

SRHSB Annual Conference 2026 - Amsterdam, September 16-18



Provisional Programme

Wednesday, 16 September

- 08:00-09:00 Registration
09:00-09:05 Welcome to be announced soon!!
09:05-09:15 Opening of the Congress; Dr. Ian Pople, Dr. D.P. Bakker, Carola McDonald

Session 1: Embryology and imaging in spinal dysraphism

Cutting-edge insights into imaging of spinal dysraphism's and fetal brain MRI changes, advancing precision diagnostics in spina bifida.

- 09:15-10:00 Keynote Speaker 1
Prof. A. Rossi (Professor of Neuroradiology, Italy, Genoa)
Title: *Revisiting spinal dysraphisms: classification, controversies and clinical impact*
- 10:00-10:30 Keynote Speaker 2
Prof. M. Aertsen (Consultant Radiologist, UZ Leuven)
Title: *The spectrum of brain changes in spina bifida on fetal MRI*
- 10:30-11:00 ☕ Break

Session 2: Embryology of spina bifida and hydrocephalus

Unlocking the origins of spina bifida and hydrocephalus, this session explores embryological development, revealing new insights into early disease formation.

- 11:00-11:30 Keynote Speaker 3
Dr. B. de Bakker (Assistant Professor, Obstetrics and Gynaecology, Amsterdam UMC)
Title: *Micro-CT of the nervous system*
- 11:30-11:40 Abstract Presentation #1
Nyske Engel (Amsterdam UMC, The Netherlands)
Title: *Quantitative and qualitative brain changes in fetuses with spina bifida: insights from micro-CT at 15-23 weeks of gestation*
- 11:40-11:50 Abstract Presentation #2
Chagajeg Soloukey (Erasmus UMC, Rotterdam, The Netherlands)
Title: *Continuous intraoperative mapping for pediatric spinal dysraphism surgery: a pilot cohort study*
- 11:50-12:00 Abstract Presentation #3

Ingeborg Linskens (Amsterdam UMC, The Netherlands)

Title: *Overview of available test in the Dutch prenatal screening program with special focus on spina bifida detection by structural anomaly scans: case characteristics and pitfalls from screening*


12:00-12:10

Abstract Presentation #4

Antoinette Botman (Children's Hospital at Westmead, Sydney, Australia)

Title: *Developing an Australian national Spina Bifida Patient Registry - preliminary results of a scoping review on meaningful data to be captured*

12:10-13:00

 Lunch

Session 3: Fetal surgery in spina bifida

Exploring how prenatal intervention is transforming outcomes and redefining the future of neonatal care.

13:00-13:45

Keynote Speaker 4

Prof. Dr. J. Deprest (Professor in Obstetrics and Gynaecology, Leuven/London)

Title: *Surgical repair of spina bifida before birth today and tomorrow*

13:45-14:15

Keynote Speaker 5

Dr. Chagajeg Soloukey (Erasmus UMC, Rotterdam, The Netherlands)

Title: *Patient proximity*

14:15-14:45

Keynote Speaker 6

Dr. K. Jansen (Paediatric Neurologist, Leuven, Belgium)

Title: *Long-term outcome before and after fetal surgery in spina bifida*

14:45-15:15

Keynote Speaker 7

Dr. L. Mazzone (Paediatric Surgeon, Zurich)

Title: *Outcomes of 5-year-old patients after open prenatal spina bifida aperta repair in Zurich*

15:15-15:25

Abstract Presentation #5

Chagajeg Soloukey (Erasmus UMC, Rotterdam, The Netherlands)

Title: *Prevalence of structural brain anomaly patterns after prenatal repair of spina bifida aperta: a nationwide multicenter MRI study with comparison to a postnatal cohort*

15:25-15:35

Abstract Presentation #6

Ryan Juncker (Ohio State University, Columbus, USA)

Title: *Functional outcomes after postnatal closure of myelomeningocele below S1: an argument to consider prenatal closure of S2 lesions*

