

CONFERENCE REPORT: 2ND INTERNATIONAL CONFERENCE ON PAEDIATRIC ACQUIRED BRAIN INJURY, 20-23 SEPTEMBER 2017, ROME, ITALY

Pre-conference workshops

1. Neuropsychological, Behavioural Assessment and Treatment of Children with Acquired Brain Lesions: From Disorders of Consciousness to School Re-entry.

This half day seminar was a thorough presentation of the treatment programme for children and young people with acquired brain injury as they are assessed and treated in the Nostra Famiglia Centres in Milan, Sudan and a South American site. Presentations were followed by an enthusiastic discussion about the common challenges rehabilitation specialists have in supporting the successful reintegration of children post ABI into academic programmes around the world run by those who seem to have few resources to address these students' needs and often are completely ignorant of the learning and emotional issues affecting the child with a new ABI.

2. Neuro-Disability and Social Exclusion: a Need, and a Way, to Reduce Risk of Detention and Displacement of Young People with Brain Disorders.

A provocative and culturally diverse description of the prevalence of brain injuries in vulnerable populations. Children and young people outside of family care are often without protection and cultural and language barriers make it difficult to access support and help promote resilience. Research and clinical/policy initiatives that may be of benefit to children with neuro-disabilities who are at risk of detention of various forms were presented. Reference was made to the significant language deficits in many of these young people where verbal communication is the modality of choice in the legal and penal systems. The TBI group of offenders have a 90% of re-offending two years after release. The long term costs to the state of not identifying and rehabilitating TBI victims was emphasised as an important way to motivate for funding

3. Advanced Neuroimaging for Identification of Children at Risk Towards Sports Related Brain Injuries.

This pre-conference session was presented by an international panel of speakers who provided details of cutting edge research informing our knowledge of neural mechanisms underpinning delayed recovery from child concussions. Findings across multiple imaging modalities were described and results discussed from a translational perspective, highlighting that, while they provide important insights into recovery, these 'experimental' techniques are not yet ready for use in routine clinical practice.

4. Disorders of Muscle Tone in Children After Acquired Brain Injury: Diagnosis, Evaluation and Therapeutic Approaches.

This session explored issues relating to the fact that moderate to severe acquired brain injury (ABI) can result in the development of movement disorders such as spasticity or dystonia, which adversely affect function and quality of life. Initially, issues relating to diagnostic classification were presented in addition to neurosurgical approaches. The second part of the session was focused on the rehabilitative approach and it consisted of the presentation of some significant case reports with a multi-disciplinary focus. Every presentation was followed by a very interesting and exhaustive discussion.

Main conference

“It’s a pleasure to welcome you here in Rome” said Enrico Castelli (Italy) Conference Chair, at the opening ceremony of the 2nd International Conference on Paediatric Acquired Brain Injury (ABI).

Over 400 delegates including physicians, allied health professionals, educators, social workers and legal professionals, attended the conference from 43 countries, to look at new strategies for improving the outcome and quality of life for children and young people (CYP) with ABI. Mariella Enoc (Italy) President, Bambino Gesù Children’s Hospital, Rome said:” Our hospital has innovation as one of its key values; we really need innovation because the children need it”.

Carol Hawley (UK), IPBIS Chair reiterated the welcome to Rome and thanked the conference supporters; ITOP spa Officine Ortopediche, The Sarah Jane Brain Foundation, Allergan and A Circle spa as well as many exhibitors.

The conference focussed on the development of new assessment tools, innovative therapies and devices, rehabilitation programmes, teaching strategies, psychological and social support, increasing the potential for recovery in CYP with ABI, and providing support to families.

