family advocacy, foundation-led vocational guidance, peer mentorship, and emerging remote work opportunities. Participants across both countries reported strong educational aspirations but limited structured transition-to-employment support. Similar systemic challenges were observed across settings, alongside differences in organisational and policy-level employment support.

Discussion: These findings highlight the need for accessible workplace policies, employer sensitisation initiatives, and coordinated vocational transition programmes tailored to Asian contexts. This regional update contributes to health psychology by amplifying lived experiences from underrepresented regions and informing culturally responsive employment inclusion strategies. Strengthening collaboration between healthcare providers, disability organisations, and policymakers is essential to improving workforce participation and long-term quality of life outcomes for individuals with Spina Bifida.

N°9 DTI-ALPS as a prognostic biomarker of glymphatic function in idiopathic normal pressure hydrocephalus

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Background: The pathophysiology of idiopathic normal pressure hydrocephalus (iNPH) remains incompletely understood. Since the discovery of the glymphatic system in 2012, evidence suggests its dysfunction may contribute to iNPH, particularly through impaired metabolic waste clearance from cerebrospinal fluid. The DTI-ALPS index (Diffusion Tensor Imaging Along the Perivascular Spaces), developed by Taoka et al. in 2017, provides a non-invasive estimate of glymphatic function. While its diagnostic utility and correlation with response to cerebrospinal fluid tap test (CSF-TT) have been explored, its prognostic value and longitudinal evolution remain unclear. This study evaluates the DTI-ALPS index in patients with suspected iNPH, correlating imaging findings with functional outcomes before and after CSF-TT and at 6-month follow-up.

Methods: A prospective cohort of patients with suspected iNPH is being followed as part of the MiNPHI study (Montreal Idiopathic Normal Pressure Hydrocephalus Initiative). To date, 23 patients have been recruited. The DTI-ALPS index was measured in patients who underwent diffusion MRI. Functional assessment included 10-meter walking speed, the Timed Up and Go (TUG), and the Berg Balance Scale, measured before and after CSF-TT and at 6-month follow-up. Patients eligible for surgical treatment underwent ventriculoperitoneal shunting (VPS). At follow-up, 12 patients were evaluated (9 operated, 3 non-operated). Correlation analyses will assess relationships between baseline DTI-ALPS values and functional outcomes, as well as their changes over time. Changes in DTI-ALPS and comparisons between responders and non-responders to CSF-TT and VPS will also be evaluated.

Findings: Analyses of the relationship between DTI-ALPS values, functional outcomes, and response to CSF-TT and VPS are ongoing. Results will be presented at the conference.

Discussion: This study aims to clarify the role of glymphatic dysfunction in iNPH and determine whether the DTI-ALPS index can serve as a prognostic biomarker for diagnosis, patient selection, and therapeutic monitoring.

N°10 | Anxiety and depression in parents of children with spina bifida and hydrocephalus in Niger

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Background: Neural tube defects such as spina bifida and hydrocephalus impose a significant clinical and psychosocial burden on families. Data on caregiver's mental health in low-resource settings remain scarce. This study aimed to assess anxiety and depression among parents of affected children in Niger.

Methods: A cross-sectional study was conducted on October 25, 2025, during World Spina Bifida and Hydrocephalus Day at the National Hospital of Niamey, Niger. Parents of children with spina bifida, encephalocele, and/or hydrocephalus who were invited to participate during the event were included in the study. Sociodemographic data were collected using a structured questionnaire. Anxiety and depression were assessed using the Hospital Anxiety and Depression Scale (HADS). Scores were categorized as normal (≤7), borderline (8–10), or indicative of clinically significant symptoms (≥11). Data were analyzed using Microsoft Excel and Epi Info version 7.2.2.6. Given the observational nature of the study conducted during a public health event, formal ethical approval was not required in accordance with local regulations. Written informed consent was obtained from all participants.

Findings: Forty-nine families participated. The mean age of mothers was 29.2 years, and children's mean age was 23.9 months. Spina bifida was the most frequent diagnosis (65%), followed by hydrocephalus (25%). Definite anxiety symptoms were found in 57.1% of caregivers, borderline in 24.5%, and absent in 18.4%. Definite depressive symptoms were present in 24.5%, borderline in 28.6%, and absent in 46.9%. Co-occurring anxiety and depression affected 18.4% of participants.

Discussion: Caregivers showed a high burden of anxiety and notable depressive symptoms. These findings highlight the need for integrated mental health support within neurosurgical care in low-resource settings and support routine psychological screening of caregivers.

N°11 | Urinary incontinence and health-related quality of life in children with spina bifida: preoperative versus postoperative assessment after continence surgery

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Background: Urinary incontinence significantly impairs quality of life (QoL) in children with spina bifida, affecting psychosocial well-being, independence, and social integration. There is limited data from the Indian setting using validated QoL instruments. This study evaluates the impact of continence surgery on health-related QoL using a standardized and objective assessment tool.

Methods: Children under 18 years of age with spina bifida who underwent continence surgery were included. QoL was assessed using the validated Pediatric Incontinence Questionnaire (PinQ). Parents of children <12 years completed the questionnaire, while older children were interviewed directly. The PinQ consists of 20 questions scored on a Likert scale (0–4), with a maximum score of 80; higher scores indicate greater QoL impairment. Preoperative and postoperative scores were compared across five domains: self-esteem, family and home, social relations, mental health, and independence.

Findings: There was a statistically significant improvement in overall QoL following continence surgery. Improvements were observed across all five domains, with marked reduction in the impact of urinary incontinence on daily functioning and psychosocial well-being. Lower postoperative scores reflected enhanced independence, better social participation, and improved self-esteem.

Discussion: Continence surgery leads to substantial improvement in QoL in children with spina bifida. In the Indian context, this study highlights the transformative effect of achieving continence on multiple aspects of a child's life. These findings reinforce the importance of timely surgical intervention and support its role as an essential component of comprehensive spina bifida care.

N°12 | Knowledges and practices of perinatal healthcare professionals regarding folic acid and neural tube defects

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Background: Periconceptional folic acid supplementation of 0.4 mg/day is believed to reduce the number of malformations by 72%. In Côte d'Ivoire, folic acid supplementation is prescribed during pregnancy, and food fortification with folic acid is still poorly understood. The aim of our study was to assess the knowledges and practices of perinatal professionals.

Methods: Survey based on a google form questionnaire with 25 items divided into three chapters: socio-professional data, knowledge about NTDs, folic acid recommendations, and practices. 220 responses were recorded.

Findings: Midwives represented 55.9%, followed by obstetrician-gynecologists, 8.2%. Responses regarding folic acid were accurate in 60 to 80%, and in 27 to 60% regarding its role. Folic acid was found in green vegetables in 88%. Ninety-five percent responded that spina bifida was an NTDs. ninety-five percent reported receiving 0 to 5 nervous system malformations per month. folic acid deficiency was cited as a risk factor for NTDs in 95.4% of cases. Folic acid should be recommended to all women wishing to become pregnant in 79.5%. The time of prescription was before pregnancy in 49.3% of cases and during pregnancy in the same proportion. the dosage was 0.4 mg for women without risk factors in 37.5% of cases, and 5 mg for women with risk factors in 63.9%. For 44.2% of respondents, supplementation should begin 4 weeks before conception and continue 12 weeks after. The obstacle to achieving adequate folate status among pregnant women was the fact that they did not seek medical advice before pregnancy in 82.9%.

Discussion: Folic acid and its role in the occurrence of NTDs are relatively well known. However, recommendations regarding its prescription are less well known. Furthermore, women did not seek medical advice before pregnancy. Adequate supplementation by following recommendations is important for preventing the occurrence of neural tube defects.

N°13 | Universal Accessibility to Voting — Measures Implemented in Quebec

Julie Fontaine, Anne Claire Pelletier
Élections Québec, Canada

Background: Accessibility manifests in multiple ways in the context of electoral participation. Beyond ensuring the physical accessibility of polling locations and the reference tools developed to uphold those standards, a wide range of initiatives has been introduced; this presentation will highlight them.

Methods: We will present specific measures introduced to allow voters with particular needs to vote. We will also discuss our general communications efforts toward electors, and the information and training tools we deploy.

Findings: Next, we will describe pilot projects and initiatives tested to respond to accessibility needs and to evaluate their effects on voters and other election stakeholders. We will share the outcomes they have produced or that we hope to achieve.

Discussion: Élections Québec also established a citizens' advisory committee specifically focused on universal accessibility. Created in 2018, the committee is composed of electors from diverse backgrounds who possess personal or professional expertise on accessibility issues, including people for whom accessibility is a daily concern. We wish to present the committee's work and accomplishments.

Nº14 | Cystatin C provides stable kidney function estimates across lesion levels in adults with spina bifida

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Background: Serum creatinine–based estimation of glomerular filtration rate (eGFR) is often unreliable in individuals with spina bifida due to reduced muscle mass from paralysis, which varies by spinal lesion level and sub-phenotype. Serum cystatin C, independent of muscle mass, may provide a more accurate alternative. We hypothesized that creatinine-based equations overestimate eGFR at higher lesion levels relative to cystatin C–based equations, while cystatin C estimates remain stable.

Methods: We conducted a retrospective analysis of 155 adults with spina bifida. eGFR was calculated using five equations (Cr-eGFR-2009, Cr-eGFR-2021, CysC-eGFR-2012, Zappitelli-CysC-eGFR, and CrCysC-eGFR-2021). Estimates were compared across five lesion levels and two sub-phenotypes (myelomeningocele vs non-myelomeningocele).

Findings: Creatinine-based eGFR increased with higher lesion levels (both $P < .001$), overestimating kidney function by a median of 12 mL/min/1.73 m² in thoracic-level myelomeningocele compared with cystatin C estimates. All three cystatin C–based equations were stable across lesion levels ($P > .39$) and highly correlated ($\rho = 0.84–0.94$), with P30 exceeding 90% for all pairwise comparisons. However, biases of up to ±7.8 mL/min/1.73 m² and limits of agreement wider than ±40 mL/min/1.73 m² were observed.

Discussion: Creatinine-based equations consistently overestimated kidney function at higher lesion levels and in myelomeningocele. In contrast, cystatin C–based estimates were stable across lesion levels, supporting their use in this population. Nonetheless, variability between cystatin C–based equations suggests caution when interpreting results interchangeably.

N°15 | Health equity gaps in spina bifida and hydrocephalus: insights beyond global disability frameworks

Lyudmil Ninov, Egidia Pichon, Jessica Congionti, Victoria Sandoval, Sylvia Roozen
International Federation for Spina Bifida and Hydrocephalus, Belgium

Background: Global evidence, including frameworks from the World Health Organization (WHO), has significantly advanced understanding of disability-related health inequities. However, these frameworks often do not capture the condition-specific and lifelong care trajectories of people with spina bifida and hydrocephalus (SBH). As a result, important dimensions of inequity-particularly those affecting continuity of care, system navigation, and long-term financial burden - remain insufficiently understood. The primary objective is to assess how early findings from member input and survey data align with established global evidence on disability and health equity. The study also aims to identify key similarities, divergences, and condition-specific equity gaps that may not be fully captured in broader disability datasets.

Methods: A mixed-methods descriptive approach was used, combining qualitative input from member contributions with preliminary quantitative results from a structured survey consisting of two core questions. IF Member inputs were thematically organised into key health system domains. Survey responses were summarised descriptively. The preliminary findings were then compared against established WHO disability and health equity evidence through a structured comparative framework covering access to care, financial protection, continuity of care, and data availability.

Findings: Initial results indicate strong alignment with existing WHO evidence on disability-related barriers, particularly regarding access constraints, financial burden, and fragmented care pathways. However, condition-specific patterns suggest a compounded burden for individuals with lifelong neurodevelopmental conditions, particularly in relation to continuity of care and cumulative system navigation challenges. Significant gaps in disaggregated data remain a consistent barrier to fully capturing these inequities.

