# Innovation and collaboration in hydrocephalus and spina bifida research: Health team reflections on the SRHSB annual conference 2025

The 2025 annual conference of the Society for Research into Hydrocephalus and Spina Bifida (SRHSB) took place in Columbus, Ohio. The Nationwide Children's Hospital, which hosted the conference, is an eminent clinical and research institution, supporting patients from across the United States and around the world.

Staff from the Shine Health Team were delighted to attend the conference remotely and spent three days listening to the fantastic array of research talks. The lectures and abstract presentations covered a wide range of topics, from the molecular origins of neural tube defects (NTDs) and hydrocephalus to prevention efforts, novel therapeutic approaches, and lived experiences. The theme of connecting innovation and collaboration was strongly evident throughout, many of the presented studies were cross-disciplinary and the benefits of pooled expertise were clear in the high standard and originality of the work.

## Day 1

### Opening remarks:

The conference began with opening remarks from organiser **Albert Isaacs (MD, PhD)**, a paediatric neurosurgeon and researcher at the host hospital/institute. Delegates and speakers were given a warm welcome, and the exciting programme was laid out. Thanks were given to the conference sponsors Sophysa, Medtronic, and the Nationwide Children's Hospital, and to other exhibiting companies Clarus Medical, Isto Biologics, and Johnson & Johnson MedTech. Gratitude was also expressed to educators in the Nationwide Children's Hospital Fetal Medicine Centre for providing training including a fetoscopic myelomeningocele repair simulation.

### Welcome Address:

The welcome address was delivered by cultural historian **Stephen Kern (PhD)** who gave a talk entitled "Historical Background to Modern Neuroscience." We were given an overview of the theory and practice of scientific efforts to understand the "complex inner sequence of the mind". The talk covered early pseudoscientific theories of phrenology and physiognomy and their influence on society and literature. Aspects of anthropology, psychology, neuroanatomy, and cellular and molecular neurobiology were also discussed. The welcome address highlighted the significant advancements we've made in our understanding of the brain and the mind.

### Keynote Lecture:

The first Keynote Lecture was delivered by the President of SRHSB **Ian Pople (MD, FRN)**. We were given insights from an impactful 35-year paediatric neurosurgery career spent first in the UK working for the NHS then at Sidra Medicine in Qatar.

Mr Pople first fell in love with Paediatric Neurosurgery at Great Ormond Street Hospital (GOSH) and that's when he first encountered hydrocephalus. Later, while working at Frenchay Hospital, he introduced an open-door policy to enable patients with hydrocephalus to have checks when needed to provide better continuity of care.

The talk went on to cover the evolution of our medical understanding of hydrocephalus and different treatments including shunts, endoscopic third ventriculostomies, and choroid plexus cauterisation.

Mr Pople spoke about the research he has been involved in over the years which has been centred on improving patient quality of life, avoiding shunt infections, complications, and revisions. He conducted research into bacterial adhesion and preventing shunt infection, alongside Prof Roger Bayston (Shine Trustee and Professor Emeritus at the University of Nottingham). Mr Pople was also involved in the pioneering DRIFT trial showing the benefits of drainage, irrigation and fibrinolytic therapy (DRIFT) for post haemorrhagic ventricular dilatation (enlargement of the ventricles after a bleed) which is often the result of prematurity in newborns.

## Session 1: Engineering in Hydrocephalus 1

*Invited Lectures*

The first Invited Lecture was given by **Peter Chiarelli (MD DPhil)** who gave an overview of different methods of evaluating CSF flow through shunts with a view to improving hydrocephalus management. He described working in a highly collaborative, multidisciplinary team with fellow neurosurgeons plus neuroscientists, engineers, and physicists. Dr Chiarelli developed a non-invasive method for measuring CSF flow in shunted hydrocephalus to aid the clinical assessment of shunt failure. The novel neuroimaging approach uses phase-contrast MRI to quickly measure cerebrospinal fluid (CSF) flow through the inner shunt tubes. It can be easily translated to routine clinical practice as it uses existing imaging approaches and does not alter the clinical pathway. The method provides a rapid, reliable, and straightforward means of measuring shunt flow to allow earlier detection and treatment of shunt failure.

