

Connecting science and support: Insights from the Health Team on the SRHSB Annual Conference 2024

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The Shine Health Team had the great pleasure of attending the [annual conference](#) of the Society for Research into Hydrocephalus and Spina Bifida. This year's conference was held in Manchester from the 4th-6th of September and brought together a range of different experts from around the world. The talks covered a variety of research topics: from basic science to emerging surgical techniques, clinical care innovations, and accounts of lived experience. This provided a comprehensive overview of some of the latest research into spina bifida, hydrocephalus, and related conditions. We are delighted to be able to use this research blog to share a glimpse into the conference and some of the exciting work that was presented.

DAY ONE: Cerebrospinal fluid dynamics and innovative therapies

The first day of the conference featured sessions looking at the complexities of cerebrospinal fluid (CSF) dynamics and new approaches to managing hydrocephalus and spina bifida.

The first keynote session by David Limbrick covered insights into how hydrocephalus develops in newborns and explored innovations in treatment. The overview included the genetics of congenital hydrocephalus, the complexity of post haemorrhagic hydrocephalus (PHH) and its impact on early development, and the role of the immune system and inflammation in hydrocephalus. This review by [Limbrick and de Vries \(2022\)](#) contains some of the discussed approaches to managing post haemorrhagic hydrocephalus, including promising results from washing out blood and debris from the ventricles (neuro-endoscopic lavage) following a bleed into the ventricles.

The second keynote session by Satish Krishnamurthy explored the theory of osmolarity and hydrocephalus. He presented evidence that suggests that problems with clearing large molecules from the CSF might be the basis of hydrocephalus development. The build-up of large molecules could affect how water moves into the brain's fluid-filled spaces and cause water to accumulate alongside them, increasing the volume and pressure in the brain. Understanding how the brain clears these molecules might offer new insights into treating hydrocephalus. These concepts are discussed in more detail in the paper by [Krishnamurthy and Li \(2014\)](#).

Multiple impactful sessions discussed the use of stem cells in a pioneering approach to hydrocephalus treatment. Patricia Paez-Gonzalez, Luis Manuel Rodriguez, and Javier Lopez-de-San-Sebastian all presented work on this novel therapeutic approach. The ventricle lining, known as the ependyma, is important for regulating many brain functions, including the flow of CSF. The ependyma becomes damaged by the build-up of CSF in the ventricles that occurs in hydrocephalus: the damage persists even if the intracranial pressure is successfully controlled with treatment, e.g., shunting. The presented studies showed that the ventricle lining can be repaired and restored by applying different types of stem cell treatments. While still some way from being translated into an approved clinical treatment, the research is a big step forward in hydrocephalus research. Read more about stem cell therapies for hydrocephalus in the article by [Rodriguez-Perez et al. \(2024\)](#)

The fascinating series of afternoon talks covered a mixture of basic science and clinical practice, for example:

- Shereen Nizari discussed a novel non-invasive method for studying the interface between the blood and the CSF. The technique has the potential to help in the development of new diagnosis and treatment methods for hydrocephalus.
- Benedetta Pettorini discussed the challenges of choosing the right treatment at the right time for hydrocephalus associated with open spina bifida. Shunt valve selection for hydrocephalus is a process that is explored in [Hall et al. \(2021\)](#), a review that Benedetta Pettorini coauthored.

DAY TWO: Lesion repair, hydrocephalus management, and pre-clinical models

Surgical interventions for spina bifida and hydrocephalus were the focus of the opening keynote sessions on day 2 of the conference. Sofia Mastrodima-Polychroniou presented an overview of the advancements in fetal surgery for spina bifida. The open repair method is similar to a c-section and offers some babies in the UK the chance to undergo spinal repair before birth. During the surgery, the mother's lower abdomen and uterus are opened, and the baby's spinal lesion is closed in layers while the baby remains in the womb; the mother's incisions are then stitched back up. While not as common as lesion repair after birth, this is the gold-standard fetal surgery approach commissioned by the NHS. The outcomes following open fetal surgery for spina bifida, while still an area of ongoing research, show promising improvements in motor function and in preventing hindbrain herniation in children after birth (a significant cause of death in infancy). The first three years of the service under NHS Commission have been running successfully, with outcomes at least comparable to the initial study of fetal surgery for spina bifida. Shine has more information on [Fetal Surgery for spina bifida](#), and you can read more details about the results of the NHS commissioned service in abstract number OP.0027 [Mastrodima-Polychroniou et al. \(2023\)](#)