Discussion: These preliminary findings highlight the need for more granular, condition-specific health equity data within global disability frameworks. They suggest that existing models may underestimate the layered and lifelong nature of inequities experienced by persons with spina bifida and hydrocephalus. Further validation through broader member consultation is ongoing and will strengthen implications for targeted health system reforms and equity-oriented policy development. Strengthening data systems and integrating these dimensions into policy and service design are critical to improving equity and quality of life.

N°16 | Clean intermittent catheterization practices among myelomeningocele patients in Addis Ababa: role of caregiver awareness

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Background: Myelomeningocele (MMC), a severe form of neural tube defects, is associated with neurogenic bladder leading to urinary tract infections and renal complications. Clean intermittent catheterization (CIC) is an effective intervention to reduce morbidity. This study assessed CIC practices and the role of caregiver awareness among MMC patients in two major hospitals in Addis Ababa, Ethiopia.

Methods: A prospective cross-sectional study was conducted among 260 MMC patients and caregivers attending follow-up clinics at Zewditu Memorial Hospital and St. Peter Specialized Hospital from June to July 2024. Data were collected using interviewer-administered questionnaires and medical record review. Statistical analysis was performed using SPSS, with logistic regression to identify factors associated with CIC practice.

Findings: Only 30.4% of patients had ever practiced CIC, and 28.5% were current users. Caregiver awareness of renal complications was strongly associated with CIC practice. Caregivers with this knowledge were significantly more likely to practice CIC (AOR ≈ 34, 95% CI: 9.2–125.5, $p<0.001$). Other factors such as socio-economic status and caregiver education were not significantly associated. Most caregivers reused catheters and used water with detergent for cleaning.

Discussion: CIC utilization among MMC patients is suboptimal. Caregiver awareness is the strongest predictor of adherence, highlighting the need for targeted education and standardized guidelines. Improving awareness and early initiation of CIC could reduce preventable renal complications in low-resource settings.

Nº17 | Empowering early journeys: a co-designed developmental and peer support pilot for families of children with spinal bifida

Melissa Goktogan, Corrine Browne
Sydney Children's Hospital, Australia

Background: Spinal dysraphism requires lifelong management that often places a significant emotional load on families. In traditional multidisciplinary clinics, clinical time is frequently dominated by medical concerns over early developmental milestones. The first five years of life represent a vital window for neuroplasticity and independence. This study aims to pilot and evaluate a "Developmental Day" programme providing condition-specific support for families of infants (0–2 years) and children (2–5 years) to improve parental confidence and psychosocial resilience through a dedicated, therapist-led environment.

Methods: This study utilises a mixed-methods co-design approach. Participants include families recruited from the Sydney Children's Hospital Spinal Dysraphism Service. An initial scoping questionnaire identifies family priorities to inform the programme's co-design. Evaluation is conducted through pre- and post-pilot surveys measuring shifts in parental confidence across four key domains: supporting physical development, equipment advocacy, managing emotional/social challenges, and connecting with peers. Quantitative Likert scales track changes in the perceived developmental trajectory and resilience, while qualitative feedback captures the most helpful programme components and future suggestions.

Findings: Data collection and the pilot phase are currently in progress. Preliminary scoping results indicate that parents prioritise practical strategies for motor development and equipment needs, alongside a desire for moderated peer connection to reduce social isolation. Full analysis of the comparative pre- and post-survey data regarding parental confidence and programme satisfaction will be presented at the conference.

Discussion: This project demonstrates the value of moving beyond medical management toward a holistic, family-centred model of care. By creating a dedicated space for education, services can more effectively address the developmental and emotional priorities that are central to a child's long-term autonomy. This co-designed pilot provides a reproducible framework for other global spinal dysraphism services to enhance early intervention outcomes, foster community resilience, and empower parents to navigate the developmental journey with greater confidence.

N°18 Measuring hemi cord symmetry in split cord malformation to help predict lower limbs sensory-motor outcomes

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Background: Split cord malformation (SCM) refers to a sagittal division of the spinal cord into two symmetrical or asymmetrical hemi cords. Lower limbs sensory-motor deficits are frequent and often asymmetric. The aim of this study was to evaluate the role of hemi cord symmetry in predicting lower limbs sensory-motor outcomes.

Methods: A 12-year, multi-center, retrospective study of 75 patients was conducted. Data regarding clinical manifestations were extracted from medical records and hemi cords symmetry was assessed by a single trained investigator from the most recent MRI using the Picture Archiving and Communication System. The symmetry of each hemi cord was determined at the most asymmetrical level of the spinal cord.

Findings: Forty patients had type I SCM and thirty-five had type II SCM. Hemi cords were asymmetric in 48/75 (64%) patients. Patients with asymmetrical hemi cords had greater lower limb sensory-motor deficits ($p<0,05$) than those with symmetrical hemi cords (36/48 vs 5/27). For children with asymmetrical hemi cords and lower limb deficits, the deficits were greater on the smaller hemi cord side for 33/36 (92%) patients. We did not find any differences between type I and type II SCM.

Discussion: Evaluating hemi cord symmetry in case of SCM may be helpful in predicting lower limbs sensory-motor outcomes. Regardless of type of SCM, children with asymmetrical hemi-cords tend to have greater lower limb sensory-motor deficits and therefore should have closer multidisciplinary monitoring.

N°19 Mortality Through 2021 Among Persons Born With Spina Bifida in Metropolitan Atlanta, 1981-2018

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Background: Information on prevalence, predictors, and causes of mortality is sparse among persons born with spina bifida (SB), especially adults over age 25 years.

Methods: Individuals with SB born in 1981-2018 were identified in surveillance data from the Metropolitan Atlanta Congenital Defects Program, an active population-based birth defects surveillance system, and linked with Georgia death certificates (1981-2021). Survival probability was assessed using Kaplan-Meier curves. Selected factors were examined using Cox proportional hazards regression, estimating crude (cHR) and adjusted hazards ratios (aHR) and 95% confidence intervals (CIs).

Findings: Of 458 infants born with SB, 341 met eligibility criteria; 18% (n = 61) died. The overall 25-year and 35-year survival probabilities were 82% and 75%, respectively. Survival improved between 1981-1999 and 2000-2018 for individuals with isolated SB ($p < 0.05$), but not for those with multiple defects ($p = 0.41$). Preterm birth (aHR = 2.28; 95% CI = 1.32, 3.95), having multiple major birth defects (aHR = 2.07; 95% CI = 1.04, 4.13), or upper-level spinal lesion (aHR = 3.86; 95% CI = 2.23, 6.69) was associated with increased mortality risk. SB was often listed as the cause of death, even among adults; respiratory and cardiovascular conditions and infections were other commonly listed causes for mortality after infancy.

Discussion: Survival for individuals with isolated SB improved over time; further improvements might be achieved by targeting age-specific risk factors in clinical and public health settings.

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N°20 | Designing Mind-Friendly Environments for People with Hydrocephalus: Enhancing Accessibility and Wellbeing

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Background: Accessibility is more than physical access. For people living with Hydrocephalus and other disabilities, participation and inclusion are also shaped by cognitive, sensory and social aspects of the environments around them. Many accessibility needs are not always visible or addressed within traditional approaches. Creating mind-friendly environments requires a broader understanding of how spaces, services and communities can support confidence, independence, comfort and belonging.

Panel Description: This panel explores how inclusive design can contribute to the well-being and participation of people living with Hydrocephalus by moving beyond traditional concepts of accessibility. Bringing together lived experience, universal design expertise and practical examples from the built environment, the panel will discuss how environments can be designed to reduce cognitive load, support predictability and choice, enable safe transitions and create spaces where people feel comfortable and able to participate.

The discussion will introduce the principles of universal design and explore the importance of cognitive and sensory accessibility, including clear navigation, flexible spaces, opportunities for pause and environments that support emotional safety. A case study from Quebec/Montreal will demonstrate how these principles can be translated into practice.

Through dialogue between people with lived experience, designers and other stakeholders, the panel will reflect on how inclusive environments can be created from the start and how collaboration can help build communities where everyone can participate and belong.

Objectives:
Participants will:

- Understand accessibility as a multidimensional concept, including physical, cognitive, sensory and social aspects.
- Explore the value of mind-friendly environments for people living with Hydrocephalus and others with diverse needs.
- Learn how universal design principles can be applied in practice.
- Recognise the importance of lived experience in shaping inclusive environments.
- Identify opportunities to advance more accessible and inclusive communities.

N°21 | Transition Readiness and Self-Management in Spina Bifida: Comparing Pediatric and Adult Clinic Populations Using the TRAQ-SB

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Background: Transition readiness is a critical component of spina bifida (SB) care, yet few studies evaluate changes in readiness and self-management over time. The Transition Readiness Assessment Questionnaire–Spina Bifida (TRAQ-SB) is a validated, disease-specific instrument. Our SB care model, with dedicated pediatric and adult clinics, integrates an Individualized Transition Plan (ITP), a structured goal-setting framework initiated at age 14. Although national transition guidelines exist, implementation varies, and outcome data demonstrating the effect of structured programs are limited. The purpose of this project is to use our >10 years of experience with a structured transition program to assess whether our approach improves readiness and self- management skills, and to compare TRAQ-SB scores between pediatric and adult cohorts to identify the domains showing the greatest improvement.

Methods: TRAQ-SB data were collected from patients in the pediatric transition readiness clinic and from adults who completed transition and are followed in the adult SB clinic. The TRAQ-SB evaluates five general domains, managing medications, appointment keeping, tracking health issues, talking with providers, and Spina Bifida–Specific Transition Activities, which include recognition and management of shunt symptoms, bowel, bladder, skin, and equipment-related issues. Each item was scored on a 5-point Likert scale, where 1 = "No, I do not know how," 2 = "No, but I want to learn," 3 = "No, but I am learning to do this," 4 = "Yes, I have started doing this," and 5 = "Yes, I always do this when I need to." Mean scores (1–5 scale) and the proportion achieving independence (≥4) were compared between pediatric and adult cohorts.

Findings: A total of 64 pediatric (mean age 16.6 ± 2.1 years, 50.6% female) and 101 adult (mean age 32.4 ± 10.2 years, 39% female) participants completed the TRAQ-SB. Adults demonstrated higher readiness across all domains of the TRAQ-SB, including managing medications (4.38 vs. 4.10), appointment keeping (4.22 vs. 3.82), tracking health issues (4.29 vs. 3.91), and talking with providers (4.46 vs. 4.12). Within the Spina Bifida–Specific Transition Activities domain, the greatest improvements were observed in bowel management (4.45 vs. 3.85), recognition of shunt malfunction (4.15 vs. 3.51), and equipment management (4.28 vs. 3.25). The three bladder-related items, practicing bladder management, recognizing symptoms of urinary tract infection, and addressing bladder problems, were among the highest-scoring questions for both cohorts (pediatric means 4.45, 4.28, and 4.31; adult means 4.40, 4.60, and 4.58), reflecting strong early emphasis on bladder care and sustained independence after transition. Adults were more likely to report independence (scores ≥4) across all items, reflecting growth in both general and condition-specific self-management skills fostered by the ITP framework.

Discussion: The TRAQ-SB effectively differentiates readiness between pediatric and adult SB clinic populations and demonstrates improvement across all domains of transition readiness. While increasing age and experience naturally contribute to greater self-management, the largest gains in bowel management, shunt recognition, and equipment management likely reflect the impact of targeted ITP interventions emphasizing daily self-care and problem-solving.
Longitudinal integration of structured goal-setting and individualized transition planning beginning in adolescence enhances real-world readiness for adult care and provides a reproducible model for lifespan SB programs.

N°22 | Bringing hope to an ageing population

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Background: Idiopathic Normal Pressure Hydrocephalus (iNPH), estimated to affect up to 8 million people worldwide, remains significantly underdiagnosed in the United States. Its hallmark symptoms—gait and balance impairment, cognitive decline, and urinary incontinence—closely mimic those of Parkinson's disease and Alzheimer's disease, leading to frequent misdiagnosis. For decades, many individuals with iNPH have gone untreated, in part due to skepticism within the medical community, particularly in neurology, regarding the condition's validity as a distinct and treatable disorder. Yet when identified early, iNPH is one of the few reversible causes of dementia, with the potential for life-changing outcomes.

