



Official Newsletter

Issue 3 September 2022

Message from the Chair



Beth Wicks IPBIS Chair

Welcome to the third issue of the International Paediatric Brain Injury Society (IPBIS) Newsletter. I am really pleased to share this newsletter with you and bring to you the latest news from the IPBIS.

Thank you for your interest in all things relating to paediatric brain injury and for you efforts to continue learning from and connecting with others from around the world.

We know that our website has been out of date for some time and this is because we have been developing a new site which will be much more dynamic and up to date. We hope that this will be finalized and launched at our NYC conference.

It is generally exciting times for IPBIS – we are thrilled to be bringing paediatric brain injury practitioners and researchers from around the world together again at our first in-person conference since 2018. We have a fantastic program planned and hope that you will join us in New York City (USA) from September 21 to 24, 2022 at the Joint Conference on Brain Injury. See the 'IPBIS Board Updates and Events' section below for more and we hope to see you in NYC!

We are also delighted to announce that our two future International conferences will be held in Glasgow, UK, in 2024 and Calgary, Canada, in 2026. More information will be shared at our NYC conference and then on our website.

We hope you enjoy this newsletter. Please share with your colleagues and <u>click here</u> to subscribe. Find out more about IPBIS by visiting our <u>website</u> and by following us on Twitter @IPBIS. Become a member of IPBIS and join us in advancing paediatric brain injury research and disseminating knowledge that matters to you!

With warm regards, Beth Wicks, Chair, IPBIS Board of Governors



HOT TOPIC: Improving outcomes related to education, employability, and quality of life following brain injury



Dr. Melissa McCart
The Center on Brain
Injury Research and
Training, University of
Oregon, USA



Dr. Deanne Unruh
College of Education,
University of Oregon,
USA



Dr. Douglas Gomez
The Center on Brain
Injury Research and
Training, University of
Oregon, USA

Since 1993, the Center on Brain Injury Research and Training, (CBIRT), at the University of Oregon has conducted research and training to improve the lives of children and adults with traumatic brain injury (TBI). CBIRT's research focuses on developing interventions to improve outcomes related to education, employability, and quality of life. Their training activities promote the use of best practices among educators and other professionals who serve individuals with TBI. CBIRT is also actively involved in state efforts to improve concussion management and educational services.

At the 2022 Joint
Conference on Brain
Injury in NYC (September 21-24, 2022), Melissa
McCart (Co-Director,
CBIRT), and research
faculty members, Deanne
Unruh, and Doug Gomez
will present on selected

recent CBIRT activities. Dr. McCart will present an overview of the Oregon TBI Educational Team. The Team provides statewide leadership, training, consultation, online tools, and other support for return to school following a concussion. The presentation will focus on the impact that the Team has had on educational services in the state. Dr. McCart will also highlight recent legislative and policy efforts that CBIRT has spearheaded. These efforts include OR House Bill 4140 which outlines

the process for temporary accommodations for students who have been diagnosed with a concussion or other brain injury and revisions to the Oregon Administrative Rules that now allows for a guided credible history interview as an alternative to the medical statement to validate eligibility under the TBI special education category.

Dr. Unruh will present on the Return to School Project, CBIRT's current cooperative agreement with the Centers for Disease Control and Prevention. The project is studying an established return to school program for students with TBI. This research is unique in that it allows CBIRT to evaluate an existing model of support for students with brain injuries, rather than develop a new approach that may take years to translate into practice. The results will help close the research-practice gap.

The COVID-19 pandemic required the research team to temporarily revise their approach to the Return to School Project. Dr. Gomez will present the findings of a qualitative study that used focus groups and interviews with students, parents, and school and medical personnel to explore the school experiences of students with brain injury and the services they received during the COVID-19 school closures.

Dr. Gomez will also discuss the Back to School Project, a longitudinal qualitative study, that tracked students with TBI from hospital discharge through their return to school and then for several years of school to better understand the experiences of students and parents in the education system following TBI. The findings of this study will be submitted for publication this summer.