A lively discussion followed Ian Pople's session, which explored the challenges of managing hydrocephalus with shunts or by endoscopic third ventriculostomy (ETV) plus or minus choroid plexus coagulation. The talk and the range of views shared afterward by different experts highlighted the importance of personalised treatment plans. Ian Pople's [chapter in the Oxford Textbook of Neurosurgery](#) was co-written with William Singleton and discusses the different endoscopic approaches to hydrocephalus management.

Kim Wouters presented a fascinating review during the abstracts session, examining non-invasive methods for the normal pressure hydrocephalus (NPH) diagnosis. The review showed promising techniques, such as specialised electroencephalogram (EEG), have been developed that could help identify the patients with NPH who are most likely to respond to shunt treatment. This could potentially speed up therapy as there is currently a bottleneck caused by the time and expertise required to perform extended lumbar drainage (ELD) testing. Read more about how EEG data can be used to predict shunt responsiveness in NPH in this paper by [Aoki et al. \(2020\)](#).

The afternoon presentations explored different models of hydrocephalus and spina bifida. Models are used to further our understanding of the conditions and to test diagnosis and treatment methods before they reach the patient testing stage. Pat McAllister gave an overview of large animal models for hydrocephalus and the advantages, limitations, and uses for each

model. This session was particularly informative for the lab-based researchers at the conference; it will potentially influence the design of future studies and improve the quality and relevance of the research produced.

Christopher Roberts gave the Norman Guthkelch Award 2024 Plenary Presentation. His work analysing CSF flow in ventricular catheters for hydrocephalus in children has huge implications for future shunt design. About half of shunt failures in children are due to blockage by various brain tissues growing into the holes of the ventricular catheter (the short tube that sits in the ventricles and draws out CSF). The promising research may help us understand why and how shunts fail and to test ways that failure could be prevented. Read more about the CSF flow modelling in [Faryami et al.'s preprint paper](#)

DAY THREE: CSF pathways, and patient experiences and perspectives

The first part of the morning explored how CSF is produced, flows through, and drains from the brain.

The keynote session from Roxana Carare provided insights into the aging brain and links to hydrocephalus and dementia. As we age, the brain becomes less able to clear out a protein called amyloid-beta, contributing to conditions including Alzheimer's disease. Amyloid-beta is normally removed through enzymes and different drainage systems involving the blood and lymphatics. However, with aging and conditions that affect the brain's arteries, amyloid-beta can build up and disrupt the brain's structure and function. This can contribute to Alzheimer's but may also prevent the clearance of other waste products. Research is focusing on how aging and other factors, such as diet, impact these drainage systems to hopefully help direct prevention and treatment efforts. You can read more about this research on the [Carare group's research theme pages](#).

Hannah Botfield's keynote session focused on idiopathic intracranial hypertension (IIH). IIH is a relatively rare condition where early diagnosis and treatment are essential to prevent permanent eyesight damage. Rates of IIH are rising along with rising obesity levels, and managing IIH remains a clinical challenge. Research is helping improve our understanding of the condition and the best approach to treatment. Ongoing studies include those evaluating weight-loss strategies (including surgery), stenting, and novel drug treatments, including repurposing inhibitors from existing therapies – reducing the clinical testing timeline. Hannah Botfield coauthored a detailed review of the evidence behind how IIH develops and how it can be managed: [Mollan et al. \(2016\)](#)

Jaleel Miyan gave a powerful and persuasive keynote session examining the essential role of CSF composition and flow pathways in brain development [Miyan \(2009\)](#). The cerebral cortex is the part of the brain responsible for higher functions like thinking and memory. CSF inside the brain has been shown to support stem cell growth, but the role of CSF circulating outside the brain is less well-studied. During brain development changes in the contents of the CSF and its flow are critical for the typical growth of the cerebral cortex. Studies in animal models of spina bifida and humans with the condition suggest that CSF needs to reach particular parts of the developing brain to enable proper cell growth and organisation. Problems with fluid flow or what the CSF contains (including differences in folate types/levels) might lead to developmental brain disorders.