Methods: A landmark NIH-funded clinical trial conducted by the Hydrocephalus Association's Adult Hydrocephalus Clinical Research Network, in collaboration with additional centers, has now provided definitive evidence that shunting is an effective treatment for iNPH. Published in the New England Journal of Medicine, these findings represent a critical turning point—validating iNPH as a legitimate diagnosis and establishing a clear, evidence-based treatment pathway.

Findings: The implications are profound. As the population ages, increasing numbers of older adults present with symptoms commonly attributed to neurodegenerative disease. This research underscores the importance of including iNPH in the differential diagnosis and pursuing appropriate imaging to identify ventricular enlargement indicative of a treatable condition. While some patients will ultimately be diagnosed with Alzheimer's or Parkinson's disease, others may have iNPH—and the opportunity for meaningful recovery.

Discussion: With this new level of evidence, organizations serving the hydrocephalus community are uniquely positioned—and obligated—to expand education and awareness efforts among both healthcare professionals and the public. By improving recognition and diagnosis of iNPH, we can help ensure that more patients receive timely, effective treatment and renewed quality of life.

Nº23 | Inconsistent weight management strategies for individuals with Spina Bifida utilized by healthcare providers

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Background: Spina bifida is a congenital neural tube defect that predisposes individuals to a range of physical limitations and medical complications, which are associated with reduced physical activity and a heightened risk for obesity. Obesity can often compound these physical impairments which contributes to the significance of weight management as a health concern.

Methods: Using a cross-sectional survey, this study examined healthcare provider beliefs, attitudes and knowledge of weight management care. Survey respondents are representative of various healthcare professions and clinical settings across the United States.

Findings: As the survey results indicate, healthcare providers consider both physical and social factors important for effective weight management. Importantly, the lack of weight management training, institutional support, and standardized metrics for diagnosing obesity in those with spina bifida were identified. Respondents who received weight management training were more confident in caring for overweight and obese patients who are under 50 years old.

Discussion: Overall, these findings highlight the urgent need for evidence-based guidelines for diagnosing and managing obesity in individuals with spina bifida, ensuring effective and equitable care.

N°24 | Video-based kinematic gait analysis to predict shunt response in idiopathic normal pressure hydrocephalus

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Background: Idiopathic normal pressure hydrocephalus (iNPH) is a neurological condition of the elderly characterized by gait disturbance, urinary incontinence, and neurocognitive impairment. Ventriculoperitoneal shunting (VPS) is the standard treatment for iNPH. Surgical decision-making relies on multimodal assessment, including gait response to a cerebrospinal fluid tap test (CSF-TT). However, current evaluation methods lack objective, quantifiable biomarkers to reliably predict shunt response, with a reported response rate ranging between 30 and 80%. This study aims to identify kinematic gait biomarkers using video-based quantitative analysis to objectively measure locomotor changes following CSF-TT.

Methods: Ten patients with suspected iNPH were prospectively recruited. Sagittal-plane gait videos were recorded before and after CSF-TT. Joint landmarks were automatically extracted using MediaPipe pose estimation. Spatiotemporal gait parameters were computed using custom Python scripts, including step time, stride time, cadence, step length, gait speed, step height, and gait asymmetry indices. Pre and post CSF-TT gait parameters were compared using paired Wilcoxon signed-rank tests.

Findings: Significant improvements in spatiotemporal gait parameters were observed following the CSF-TT. Mean step time decreased by 12.3% ($p = 0.004$, $r = 0.854$) and mean stride time by 11.0% ($p = 0.014$, $r = 0.757$). Cadence significantly increased by 15% ($p = 0.006$, $r = 0.822$). Gait speed showed a trend toward improvement (+25.9%, $p = 0.065$, $r = 0.596$). Step length and step height did not change significantly.

Discussion: This study suggests that video-based pose estimation may capture clinically meaningful kinematic changes following CSF-TT in iNPH. This automated, low-cost approach could complement standard physiotherapy assessments and provide objective, quantifiable biomarkers to support surgical decision-making.

N°25 | Restoring independence with continent catheterizable channels in neurogenic bladder

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Background: Neurogenic bladder in patients with spina bifida is associated with urinary incontinence, recurrent infections and dependence on caregivers, significantly impacting quality of life. Continent catheterizable channels (CCC), such as the Mitrofanoff procedure, enable clean intermittent catheterization (CIC) via an abdominal stoma and promote independence. This study evaluates long-term clinical and functional outcomes of CCC.

Methods: A retrospective study was conducted at our centre between 2008 and 2019. Seventy patients underwent CCC creation, of whom 51 with a minimum follow-up of 5 years were included. Techniques included Appendicovesicostomy (n=48), Spiral Monti (n=2) and detrusor tube (n=1). Patients were followed until December 2024. Outcomes assessed included complications, channel function and compliance with CIC.

Findings: No major immediate postoperative complications were observed. Long-term complications included urinary tract infections in 9 patients, primarily related to improper CIC technique, stomal stenosis in 2 patients, and channel stricture in 2 patients. All patients remained compliant with CIC and continued to use channel effectively. Patients demonstrated improved independence in daily activities and reported high satisfaction with their quality of life.

Discussion: Bladder augmentation with continent catheterizable channels is a safe and effective long-term solution for neurogenic bladder, offering durable continence, renal preservation, and improved independence. Despite excellent outcomes and low complication rates, it remains underutilized, highlighting its importance in comprehensive spina bifida care.

N°26 | 20 years of the UN Convention on the Rights of Persons with Disabilities: Perspectives on the world

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Background: The UN Convention on the Rights of Persons with Disabilities (UNCRPD) was adopted in 2006 as a landmark commitment to advancing the rights, dignity and inclusion of persons with disabilities worldwide. Since then, 184 countries have ratified the Convention, creating a shared framework for promoting equality, accessibility and participation. Twenty years after its adoption, this panel provides an opportunity to reflect on progress made, challenges that remain and the opportunities the Convention offers to further advance disability rights globally.

Panel Description: This panel discussion will explore the implementation of the UNCRPD from a global perspective, bringing together voices from different regions of the world to reflect on national experiences, achievements and ongoing challenges. Panelists will discuss how disability rights are translated into practice across different contexts, considering differences in policies, resources, healthcare systems and social environments.

The discussion will highlight progress achieved since the adoption and ratification of the Convention, while also identifying areas where further action is needed to ensure that persons with disabilities fully enjoy their human rights. Through international dialogue and exchange of experiences, the panel will explore how global commitments can support meaningful change at national and community levels.

The session will feature perspectives from disability rights leaders, including representatives from different regions of the world, and will include an opportunity for audience questions and discussion.

Objectives:
Participants will:

- Reflect on 20 years of progress since the adoption of the UNCRPD.
- Explore regional perspectives on disability rights implementation and inclusion.
- Identify achievements, challenges and opportunities for advancing the rights of persons with disabilities.
- Discuss the role of international frameworks in supporting meaningful change.
- Strengthen understanding of the importance of lived experience in shaping disability policies and practices.

N°27 | Innovative treatment modalities for Spina Bifida repair surgery using a large animal model

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Background: Efforts to understand the genetic and environmental contributions underlying the etiology of neural tube defects, including spina bifida (SB), have identified scores of candidate genes and risk factors. Basic science studies have been performed primarily in small animal models (rodents), yet their relevance to understanding the biology of human SB and related comorbidities such as hydrocephalus have been limited. We have recently established PASTURES (Preclinical Advancements in Spina Bifida Treatment Using Research in Experimental Sheep), a national center to develop innovative treatment modalities for the surgical repair (fetal and postnatal) of SB.

Methods: A mixed-breed sheep flock with a spontaneous occurrence of SB was maintained for over 20 years prior to being moved to the University of Wisconsin Arlington Sheep Research Unit and now forms the foundation of the PASTURES clinical research program.

Findings: Genomic, transcriptomic, and whole-genome methylation profiling across embryonic tissues revealed both shared and lineage-specific perturbations underlying failed neural tube closure. Heritability estimates (0.42-0.68) support a substantial genetic contribution.

Discussion: Using a sheep population with naturally occurring SB, we quantified the disorder's heritability and performed the first integrated multi-omics, multi-tissue analysis of this condition in any mammalian species. The work identified genetic targets for potential intervention that are currently being developed as stem cell-derived biologics for application in conjunction with fetal SB repair surgeries to enhance surgical outcomes and mitigate comorbidities associated with SB.

N°28 | Sleep-disordered breathing in infants with myelomeningocele and Chiari II malformation: evaluating current diagnostic pathways

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Background: Children with myelomeningocele (MMC) and associated Chiari II malformations are at risk for sleep-disordered breathing (SDB). Despite this high-risk profile, diagnostic pathways for respiratory screening are often reactive rather than proactive. This study investigates the prevalence and management of SDB within a specialist spinal dysraphism service to evaluate current clinical practices. The primary objective is to review existing referral patterns and determine if standardised time frames for sleep assessments could improve clinical outcomes and inform future service guidelines.

Methods: This study utilises a retrospective case series of infants with MMC born within the last four years at the Sydney Children's Hospital(SCH). Key data points include clinical presentation (gestation and MMC level), degree of tonsillar descent, and surgical history (antenatal vs. postnatal closure and shunt complications). Evaluation focuses on the timing of referral, formal sleep studies, and sleep study results and outcomes. This multidisciplinary project represents a collaboration between the Sleep Medicine, Neurosurgery, and Rehabilitation teams. The protocol has obtained formal ethics approval through SCH.

Findings: The project is currently in the data collection phase following ethics clearance. Preliminary clinical observations suggest variability in the timing of respiratory reviews and the triggers for sleep study referrals. Detailed analysis regarding the correlation between MMC level, surgical interventions, and SDB severity, as well as the impact of these findings on current diagnostic protocols, will be presented at the conference.

Discussion: Proactive respiratory screening is critical for the management of high-risk infants with MMC and Chiari II malformation. By identifying inconsistencies in current diagnostic timing, this study highlights the necessity for integrated, standardised sleep assessment pathways. These findings will provide the evidence base required to move toward a proactive screening model, potentially reducing respiratory morbidity and improving the long-term neurodevelopmental outcomes for this complex paediatric population.

N°29 | Development and Implementation of an After Visit Summary in an Interdisciplinary Spina Bifida/Spinal Cord Injury Outpatient Clinic

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Background: The Spina Bifida / Spinal Cord Injury (SB/SCI) Clinic at Holland Bloorview Kids Rehabilitation Hospital (HB) in Toronto, Ontario provides healthcare by an interdisciplinary team to patients from across the province. Clinic visits are lengthy and information-dense, leading to challenges for patients / families with retention and follow-through on recommendations. Research suggests that after-visit summaries (AVS) can enhance recall of recommendations, support adherence to care plans, and increase patient / family satisfaction. As such, this Quality Improvement initiative aimed to develop and pilot an interdisciplinary AVS in the SB/SCI Clinic at HB.

Methods: Stakeholder engagement was completed in late 2024. The AVS template was developed and revised with launch in August 2025. Data collection included percentage of clinic visits with AVS completion (Outcome Measure) and percentage of disciplines contributing to each AVS (Process Measure). Families were contacted within two weeks of their clinic visit to gather feedback. Feedback was also elicited from the interdisciplinary team regarding workload, cognitive burden, and other unanticipated effects (Balancing Measure).

Findings: The AVS was trialed in 36 clinics (150 patient visits) from August 2025 – April 2026. 100% of families received a completed AVS in 20/36 clinics with 60 – 83% completion in the remaining clinics. There was variability in completion by discipline. Half of the families were successfully contacted post-clinic; all reported that the AVS was helpful. Benefits included improved retention and completion of recommendations. Staff reported some increase in cognitive workload and lack of clarity around in-clinic process but overall improved access to interdisciplinary recommendations in one place.