15:35-15:45

Abstract Presentation #7

Charlotte Kik (University of Toronto, Toronto, Canada)

Title: *Development of a Core Outcome Set for Fetal Spina Bifida: Preliminary Results from an International Delphi Study (COSMIC)*

15:45-15:55

Abstract Presentation #8

Petra Aden (Oslo University Hospital, Oslo, Norway)

Title: *How a New Classification Changes Epidemiology - Two Years' Experience with the Orpha Revised Coding System*

15:55-16:15

 Break

Session 4: Transition

Bridging pediatric and adult care, enhancing collaboration, sharing insights through panel discussions, and elevating the patient's perspective.

16:15-16:45

Keynote Speaker 8

Dr. A.L. van Staa (Rotterdam University of Applied Sciences, Rotterdam, The Netherlands)

Title: *Transition*

16:45-17:05

Keynote Speaker 9

- N. Bakal & I. Bakal with Carola McDonald** (Nurse Practitioner, Amsterdam UMC)
Title: *The patient's voice: experience in transition (interview)*
- 17:05-17:45 **Discussion Panel with Kate Steel** (SHINE, UK), **Dr. O. de Wit** (Rehabilitation Physician)
Discussion: *'Bridging the gap'*
- 17:45-17:55 **Abstract Presentation #9**
Iris van Wijk (De Hoogstraat Rehabilitation, Utrecht, The Netherlands)
Title: *Youth-led implementation of transition tools in spina bifida care: bridging the gap between policy and practice*
- 17:55-18:10 Short break before AGM
- 18:10-18:40 **SRHSB Annual General Meeting (SRHSB Members Only)**

Thursday, 17 September

Session 5: Tethered Cord Syndrome

Unlocking the mysteries of tethered cord syndrome: latest updates, dilemmas in untethering, and spine shortening vs. untethering.

- 08:30-08:55 **Keynote Speaker 10**
Dr. D.P. Bakker (Paediatric Neurologist, Amsterdam UMC, The Netherlands)
Title: *Spina bifida, posterior fossa & tethered cord*
- 08:55-09:20 **Keynote Speaker 11**
R. Feller (Neurosurgeon, Amsterdam UMC, The Netherlands)
Title: *Tethered cord treatment options: Untethering vs spine shortening*
- 09:20-09:45 **Keynote Speaker 12**
Dr. J. Spoor (Neurosurgeon, Erasmus UMC, Rotterdam, The Netherlands)
Title: *Lipomenigocele*
- 09:45-09:55 **Abstract Presentation #10**
Sabri Bouharrate (Erasmus UMC, Rotterdam, The Netherlands)
Title: *1-year urological outcomes in paediatric lumbosacral spinal lipoma surgery: a retrospective international dual-centre cohort study*
- 09:55-10:05 **Abstract Presentation #11**
Sabri Bouharrate (Erasmus UMC, Rotterdam, The Netherlands)
Title: *New Orphanet Classification for Spinal Lipomas: Validation, feasibility, and observed limitations in 169 patients based on pre-operative MR*
- 10:05-10:25  Break

Session 6: Hydrocephalus 1

- 10:25-10:45 **Keynote Speaker 13**
Prof. Nanna MacAulay (University of Copenhagen, Copenhagen, Denmark)
Title: *Pharmacological modulation of CSF secretion to reduce ICP - starting with rats, but aiming for the clinic*
- 10:45-11:05 **Keynote Speaker 14**
Dr. Hannah Botfield (University of Birmingham, Birmingham, UK)
Title: *TBC*

