

The International Paediatric Brain Injury Society and the North American Brain injury Society – Joint Conference on Brain Injury

Five hundred delegates from 21 countries attended the 2022 Joint Conference on Brain Injury which took place in September at the iconic New Yorker Hotel in MidTown Manhattan, New York. Delegates were welcomed to the conference organised by the International Paediatric Brain Injury Society (IPBIS) and the North American Brain Injury Society (NABIS), by Conference Chair Ronald Savage (USA) and Co-Chairs Roberta DePompei (USA), Beth Wicks (UK) and Brian Greenwald (USA).

Progress in the field of paediatric brain injury has continued at a pace despite the pandemic, and there was much to discuss at this first face-to-face IPBIS conference in four years. The multidisciplinary event had a broad programme spanning research studies to practical and applied techniques for improving outcomes for children and young adults with brain injury. As well as pre-conference courses, keynote lectures and invited talks, participants shared their work through a peer-reviewed abstract process as oral presentations and posters. The conference abstracts will be published and indexed in the Journal of Head Trauma Rehabilitation later this year.

At the official opening Dr Savage said: “On behalf of the IPBIS and NABIS I am delighted to open this joint conference and my thanks to everyone involved in its organisation. My thanks also to Patrick Donohue and the International Institute for the Brain for sponsoring the Sunset Gala Liberty Cruise.

Dr Savage thanked the conference sponsors, particularly iBrain, Hackensack Meridian, JFK Johnson Rehabilitation Institute, Carf International, NYU Langone Health, Kennedy Kruger Institute and Johns Hopkins Medicine, as well as the many exhibitors.

Respecting decisions despite the brain injury

“This lecture will set the tone for the conference” said Dr Greenwald in his introduction to keynote speaker, Debjani Mukherjee (USA) who discussed the dignity of risk and its implications for brain injury.

Dignity and indignity, risk and safety are pairs of concepts on a continuum which can have blurred boundaries and differing interpretations. Risk is typically defined and apprehended by a third party and will change according to time, place, and context. When the dignity of risk is considered it typically involves the person who is deemed to be taking the risk and the other who is considering protection or safeguards and weighing it up in a specific moment in time, based on information and conceptualisation. This can lead to reflexive responses and confirmatory bias. Who decides what is risk and what is the evidence?” asked Dr Mukherjee.

The dignity of risk can be applied to a wide range of situations in brain injury including discharge planning, decisional capacity assessment and surrogate decision making. She said: “The dignity of risk is a concept that is simple but difficult to

honour and practice. It is about respecting or honouring the decisions that people make and minimising paternalism and parentalism. What we may think of as risky for the patient might not allow them to do what they really want to do. At its core it is about social justice.”

Dr Mukerjee cited Robert Perske who fought for fair and richer social justice for people with disabilities. He questioned the USA approach of ‘over protection’ and emphasised the need to allow people to live in the real world and give them opportunities to succeed. A person with a brain injury may not be able to communicate but they may be able to understand the relevant information and make a decision. They may verbalise but are unable to carry out the task. It is important to consider all aspects of the choice and the right to decide. “There’s a fine balance between duty of care and dignity of risk” concluded Dr Mukerjee.

Using a biopsychosocial approach to deciphering psychiatric disorders

“You have to consider that the psychiatric disorder that presents may pre-date the TBI; one-third of children will have a psychiatric disorder at the time of their accident” said Jeffrey Max in his opening words.

Paediatric TBI and psychiatric disorders are a significant, independent, and overlapping public health significance. Dr Max reviewed the pre-injury psychiatric disorders as well as the brain-behaviour relationships within a developmental biopsychosocial model of psychiatric disorder. He discussed novel (post-injury onset) psychiatric disorders (NPD) which are common and complicate child function after injury.

Children who have a TBI are on average behaviourally affected before their injury. This may be due to a higher risk of injury in children with high impulsivity and risk-taking behaviours corresponding with the diagnoses of externalising disorders such as attention-deficit/hyperactivity disorder (ADHD), in the absence of known pre-injury brain damage. Often the child or adolescent with TBI presents to a mental health professional at a variable amount of time after the injury which requires a retrospective account of the pre-injury status and post-injury course of the presenting psychiatric syndrome.

There is a close relationship between psychiatric disorders and family function. NPDs, which include personality change due to TBI, secondary ADHD, as well as other disruptive behaviour disorders, and internalising disorders, are associated with specific injury and psychosocial variables, including family dysfunction, and can be measured soon after injury. This enables the potential recognition of children who are at high risk for psychiatric problems before they appear. In theory categorising the behavioural complications of TBI into psychiatric syndromes enables a logical pharmacological and psychological treatment approach but as Dr Max said ‘nothing really works’. Pharmacological research for NPDs is negligible, but psychotherapy research is showing promise in areas of behaviour such as self-regulation, communication, and aspects of family function, but not specifically for NPDs. Dr Max

said: “Management of psychiatric problems associated with cognitive function impairments is particularly challenging”.