Discussion: The AVS has been successfully introduced in the SB/SCI Clinic at HB. Future steps include evaluating discipline-specific challenges with AVS completion and implementing design recommendations from the clinical team. Longer term, the AVS will be introduced to other interdisciplinary clinics at HB.

N°30 | Bio-inspired self-cleaning catheter material and design

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Background: Ventricular catheters (VCs) for treatment of hydrocephalus are fraught with high rates of obstruction and infection. We present a new VC material and design that reduces bacterial and cellular adhesion, a computational fluid dynamics (CFD) model to simulate catheter behavior in the ventricular space and a new curved flanged design that self-cleans to remove biodebris, and animal trial data to prove its biocompatibility.

Methods: The bacterial adhesion was tested by incubation of S. epidermidis (10E5 CFU/mL), the most common pathogen leading to infections, to mimic bacterial meningitis on flat sheets of various VC surfaces. An array of commercially-available standard-of-care (SoC) VCs were evaluated against our liquid-infused polydimethylsiloxane (iPDMS) material, quantified by crystal violet staining. The cellular adhesion of astrocytes, microglia, and choroid plexus was validated followed by confocal imaging to visualize coverage. The self-cleaning ability of the new VC is verified in silico using CFD. Finally, the biocompatibility was tested in C57BL/6 mice (n=10) by implanting iPDMS and SoC material in the right ventricle over a 1-week period followed by H&E and special stains to visualize material-caused tissue damage.

Findings: iPDMS showed at least 90% reduction in bacterial adhesion ($P \leq 0.001$; n=6) and almost no cellular attachment compared to SoC materials. CFD simulations of the curved flanged design showed a 10-fold increase in shear forces, combined with the 90% decrease in detachment forces show promise of self-cleaning capabilities. The mice brain sections near the site of implant showed no significant differences in cell viability between the iPDMS and SoC material.

Discussion: iPDMS showed a significant reduction of biomolecular adhesion whilst maintaining proven biocompatibility. The self-cleaning flange design showed promising outcome in reducing the chance of post-implantation infection and obstruction for treating hydrocephalus.

N°31 | Early urologic outcomes after prenatal vs postnatal myelomeningocele repair: A single-centre retrospective study

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Background: Myelomeningocele (MMC) is associated with neurogenic bladder and bowel dysfunction and long-term risks to renal health. While postnatal closure remains the standard of care, prenatal repair has been introduced with the goal of improving neurological and functional outcomes. The early urologic impact of prenatal versus postnatal repair, however, remains unclear. This study aimed to compare early urological outcomes between these two approaches in a paediatric cohort.

Methods: This was a retrospective single-centre chart review conducted with institutional approval (REB #1000077457). All children with MMC who underwent surgical repair up to the end of 2024 were included. Variables collected included demographics, repair type, catheterization practices, bladder and bowel treatment, mobility support needs and more. Between-group comparisons were performed using Fisher's Exact test. Data collection is ongoing, and updated findings will be presented at the time of the conference.

Findings: The prenatal repair group comprised 18 patients and the postnatal repair group comprised 60 patients. Baseline sex distribution was similar between groups. Clean intermittent catheterization (CIC) was significantly more common in the prenatal repair group (100% vs. 75%, p=0.02). Beta-blocker use was also significantly higher in the prenatal group (83% vs. 47%, p=0.01). Early vesicoureteral reflux confirmed on voiding cystourethrogram was more prevalent following prenatal repair (43% vs. 9%, p=0.01), though later reflux rates were comparable between groups. A trend toward higher bladder trabeculation was observed in the prenatal group at later imaging (38% vs. 13%, p=0.06). No significant differences were found in any other variable collected.

Discussion: Prenatal MMC repair did not demonstrate an early urologic advantage in this cohort and appears to follow a clinical trajectory similar to postnatal repair. Given the higher proportion of prenatal repair patients who require beta-agonists, it seems appropriate that our institution initiates CIC for all prenatal repair patients.

N°32 | Bladder surgery is essential yet underperformed for social continence in neurogenic bladder

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Background: Social continence is a critical yet often unmet goal in children with neurogenic bladder (NGB), directly influencing independence, dignity, and quality of life. A minimum dry interval of ≥3 hours is essential for meaningful participation in daily activities. However, conventional medical management frequently fails to achieve this threshold. This study challenges the prevailing reliance on conservative therapy and evaluates the transformative impact of surgical intervention, while highlighting its concerning global underutilization.

Methods: Fifty children with NGB secondary to spina bifida were initially managed with clean intermittent catheterization and anticholinergics. Patients failing to achieve dry intervals >2 hours underwent surgical intervention. Procedures included bladder augmentation (n=40), bladder neck procedures (n=28), and Mitrofanoff creation (n=42). All patients were followed for a minimum of 4 years. The primary outcome was achievement of socially acceptable continence (dry interval ≥3 hours).

Findings: Medical management alone achieved adequate continence in only 8/50 patients (16%). In contrast, surgical intervention resulted in sustained dry intervals ≥3 hours in 39/42 patients (92.8%), with most achieving 3–6 hours of dryness. These outcomes were durable over long-term follow-up. Only three surgically treated patients failed to reach the target threshold.

Discussion: Bladder surgery is not merely an adjunct but a decisive intervention for achieving true social continence in NGB. The stark contrast in outcomes underscores a critical gap in current practice, where this highly effective yet underperformed surgery remains overlooked worldwide. Early integration of surgical strategies can shift patients from persistent incontinence to functional independence, with profound implications for quality of life and long-term psychosocial outcomes.

Nº33 | Virtual Multidisciplinary Transition Clinic Improves Outcomes for Pediatric Urology Patients Transitioning to Adult Care

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Background: Transitioning from pediatric to adult urologic care is often fragmented, leading to gaps in treatment and increased morbidity. In Ontario, Canada, transition occurs abruptly at age 18 when pediatric specialists can no longer provide care. We evaluated whether a structured virtual multidisciplinary transition clinic improves continuity of care and reduces acute healthcare utilization.

Methods: Between December 2024 and September 2025, 33 pediatric urology patients with complex congenital conditions participated in a virtual transition clinic involving pediatric urologists, adult urologists, and nurse practitioners. All patients attended the virtual clinic prior to age 18. Comprehensive chart review documented demographics, underlying conditions, and post-transition outcomes. The Transition Readiness Assessment Questionnaire (TRAQ) was administered at baseline and one-year post-transition. Primary outcome was successful transition, defined as adult urology follow-up within six months without emergency department (ED) visits or hospitalizations. Secondary outcomes included TRAQ score changes (paired t-test), median time to follow-up, and ED utilization and hospitalization rates.

Findings: Among 33 patients (mean age 17.9±0.6 years, 58% male) with neurogenic bladder/spina bifida (45%), posterior urethral valves (21%), or bladder exstrophy (12%), successful transition was achieved in 91% (95%CI:75-98%). ED utilization remained minimal with 6.1% ED visits and 3.0% hospitalizations, none urologic. Adult urology follow-up was established in 91% at median 4.2 months. Among patients completing surveys (n=10), TRAQ scores improved significantly from 4.29±0.42 to 4.64±0.31 (p=0.012). Planned surgical procedures occurred in 24% within six months, with no patient experiencing care gaps exceeding six months.

Discussion: A structured virtual multidisciplinary pediatric-to-adult urology transition clinic achieved a 91% successful transition rate with minimal acute care utilization and significant improvements in patient readiness. The virtual format facilitated seamless coordination between pediatric and adult providers while maintaining continuity during the critical transition period. These findings support implementation of virtual transition clinics as an effective, scalable model for adolescents with complex urologic conditions, particularly relevant for healthcare systems with geographic barriers or specialist access limitations.

Nº34 | Chromosomal 22q11.2 microdeletion confers substantial meningomyelocele risk: a case report

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Background: Meningomyelocele, a severe subtype of spina bifida, is the most common developmental defect of the central nervous system. The cumulative risk of meningomyelocele arises from inherited variants, rare and de novo copy-number variants, and environmental factors, most notably folic acid deficiency. We describe a familial occurrence of neural tube defects and related urological anomalies in an Estonian pedigree.

Methods: The healthy parents had two daughters. The 16-year-old sister was born with a meningomyelocele, foot deformities and a neurogenic bladder. The 13-year-old sister was born with a spina bifida occulta. She had a mild postnatal growth retardation and bilateral dilation of the ureters and renal pelvis with vesicoureteral reflux (3rd stage). Both sisters had a low birth weight, a very low folic acid level, and a Chiari I malformation. The mother's first cousin was also born with a meningomyelocele.

Findings: Chromosomal microarray analysis (CMA) demonstrated paternally inherited ~729 kb interstitial deletion in the 22q11.21 region in both patients. The deletion involves five disease-associated OMIM genes and partially overlaps with the 22q11.2 microdeletion syndrome region. CMA identified also maternally inherited interstitial CNVs: the younger sister had a ~1.35 Mb deletion in the 1q21.1-q21.2 region overlapping with the 1q21.1 microdeletion syndrome region; the older sister had a ~1.6 Mb deletion in the 2q11.2 region encompassing seven disease-associated OMIM genes. The identified alterations are characterized by incomplete penetrance and variable expressivity of clinical features.The 22q11.21 region harbors an important neural tube-expressed CRKL gene - a key downstream effector of the planar cell polarity (PCP) pathway, with a regulatory role in neural crest cell migration and differentiation.

Discussion: Our results provide additional evidence of 22q11.2 microdeletion contributing to substantially increased risk of meningomyelocele, which could be partially alleviated by folate supplementation.

N°35 | Unrecognized sleep problems in children with spina bifida: A simple screening approach

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Background: For many children with spina bifida (SB), challenges do not end with mobility or bladder care—sleep itself may be affected. Breathing problems during sleep often go unnoticed, yet they can impact growth, learning, and overall well-being. In resource-limited settings, simple screening tools like the Pediatric Sleep Questionnaire (PSQ) may help identify children at risk.

Methods: This prospective study included 65 children aged 2–18 years with SB. Clinical details and symptoms were recorded, and caregivers completed the PSQ. A score ≥0.33 indicated high risk for sleep-disordered breathing (SDB). Radiological evaluation for adenoid hypertrophy was performed. Associations between PSQ scores and clinical factors were analyzed.

Findings: The mean age was 9.99 ± 5.1 years, with a male predominance. Nearly 1 in 5 children (18.46%) were identified as being at high risk for SDB. Many children had symptoms such as snoring, mouth breathing, bedwetting, and delayed growth—signs often overlooked in routine care. All children with the highest PSQ scores had enlarged adenoids, suggesting a clinically relevant association, although statistical significance was not reached. No association was found with gender or body weight.

Discussion: Sleep-related breathing problems in children with SB are common but frequently unrecognized. A simple questionnaire like the PSQ can help uncover these hidden concerns. Early identification offers an opportunity to improve health, development, and quality of life in this vulnerable group.

N°36 | Perineal rehabilitation in pediatrics (ages 0-18) with a focus on spina bifida, lessons learned from our new clinic

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Background: Management of neurogenic bladders and bowels in pediatrics 0-18 years old within a multidisciplinary team at clinics specializing in myelopathies: urologist, physiatrist, nurses, pediatrician, physical therapist. Starting a new offer of service: pediatric pelvic and perineal reeducation (PPR) to overcome communication issues when patients receive PPR in private clinics.

Methods: Clients registered at our clinics specializing in myelopathies (Quebec City and remote areas). Triage by our two clinical nurses specializing in urology (data collection and urodynamic assessment); evaluation by the urologist and/or pediatric physiatrist, who refers the patient to physiotherapy if there is potential for rehabilitation. In physiotherapy: Explanation of the physio-patho-anatomy of elimination functions, teaching of postural and breathing techniques, biofeedback and electrostimulation on a machine with surface electrodes or anal/vaginal probes depending on the age and maturity of the client, exercise program.