Al Condeluci (USA) opened the conference with a powerful and stimulating Keynote Lecture on the use of social capital as an antidote to social isolation. Dr Condeluci is CEO of Community Living and Support Services (CLASS), and teaches at the University of Pittsburgh. “People who experience disability are isolated, and all the work we’ve done has led to lives of increased isolation” said Dr Condeluci. He discussed the goal of rehabilitation which is to restore function, but pointed out that it also needs to provide opportunities for the individual to participate in the community. Dr Condeluci said “We silo people. We need to change the world so that these individuals are accepted into the community, not create a special community for them”. Relationships produce social capital by shaping attitudes, facilitating change and helping people accomplish more. “It is important for children with disability to get to know other children. Putting them at the back of the classroom doesn’t

provide social capital; it's the similarities not the differences that are important" concluded Dr Condeluci.

George Prigatano (USA), Emeritus Chairman, Department of Neuropsychology at Barrow Neurological Institute at the Dignity Health St Joseph's Hospital and Medical Center, Phoenix, reinforced the sentiments expressed by Dr Condeluci, namely that the single largest outcome for CYP with ABI is social isolation. Dr Prigatano introduced his Keynote Lecture by stating that before you deliver psychological care it is imperative to understand what it is like to be a child with a brain injury. He examined the importance of both the environment and education in rehabilitation. Resilience is required by CYP in order to adapt to their losses and ongoing stresses, together with a sense of self-worth, and the skills to manage their own limitations. CYP with ABI need to be in an academic setting where they can perform and Dr Prigatano discussed three approaches to management; the context sensitive family-based approach to development, the family-centred approach and parent-based model and the individual psychotherapy approach.

A recurring message throughout the conference was that 'children are not little adults', highlighted by the evidence-base showing that they do not respond in the same way as adults with brain injury. The problems associated with assessing and diagnosing very young children up to the age of five years were discussed. Falls are common in this population at an age when a vast amount of developmental change is occurring in the brain. The 'plasticity versus vulnerability' debate continues; defining measurable symptoms, an accurate diagnosis and subsequent assessment in this age group is crucial, but remains extremely problematic. Speakers concluded that there is much work to do to address these challenges.

Daria Riva (Italy) Fondazione IRCCS, Istituto Neurologico Carlo Besta, Milan discussed the complexity of the brain and that injury severity and outcome very much depend on the site of the injury, the age of the child, amount of damage, together with other factors including cognitive reserve and rehabilitation. Brain injury occurring at a stage of rapid brain development will have a long-term impact and there are different trajectories for neurological recovery. However, very often parents of young children presenting at the Accident and Emergency Department are told that there is no brain injury, and consequently follow-up is absent, and the significance of the injury in terms of the child's life trajectory is ignored. Data from New Zealand was presented from a 25 year period, monitoring the long-term outcomes on the 0-5 years age group with mild TBI. The study concluded that there were detectable ongoing issues into adulthood including antisocial and criminal behaviour. This was supported by several speakers who emphasised that the consequences of injury at an early age continue well into later life, and even mild TBI is a chronic condition which requires long-term and regular follow-up.

Paediatric concussion continues to stimulate much debate, with a large variation of guidance available, particularly within schools and relating to sports. The problem is

amplified because of the lack of objective biomarkers which hinders the identification of the underlying changes that may be ongoing following a mild head injury.

The return to education for CYP with ABI was also a common theme throughout the conference, highlighting the significant issues and presenting some support solutions. The return to school process is often delayed and extremely stressful for CYP with ABI. Families feel that schools are underprepared and slow to respond to their needs, and teachers report limited understanding of ABI. Schools have a crucial long-term role as major neurorehabilitation (NR) providers, and need to be prepared and trained for the return of the child with ABI. Unfortunately current attitudinal research showed that educators have very limited knowledge and continue to have misconceptions about ABI e.g. that the child is actually in control of their own recovery.

Evidence-based training tools and support information were discussed involving different implementation methods to increase the knowledge base for teachers, and to provide ongoing support. Training all teachers is not feasible but if special needs teachers can be made aware of ABI and provided with support tools then this will go a long way to addressing the problems. A range of apps and online problem-solving interventions are now available including the use of virtual reality for CYP to facilitate all aspects of rehabilitation including social interaction, day-to-day tasks as well as learning and memory problems. Transition programmes also have a major role to play in optimising the child's recovery and formalising the programme for each individual. However formalised transition programmes are not a common occurrence.