To learn more about CBIRT's activities visit their <u>website</u> and join Melissa, Deanne, and Doug at the 2022 Joint Conference on Brain Injury in NYC.



The National Acquired Brain Injury Learning and Education Syndicate (N-ABLES)

Supporting education professionals in the United Kingdom to better understand and manage acquired brain injury.



The N-ABLES Team

Who We Are

The National Acquired Brain Injury Learning and Education Syndicate (N-ABLES) was formed in 2018. It aims to identify ways to support education professionals in gaining a minimum level of awareness and understanding about acquired brain injury (ABI) and the educational requirements of children and young people with this condition. The group has 9 steering group members, including researchers, psychologists, teachers, allied health professionals and those working in the charity sector.

N-ABLES is a special interest group which is part of the United Kingdom Acquired Brain Injury Forum (UKABIF) — a national charity which aims to increase awareness and improve services for people with ABIS — see www.ukabif.org.uk.

Our Long Term Goals

- Raise awareness of the challenges of childhood ABI within the education system (e.g., amongst policy makers and parliamentarians)
- Identify and share good practice in support of the education of children and young people with an ABI
- Increase awareness and understanding of ABI within the education system
- Create opportunities and collaborations for research focused on ABI and the education system

How N-ABLES formed

In 2017, the All-Party Parliamentary Group on Acquired Brain Injury (APPG on ABI) was established to raise awareness of ABI and improve support for those with lived experience. A year later, they published "Acquired Brain Injury and Neurorehabilitation: Time for Change". This report focused on the importance of rehabilitation in four key areas, one of which was education. It acknowledged that much of a child's rehabilitation following an ABI takes place outside of hospital and healthcare services, when the child or young person has returned to education, and that all educational professionals should have a "minimal level of awareness and understanding about ABI and the educational requirements of children and young people with this condition". It also highlighted that substantial lack of awareness, training and understanding of ABI in this sector.

What Has Been Done

N-ABLES was formed to help fulfil the recommendations of the Time for Change report. We have worked alongside children, young people and their families, professionals, and government officials to produce resources to help educational professionals identify, understand and support those with ABI in their classrooms. These free resources include:

- ABI Return: this booklet includes an introduction to ABI, things to look for in the classroom, ideas for intervention, what makes a successful return to school and signposting to other helpful resources.
- ABI Return poster: designed to be child centred, it displays the guiding



The National Acquired Brain Injury in Learning and Education Syndicate

principles of helping a child return to education.

- A checklist for special education needs coordinators (SENCOs) and keyworkers: a practical resource to ensure vital steps have been carried out before a child or young person returns to school.
- Supporting information sharing within school document: a practical resource for healthcare professionals to share useful and individual information about a child's ABI with educational professionals.
- Children and young people living with ABI have shared their views on 'what works' in a successful return to education, with key messages for professionals to consider.

These resources have been promoted at conferences, in articles in educational magazines and have highlighted the range of free online training for educational professionals.

In addition, members of the team have worked to build understanding of childhood ABI within key organisations in the education system, including the Teaching Schools Council, Special Educational Needs Coordinator (SENCo) networks and national SEND organisations.

N-ABLES produced a film for newly qualified teachers funded by the Department for Education and have been asked to produce a series of online presentations about ABI in association with NASEN – the National Association for Special Educational Needs.