Findings: Retention issues rather than pelvic floor weakness in young people with spina bifida; improvement in elimination functions in general; improved self-esteem among clients and empowerment of young people through a better understanding of the impact of their condition on their elimination functions. A very high level of satisfaction and no more communication issues.

Discussion: Importance of multidisciplinary work that respects the neurological and psychological maturity of our pediatric clients and offers holistic care for pediatric patients with myelopathies. The involvement of the young person, their parents, and caregivers is necessary.

N°37 | Neurosurgical focus on the multidisciplinary management of patients with mild forms of closed spinal dysraphism

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Background: Currently, the indications for neurosurgical treatment of patients with fecal and urinary incontinence associated with mild forms of closed spinal dysraphism remain controversial. Challenges also include defining the clinical pathway for patients with pelvic organ dysfunction, selecting appropriate diagnostic tools, and developing effective rehabilitation programs.

Methods: Over a 7-year period, 21 children aged 6 months to 18 years with closed spinal dysraphism and confirmed tethered cord syndrome underwent surgery at our center. With 10 under dynamic observation.

Findings: Most patients referred for neurosurgical consultation had significant MRI changes and cutaneous markers, but without clear attention to pelvic organ dysfunction or quality-of-life impairment. These patients were followed dynamically, and the development of urological, proctological, orthopedic, or neurological symptoms was considered a manifestation of tethered cord syndrome and an indication for surgery.

Decision-making was more challenging in patients with pelvic organ dysfunction who had mild spinal dysraphism, minimal MRI findings (such as thickened filum terminale or filum lipoma), and no obvious external differences from healthy children. These patients were often not referred for timely neurosurgical evaluation.

Educational activities involving medical students, physicians, and patients were conducted in online and offline formats to improve awareness and facilitate earlier diagnosis. Decisions regarding surgery were made based on comprehensive evaluation and multidisciplinary team discussions. The team included a proctologist, as fecal incontinence may be an early symptom of tethered cord syndrome.

Following neurosurgical untethering procedures, pelvic floor rehabilitation using biofeedback therapy allowed near-complete recovery of pelvic organ function in children with delayed diagnosis.

Discussion: Timely identification and treatment of neurosurgical pathology in these patients requires multidisciplinary evaluation, increased awareness among healthcare providers to reduce delays in referral, and postoperative rehabilitation. In children older than 6 years with late diagnosis, pelvic floor muscle rehabilitation with biofeedback therapy remains essential for functional recovery.

N°38 | Nutritional and psychological status in individuals with spina bifida in India

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Background: Spina bifida (SB) is a lifelong disabling disorder often associated with mobility limitations, nutritional imbalance and psychosocial challenges. While global studies highlight increased risks of obesity and depression in SB, Indian data remain limited. This study aimed to assess the nutritional and psychological status of individuals with SB and examine potential associations between them.

Methods: A cross-sectional study was conducted among 27 individuals with SB (age 1–60 years) recruited from our centre. Nutritional assessment included anthropometry, body composition (InBody S10), biochemical parameters (CBC, vitamin B12, vitamin D, albumin), and dietary intake using 24-hour recall and food frequency questionnaire. Psychological status was evaluated using the Child Behaviour Checklist (CBCL) and Beck Depression Inventory (BDI). Data were analysed using SPSS v23, with $p<0.05$ considered significant.

Findings: Overweight/obesity was prevalent in 67% of adults, particularly among those using ambulatory aids. All participants had elevated body fat percentages, and central obesity was common across age groups. Vitamin D deficiency (80%) and anaemia (33% in children) were notable. Energy and protein intake were significantly below recommended levels ($p<0.05$). Most children had normal behavioural scores, while 14% of adults showed moderate to severe depression. A significant negative correlation was observed between body fat percentage and depression scores in adults.

Discussion: Individuals with SB in India exhibit a dual burden of malnutrition with high obesity and micronutrient deficiencies. While psychological status is largely stable, a vulnerable subgroup shows depressive symptoms. These findings underscore the need for multidisciplinary interventions integrating nutritional rehabilitation, mobility support, and mental health care to improve long-term outcomes and quality of life.

N°39 | Challenges of TMS in children under 9 for tethered cord syndrome diagnostics: need for multicenter collaboration

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Background: Diagnosing the causes of recurrent or progressive urological, proctological, or orthopedic disorders in children who appeared healthy at birth remains challenging. Therefore, identifying pathological functional changes in the nervous system using instrumental methods is important, particularly in children with a closed form of spinal dysraphism.

Methods: We retrospectively analyzed the results of 35 transcranial magnetic stimulation (TMS) in 15 children aged from 6 months to 9 years with diagnosed closed form of spinal dysraphism.

Findings: In our center, children aged 1–9 years with suspected closed spinal dysraphism underwent TMS in diagnostically complex cases of tethered cord syndrome. These patients presented clinical symptoms despite minimal or absent MRI changes and no abnormalities on routine nerve conduction study (NCS) of the lower extremities. Examinations were conducted in a specialized center with a high concentration of such cases. Pathological findings detected via TMS were considered manifestations of tethered cord syndrome. Retrospective analysis confirmed this, showing clinical improvement after neurosurgical treatment.

Discussion: The use of TMS, particularly in dynamic assessment of children under 9 years, appears to be a valuable adjunctive criterion in confirming tethered cord syndrome and determining indications for surgery. In clinical practice, this approach may help prevent irreversible neurological deficits in children with closed spinal dysraphism.
This method is especially relevant in cases with minimal MRI changes, presence of urinary and/or bowel dysfunction, and normal routine NCS findings. Such studies should be performed in specialized centers with sufficient patient flow. Both with this, there is a high demand for multicenter collaboration to establish standardized age-based reference values for children under 9 years old. This improves diagnostic accuracy, facilitates differentiation between normal and pathological findings, and supports timely intervention to prevent long-term neurological complications.

N°40 | Unmet Assistive Devices Needs among Children with Spina Bifida in Ethiopia: A Cross-Sectional Study

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Background: Spina bifida is a common congenital anomaly associated with lifelong physical, functional, and psychosocial challenges. Assistive devices (AD) are critical for promoting independence, yet access remains limited in low-resource settings such as Ethiopia. The study examines the magnitude of assistive device needs among children with spina bifida attending physiotherapy services in selected hospitals of Ethiopia.

Methods: An analytical cross-sectional study was conducted from August to September 2025 at St. Peter Specialized Hospital (Addis Ababa) and Hiwot Fana Comprehensive Specialized Hospital (Harar). A total of 100 children aged 0–18 years with confirmed spina bifida were consecutively recruited via census method. Data were collected using a structured data collection tool supplemented by medical record review. Descriptive statistics summarized demographic, clinical, and functional data.

Findings: Of the 100 children, 62% were male and 92% were below five years of age at their first physiotherapy visit. Most cases were myelomeningocele (87%), and nearly half (45%) had hydrocephalus. Mobility limitations were substantial, with only 14% fully ambulatory, 55% partially mobile, and 31% non-ambulatory. Rehabilitation needs were considerable: all children required physiotherapy, 39% needed occupational therapy, and 11% required community-based rehabilitation. AD needs were high - 52% required wheelchairs, 48% orthosis, and 30% posterior walkers - yet only 4% had access to even a single device, often without maintenance.

Discussion: Children with spina bifida in Ethiopia face major unmet needs for assistive Device and rehabilitation. Addressing these gaps is essential for improving independence, educational access, and quality of life.

N°41 | SBH and Employment: Valuing Skills, Respecting Needs and Rethinking Productivity

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Background: Many adults living with SBH face challenges that can affect education, employment and participation in the workplace. Fatigue, headaches, cognitive difficulties and fluctuating energy levels may impact daily functioning, yet these experiences are often invisible and poorly understood. As a result, individuals may face barriers related to disclosure, workplace expectations and access to appropriate support.

At the same time, people living with SBH bring valuable skills, experience and contributions to the workforce. Creating more inclusive workplaces requires moving beyond assumptions about productivity and recognising the importance of reasonable accommodations, flexibility and understanding.

Roundtable Description: This interactive roundtable will explore the experiences of people living with SBH in the workplace and discuss how employers, employees, healthcare professionals and employment support organisations can work together to promote inclusion and job retention.

Through lived experience perspectives, professional insights and practical discussion, participants will examine common workplace challenges, including managing fatigue, cognitive demands and communication around invisible disabilities. The session will highlight examples of workplace adaptations, such as flexible working arrangements, organisational strategies and supportive environments that enable individuals to thrive.

The roundtable aims to create dialogue between different stakeholders and identify practical approaches to valuing skills, reducing misconceptions and supporting sustainable employment for people living with SBH.

Objectives:
Participants will:

- Increase awareness of the invisible challenges that may affect people living with Hydrocephalus in the workplace.
- Explore strategies for effective communication, disclosure and mutual understanding between employees and employers.
- Share examples of reasonable accommodations and workplace practices that support inclusion and job retention.
- Highlight the skills, experiences and contributions of people living with Hydrocephalus.
- Identify opportunities for collaboration between individuals, employers, healthcare professionals and support organisations to create more inclusive workplaces.

N°42 | Health-related quality of life in children with spina bifida: a review of quantitative HRQoL studies

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Background: Spina bifida (SB) is a rare and complex congenital condition associated with lifelong medical, functional, and psychosocial challenges. Health-related quality of life (HRQoL) is an important outcome in pediatric SB care. An updated synthesis of the literature is needed to support clinical practice and guideline development.

Methods: A literature review using PRISMA guidelines was conducted within the framework of eUROGEN, in collaboration with ITHACA and the European Association of Urology. Five databases (Embase, PubMed, PsycInfo, CINAHL, and the Cochrane Library) were searched for quantitative HRQoL studies published from 2016 to January 2025 in children and adolescents (0–18 years) with spina bifida, using a broader search strategy covering spinal dysraphism. Study characteristics, HRQoL instruments, outcomes, and factors associated with HRQoL were extracted and synthesized at domain level.

Findings: Thirty-three studies including 2,607 children were identified. Across studies, children with SB consistently reported lower HRQoL than healthy peers, particularly in physical, social, and school-related domains. Bladder and bowel function emerged as a stable HRQoL domain with clinical impact across ages and countries. The factors most consistently associated with lower HRQoL were urinary and fecal incontinence and limited family or social support. Most studies were cross-sectional (64%), and intervention studies indicated improved HRQoL following structured bladder and bowel management. Generic HRQoL instruments were most commonly used (n=17), while SB-specific instruments were primarily applied in psychometric validation studies (n=9).

Discussion: Children with spina bifida experience lower HRQoL than their peers, influenced by medical, psychosocial, and environmental factors, including opportunities for participation in everyday life. Recent advances in condition-specific HRQoL instruments offer opportunities for more standardized, clinically relevant, and patient-centered assessment. Better use of these tools may support earlier identification of needs, guide targeted interventions, support multidisciplinary follow-up, and ultimately improve quality of life for children and their families.

N°43 | Preventing neural tube defects in Latin America: a regional call to action on folic acid fortification and surveillance

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Background: Key stakeholders from the public sector, academia, civil society, healthcare providers, and food industry came together to advocate for a comprehensive regional plan of action to advance large-scale food fortification (LSFF) strategies in Latin America. The aim was to strengthen neural tube defects prevention through improved policy alignment, epidemiologic surveillance systems and streamlined program MEL for LSFF programs, with special attention to folic acid fortification and supplementation across the region.

Methods: This paper arises from a multisector stakeholder consultation and is based on a narrative review of regional evidence and country experiences. Comparative case studies from Latin American countries with established fortification and surveillance systems (Costa Rica, Chile, Argentina, Brazil, and Mexico) were analysed to identify enabling factors, outcomes, and implementation gaps.