The second Invited Lecture was delivered by **Raudel Avila (PhD)** who discussed wearable and implantable devices for monitoring hydrocephalus. Dr Avila's research group is an interface between engineering and medicine. Palpation of the soft spot on a baby's head (the anterior fontanelle) is commonly used to clinically assess intracranial pressure (ICP) but it's neither quantitative nor objective. Dr Avila and his research team have developed methods to enable non-invasive, wireless, quantitative assessment of ICP in infants. Their research has involved mapping changes in fontanelle shape/displacement in relation to different pressures. They have created a wearable headband sensor for use in neonatal care to measure ICP by proxy. The approach may facilitate early diagnosis and treatment, and post-operative monitoring of hydrocephalus.

***Abstract Presentations were moderated by Karen Diefenbach (MD) & Carolyn Harris (PhD)***

**Amy Huang (BASc)** was the 2024 Waite Bursary Award Recipient, and she presented her research into "Bio-inspired self-cleaning catheter material and design." The study involved testing new adaptations in the shape and composition of the proximal catheter to reduce shunt complications. To increase fluid flow and reduce blockage curved flaps were included in the catheter eyelets. SLIPS material was tested and found to reduce the risk of bacterial adhesion and infection. The presentation showcased a novel approach to catheter design aimed at reducing shunt failure.

**Ahmad Faryami (PhD)** presented novel research into benchtop model that can accurately mimic CSF flow. By examining how CSF flows through different types of chambers and valves under different flow conditions the research may help us to understand shunt overdrainage and underdrainage better. Hopefully in future the research will lead to improved shunt design and better outcomes for patients.

**Kenae Thompson (BS)** discussed using a model system for testing the impact of different ventricular catheter placements and conditions. The model can be used to test the amount of ventricular tissue pulled into the catheter and the resulting changes in CSF flow and structure of the ventricle walls. The approach has great potential for refining shunt design and placement.

**Prashant Hariharan (PhD)** had developed an "organ-on-a-chip" model of the choroid plexus, the region of the brain that secretes CSF. This preclinical model is made from cells and silicone arranged to replicate the structure and function of the choroid plexus. It can be used to study how injury affects fluid secretion in the brain and to help screen for possible therapies. The model has great potential for streamlining the drug development pipeline for hydrocephalus treatment.

## Session 2: Engineering in Spina Bifida & Hydrocephalus

*Invited Lectures*

The third Invited Lecture was delivered by **June Goto (PhD)** who shared preclinical insights into therapies targeting the immune cells and CSF secreting structures of the brain in neonatal hydrocephalus. Dr Goto described the discovery of a gene called Ccdc39 which was involved in the development of the hair-like structures that line the ventricles of the brain (medial wall ependymal cilia). Proper development of the cilia is crucial for normal CSF flow and brain development. Dr Goto had created a mouse model of neonatal hydrocephalus by mutating Ccdc39. One of the presented uses of this model was in studying the effects of a medication called bindarit which blocks proinflammatory cell signalling and the activity of immune cells (microglia) in the brain. Reducing inflammation in the brain (neuroinflammation) is crucial for brain development in neonatal hydrocephalus. Treatment with bindarit combined with CSF diversion surgery by shunt or ETV may promote brain (neuronal) development and thereby improve outcomes in neonatal hydrocephalus.

The fourth Invited Lecture by **James Pat McAllister II (PhD)** gave us an insightful overview of large animal models and experimental methods used for studying hydrocephalus. Hydrocephalus in humans is extremely variable and the same is true in animal models which also vary in how representative they are of human pathology. There was critical discussion of the limitations and uses of preclinical models and the considerations when selecting models

for study e.g. side effects of the method used to induce hydrocephalus, the severity of the resultant ventriculomegaly, anatomical and lifespan differences. The talk highlighted the need to consider future translation to clinical studies and routine practice when using models, potentially helping preclinical researchers in attendance to improve the design of their future studies.

*Abstract Presentations were moderated by Mark Hester (PhD)*

**Kenae Thompson (BS)** presented research into creating a synthetic gel that simulates brain tissue to allow a bench-top investigation of hydrocephalus. Some of the cells of brain that help give it structure are called astrocytes, and they are sensitive to pressure change but their response to raised ICP in hydrocephalus hasn't been studied in detail. To address this research gap, a hydrogel model was created for astrocytes to be grown on which can be modified to mimic the pathological conditions of hydrocephalus, including raised pressure. This bench-top model will allow researchers to study the effects hydrocephalus on the brain at the cellular and molecular level.