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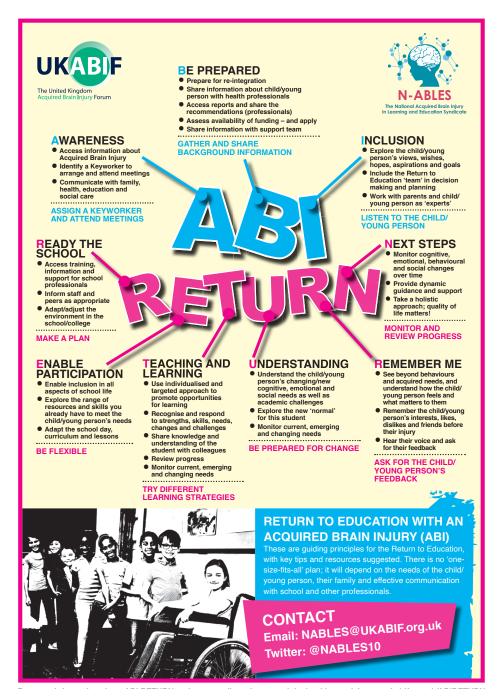
One of the group's highest priorities is to influence policy change and following a parliamentary question in the UK Parliament's House of Commons, several members of the group met with the then Minister for Children and Families. The team was able to highlight the extent of the issues for children and young people with acquired brain injuries and the Minister gave some useful suggestions to help move towards better outcomes. The group continues to meet with representatives from the Department for Education to follow up these leads to work towards lasting change.

The N-ABLES group are very much looking forward to hosting a roundtable at this year's IPBIS Conference in New York, which aims to promote discussion of the ways in which good practice in enhancing educational support can be shared amongst people from different nations. We hope the Round Table will provide an opportunity to think about what works in supporting children and young people after a brain injury and how we can persuade policy makers to come on board with our visions. We also hope to bring together an international community focusing on guidance, policy change and consensus on areas for future research.

Next steps

At the end of 2021, the UK Government agreed to a government-wide strategy for ABI. The strategy will bring together officials from many relevant government departments, including education, with the shared aim of improving lives for children and adults with an ABI nationally. The N-ABLES team has provided input to the Call for Evidence and will continue to input to the strategy and agreed work plan.

N-ABLES are continuing to promote their work and resources at conferences, completing more online teaching and improving their social media reach. Members of the group are undertaking a literature review on returning to school after ABI to understand gaps in the literature and current guidance with the aim of developing a future research strategy. There are also plans in the pipeline to build the range of resources, and to explore best practice



for providing ongoing educational support, concussion management and transition planning for children after ABI. You can download the current resources for free on their website at www.UKABIF.org.uk/ NABLES.

Find out more

Visit our <u>website</u>.
Contact us on <u>twitter</u>.
Email: NABLES@UKABIF.org.uk

To provide feedback on our work to enable us to design new resources, click here.

References

All Party Parliamentary Group on Acquired Brain Injury (2018). Time for change.





Researcher Spotlight

Dr. Vicki Anderson

Director of Psychology Services at The Royal Children's Hospital, Melbourne

Director, Clinical Sciences Research, Murdoch Children's Research Institute (and Group Leader, Brain and Mind Research Professorial Fellow at the University of Melbourne (Psychology & Paediatrics).

Current role and location

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anderson

Key research interests

My clinical and research interests primarily focus on improving outcomes from early childhood brain disorders. At The Royal Children's Hospital, I lead a team of talented clinical psychologists and neuropsychologists who work across acute care, chronic illness and rehabilitation. Insights and questions from my clinical work with children and families has guided the direction of my research



Dr. Vicki Anderson

programs. My research team, Brain and Mind, has contributed to establishing the unique vulnerability of the young brain to injury and working to better understand factors contributing to resilience and vulnerability in young children. While our early target was cognitive consequences of injury, feedback from our patients and their families has highlighted the critical importance of social and emotional function for well-being and quality of life after early brain insult and the importance of the family in maximising these outcomes. Taking up this challenge, members of my team have successfully designed and trialled parent-focused e-health interventions to support families, which are now implemented in routine practice.

A second research passion is in the development of assessment tools and interventions that can accurately evaluate the impact of early brain injury and guide treatments. Working closely with international and local collaborators, we designed and published the Test of Everyday Attention for Children, now used by psychologists across the world. To fill a gap in community knowledge of concussion and its recovery, we have developed HeadCheck, a free, interactive digital health tool for guiding parents and young people back to normal activities following a concussion. Our current project is development and standardisation of 'PEERS' a novel, comprehensive iPad delivered assessment tool tailored to detect the social cognitive difficulties associated with early brain injury.