- 11:05-11:15 **Abstract Presentation #12 SRHSB Integra Travelling Fellowship 2025 Award**
Chagajeg Soloukey (Erasmus UMC, Rotterdam, The Netherlands)
 Title: *Variation in cerebrospinal fluid diversion rates and practices for myelomeningocele-associated hydrocephalus: a mixed-methods analysis*
- 11:15-11:25 **Abstract Presentation #13 Waite Bursary 2025 Award**
Elena Pinkney (University of Manchester, Manchester, UK)
 Title: *Identifying CSF factor(s) responsible for the developmental defect in hydrocephalus*
- 11:25-11:35 **Abstract Presentation #14 Waite Bursary 2025 Award**
Anissa Valverde (Wayne State University, Detroit, USA)
 Title: *Comparative Analysis of Flow Resistance in New versus Explanted Hydrocephalus Shunt Valves: A Multi-Center Benchtop Study*
- 11:35-11:45 **Abstract Presentation #15 Waite Bursary 2025 Award**
Martina Rivero Garcia (University of Barcelona, Barcelona, Spain)
 Title: *How does meningitis lead to development of hydrocephalus?*
- 11:45-12:00 **Keynote Speaker 15**
Dr. Chris Roberts (Wayne State University, Detroit, USA)
 Title: *TBC*
- 12:00-12:45 Lunch 🍽️ - Sponsor Round

Session 7: Urology in Spina Bifida

Cultural approaches, self-catheterization adherence, and bowel management: antegrade vs. retrograde irrigation.

- 12:45-13:15 **The Welburn Lecture**
Prof. Dr. Ahmad Elderwy (Professor of Paediatrics, Asyut, Egypt)
 Title: *The dilemma of spina bifida in Egypt*
- 13:15-13:40 **Keynote Speaker 16**
Mrs. T. de Kraker (Nurse practitioner, Amsterdam UMC, Amsterdam, The Netherlands)
 Title: *Therapy compliance in neurogenic bladder*
- 13:40-14:05 **Keynote Speaker 17**
Dr. J.R. de Jong (Pediatric Surgeon) & **Janine van Leeuwen** (Nurse Practitioner)
 (Amsterdam UMC, Amsterdam, The Netherlands)
 Title: *Bowel irrigation via Chait trapdoor - a surgical intervention*
- 14:05-14:30 **Keynote Speaker 18**
Prof. Dr. R.J.M. Nijman (Urologist, Groningen UMC, Groningen, The Netherlands)
 Title: *European guidelines for bladder management in spinal dysraphism*
- 14:30-14:40 **Abstract Presentation #16**
Jenny Sacree (Sidra Medicine, Doha, Qatar)
 Title: *Embedding longitudinal clinical intelligence: Development of a spina bifida registry and registry-driven urological pathway standardisation*
- 14:40-14:50 **Abstract Presentation #17**
Femke Bannink Mbazzi (MRC/UVRI & LSHTM Uganda Research Unit, Entebbe, Uganda)
 Title: *Clean intermittent catheterization among children with spina bifida and their caregivers in Uganda: a mixed method study*
- 14:50-15:00 **Abstract Presentation #18**
Pierre Mertens (Child-Help International, Antwerp, Belgium)
 Title: *A peer-driven, low-cost neurogenic bladder care model for low income settings*
- 15:00-15:10 **Abstract Presentation #19**
Annick Viaene (University Hospital Ghent, Ghent, Belgium)
 Title: *The impact of fecal and urological (in)continence on activities, participation, and quality of life in patients with spina bifida*

15:10-15:30 ● Break

Session 8: Rehabilitation and Orthopedics

Use of gait analysis in spina bifida, scoliosis, sports with physical disabilities, and evaluation of quality of life in spina bifida.