**Andrew Tidball (PhD)** showcased a lab-grown brain tissue model (called SOSR-COs). The model provides a faster and more efficient way to study cellular and molecular changes involved in neural tube defect (NTD) formation. The research showed NTDs were associated with changes in a process called apical constriction (how cells tighten at the top to shape the neural tube). The SOSR-CO model can be used to understand the causes and mechanisms involved in NTD development and has potential applications for drug development and screening for teratogenicity (side effects that impact fetal development).

**Jorge A. de Tejada, PhD** gave a virtual presentation about using enhanced imaging methods to improve hydrocephalus diagnosis. Raman spectroscopy is a technique that analyses how a substance scatters light to glean information about its molecular structure and composition. In this talk we learned how using machine learning alongside ramen spectroscopy could offer a highly accurate, affordable means of diagnosing hydrocephalus. Further clinical studies are needed but early data suggest enormous clinical potential.

*Fireside Chat moderated by* **Monica Chau, PhD and the expert panel was comprised of: Peter Chiarelli (MD DPhil); June Goto (PhD); Raudel Avila (PhD); and Carolyn Harris (PhD).**

The fireside chat focused on innovations and the future of engineering in spina bifida and hydrocephalus. It was a fascinating wide-ranging discussion among experts. When considering purpose and impact in research the panel highlighted the importance of bridging the gap between basic research and application. They stressed the need to develop non-invasive methods for obtaining quantifiable patient data and the value of being able to link symptoms with clinical measurements. All panellists recognised the importance of considering patients as individuals, and considering the variation in people, anatomy, condition, and symptoms.

The importance of multidisciplinary collaboration was discussed, particularly work that brings together clinicians and engineers. Variation in experience and expertise is so valuable, but the panel also acknowledged that it can make communication harder. It was suggested that concerted efforts to communicate well are especially needed in multidisciplinary teams to be able to reap the benefits of different expertise while avoiding the difficulties.

The panellists talked about difficulties of testing innovations because of the tension between the desire and need for advancement, and with wanting to use approaches with a strong track

record. At some point the track record needs to be established but doing so is challenging. Clinical trial recruitment was described as being similarly difficult, because parents and participants can struggle with randomisation, often having a strong preference for a particular treatment.

Two common bottlenecks in the research pipeline were identified by the panel: time and money. Innovations to improve efficiency are crucial for helping to push past these bottlenecks.

The panel voiced support for the research priorities developed by the Hydrocephalus Association in the USA in collaboration with patients. The priorities are: 1) Developing non-invasive therapies and one-time therapies 2) Reducing the burden of current treatments (make treatments better) 3) Improving the screening and diagnosis of hydrocephalus 4) Improving quality of life for people with hydrocephalus 5) Improving patient access to care.

Patient involvement and insight were highlighted as being essential for ensuring relevance and impact of research. Patient perspectives keep research meaningful. The panel discussed the pressing need to connect physicians and scientists with patients. This is a priority for Shine and something we facilitate through our research support activities.

# Day 2

## Session 3: Advances in Hydrocephalus

*Invited lecture*

The first Invited Lecture on day 2 was delivered by **Bonnie Blazer-Yost (PhD).** The talk focused on using genetic models of hydrocephalus to understand and therapeutically target CSF production. The research demonstrated that transient receptor potential vanilloid 4 (TRPV4) is a key regulator of CSF production and potential therapeutic target in hydrocephalus. TRPV4 is a channel protein located in cells of the choroid plexus, it's activated by changes in electrolyte balance, pressure, and temperature. Further research showed that targeting TRPV4 directly and indirectly via SGK1 can reduce hydrocephalus by altering the fluid balance and does not appear to cause adverse effects. The research may lead to non-surgical treatments for hydrocephalus.

*Abstract Presentations III* Moderated by **June Goto (PhD)**

**Aaron Gonzales (MS)** presented his research looking at topographical solutions to shunt obstruction. A major cause of shunt failure is cell adhesion and obstruction of shunt catheter holes. It's known that cells behave differently on different surface textures. The researchers explored different topographical PDMS surfaces with a view to designing the optimal surface to reduce astrocyte attachment and proliferation. Researchers identified a surface design that appears to have potential in reducing cell adhesion, and a possible effect on proliferation. The surface modifications would be compatible with commonly used shunt catheter materials and coatings so could be used to enhance existing treatments.