Summary of recent research

A. IMPACT OF EARLY BRAIN INJURY: DO CHILDREN REALLY RECOVER BETTER?

Over several decades we have conducted multiple prospective, longitudinal studies of children (0-16) with acquired brain injury, (TBI, stroke, CHD, cancers, cerebral infections). My cocollaborator, Prof. Cathy Catroppa and I and our team of senior researchers, clinicians, post-docs, and students have followed children from time of injury to 20+ years post-insult using a biopsychosocial model and explored brain (injury, MRI, genomics, proteomics) and environmental (SES, family) influences on outcomes. Our current project will integrate our databases from these studies and others nationally and internationally, providing a very large, comprehensively assessed sample to provide definitive knowledge regarding recovery pathways and factors influencing risk and resilience.

B. SOCIO-EMOTIONAL OUTCOMES FOLLOWING EARLY BRAIN INSULT

Feedback from our patients and their families has highlighted the critical importance of social and emotional function for well-being and quality of life after early brain insult and the importance of the family in maximising these outcomes. However, there is a dearth of child-friendly, ecologically valid measurement tools to assess the nature and degree of these difficulties after early childhood brain insult. Again, using a bio-psycho-social model we have explored the 'socio-emotional profile' of childhood

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ABI, and this has led to the development of an ABI-focussed assessment tool.

C. CHILD CONCUSSION

Our current concussion program, 'Take CARe' aims to improve community knowledge of concussion and its outcomes and to build knowledge to improve care for children following concussion. Our model emphasises that post-concussive symptoms (PCS) can be due to a variety of factors and, in order to treat these effectively, we need to take a multi-modal, individualised approach to intervention. Our multidisciplinary team focuses on: i) prevention: providing early and accessible evidence-based community guidance, via a digital health tool; ii) early intervention: design, pilot and trial of a multimodal intervention (Concussion Essentials); and iii) treating chronic persisting post-concussive symptoms.

D. TRANSLATION INTO PRACTICE

- Publication of the Test of Everyday Attention for Children, used by psychologists across the world;
- HeadCheck a digital health tool for monitoring child post-concussion symptoms based on findings from the international paediatric sports concussion guidelines of the International Consensus on Sports Concussion.
- iii) Paediatric Evaluation of Emotions, Relationships and Socialisation (PEERS & PEERS-Q) iPad delivered assessment tool for social cognition + parent/teacher-rated questionnaire tapping social cognition and social competence
- iv) Accessible, low burden, e-health approaches to child and parent-focused psychosocial treatments as a means of maximising child outcomes and improving family function – Take a Breath, Signposts for Building Better Parents, Cool Kids (adapted for adolescents with ABI)

Find out more

<u>Click here to access a reference list</u> sharing outcomes of this work, and access the following web links for more information:

- i) PEERS app
- ii) HeadCheck app
- iii) Concussion and Stroke research
- iv) Flagship programs
 - Neurodevelopment
 - High-risk-infants

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IPBIS Board Updates and Events

1. 2022 Joint Conference on Brain Injury

Still time to register for the International Paediatric Brain Injury Society & North American Brain Injury Society 2022 Joint Conference on Brain Injury in New York!



Join IPBIS in New York for the 2022 Joint Conference on Brain Injury organized by the <u>International Paediatric Brain Injury Society</u> and the <u>North American Brain Injury Society</u>! The conference will be held September 21-24, 2022, at the Wyndham New Yorker Hotel.