- 15:30-16:00 **Keynote Speaker 19**
Dr. Eveline Boeker (Rehabilitation Physician), **Susan de Koning** (Movement Scientist) & **Eefje Muselars** (Paediatric Physical Therapist) (Amsterdam UMC, Amsterdam, The Netherlands)
Title: Evaluation of multilevel orthopaedic management in spina bifida
- 16:00-16:25 **Keynote Speaker 20**
Dr. A. Stadhouders (Orthopaedic surgeon), **Marieke Hijma** (Occupational therapist) (Amsterdam UMC, Amsterdam, The Netherlands)
Title: Sitting and scoliosis management in spina bifida
- 16:25-16:50 **Keynote Speaker 21**
Eefje Muselaers (Paediatric physical therapist), **Eveline Boeker** (Rehabilitation physician) (Amsterdam UMC, Amsterdam, The Netherlands)
Title: Enhancing participation in regular sport clubs for children with a physical disability - a qualitative study
- 16:50-17:10 **Keynote Speaker 22**
Dr. H. Vreugdenhil (Psychologist) and **Miss J. Boekhoff** (Social Worker) (Amsterdam UMC, Amsterdam, The Netherlands)
Title: Evaluation of QOL in children with spina bifida and family centred care
- 17:10-17:30 **Keynote Speaker 23**
Dr. M. Alsem (Rehabilitation Physician, WKZ Utrecht, Utrecht, The Netherlands)
Title: Interprofessional care in spina bifida
- 17:30-17:40 **Abstract Presentation #20**
Bronwyn Warner (Shine Charity, Peterborough, UK)
Title: Evaluating a Transcutaneous Spinal Stimulation (tSCS) service using the NISE-Stim protocol in paediatric spina bifida physiotherapy
- 17:40-17:50 **Abstract Presentation #1**
Santiago Vallasciani (Sidra Medicine, Doha, Qatar)
Title: Neonatal clean intermittent catheterisation in spina bifida: proactive or reactive?
- 17:50-18:00 **Abstract Presentation #22**
Jesper Vinken (Erasmus UMC, Rotterdam, The Netherlands)
Title: How effective is bipolar fixation for scoliosis in children with spina bifida? A case series
- 18:00-18:10 **Abstract Presentation #23**
Hosseini Razaghi (Erasmus UMC, Rotterdam, The Netherlands)
Title: Primary or reconstructive closure following myelomeningocele repair: a multicentre retrospective cohort study comparing neurosurgical and plastic surgery practice
- 18:10-18:30 **Short break before SRHSB Society Dinner**
- 18:30-21:30 **SRHSB Society Networking Dinner - Amsterdam UMC**

Friday, 18 September

Session 9: Paediatrics

From bone fragility to breakthrough bacteriophage therapy for urinary tract infections, this session explores innovative, multidisciplinary strategies to tackle key complications in spina bifida care.

- 08:30-08:50** **Keynote Speaker 24**
Dr. M.W. Bijlsma (Paediatrician, Amsterdam UMC, Amsterdam, The Netherlands)
Title: *Bone fragility and osteoporosis fractures in spina bifida*
- 08:50-09:15** **Keynote Speaker 25**
Dr H. Herrema (Amsterdam UMC, Amsterdam, The Netherlands)
Title: *Bacteriophage treatment in urinary tract infections: Evidence and emerging applications*
- 09:15-09:25** **Abstract Presentation #24**
Madison Phipps (Children's Health Ireland at Temple Street, Dublin, Ireland)
Title: *Improving vitamin D monitoring in spina bifida through opportunistic testing: A quality improvement project*
- 09:25-09:35** **Abstract Presentation #25**
Arend Bokenkamp (Emma Children's Hospital AUMC, Amsterdam, The Netherlands)
Title: *Comparison of creatinine and cystatin C-based estimated GFR with respect to severity of spina bifida*
- 09:35-09:45** **Abstract Presentation #26**
Jenny Smith-Wymant (Shine Charity, Peterborough, UK)
Title: *Spina bifida mortality trends in England and Wales from 2001-2023*
- 09:45-09:55** **Abstract Presentation #27**
Khalil St Brice (University of West Indies, Trinidad)
Title: *Myelomeningocele management in a low-resource Caribbean setting: A single-institution experience from Trinidad*
- 09:55-10:15** ● Break

Session 10: Hydrocephalus 2

Scientific update in hydrocephalus: VP shunt vs. third ventriculostomy – evaluating different approaches.