**Santino Cua (MD)** shared proteomic insights into the disruption of the barrier between the blood and CSF in post-infectious and post-haemorrhagic hydrocephalus. White blood cells infiltrate the CSF in post-infectious and post-haemorrhagic hydrocephalus. By analysing the protein content of CSF samples, key genes associated with PHH were identified. These included IQGAP-1, and others involved in blood-CSF barrier disruption and migration of white blood cells

in inflammatory hydrocephalus. In future these findings may support design of targeted therapies to prevent or treat hydrocephalus in premature infants.

**Maria Garcia-Bonilla** presented on behalf **of Owen Limbrick.** A model of post haemorrhagic hydrocephalus (PHH) was presented that showed a number of pathological changes in the brain. Changes were identified associated with memory and cognition including reduction in hippocampus size and thinning of the perirhinal cortex. Certain brain support cells (astrocytes) became more active when proinflammatory cytokines were detected. The model has potential testing the effects of novel treatments on cognition and memory in hydrocephalus.

**Asma Redwan (PhD)**'s work examines the disease processes associated with hydrocephalus developing. This presentation explored the role of extracellular vesicles in PHH. PHH is a disease associated with inflammation of the brain involving the activation of cytokines and inflammatory signalling. Extracellular vesicles are tiny sacs released from cells to allow them to communicate with each other. Extracellular vesicles taken from CSF of PHH patients had been injected into the ventricles of mouse models which had induced the molecular changes associated with inflammation. This suggests extracellular vesicles have a role in the PHH disease process and may be a future therapeutic target.

**Laiba Taufiq (MS)** was the 2023 Waite Bursary Award Recipient who delivered a virtual presentation on the overlapping morphological and molecular changes associated with depression and hydrocephalus. Common changes in both conditions were noted and included thinning of the cortex and enlargement of the ventricles. The research also showed that multivitamins may protect the brain from inflammation and stress-related damage in depression and hydrocephalus models.

**Madelynn Thomas (BS)** had conducted a multicentre shunt biobank study into ventricular catheter obstruction. It's a common cause of shunt failure and the obstructions are mainly composed of astrocyte and macrophage cell types; microglia account for a smaller proportion. A large database was examined of patients whose hydrocephalus was treated with shunts and outcomes were interrogated. The study showed that age of the first surgery, the length of time a ventricular catheter has been implanted, and proximity of the catheter to the ventricle wall all affect likelihood of obstruction. Catheters need a fluid buffer to prevent tissue encroachment of the shunt so if it's too close to the wall there's an increased risk of obstruction. Overall, the findings indicate obstruction is caused by multiple factors, all of which need to be considered in catheter design and placement to reduce shunt failure.

## Session 4: Advances in Spina Bifida & Related Disorders

**Invited Lecture VI** was delivered by **Bermans Iskandar (MD)** who shared advancements in the preclinical study of spina bifida treatment using research in experimental sheep models. After an occurrence of heritable spina bifida was reported on a US sheep farm, researchers sought to establish a sheep model and research facility for studying spina bifida. Goals of the "Tim George herd" were to research genetics and epigenetics of heritable spina bifida, to study the preventative effects of folate supplementation and identify other means of prevention. It also hoped to study multisystem effects of spina bifida, and to test new and improved surgical repair methods. Creating these models of heritable spina bifida enable the study of the genetic and environmental causes of the condition and potentially screening for treatments.

**Abstract Presentations IV** were moderated by **Eric Sribnick (MD PhD)** and **Adolfo Etchegaray (MD)**

**Sasidhar Karuparti (MS)** gave the first abstract presentation of the session on comparing **brain development and the need for CSF diversion in spina bifida versus myeloschisis.** Research had shown that, after prenatal repair, patients with myeloschisis were more likely to require CSF diversion compared to those with myelomeningocele. However, those with myelomeningocele were more likely to require earlier surgery. After postnatal repair, fewer patients with myeloschisis exhibited a change in brain structure known as tectal beaking, compared to those with myelomeningocele. The difference in Chiari II rates was non-significant, potentially due to sample size. These findings suggest there may be significant clinical differences between lesion types with implications for patient counselling and treatment.