Findings: Across the region, mandatory folic acid food fortification, combined with epidemiologic surveillance systems and structured MEL systems for LSFF programs, was consistently associated with substantial reductions in neural tube defects. Costa Rica reported reductions of 45% in spina bifida and 50% in anencephaly, alongside major declines in infant mortality. Chile observed a 40–55% reduction in prevalence following wheat flour fortification. Argentina reported reductions of 45.6% in spina bifida and 53.7% in anencephaly, while Brazil showed an estimated 30% national decrease in the national prevalence of NTDs. Mexico demonstrated a 59% reduction in neural tube defects following wheat and maize flour fortification supported by epidemiologic surveillance data. However, fragmented surveillance coverage and weak MEL systems for LSFF programs persist in several countries, constraining program evaluation and policy optimisation.

Discussion: The stakeholder consultation and regional evidence confirm that neural tube defects are largely preventable through scalable, cost-effective interventions. Strengthening mandatory fortification, surveillance systems, and monitoring frameworks, supported by multisector collaboration, is essential. A joint regional strategy is needed to harmonise policies, improve equity, and ensure sustained reductions in preventable congenital anomalies across Latin America.

N°44 | Social Integration Through Sport and the Outdoors in Youth Living with Spina Bifida

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Background: Participation in sport and outdoor activities is a powerful lever for social integration, well-being and personal development for young people living with spina bifida. The Centre d'intégration à la vie active (CIVA) has developed a community intervention model that uses sports and the outdoors as concrete tools to promote autonomy, social participation and a sense of belonging. This panel aims to present this intervention model and to highlight the impact of these activities through the testimonies of young people with spina bifida who actively participate in them.

Methods: Presented by CIVA, this discussion panel will last approximately one hour and will bring together stakeholders from the organization as well as young participants involved in the sports and outdoor activities offered by CIVA. The discussion, moderated in a semi-structured manner, will explore the young people's journeys, the obstacles encountered, the facilitating factors and the impact of these activities on their social integration and quality of life. Exchanges with the public will enrich the reflection.

Findings: The testimonies will highlight several positive effects, including the development of meaningful social relationships, greater self-confidence, a sense of competence, and increased participation in community life. We will also address the challenges related to accessibility, adapting activities and the support needed for sustainable participation.

Discussion: This panel highlights the potential of sport and the outdoors as levers for social integration in interventions with young people living with spina bifida. The CIVA model illustrates how inclusive community-based approaches can contribute to autonomy, empowerment and social participation, with relevant implications for the health, leisure and public policy sectors.

N°45 | Prenatal Repair of Spina Bifida: Expectations, Evidence and the Journey Towards Better Quality of Life

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Background: Spina bifida develops early in fetal life and is the most common developmental defect of the nervous system. Prenatal surgery for spina bifida has been performed for 28 years in the United States and for more than 21 years in Poland, the first country in Europe to introduce this procedure. Prenatal repair aims to reduce the duration of exposure of the spinal cord and nerves to toxic amniotic fluid and mechanical trauma. Comparative analyses indicate that children who undergo prenatal repair are less than twice as likely to require ventriculoperitoneal shunts for hydrocephalus. Prenatal myelomeningocele surgery may also improve motor function and urinary and digestive function and has been associated with improved quality of life.

Session Description: This interactive workshop will draw on more than two decades of experience with prenatal spina bifida surgery in Poland, together with the international development of the procedure. It will explore the rationale, experience and evidence surrounding prenatal repair and its potential benefits and limitations. Particular attention will be given to hydrocephalus, motor function, urinary and digestive function, and quality of life. The workshop will also provide an opportunity to discuss expectations of prenatal surgery and what it may mean for children and families in the long term.

Objectives:
By the end of the workshop, participants will:

- Understand the development and rationale of prenatal repair of spina bifida.
- Review the experience and evidence regarding prenatal and postnatal repair.
- Discuss the potential benefits and limitations of prenatal surgery.
- Consider the impact of prenatal repair on functional outcomes and quality of life.
- Reflect on realistic expectations for children and families undergoing prenatal repair.

N°46 | Bone health in youth with spina bifida and hydrocephalus before and after exercise training

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Background: Children and adolescents with spina bifida and hydrocephalus often have muscle weakness, paralysis, and difficulty walking. Because bones adapt to the forces placed on them, reduced mobility may contribute to the higher risk of fractures and low bone mineral density (BMD) seen in this population. However, the reasons for poor bone health are not fully understood, and it is unclear whether exercise can help. In this pilot study, we will use advanced imaging (HR-pQCT) to better understand bone structure and strength, and to examine whether a short-term training program can improve bone health.

Methods: Participants aged 5–21 years with spina bifida and/or hydrocephalus will be recruited from a 10-week training program preparing for the Défi Sportif AlterGo competition, along with age- and sex-matched peers not involved in structured training. Bone health will be assessed before and after the program using DXA (to measure overall bone density at the distal femur) and HR-pQCT (to measure bone density and microarchitecture at the distal tibia). Baseline results will be compared to published norms, and changes over time will be analyzed using statistical models that account for repeated measurements.

Findings: We expect participants with spina bifida and hydrocephalus to have smaller bone cross-sectional area and lower BMD at baseline. This is important because a bone with a smaller cross-sectional area has less resistance to fracture in bending and compression.

Discussion: Understanding bone health and the potential benefits of exercise will help guide early, practical strategies—such as regular physical activity—to support stronger bones and reduce fracture risk as children grow.

N°47 | Industrial feasibility and economic assessment of double-fortified salt with iodine and folic acid in Ethiopia

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Nutrition International

Background: To assess industrial feasibility and economics assessment of industrial processing and co-fortifying salt with iodine and folic acid (DFS-IoFA) in Ethiopia.

Methods: Systematic assessment of salt production and installed infrastructure, processing and fortification, laboratory capacities, and supply chain, relevant for national scale-up of DFS-IoFA at Central Iodization Facilities (CIFs) in Ethiopia. Information on the initial and recurring cost of industrial upgrade, premix supply and government regulatory activities, and NTD-related medical costs were used to estimate population level economic benefits projected over 10 years using disability-adjusted life years (DALY) averted, an ingredient-based costing model, incremental cost effectiveness ratio (ICER), and cost-benefit analysis. This evidence was presented to the government to ensure buy-in for scale-up.

Findings: A total of 14 CIFs had capability of producing DFS-IoFA at scale. One CIF was selected to produce 3MT each of: 1) iodized salt; 2) iodized salt with low concentration (~200 ug/day) of folic acid; and 3) iodized salt with high concentration (~600 ug/day) of folic acid for a community-based intervention trial to assess the impact of DFS-IoFA on folate status. Ethiopia's experience in iodine premix supply management was leveraged on for sustainable folic acid premix supply, which can be supplied by private sector. At least 94% of iodine and folic acid were retained over 10 months in ambient environment storage conditions. Average population level projected per-capita cost of co-fortifying salt with iodine and folic acid was US$0.03/year with an ICER of US$4 per DALY averted. Scaling up DFS-IoFA at population level is estimated to yield up to US$259 in economic returns for every US$1 invested.

Discussion: DFS-IoFA can be produced and is cost-effective, potentially resulting in high health and economic returns on investment for Ethiopia. Multisectoral engagement resulted in governmental ownership and commitment to accelerate policy development for mandatory DFS-IoFA in Ethiopia.

N°48 | Youth Leadership Forum: Building Confidence, Connections and Leadership for the Future

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[1]A Song A City
[2]International Federation for Spina Bifida and Hydrocephalus

Background: Young people living with Spina Bifida and Hydrocephalus experience unique opportunities and challenges as they navigate education, independence, employment, relationships and participation in society. As future leaders, advocates and role models within the global SBH community, they play a vital role in shaping more inclusive healthcare systems and communities. The Youth Leadership Forum provides a dedicated space for young people (age 18-35yrs) from different countries to connect, share experiences and learn from one another in a supportive and interactive environment.

Session Description: This interactive forum explores the theme of self-leadership across the life course, encouraging participants to reflect on their personal experiences, strengths and aspirations while developing practical leadership and self-advocacy skills. Through facilitated discussions, peer exchange and reflective activities, participants will explore topics such as identity, resilience, self-awareness, advocacy and community leadership. The session emphasises learning from lived experience and creating meaningful connections with peers from around the world, while encouraging participants to identify practical actions they can take within their own communities after the conference.

Objectives:
By the end of the session, participants will:

- Reflect on their personal experiences, strengths and aspirations as young people living with SBH.
- Strengthen their confidence, self-awareness and self-advocacy skills.
- Learn from the experiences and perspectives of peers from different countries and cultures.
- Explore leadership as a tool for personal growth, community engagement and advocacy.
- Identify practical actions to continue their leadership journey and contribute to the global SBH community beyond the conference.

N°49 | Ping Pong Session: Genetics and Neural Tube Defects – Separating Facts from Myths

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Background: Advances in genetics are transforming our understanding of neural tube defects (NTDs), including Spina Bifida. While folic acid deficiency remains a well-established and preventable risk factor, research increasingly demonstrates that NTDs result from a complex interaction between inherited genetic susceptibility and environmental influences. Despite growing scientific knowledge, many individuals and families still have questions about inheritance, recurrence risk, genetic testing, and what current research means for prevention and risk reduction for future pregnancies. The recently developed IF Genetics Factsheet provides accessible, evidence-based information to support informed discussions between families and healthcare professionals.

Session Description: This highly interactive "Ping Pong" session will bring together genetics experts and the audience in a dynamic exchange of questions and answers. Rather than traditional lectures, participants will actively shape the discussion by posing real-world questions and challenging common misconceptions.

Topics may include:

- Is Spina Bifida a genetic condition?
- What role do genes and environmental factors play?
- Should families consider genetic counselling or genetic testing?
- What is the recurrence risk for future pregnancies?
- How can genetics contribute to prevention, personalised care and future research?
- What clinical interventions will shape the future of spina bifida management?

Experts will provide practical, evidence-based responses in language that is accessible to both professionals and people with lived experience.

Learning Objectives:
At the end of this session, participants will be able to:

- Understand the multifactorial nature of neural tube defects.
- Explain the role of genetics alongside environmental and nutritional factors.
- Recognise when genetic counselling or testing may be appropriate.
- Apply evidence-based information to support shared decision-making with individuals and families.
- Identify current opportunities and future directions in genetics research for Spina Bifida and related neural tube defects.

This session aims to bridge the gap between science and lived experience, empowering participants with reliable knowledge while encouraging open dialogue between researchers, clinicians, and the global Spina Bifida and Hydrocephalus community.

N°50 | Workshop on Mental Health Workshop for Parents and Caregivers

Moderator:
Roy Fu
Spina Bifida Hydrocephalus Quebec

Expert :
Prof Dr Alexander Von Gontard
Governor Kremers Centre, Department of Urology, Maastricht University Medical Centre, Maastricht, The Netherlands

Background: Mental health and emotional wellbeing are important aspects of living with Spina Bifida and Hydrocephalus, not only for individuals with SBH but also for parents and caregivers who support them throughout different stages of life. Families may experience questions and concerns related to diagnosis, development, independence, transitions, social participation and the emotional impact of lifelong care needs. Creating opportunities for open discussion and shared learning is essential to support families and strengthen their ability to navigate these challenges.

Session Description: This interactive workshop provides a dedicated space for parents and caregivers to discuss questions and experiences related to mental health and wellbeing within the SBH community. The session will focus on the topics and concerns brought forward by participants themselves. Through an open dialogue format, participants will have the opportunity to ask questions, share experiences and explore practical approaches to supporting emotional wellbeing, resilience and healthy development across the lifespan.
The workshop aims to create a safe and supportive environment where parents and caregivers can learn from expert guidance as well as from each other's experiences.

Objectives:
By the end of the session, participants will:

- Gain greater understanding of mental health challenges and support needs related to SBH.
- Discuss questions and concerns arising from their own experiences as parents and caregivers.
- Exchange experiences and practical strategies with other families.
- Explore ways to support emotional wellbeing, resilience and independence across different life stages.
- Strengthen connections within the global SBH family community.