Addressing the many challenges in brain injury management

Millions of children sustain mild TBI (mTBI) annually, and the numbers seeking care are increasing dramatically. Children with mTBI often report post-concussive symptoms that are most severe acutely, but persist for weeks or months, and can result in functional disability and a reduced quality of life. Predicting outcomes is complex and early diagnosis essential. Evidence-based guidance is required to manage mTBI and more research required to inform clinical care and improve outcomes. A gold standard for diagnosing and predicting the prognosis of mTBI is lacking. Keith Yates (Canada) discussed the Advancing Concussion Assessment in Pediatrics (A-CAP) study that assessed a range of neurobiological and psychosocial markers with the goal of improving the diagnosis and prognostication of outcomes of paediatric mTBI.

Vicki Anderson (Australia) presented a 20-year study tracking the long-term outcomes from child TBI and found that the age at which the child sustained the injury, and the injury type were important predictors. The younger age group had worse outcomes and a severe injury compounded the problem. Dr Anderson leads the Take Care concussion programme in Melbourne which aims to better diagnose, manage, and treat child concussion. She discussed the HeadCheck app that helps trainers and coaches to recognise the symptoms of a suspected concussion and its severity and provides support for parents. Dr Anderson also discussed interventions such as Concussion Essential, an online symptom targeted intervention and COPE, a cognitive behavioural programme.

Eli Gunnarson (Sweden) highlighted that the diagnosis of stroke is often delayed in children - much later than adults – because the symptoms can be different and this impacts on the long-term consequences. Children also tend to have many deficits after a stroke and predicting long-term outcomes is difficult but requires long-term monitoring and follow-up. There is a need for specific speech and language and communication interventions, and a patient-centered approach to management. Family function has an impact on recovery and Catherine Aaro Johnson (Sweden) emphasised that parents need specific support so they can help improve their child's cognitive function.

Assessing children with disorders of consciousness is problematic and a range of measures are available but as Beth Slomine (USA) said ‘the validation is lacking and much more research is required’. Epilepsy can be a therapeutic challenge and approximately one third of patients do not become seizure free with antiseizure medications. This treatment gap has motivated research for new therapeutic options, such as cannabidiol (CBD). CBD differs from other cannabis derivatives because of its consistent efficacy and lack of psychoactive effect, and it is now recommended in some countries for therapy in patients with Dravet and Lennox-Gastaut syndromes. Michael Barnes (UK) highlighted the need to improve access to CBD for children

particularly with severe epilepsy.

Return to Education – ABI training is critical for educators

A much discussed topic at the conference was Return to Education (RtE). There is a considerable amount of work being progressed around the world to identify, address, and monitor the needs of children and young adults with ABI when they RtE, and at critical points in their education such as transition from primary to secondary schools, as well as support resources for healthcare providers, teachers, and families.

However, many challenges and barriers are global, particularly with regard to ABI training, particularly for educators. Communication between all stakeholders can be problematic, lack cohesion and consistency. Few countries, apart from Australia and Canada, are managing the RtE with any degree of consistency in their approach or implementing national standards.

Juliet Haarbauer-Krupa (USA) chaired a course looking at the issues of TBI and RtE and emphasised the need for supporting and monitoring children and young people long-term. Nick Reed (Canada) highlighted the progress in Canada with a range of programmes and guidance for educators, young people, and their families as well as a concussion code of conduct process for removing students from play for sports professionals. “We also have a Youth Concussion Awareness Network and concussion clubs in high schools run by young people using resources that we provide” said Nick. The need to train educators about ABI was reinforced by many speakers including Emily Bennet (UK) who also chaired a roundtable on the topic: “Unfortunately the majority of people who are supporting these children in education tend to know the least about their needs. ABI education and training is crucial.”

Programmes available for educating teachers such as the ‘Return to School’ website (Melissa McCart USA) and BrainSTEPS (Brenda-Eagen Johnson, USA) were discussed.

The quality and the quantity of pretend play of preschool-aged children with an ABI has been found to be significantly below that of their neurotypical peers which impacts on their learning and development. Adrienne Thorne (USA) said that ‘pretend play is essential’ and she described ‘Learn to Play’, an intervention to support development.

Criminal justice systems are inadequate for supporting young offenders with ABI

Many children and young people with ABI are likely to have contact with the criminal justice system (CJS) with major personal, social, and economic consequences. Evidence emphatically links ABI to offending in young people, with prevalence rates as high as 60% amongst prisoners. The CJS in most countries discriminates against those with an ABI because of the lack of recognition and understanding about the ‘hidden disabilities’ associated with ABI. This results in many barriers to accessing justice and the inappropriate use of standard criminal justice interventions. Huw

Williams (UK) introduced the global problem by saying that ‘prisons are brain injury centres but without the resources’. The CJS has to adapt to young people with ABI and the UK is leading the way with improvements such as brain injury screening, assessment, management, and support services available within the system.