**Fabio Rossi (MS)** was the 2025 Waite Bursary Award Recipient who gave a virtual presentation on his research into folate metabolism in the brain in human hydrocephalus**.** The study had demonstrated that people with spina bifida and different types of hydrocephalus have reduced levels of folate carrier proteins FDH and FOLR1. This suggests that disruption of folate pathways is an important feature in the development of these conditions.

**Sasidhar Karuparti (MS)** shared clinical research comparing some key effects of prenatal and postnatal lesion repair in myelomeningocele. The difference in BMI, head circumference, and extra-axial CSF (subarachnoid space measurements) was examined in patients treated with either pre or post-natal repair. Children were more likely to be overweight if they had undergone prenatal repair compared with postnatal repair. Children treated prenatally had larger head circumferences compared with those treated postnatally. The potential long-term cognitive impact of this difference is currently unknown.

**Ben Hewitt (MD)** was the 2024 recipient of the SRHSB/Integra Travelling Fellowship Award; he shared his research into prevention of Post Haemorrhagic Hydrocephalus (PHH). Differences were observed in cortex RNA expression in PHH samples. Haemorrhage was associated with downregulation of ion transporters (possibly suggesting association with oedema) and upregulation of iron binding and removal proteins. Decorin (a potential treatment for post haemorrhagic hydrocephalus) significantly increased expression of iron binding genes but also of genes associated with autophagy. The research also demonstrated there's a window of ~24 hours after a bleed in which hydrocephalus could be prevented. The studies overall indicate there are modifiable factors that can prevent PHH development.

## The Welburn Lecture

The Welburn Lecture was introduced by **Christy Monson (ACPNP)** and presented by **Mr. Joe Blundo.** The lecture was an unusual discussion of the way the English language has developed over time. It began with a poetic and colourful portrait of Columbus before moving on to describe the many was that the English language is always evolving, adaptable, beautiful, versatile: "Change is the only constant."

## Session 5: Advances in Spina Bifida & Related Disorders II

The **Invited Speaker VII** was **Steve Hwang (MD)** who gave a clinical talk on Tethered Cord and 3-Column Osteotomies. There is an increasing body of literature supporting not detethering the spinal cord prior to surgical correction of scoliosis if the tethered cord isn't symptomatic. In practice benefits and risks of detethering are generally best considered on a case-by-case

basis. Research suggests spinal column shortening can be a safe and effective alternative to traditional detethering in spina bifida.

**Abstract Presentations V session** was moderated by **Jonathan Pindrik (MD)**

Research presented by **Sasidhar Karuparti (MS)** compared endoscopic third ventriculostomy (ETV) +/- choroid plexus cauterisation (CPC) with VP-shunting in patients with spina bifida associated hydrocephalus who'd had pre or postnatal repair. Those treated with ETV+/-CPC had less time to failure and smaller ventricle decreases than those treated with VP shunts, regardless of whether the lesion was repaired before or after birth. No difference in revision rate was detected between the two CSF diversion methods. This work has implications for treatment selection in hydrocephalus associated with myelomeningocele.

**Dhruti Doddaballapur (BSc)** delivered a virtual presentation of research into Parkinson's disease showing that chemical processes in CSF may play an important role in the development of the condition. One key process involves making a substance called BH4, which helps the brain produce important signalling chemicals like dopamine. BH4 is made from vitamin B9 and is mostly produced in a part of the brain called the choroid plexus. Changes in BH4 have already been linked to Parkinson's.

**Gwendolyn Sebring (BS)** shared research into the therapeutic potential of viral vector therapy targeting the choroid plexus to ameliorate symptoms of neonatal hydrocephalus. The therapy was found to reduce CSF production and ventricular volume in a mouse model with no apparent off-target or adverse effects. If successfully translated to humans viral vector therapy targeting the choroid plexus could reduce the need for CPC or shunt surgery and the associated complications.

**Joan Jasien (MD)** presented a research study aimed at determining whether regions of the brain associated with neurodegeneration differed between APOE4 carriers and noncarriers in young adults with spina bifida. Early left amygdala volumetric reduction was found in APOE4 carriers but no neurocognitive differences were detected. This suggests emotional/behavioural/cognitive functions associated with the left amygdala should be explored further and compared between carriers/non-carriers to determine if the volumetric reduction is, or becomes, clinically significant.