- 10:15-10:45** **Keynote Speaker 26**
Dr. S. Roosendaal (Neuroradiologist, Amsterdam UMC, Amsterdam, The Netherlands)
Title: *Imaging of hydrocephalus*
- 10:45-11:15** **Keynote Speaker 27**
Dr. K.M. Slot (Neurosurgeon, Amsterdam UMC, Amsterdam, The Netherlands)
Title: *Ventriculoperitoneal shunting versus endoscopic third ventriculostomy*
- 11:15-11:45** **Keynote Speaker 28**
Dr. D. Buis (Neurosurgeon, Amsterdam UMC, Amsterdam, The Netherlands)
Title: *Hydrocephalus management in infants*
- 11:45-11:55** **Abstract Presentation #28**
Benjamin Hewitt (University of Birmingham, Birmingham, UK)
Title: *Convergent transcriptomic and proteomic signatures define injury pathways in neonatal intraventricular haemorrhage*
- 11:55-12:05** **Abstract Presentation #29**
Molly Perham (Bristol Royal Hospital for Children, Bristol, UK)
Title: *Mind the Gap: Strengthening transitional care for young people with hydrocephalus in the UK: Overview of a pilot transition event in South West England*

- 12:05-12:15** **Abstract Presentation #30**
Ram Guru Dev Palaparathi (Guntur Medical College and Government General Hospital, Guntur, India)
Title: *Congenital obstructive hydrocephalus secondary to fourth ventricle neuroepithelial cyst: a rare aetiology managed with marsupialization of the cyst*
- 12:15-12:25** **Abstract Presentation #31**
Pat McAllister (Virginia Commonwealth University, Richmond, USA)
Title: *Single-cell profiling of neurodevelopmental and neuroinflammatory dysregulation in experimental hydrocephalus*
- 12:25-12:35** **Abstract Presentation #32**
Maria Garcia Bonilla (Virginia Commonwealth University, Richmond, USA)
Title: *ADAM10-dependent disruption of N-cadherin and ventricular zone in post-hemorrhagic hydrocephalus*
- 12:35-12:55** **Keynote Speaker 29**
Dr. Monica Chau (Chief Scientific Officer, Hydrocephalus Association, USA)
Title: *The patient-led research priorities in hydrocephalus*
- 12:55-13:05** **Abstract Presentation #33**
Ryan Juncker (Ohio State University, Columbus, USA)
Title: *Glycoprotein Non-Metastatic Melanoma Protein B (GPNMB) as an immune modulator in post-hemorrhagic hydrocephalus*
- 13:05-13:15** **Abstract Presentation #34**
Sebastian Pernal (Wayne State University, Detroit, USA)
Title: *Sphingosine-1-phosphate is heterogeneous and is not independently predictive of shunt revision burden in patients with posthemorrhagic hydrocephalus*
- 13:15-13:25** **Abstract Presentation #35**
Henrik von Ahn (Umeå University, Umeå, Sweden)
Title: *The impact of spinal flow restriction on craniospinal compliance in normal pressure hydrocephalus*
- 13:25-13:35** **Abstract Presentation #36**
Jonathan Pindrik (NCH, Ohio State University, Columbus, USA)
Title: *Post-Shunting Acquired Craniosynostosis (PSAC) following Cerebrospinal Fluid (CSF) Shunt insertion for treatment of hydrocephalus: Systematic literature review and meta-analysis*
- 13:35-13:45** **Abstract Presentation #37**
Frank Kaphesi (Kamuzu University of Health Sciences, Malawi)
Title: *Comparison of motor development in children with hydrocephalus after treatment with third endoscopic ventriculostomy and ventriculoperitoneal shunt: A cross-sectional study*
- 13:45-14:00** **Closing Remarks**
Dr. R. Verbeek (Pediatric Neurologist, Amsterdam UMC, Amsterdam, The Netherlands)
-  Closing meeting refreshments