Technology developments may assist targeted rehabilitation

The use of neuroimaging as a tool for understanding and predicting long-term brain-behaviour relationships after TBI has been limited by the relatively poor sensitivity of routine clinical imaging for detecting diffuse axonal injury (DAI). However, newer magnetic resonance-based imaging techniques demonstrate improved sensitivity to DAI and these techniques hold promise for identifying imaging predictors and correlates of chronic function, both globally and within specific neuropsychological domains. These imaging techniques may allow earlier identification of possible chronic sequelae of tissue injury for each child with TBI. However, Miriam Beachamp (Canada) highlighted the problems of MRI and children because they will not stay still for long periods of time and the quality of the images is not always ideal. However, parental concern about imaging has been shown to be a predictor of success so it is important to educate the parents before the imaging technique is used.

Structural neuroimaging technologies will help in targeting rehabilitation interventions for those patients most likely to benefit from them but as Linda Ewing-Cobbs (USA) commented: “More research is needed to generate ‘big data’ with more targeted approaches”.

Alina Roštšinskaja (Estonia) described the PowerVR Program, for the remediation of social deficits, including social confidence, which can be a major issue in children with neurological disorders. The programme uses virtual reality to introduce children to challenging situations, but in a safe environment, and provides strategies to help them adapt.

Pre-conference courses – an overview

Delegates attended a wide range of pre-conference courses. The Teen Online Problem-Solving (TOPS) Therapy for Adolescents with TBI, a problem-solving intervention, provided training and international applications for the tool. Shari Wade (USA) chaired the session and speakers discussed the evidence-base for TOPS, reviewed the tool and website, and discussed how TOPS has been integrated into other countries such as Canada, Italy, and the UK.

Barry Willer (Canada) chaired a session looking at the many controversies in the management of concussion in children and adolescents. Speakers discussed the long-term effects on physiological recovery, emotion regulation, families, and support from healthcare providers.

David Putrino (USA) discussed the challenges, triumphs and questions related to integrating novel technology into brain injury rehabilitation, predominantly for adults but just as applicable to children. Speakers looked at how to use novel technology successfully in their rehabilitation programmes and maximise compassionate care.

Other courses included the use of applications to develop executive function skills, clinical applications of the Coma Recovery Scale-Revised, and perspectives on paediatric ABI from an integrated systems of care approach.

Presentation of Awards

2022 Jane Gillett Award

The 2022 Jane Gillett Award, named in honour of the founder of the IPBIS, and supported by Gluckstein Personal Injury Lawyers, was Arend de Kloet (The Netherlands). Beth Wicks, IPBIS Chair presented Arend with a cheque for \$1000.

2022 Robert D Voogt Award

Brenda-Eagan Johnson (USA) was the winner of the 2022 Robert D Voogt Award, named in honour of the founder of NABIS, for her work on BrainSTEPS, the Brain Injury School Consulting Programme. Dr Ronald Savage presented Brenda with a cheque for \$2000 and a trophy.

Adult Oral Abstract Award

The Adult Oral Abstract Award was presented to John Yue (USA) for Neuroinflammatory Biomarkers for Traumatic Brain Injury Diagnosis and Prognosis: Results From the Track-TBI Pilot Study.

Paediatric Oral Abstract Award

The Paediatric Oral Abstract Award was presented to Claudia Corti (Italy) for Very Long-Term Follow-Up in Children With Disorders of Consciousness After Severe Acquired Brain Injury.

Best Adult Poster Award

The Best Adult Poster Award was presented to Brandon Lucke-Wold (USA) for Cerebrospinal Fluid Leak in Facial Trauma: Identifying Clinical Risk Factors With a Retrospective Analysis.

Best Paediatric Poster Award

The Best Paediatric Poster Award was presented to Irwin Gill (Rep of Ireland) for Establishing an Acute Rehabilitation Service in a Tertiary Paediatric Hospital: A Quality Improvement Project.

Two projects to support

Unmasking brain injury

The IPBIS supports an initiative developed by Hinds Feet Farm (HFF), a USA-based rehabilitation provider, called Unmasking Brain Injury. The project promotes awareness of the prevalence of brain injury, gives survivors a voice and the means to educate others about what it is like to live with a brain injury, shows that people living with a disability due to their brain injury are like anyone else, deserving of

dignity, respect, compassion and provides them with the opportunity to prove their value as citizens in their respective communities.

To date, the work has been mainly with adults and mostly within the USA. To expand the project the IPBIS and HFF have produced guidance for use with children and young people globally. For further information visit:

<http://unmaskingbraininjury.org>

The IPBIS Toolbox

Numerous tools and programmes are available for the rehabilitation of children, adolescents, and young adults with ABI. However, not all countries, professionals, and families, in particular within the Low-and Middle-income Countries, may be aware of the wide range available. The IPBIS produces a 'Toolbox' entitled 'Guidance for the post-discharge rehabilitation of children, adolescents and young adults with ABI', containing summaries of tools and programmes that are accessible via the internet. The tools address the physical, cognitive, academic, and psychosocial problems associated with ABI, post-discharge from acute care.

The IPBIS is accepting submissions for the next edition of the toolbox, with a deadline of 28th April 2023, which will then be available online in Autumn 2023. For further information visit: <https://ipbis.org/toolbox>

Diary dates

5th IPBIS Conference: w/b 16 September 2024, Glasgow, UK.

6th IPBIS Conference: 2026 Calgary, Canada.