The use of a detailed, inter-agency 'return to school pathway' and guidance for local education services was discussed. The pathway and guidance were created collaboratively by a regional paediatric neuropsychology service, the local Educational Psychology service, and a young man with an ABI and his parents. Contributions were also sought from key professionals, including teaching staff involved in supporting CYP with ABI. Early results are encouraging and to date 12 CYP have been included in the pathway resulting in increased empowerment of parents and CYP, higher levels of confidence in teaching staff, and lower rates of non-attendance at school.

Prison officers, like teachers, do not receive any training on ABI. Crime is now a well-recognised consequence of ABI and prison is unlikely to provide the rehabilitation required for these individuals in order to prevent re-offending. Often young offenders are unaware that they have an ABI so their journey through the criminal justice system is problematic. Studies presented at the conference demonstrated the need to train probation and prison officers about ABI and to implement interventions and programmes to support young offenders.

The survival rate for many children with brain tumours is good but, as Professor David Walker (UK), Professor of Paediatric Oncology, University of Nottingham said

in his Keynote Lecture: “We need to avoid harm”. Although the tumour may be removed successfully, the consequences of surgery, chemotherapy and radiotherapy post-surgery can all cause considerable damage to the brain and lead to lifelong disability. The delays to diagnosis are a problem because the ongoing damage by the growing tumour is not reversible. “The importance of prompt diagnosis cannot be emphasised enough” said Professor Walker.

When the hospital doors close the CYP and their families often face numerous challenges in terms of their rehabilitation. Post-discharge support was highlighted in many countries as a concern and the conference heard from several speakers detailing the role of ‘outreach’ rehabilitation as an effective means of continuing care. However, the sheer volume of CYP with ABI requiring post-discharge support often means that only the most severe individuals will get any support as resources are often overstretched.

Miriam Beauchamp (Canada), Associate Professor in Developmental Neuropsychology at the University of Montreal gave the closing Keynote Lecture and focussed on the differences between children that have good outcomes following brain injury, rather than those that do not. Are there children that need more resources than others along their recovery trajectory? Dr Beauchamp explored whether the differences between these children can be used in the future to predict which children will have an absence of long-term symptoms and impairment.

In closing the meeting Beth Wicks (UK), Conference Co-Chair, thanked delegates for attending, submitting abstracts and posters and reiterated the words of Mahatma Gandhi: “You must be the change you wish to see in the world”.

The 3rd International Conference on Paediatric Acquired Brain Injury will take place on 26-28 September 2018 at Queen’s University Belfast, Northern Ireland.

Ingrid van’t Hoof receives the Jane Gillett Award

This year’s Jane Gillett Award, supported by Gluckstein Personal Injury Lawyers, was presented to Ingrid van’t Hoof, a neuropsychologist at Sweden’s Karolinska Hospital.

The Award honours the memory of Jane Gillett, a paediatric and adult neurologist at the forefront of brain injury treatment, founder of the IPBIS and one of the first to recognise that the impact of an ABI in young people may continue to emerge for many years post-injury.

As a result of Dr van’t Hoof’s work, Stockholm now has a specialist rehabilitation team based at the Astrid Lindgren Children’s Hospital, focussing on the transitional period of ABI treatment for young adults 18-25 years of age. “I’m deeply moved, proud and honoured to receive this Award” said Dr van’t Hoof.

The 1,000.00 USD Award, presented by Bernie Gluckstein also includes an original, framed work of art by a former patient of Dr Gillett.

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Post-conference workshop

4th Pink Concussions Summit: Brain Injury in Girls and Young Women Under the Age of 25.

Nineteen experts from 5 countries presented research to describe post-concussion syndrome in females from an international perspective.