N°51 | Hydrocephalus 360°

Moderator:
Danny Lamb

Background: Hydrocephalus is one of the most common and complex neurological challenges associated with spina bifida and can affect people across the life course. While advances in neurosurgical care, research and long-term management have improved outcomes, significant challenges remain, including access to specialised care, shunt-related complications, continuity of care, transition to adulthood, and differences in outcomes and services across countries. Understanding hydrocephalus requires more than a clinical perspective; it requires consideration of research, lived experience, health systems and human rights.

Session Description: This interactive roundtable will explore hydrocephalus from multiple perspectives, bringing together clinical expertise, research, lived experience and the disability and human rights perspective. Panelists will discuss current approaches to hydrocephalus management, emerging research and priorities, the realities of living with hydrocephalus, and the barriers people may face in accessing appropriate and continuous care. The discussion will also consider how the global SBH community can work together to improve outcomes, strengthen services and ensure that people with hydrocephalus are included in decisions about future care and independent living.

Objectives:

- Explore hydrocephalus across the life course from clinical, research, lived experience and rights perspectives.
- Discuss current challenges and opportunities in hydrocephalus management and long-term care.
- Highlight differences in access to care and support across settings.
- Identify priorities for research, clinical practice, services and advocacy.
- Consider how the global SBH community can work together to improve care, participation and quality of life.

COUNTRY UPDATE ABSTRACTS

CU1 | Transcutaneous Spinal Stimulation (tSCS) using the NISE-Stim Protocol in Paediatric Spina Bifida Physiotherapy

Kate Steele
SHINE: Spina bifida - Hydrocephalus - Information - Networking – Equality, United Kingdom

Background: Physiotherapy in spina bifida has traditionally aimed to compensate for functional loss and prevent complications. In spinal cord injury, there's strong evidence supporting the use of tSCS neuromodulation therapy to improve functional outcomes. The published evidence for this neurorehabilitative therapy in spina bifida is more limited but shows promise.
Since 2022, Shine has provided a tSCS service to Shine members, predominantly children but also some adults with spina bifida.

Methods: Service delivery is via pop-up clinics across the UK and remote support. The service uses the NISE-Stim protocol developed for spina bifida by Gerti Motavalli and Dr Gad Alon. Portable stimulation units with adhesive electrodes are used to provide targeted electrical stimulation over the spine and peripheral muscles. Parameters are personalised according to the child's baseline physiology and therapeutic goals.
We screen potential service users for practical and medical suitability. Following preassessment, most will engage in long-term, consistent therapy.

Findings: We have found the service to be safe: there have been no serious adverse effects attributable to NISE-stim, including in those with programmable ventriculoperitoneal shunt valves. Any side effects tend to be mild and temporary, such as skin irritation or discomfort. We perform clinical assessments at the start of therapy and at 6-monthly intervals, with remote support available in -between appointments. Our assessments show multiple functional domains improve in the treated children, the majority within 3 months of starting therapy. We see gains in strength and movement quality, progression in milestones and skill development, and increased participation and activity. There's also evidence of improvement in posture, sensation, circulation, and bowel management.

Discussion: NISE-Stim is a promising new treatment for people with spina bifida. Further clinical trials are needed to build quantitative evidence of efficacy, and basic research is needed to explore the mechanisms underlying the therapeutic benefits.

CU2 | Advancing research, inspiring hope, build and strengthen community – together - Hydrocephalus Canada Update

Shauna Beaudoin, Ingrid Exner, Tanja Bessey
Hydrocephalus Canada

Background: As a result of the pandemic, online access to programs was expanded, including information resources, monthly support groups and wellness sessions. Bilingual educational webinars and digital toolkits were incorporated to strengthen knowledge exchange in collaboration with SBH healthcare and community partners. Research funds will advance evidence-based care, reflecting a strong commitment to improving quality of life for the SBH community.

Methods: Community engagement and survey findings identified caregiver support as a priority. Through a partnership with Recreational Respite and the Rexall Care Network, a five-part online workshop series was developed, delivered and bilingual digital toolkits were created.

Collaboration on education and knowledge exchange were strengthened through bilingual webinars delivered with Spina Bifida Hydrocéphalie Québec and other partners addressing the complexities of SBH across the lifespan.

Research advancement is a key strategic priority. In 2025, two research grants supported studies on iNPH post-surgical rehabilitation and social connection and isolation among youth with SBH. Additional research grants will be awarded in 2026.

Youth engagement and inclusion was enhanced through a partnership with TAP, producing accessible video that encourage physical activity and creative expression among children and youth.

Findings: Hydrocephalus Canada facilitate four virtual support groups for adults, parents and youth, with a dedicated caregiver group in development. Ongoing bilingual education webinars and information resources provide support and guidance. A re-established research program and youth engagement through our TAP partnership further supports the SBH community.

Discussion: Through community-informed programming, research investment and strong partnerships, Hydrocephalus Canada delivers meaningful, equitable services and supports that improve connection, health and quality of life.

CU3 | The Spirates: a maritime adventure uniting the SBH community in France and beyond

Benoit Fourcroy
Association Spina Bifida et Handicaps Associés (ASBH), France

Three French adults with Spina Bifida sail across the English Channel on a vessel. They travel towards Ireland and Scotland in the purpose of meeting peers. This is the journey documented in the film The Spirates of l'Estrella.

This presentation shows how the documentary goes beyond a maritime expedition to complement medical expertise, support patient empowerment, strengthen cohesion within spina bifida and hydrocephalus communities, and raise awareness among the public and policy makers.

Following preparation and execution of the voyage by a mixed team of participants with and without disabilities, the film reveals through interviews and shared experiences at sea how clinical realities, personal narratives and peer solidarity intersect.

It also highlights international impact through testimonies and images promoting inclusive adventure, patient advocacy and community empowerment, strengthening transnational links among families, clinicians and associations supporting people with spina bifida and hydrocephalus.

The initiative has gained attention in France through movie theatre screenings and a large media coverage, supporting destigmatisation and awareness, especially regarding prevention by folates.

At European level, it has increased visibility of patient representatives (ePAG) within the trans European Reference Network Eurogen/ITHACA spina bifida and other spinal dysraphism working group, reinforcing patient representation alongside clinicians in care, prevention and lived experience discussions.

By retracing its impact, the presentation underscores its role in advocacy, education, promotion of inclusive sporting activities, and how it has strengthened the French patient association ASBH by offering a tool for the health dialogue processes and by stimulating members to engage further in long-term volunteering activities.

Andrej Drdul, Terezia Drdul
Slovak Association for Spina Bifida and/or Hydrocephalus, Slovakia

Background: The Slovak Association for Spina Bifida and/or Hydrocephalus (SBaH) has been organizing camps and other activities for children and young people with these conditions for over 20 years. The primary aim of these activities has been the development of self-care and daily living skills, which are considered fundamental for independent living. However, over time we have observed that self-care competencies alone are not sufficient for a fulfilling life. Therefore, we have progressively introduced a participatory approach, actively involving participants in the planning and implementation of programs. This approach aims to strengthen their sense of responsibility within the community, as well as to develop event (program) management competencies and social skills.

Methods: The intervention consists primarily of the implementation of various activities within participants' natural living environments (e.g., schools, universities, and municipal settings), and secondarily of the regular organization of weekend programs and, in particular, summer camps for children and young people with spina bifida and hydrocephalus.
These activities are based on a holistic approach that views participants not only from a medical perspective or in terms of self-care competencies, but as individuals with their own experiences, aspirations, and developmental potential, actively participating in a community.

Findings: Participation in structured community environments provides natural opportunities to develop social and communication skills, which are essential for meaningful participation in everyday life.

Discussion: Our long-term experience indicates that when young people with disabilities are given meaningful opportunities to participate in and contribute to group activities, they develop greater self-confidence and trust in both themselves and others. This, in turn, supports their ability to engage more comfortably and effectively within society. In addition, the Association systematically develops a network of volunteers who help bridge the gap between the supportive camp environment and everyday social realities.

Liv Tørring
Norwegian association for Spina Bifida and Hydrocephalus

The Norwegian association for Spina Bifida and Hydrocephalus (RH-foreningen) is a national user-led organisation representing people with spina bifida and hydrocephalus, their families and allies. The association works to strengthen rights, access to health and rehabilitation services, and participation in society through advocacy, peer support and knowledge sharing.

As of 31 December 2025, RH-foreningen had 543 paying members and five county chapters covering all regions of Norway, three of which reported activity during the year. In 2025, the organisation finalised and began implementing a strategic plan for 2025–2029. Organisational changes included a reduction in the number of working committees to improve coordination, resource use and follow-up of strategic priorities.

Peer support remains a core activity and includes digital seminars, courses for trained peer supporters, and physical gatherings for different age groups, reflecting a life-course perspective. The association also maintains active participation in national networks and advisory bodies related to rare diseases, disability policy and rehabilitation.

Internationally, RH-foreningen manages one development cooperation programme, CADIR (Collective Action for Disability Rights), implemented in partnership with organisations in Uganda and Zambia. The programme runs from 2025 to 2029 and is funded by NORAD through the Atlas Alliance. CADIR focuses on knowledge sharing, organisational development and advocacy to strengthen disability rights and participation, building on long-standing partnerships and previous cooperation.

Dr Yean Koon Chan, Prof Dr Amaramalar Selvi Naicker, Ir Dr Kribanandan Gurusamy Naidu
Spina Bifida & Hydrocephalus Association of Malaysia, Malaysia

Background: It has been almost 2 years since the successful hosting of the 30th International Conference on Spina Bifida and Hydrocephalus 2024 which culminated in the Kuala Lumpur Declaration. SIBIAM stays committed to our mission to improve and enhance the quality of life of individuals living with Spina Bifida and Hydrocephalus (SBH) and their families.

Methods: SIBIAM has continued to organise awareness campaigns and family support activities, support advocacy initiatives, participate in local and international events (via IF), as well as provide aid to those in need from 2025 to present day.

Findings: Malaysia's multicultural community provides opportunities during the various festivities over the years for members of SIBIAM to get together and socialise, support each other and share their experiences. These activities took place in different parts of the Malaysian peninsula and across the South China Sea in Borneo in collaboration with various organizations such as the Tzu Chi Foundation and Sarawak OKU Skills Development Association (SOSDA), strengthening our network across the country. In terms of advocacy work, SIBIAM participated in a national forum organized by the Malaysian Institute of Management, focusing on disability inclusion, equal opportunities, and policy advocacy. SIBIAM had also participated in the national workshop organized by the Malaysian CSO-SDG Alliance, contributing to discussions on strategic advocacy and the implementation of Sustainable Development Goals (SDGs) in Malaysia.

Discussion: SIBIAM has strengthened community networks, expanded advocacy efforts, supported vulnerable families, and enhanced public awareness of SBH across Malaysia and internationally. However, there is still much work to be done, and we are looking forward to more collaborations and partnerships towards our mission.

CU7 | Ensuring follow-up care for Neural Tube Defect for children in German Hospitals

Jürgen Wolters, Bettina Rosenbaum
Association for Spina bifida and Hydrocephalus (ASBH), Germany

Background: Thanks to prenatal diagnostics, neonatal care, and surgical intervention, children with neural tube defects (NTDs) in Germany receive early initial care. However, the long-term course of the condition is associated with morbidity, motor deficits, bladder and bowel dysfunction, as well as orthopedic and cognitive impairments. Ensuring follow-up care for the complex long-term consequences faced by these patients is a key priority for the ASBH.

Methods: Data from Diagnosis-Related Group (DRG) statistics were analyzed. These statistics cover all inpatient treatment cases in German hospitals, thereby providing a virtually complete picture of inpatient care in Germany.

Findings: Initial descriptive results show a wide spectrum of hospitals performing between one and more than 20 surgical procedures. Results showed an average of 187 spina bifida closure cases per year across 89 sites over 3 years. Further results are expected from the analysis of the frequency of corrective surgeries and mortality following primary hospital care in correlation to having specialized departments.

Discussion: First it is hypothesized that the number of corrective surgeries and the mortality rate is depending on the volume of initial surgeries. Second hypothesis is the number of corrective surgeries and the mortality rate decrease depending on the presence of specialized departments.