This multidisciplinary event will offer a broad and varied program spanning cutting-edge research to practical and applied techniques for improving outcomes for persons with brain injury. Abstracts accepted for the Joint Conference on Brain Injury will be published and indexed in the *Journal of Head Trauma Rehabilitation*. Rehabilitation physicians, psychiatrists, psychologists, neurosurgeons, speech pathologists, occupational therapists, physical therapists, social workers, educators, nurses, case managers, advocates, legal professionals and all others committed to improving the outcome of adults and children with traumatic and non-traumatic brain injury are encouraged to participate.

Faculty and Program

The leadership of IPBIS and NABIS have assembled an outstanding group of speakers and panelists who will participate in this unique educational event.

- To see the current faculty list, <u>click here.</u>
- To view the program, click here.
- For general conference information and to register, click here.

Sunset Gala: Liberty Cruise

All attendees at the 2022 IPBIS/NABIS Joint Conference on Brain Injury are invited to attend the special evening Gala Event on September 22 during the conference. Join your conference colleagues for dinner, drinks, and entertainment with a water tour of some of New York City's iconic sights. The breathtaking views of Manhattan and Lady Liberty will not soon be forgotten. The Sunset Gala Liberty Cruise is organised independently on our behalf by a 3rd party organisation and supported by the International Institute for the Brain (iBrain). We are very grateful for this support. The price of a gala ticket is \$150 USD. Gala tickets can be purchased through the Joint Conference registration and can be added at any time until tickets are sold out. Sponsorship opportunities for this special event are also available (click here).

2. 2023 World Congress on Brain Injury IPBIS to Participate in the World Congress on Brain Injury



The 14th World Congress on Brain Injury will be held March 29-April 1, 2023, at the Convention Centre Dublin, in Dublin, Ireland. Representatives of the IPBIS leadership are developing educational sessions for paediatric brain injury professionals that will take place throughout the Congress. These include a preconference symposium led by Dr. Leigh Schrieff (South Africa), a symposium led by Dr. Peter Tucker (United Kingdom), and keynote lecture by Dr. Irwin Gill (Republic of Ireland).



Organized by the International Brain Injury Association (IBIA), the World Congress on Brain Injury is the largest gathering of international professionals working in the field of brain injury. The 2023 World Congress is being held in partnership with Acquired Brain Injury Ireland.

Call for Paediatric Brain Injury Abstracts

The IBIA and IPBIS welcomes the submission of <u>original research</u> <u>and clinical findings</u> on a broad range of brain injury topics and subspecialties. Submissions will be peer-reviewed and accepted abstracts will be presented as oral presentations or posters. All accepted abstracts will be published in a special edition of IBIA's official journal, <u>Brain Injury</u>.

For detailed information on submitting an abstract, click here.

Educational Program

The Congress leadership is inviting over 100 internationally recognized keynotes, panelists and speakers who will present the latest findings on the assessment, treatment, and future priorities in the field of brain injury research and rehabilitation. In addition, multidisciplinary brain injury professionals have the opportunity to have their research considered for presentation through the peerreviewed abstract process.

Who Should Attend?

The World Congress on Brain Injury will bring together a focused multidisciplinary group of brain injury professionals who are committed to improving the outcome of children and adults with traumatic and non-traumatic brain injury through the translation of research into clinical practice.

Delegates are comprised of rehabilitation physicians, psychiatrists, psychologists, neurosurgeons, speech pathologists, occupational therapists, physiotherapists, social workers, nurses, case managers, advocates, legal professionals and all those dedicated to advancing research and treatment for patients with brain injury.

Unparalleled Networking Opportunities

The World Congress on Brain Injury provides a unique opportunity for establishing collegial relationships with other international professionals focused on the care of persons with brain injury and/ or the science of brain injury research.

Against the backdrop of the vibrant city of Dublin, the <u>World Congress</u> will provide an unparalleled platform to share scientific results, explore new treatment paradigms, develop new friendships, and form new collaborations.

We hope you enjoyed this newsletter!

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Newsletter!

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If you are interested in becoming a member of IPBIS please click here.

Until our next edition -Thank you for all you do in the field of paediatric brain injury!