## Session 6: Therapeutics, Biomarkers, Experimental Models

**Invited Lecture VIII** was delivered by **Richard Finnell (PhD)** whose research into the biology of neural tube defects (NTDs) covered a range of approaches including prevention efforts and stem cell therapies. Novel mouse models of NTDs had been created by knocking out genes such as folate receptor (Forl1). When knocked out in mice folic acid transport into cells ceases and pups have neural tube defects among others. Evolving understanding of genetics of NTDs in humans is that single copies of multiple genes are mutated and that NTDs arise from complex gene-environment interactions. "NTDs are caused by a little bit of this and little bit of that" Clarke Fraser. Also shared was research using exosomes derived from amniotic fluid derived mesenchymal stem cells (AF-MSCs) as promising minimally invasive nanotheraputics for prenatal repair of spina bifida.

**Invited Lecture IX** was delivered by **Andy Copp (MBBS DPhil FRCPath FMedSci)** who presented research into the origins of Chiari II brain malformation in spina bifida. Higher brain defects associated with hindbrain herniation in Chiari II include cortical anomalies, callosal

hypogenesis, tectal beaking, and enlarged mass intermedia. Prenatal surgery significantly reduces risk of hindbrain herniation but all other brain changes are not preventable by fetal surgery. Until recently it was unclear what caused the association between spina bifida and Chiari II. A study was conducted to explore the causation; a mouse model was created where a genetic mutation that causes spina bifida was only expressed in the body but not the head. Despite the mice brains not containing the mutation all the mice with spina bifida developed Chiari II brain changes. The conditional mouse model of Chiari II therefore showed that the brain defects of Chiari II arise secondary to open spina bifida, implying that Chiari II develops very early in gestation because of disrupted neurogenesis. In the interesting Q&A session that followed it was theorised why the changes occur and it could be due to multiple mechanisms including CSF composition, flow (differences in cilia numbers/structure/function), and pressure.

**Abstract Presentations VI** were moderated by **Bermans Iskandar (MD)** and **James Pat McAllister (PhD)**

**Maria Garcia-Bonilla (PhD)** shared insights that rapamycin could be a potential treatment for Post Haemorrhagic Hydrocephalus (PHH). T-cells are a type of immune blood cell that were shown to overexpress mTOR signalling genes in PHH. This suggests it's a signalling pathway that could be a therapeutic target. Rapamycin is an mTOR inhibitor in clinical use for other conditions. Testing rapamycin in a mouse model of PHH suggests the drug may modulate immune cell infiltration of the choroid plexus and prevent ventricular enlargement/hydrocephalus.

**Dhruti Doddaballapur (BSc**) gave a virtual presentation looking at changes in cerebral folate, tetrahydrobiopterin and dopamine metabolism in Parkinson's disease (PD). Protein expression in CSF and tissues from PD patients were analysed and significant differences were found in folate and BH4 pathways in PD. Enzyme deficiencies, oxidative stress and calcium dysregulation were seen and suggest choroid plexus dysfunction. The research highlights importance of choroid plexus and CSF cerebral metabolism and in PD disease process. There may be potential to develop for targeted PD therapies to combat associated dopamine dysregulation and ventricular enlargement.

**Engin Deniz (MD)** shared insights using a frog/tadpole model to allow rapid and straightforward imaging of the central nervous system due to the transparency of the model and rapid growth. The model can be used to study ventriculogenesis and CSF flow dynamics throughout development. It can also be used to test loss of function mutations of genes associated with hydrocephalus in human patients e.g. DIP2 to better understand the mechanisms underlying disease development and progression.

**Alba Anguita (BSc)** gave a virtual presentation looking at the potential therapeutic benefit of a sequential stem cell-based therapy for intraventricular haemorrhage (IVH). The interaction between different cell types including ependymal, astroglial, and microglial cells is modified with stem cell treatment. The therapy also affects oedema and inflammatory reactions in the brain following IVH.

## Day 3

### Opening Remarks: Albert Isaacs, MD PhD

### Session 7: Multi-Centre Collaboration & Stakeholder Engagement

**Invited Lecture X** was delivered by **Jay Riva Cambrin (MD MSc)** on the subject of the Hydrocephalus Clinical Research Network (HCRN) . The HCRN conduct important, collaborative, and impactful, multicentre clinical research to improve diagnosis, treatment and outcomes of hydrocephalus in children. The ultimate goals are to improve the quality and length of the lives of people with hydrocephalus, reduce post-shunt surgery infections, and improve understanding of the epidemiology and outcomes of ETVs. A detailed registry of around 9 thousand patients is being created of all hydrocephalus patients at participating institutions. The talk covered insights from the network on the importance of patient centred outcomes and the potential of artificial intelligence (AI) to revolutionise medicine.