The patient therapies and perspectives session was kicked off by Dominic Thompson's keynote presentation, which returned to the field of prenatal surgery for spina bifida. The

closed/fetoscopic approach to fetal surgery was discussed and compared with the gold-standard open surgery, as in [Sacco et al. 2019](#). In fetoscopic surgery, the baby's spina bifida lesion is repaired while still in the womb through a "keyhole" style approach. Instead of opening the uterus through a single large incision (open surgery), small incisions, called ports, are made in the mother's uterus to gain access to the baby. The idea is to reduce some of the risks associated with major abdominal surgery in the open fetal surgery approach. The evidence presented suggests that the outcomes for the closed approach are not yet as positive for the baby as open repair, and there's an increased risk of premature birth. However, because fetoscopic surgery is being performed differently in different centres it's hard to draw reliable conclusions, and some centres are starting to report promising results.

Shine were pleased to award speaker Carola McDonald with the Dr Richard Morgan Prize for her work improving services and support for young people with spina bifida in the Netherlands. Carola McDonald showed how the [Ready Steady Go transition tool](#) could be used to enhance the transition experience for young people with spina bifida and their parents.

Ann Wing, who worked closely with Dr Morgan at the [Chelsea and Westminster clinic](#), spoke powerfully about her late colleague, whom so many people greatly miss for his care and commitment to helping others. She said that Dr Morgan was "always thinking of how patients could live life to fulfilment." The words resonated deeply, reminding the audience of the impact we can have when we dedicate ourselves to empowering others through our work. The society took the opportunity to thank Ann for her own work and dedication.

Aitana Ruiz de Lazcano presented some fascinating research looking into mental health and spina bifida. The work was focused on understanding how adults with spina bifida view their health, what challenges they face in terms of mental and emotional wellbeing, and what kinds of support they need to improve their quality of life. During the conference, Aitana Ruiz de Lazcano's review on memory and spina bifida was published. [Amyra et al. \(2024\)](#) highlights the importance of early cognitive assessments and early interventions to help support brain development and cognition in children with spina bifida.

The patient therapies and perspectives session in the afternoon was the last of the conference. It started with a presentation from Andy Wynd, the former chief executive of Spina Bifida and Hydrocephalus (SBH) Scotland. His reflective presentation covered the innovative ways SBH Scotland has supported people over the years. Andy Wynd shared powerful videos from young people and from parents about their lives and their involvement with the charity.

A series of presentations from Shine brought the meeting to a close. The first presentation from Gill Yaz explored our [1000 voices research](#) into ageing with spina bifida. The report by Yaz and Smith-Wymant highlights challenges in health and lifestyle as people grow older and the impact of missed opportunities for better healthcare. An overview of our spinal stimulation service by Bronwen Warner followed, showcasing the therapy's potential to improve mobility and sensation. We hope to publish the results of our service evaluation in the next couple of years and build on the growing professional interest in using the technique. The third presentation by Lindsey Reid covered Shall Wee Talk, Shine's innovative children's continence support group. Shall Wee Talk provides a safe space for children and parents to connect with their peers, share experiences, and receive expert advice on bladder and bowel management. The fourth and final presentation was from Gill Yaz and focused on Shine's collaborative [work with professionals](#), including research support, CPD training, and developing resources with and for healthcare providers. The presentations were very well received, and the Shine team was collectively

awarded the President's Talk Prize for "outstanding talks capturing the scope of Shine's activities." We were incredibly grateful for and humbled by the award. By extension, it is also an award for our members and funders for their support, contributions to our research, and engagement with our services.

Conclusion: The Power of Collaboration

The conference was a powerful reminder that progress in spina bifida and hydrocephalus care requires a multidisciplinary approach. Basic science researchers, clinicians, surgeons, allied health professionals, charities, and patients all play vital and complementary roles in advancing care. The most significant breakthroughs will be made through collaboration and exchanging ideas at events like the SRHSB annual conference.

The future of research for spina bifida and hydrocephalus looks bright, though it's clear there's still more to do. Advancements with enormous potential are on the horizon and we will endeavour to keep our members updated on progress through the [Shine Research Blog](#).