CU8 | Community-Centered Interventions for Spina Bifida and Hydrocephalus in Nigeria: 20 Years of Impact

Afolabi Fajemilo
Festus Fajemilo Foundation, Lagos, Nigeria

Background: Spina bifida and hydrocephalus are lifelong conditions associated with health, social, educational and psychosocial challenges for individuals and families. In Nigeria, these challenges are compounded by limited awareness, inadequate access to specialized healthcare and assistive technologies, stigma, and weak policy and health-system support. Established in 2006, Festus Fajemilo Foundation (FFF) pioneered disability-focused community interventions addressing unmet needs among individuals with spina bifida and hydrocephalus and their families.

Methods: Neural tube defects (NTDs), including spina bifida, are an important public health concern, with Nigeria accounting for an estimated 12,695 cases of approximately 300,000 babies born with NTDs worldwide. FFF implemented a community-centred, multidimensional approach integrating healthcare support, health education, psychosocial services, advocacy, community empowerment and partnerships. Core interventions included peer-led support groups, inclusive education, continence management, counselling, referrals, public awareness campaigns, and an annual inclusion walk. These interventions have directly reached more than 400 children and young adults living with spina bifida and hydrocephalus, covering 11 public tertiary health facilities across 5 of the 6 regions of Nigeria.

Results: FFF's interventions strengthened access to information, healthcare, and support services while promoting psychosocial wellbeing, resilience, and self-confidence. Peer-support groups facilitated experiential learning, mutual encouragement, and emotional support. Continence management, counselling, and referrals addressed critical health and quality-of-life needs. Advocacy and awareness initiatives increased visibility for people with SBH, challenged stigma and harmful practices, and strengthened participation and voice within the disability movement.

Conclusion: FFF demonstrates the potential of sustained, community-based and person-centred interventions to transform experiences of vulnerability into resilience and participation. By connecting families with healthcare, information, psychosocial support, advocacy and inclusive opportunities, FFF has contributed to advancing dignity, reducing stigma and strengthening inclusion and quality of life. This experience underscores the importance of locally led models for addressing lifelong needs associated with spina bifida and hydrocephalus in Nigeria.

CU9 | Senegal without the "H": strengthening advocacy, prevention, and multidisciplinary care through Spina-Hydro Sénégal

Ndèye Borsso NDAO
Spina-Hydro Sénégal, Senegal

Background: In Senegal, spina bifida and hydrocephalus face significant public health challenges due to persistent sociocultural stigma, late diagnoses, and limited access to specialized neurosurgical care. Spina-Hydro Sénégal was established to transform isolated clinical efforts into a structured national movement. This initiative aims to bridge the gap between acute surgical needs and the long-term, holistic management of disability through institutional advocacy and the promotion of health equity for affected families.

Methods: The association implemented a comprehensive qualitative strategy based on three integrated pillars:

- Primary prevention: Implementation of evidence-based awareness programs focused specifically on the importance of folic acid supplementation.
- Scientific engagement: Hosting multidisciplinary panels involving neurosurgeons and pediatricians to improve early intervention protocols and continuity of care.
- The "Senegal without the H" campaign: A strategic communication tool designed to deconstruct myths surrounding hydrocephalus, while providing psychosocial support to 150+ families and aligning local advocacy with the International Federation's global priorities.

Findings: The official launch, held under the patronage of the First Lady, served as a catalyst for national visibility, securing institutional commitments from the President's Health Advisor and ministerial representatives. A poignant testimony from a Member of Parliament, personally affected by her brother's condition, triggered a significant shift in public dialogue. These efforts successfully positioned SBH as a public health priority, establishing a coordinated national platform and fostering a supportive community for over 150 families who previously faced isolation and social silence.

Discussion: The Senegalese experience demonstrates that community-led organizations can drive systemic change in West Africa by combining prevention, multidisciplinary care, and high-level political engagement. By transforming social invisibility into national recognition, this model provides a sustainable framework that informs global SBH strategies and offers a replicable roadmap for regional inclusive policies.

CU10 | RAISE Resilience Program

Diana Gray
Hydrocephalus Association, USA

Background: Our mission is to find a cure for hydrocephalus and improve the lives of those impacted by the condition. This mission-based program was developed in response to research showing that parents of children with hydrocephalus experience high levels of post-traumatic stress symptoms. The RAISE program is based on the proven fact that resilience can be taught—it's about building skills. The Hydrocephalus Association RAISE program is a six-module research-informed program intended to help caregivers of children with hydrocephalus build the skills of resilience.
The curriculum was developed through a collaboration between the University of Pennsylvania Positive Psychology Program, clinical experts, former board members, and staff of the Hydrocephalus Association

Methods: The program is overseen by the Hydrocephalus Association's Support Programs team. Participants take part in a series of six facilitated group sessions led by a trained facilitator. Each interactive module lasts approximately 75 minutes and is structured as a collaborative group experience that fosters learning and meaningful connection among participants. The program is currently led by seven trained parent facilitators. Eligibility is limited to parents and primary caregivers of children ages 0–18 who have hydrocephalus.

Findings: Participants are asked to complete three short scientifically validated surveys before the first session, one month after the program ends, and six months after the program ends. The data collected through these assessments supports ongoing monitoring and evaluation of the program's effectiveness and impact.

Discussion: To date, seven parent facilitators have led eight cohorts. Participant feedback has been positive, with survey results indicating a high level of satisfaction among those who completed the program. Pre-and post-program survey data also demonstrate measurable improvements in participant outcomes, highlighting the program's positive impact.

POSTERS

Session - October 15 :

Poster ID	Title & Authors	
1P	A multidisciplinary approach to address mobility needs for children with spina bifida	**Emilie Bolduc,** Roxanne Chamberland, Tatiana Rita
2P	How a user-led SBH organization works to strengthen habilitation and rehabilitation	**Liv Tørring, Cato Lie**
4P	Integrating professionals with spina bifida into multidisciplinary spina bifida clinics	**Monica Albert Still**
5P	Growing Older with Spina Bifida and Hydrocephalus: Lived Experience Insights into Adulthood with Lifelong Disabilities	**Jennifer De Vos**
7P	Transcutaneous Spinal Stimulation (tSCS) using the NISE-Stim Protocol in Paediatric Spina Bifida Physiotherapy	**Kate Steele**
10P	Clinical decision-making in orthoses, gait alignment, and mobility optimization in pediatric spina bifida	**Sandra Sanchez**
12P	Advancing research, inspiring hope, build and strengthen community – together - Hydrocephalus Canada Update	**Shauna Beaudoin,** Ingrid Exner, Tanja Bessey
14P	Social Skills of Children and Young People with Disabilities in Slovakia	**Andrej Drdul & Terezia Drdul**
17P	A Comprehensive Approach to Supporting People with Spina Bifida: The Experience of Fundación Mónica Uribe Por Amor in Colombia	**Sonia Uribe**
21P	Persons with Spina Bifida in Montenegro – From Invisibility to Activism and Support	**Anđela Radovanović**

Session - October 16 :

Poster ID	Title & Authors	
3P	Designing Mind-Friendly Environments for People with Hydrocephalus: Enhancing Accessibility and Wellbeing	**Stella-Marie Tselepi**
6P	TONHI: The Transcranial Observational Network for Hydrocephalus Investigation	**Sofia Girotti-Switzer**
8P	Community-based wheelchair clean-up and tune-up events: A collaborative model for Spina Bifida associations	**Hannah W. Mercier, Christine Pelis**
9P	Senegal without the "H": strengthening advocacy, prevention, and multidisciplinary care through Spina-Hydro Sénégal	**Ndèye Borsso NDAO**
11P	Ensuring follow-up care for Neural Tube Defect for children in German Hospitals	**Jürgen Wolters,** Bettina Rosenbaum
13P	RAISE Resilience Program	**Diana Gray**
15P	Norwegian association for Spina Bifida and Hydrocephalus	**Liv Tørring**
16P	Spina Bifida & Hydrocephalus Association of Malaysia	**Yean Koon Chan**
20P	Spina Bifida & Hydrocephalus in Estonia	**Ann Paal**
22P	Impact of Mandatory Folic Acid Fortification on Prevalence of Congenital Heart Defects, Neural Tube Defects, and Orofacial Clefts: A Systematic Review and Meta-Analysis	**Vijaya Kancherla**

SPONSORED ABSTRACTS

SA1 | Advancing neurogenic bowel care with transanal irrigation

Megan Hutton, RN, MClSc (AHS), BScN, NSWOC, WOCC(C)
Coloplast, Canada

Background: Neurogenic bowel dysfunction (NBD) results from impaired communication between the central nervous system and the bowel and is commonly seen in individuals with spinal cord injury, multiple sclerosis, and spina bifida. NBD is associated with constipation, fecal incontinence, prolonged bowel routines, and significant psychosocial burden. Studies indicate that 70–80% of Spina-Bifida population experience constipation, while colorectal dysfunction negatively impacts quality of life and social activities in a substantial proportion of patients. The primary objective of this presentation is to review the role of transanal irrigation (TAI) as an effective, evidence-based intervention within a stepped approach to bowel management, with a focus on improving continence, autonomy, and quality of life in individuals with NBD.

Findings: Multiple clinical studies support the use of TAI in neurogenic bowel care. Christensen et al. (2003) demonstrated effective retrograde colonic washout using scintigraphic assessment, with delayed reaccumulation of feces supporting continence between irrigations. A randomized controlled trial by Christensen et al. (2006) showed that TAI significantly reduced symptoms of constipation and fecal incontinence compared with conservative bowel management in patients with spinal cord injury, while also decreasing time spent on bowel care and improving quality of life. Consensus reviews and updated treatment algorithms further position TAI as a minimally invasive, well-established option within modern NBD management.

Discussion: Transanal irrigation represents a highly effective and patient-empowering bowel emptying technique for individuals with neurogenic bowel dysfunction who have not achieved satisfactory outcomes with conservative measures. By allowing planned bowel evacuation, TAI can reduce fear of incontinence, improve continence between irrigations, and support greater independence, including use in adult and pediatric populations. When appropriately selected and supported by healthcare professionals, TAI offers meaningful clinical and quality-of-life benefits and should be considered an integral component of contemporary neurogenic bowel care.

SA2 | Uniting for Prevention: Partnership and Advocacy for Food Fortification

Kristin Sundell
GAIN

Background: Micronutrient deficiencies remain one of the world's most widespread and preventable public health challenges. Millions of women and children continue to lack access to essential vitamins and minerals, resulting in adverse health, developmental, educational, and economic outcomes. Among these consequences are neural tube defects (NTDs), including spina bifida, which can often be prevented through adequate folate intake before and during early pregnancy.

For decades, scientific evidence has demonstrated that fortification of staple foods with folic acid is one of the most cost-effective and impactful public health interventions available to prevent neural tube defects. The challenge is no longer a lack of evidence—it is achieving implementation, compliance, scale, and political commitment.

At the same time, prevention efforts must be grounded in human rights and inclusion. Persons with disabilities must never be viewed solely through the lens of medical outcomes or statistics. Individuals living with spina bifida and other disabilities are advocates, leaders, students, professionals, parents, and active members of society. Advocacy and public policy efforts must uphold the dignity, rights, and inclusion of all people.

This workshop will bring together advocates, policymakers, and technical experts to explore successful food fortification advocacy strategies and identify practical approaches that can be replicated and adapted across regions.

Objectives:
By the end of the session, participants will:

- Understand the current global landscape of folic acid fortification, including emerging initiatives
- Explore effective advocacy strategies that have contributed to policy change, improved implementation, and strengthened compliance.
- Learn from successful country and regional experiences that can be adapted in other contexts.
- Strengthen connections between advocacy for human rights and full social inclusion and efforts to prevent neural tube defects through LSFF
- Identify opportunities for collaboration, communication, and public engagement to advance food fortification policies.

ACKNOWLEDGEMENTS

Thank you for your support!

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