The **Invited Lecture XI** was delivered by **Ms. Dianne Kean**, a mother of a son (Tim) who has hydrocephalus. The deeply personal story covered the medical ableism faced during diagnosis/pregnancy, the trauma of multiple shunt failures, revision surgeries (111), and seizures. Tim was described as a "magnificent gladiator" thanks to his perseverance and "never give up never give in" attitude. The family follow a positive growth mindset "We don't worry about disabilities we build on his abilities". Dianne Kean felt as a parent her job is to help her son be "motivated, engaged, and adapt to life." After talking about the impact of multiple shunt surgeries she stressed the need for approaches to reduce shunt failure rate: "One and done" is her dream for shunt surgery. This powerful talk gave some much needed personal perspective on the impact of hydrocephalus and the importance of research in continuing to improve care for those affected.

**Abstract Presentations VII** were moderated by **Jeffrey Leonard (MD)**

**Monica Chau (PhD)** discussed the key research priorities for non-invasive therapies to improve hydrocephalus outcomes. There is a pressing need to develop non-invasive approaches to provide safer, more accessible treatment options. It's a key research priority of the Hydrocephalus Association to reduce **the risks and complications associated with traditional surgical treatments.**

**Adrien Winning (PhD)** shared caregiver perspectives on family-based psychosocial interventions for young children with spina bifida**.** The research found that 60% caregivers experience stress. Many caregivers struggle with knowing how to best support their child and how to balance independence and protection. Social isolation was a major issue, many felt other caregivers don't understand. Specialist parenting support was limited. The top four support needs identified were school advocacy, understanding the impact of spina bifida on development, support talking to children about their condition, reducing caregiver stress and supporting selfcare.

**Catherine Stephan (PhD)** had conducted a study into the use of an independence skill screening for young people with spina bifida. The aim was to use a screening tool to try and identify where interventions were needed to help improve key areas of difficulty for young people including selfcare and health, independence, social isolation, and poor mental health. The screening tool developed for caregivers showed potential in evaluating independence in young people with spina bifida, potentially helping direct treatment and support.

**Jamie Wright (MD PhD)** presented a novel design for an auto-levelling external ventricular drain (EVD) that was shown to work in an animal model. If/when translated to humans this should allow people with an EVD to move freely and should reduce the nursing care burden associated with the need for frequent levelling interventions.

**Nour Tanbar (BS)** shared insights from a study of emergency admissions in older adults (aged 65+) with spina bifida. The research showed there were an average of 6-8.6 emergency admissions per patient, this is four times higher than the general population of the same age. Common diseases that patients had alongside spina bifida were high blood pressure, raised cholesterol and urinary tract infections (UTIs). Compared to the general population of the same age there was an increased prevalence of UTIs, chronic obstructive pulmonary disease, and high cholesterol. Overall, the research shows that older adults with spina bifida have unique profile of comorbidities with high medical needs. It underscores the importance of spina bifida-specific multidisciplinary care in adults with spina bifida in supporting health and reducing reliance on emergency department use.

**Presentation of the Dr. Richard Morgan Prize by Shine Representative, Gill Yaz**

Dr Morgan was remembered as a dedicated professional and true gentleman. The 2025 prize was awarded to Nour Tanbar for her outstanding presentation entitled "Characteristics of geriatric spina bifida patients in Florida emergency departments."

## Vision 2030 Fireside Chat:

**The Future of Hydrocephalus and Spina Bifida Care Moderator's Perspective** was delivered by **Jamie Wright (MD PhD)** who shared her personal account of life with hydrocephalus and researching the condition. She stressed the need for more research, better information, better quality data to guide treatment decisions.

**Panel Discussion Moderator: Jamie Wright, MD PhD Expert Panel: David Limbrick, MD PhD; Jay Riva-Cambrin, MD MSc; Jeffrey Leonard, MD; Richard Finnell, PhD**

This was another excellent and wide-ranging discussion. Initial comments were around how patients with hydrocephalus would benefit from a better understanding of their therapeutic window, which varies depending on individual compliance and other factors. A key component of managing hydrocephalus is optimal drainage and the ability to detect when intracranial pressure (ICP) shifts outside of a safe range. Many patients prioritise improving their quality of life and are willing to undergo more surgeries if it means achieving better outcomes. Ultimately, people just want to return to normal lives.

Despite 30 years of advancements, hydrocephalus care issues persist, there is still a lack of non-invasive methods to understand the underlying mechanisms of the condition, as well as to monitor and control the disease process effectively. Current approaches have seen incremental improvements, but there are some fundamental problems that remain unsolved. The aetiology of hydrocephalus is poorly understood, which complicates both prevention and management.

Looking forward to 2030, there was hope for breakthroughs in the understanding and treatment of hydrocephalus, particularly in achieving less invasive control over cerebrospinal fluid (CSF) levels and flow. It was stressed that it's important that innovations in treatment do not outpace our understanding of the underlying physiology; this ensures that engineers can develop the most effective and targeted solutions. Preventive measures could have a significant impact, and there will hopefully be better, scalable *in vitro* models alongside improved screening capabilities.

Achieving these ambitious goals hinges on the establishment of robust research networks that emphasise prevention and foster collaboration among various stakeholders. At the 2030 SRHSB

meeting, research will likely focus on translational studies, moving findings from the laboratory to clinical settings. Research is expected to be further along the pipeline, with valuable data garnered from large animal models. Non-invasive methods of measuring ICP will also be a key focus.

Artificial intelligence (AI) is still in its early stages, but it is anticipated to undergo exponential development over the next five years. There is hope that AI will contribute positively in the future, provided it is allowed the time to mature and evolve. The success of AI applications will depend on the quality and type of information used to train these systems, necessitating the establishment of a consensus group to validate and moderate AI outputs.

Different ideas were presented for the "wish list" problems to be solved by 2030: Over-drainage has been previously underestimated, and a significant concern that must be addressed. Real-time, non-invasive ICP monitoring and improved imaging techniques to assess CSF levels are critical areas for advancement. There's a need for better neurosurgical management of chronic issues and comorbidities associated with hydrocephalus. It is vital to ensure patient access to multidisciplinary clinics, where existing solutions can be effectively implemented. Preventive measures should be enhanced through improved *in utero* treatments, alongside advancements in genetics and dietary considerations.

It was felt that currently there is sometimes a disconnect between the priorities of patients and the interests of researchers, this needs to be addressed to through public and patient involvement (PPI). Ensuring relevance, consistency, and quality of care is essential for meeting patient health and wellbeing.

It was clear throughout that effective management of hydrocephalus care does and will in future depend on a highly collaborative, multidisciplinary approach.

## President's Remarks was delivered by SRHSB President **Ian Pople (MD FRCS(N))**

Mr Pople thanked the organisers, and everyone involved in making the conference a success. He highlighted how the meeting was an important way to foster communication, and to exchange and create new ideas. He acknowledged the importance of the patient voice in driving outcomes for long-term quality of life and highlighted how the conference had helped focus attention on key areas of research and activity to help with this.

Mr Pople also thanked attendees, and for their participation throughout the conference, and urged those who are not yet members to consider joining SRHSB and come along to meetings.

Lastly, Mr Pople thanked Albert Issacs for a 'fabulous meeting' and presented him with a Glass Arabic dagger.

## Closing Remarks were delivered by conference organiser **Albert Isaacs (MD PhD)**, he expressed gratitude for all the people who made the meeting possible, as well as everyone who travelled to attend, whether crossing state lines or even oceans. Dr Isaacs described how the meeting had explored early and late-stage technologies that encouraged attendees to think differently and work collaboratively. He thanked moderators and expressed appreciation to

those who led the workshops, which had contributed greatly to the overall experience. The important contribution of the meeting sponsors and exhibitors was highlighted, and they were thanked for their support.

Dr Isaacs echoed the feelings of the Shine staff in attendance that we were grateful to have heard about the amazing advancements that have been in hydrocephalus research and were resolved to use and share what we had learned in our future work. We look forward to attending the SRHSB annual conference in 2026 and updating members on the exciting research developments and discussions.

Jenny Smith-Wymant, Shine