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Official Newsletter

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Message from the Chair



Beth Wicks

Welcome to the second issue of the International Paediatric Brain Injury Society (IPBIS) Newsletter. Our first issue (June 2021) was a great success

and we are excited to bring you more. I am really pleased to share this newsletter with you and bring to you the latest news from the IPBIS.

I wanted to highlight a few items. First, our IPBIS Webinar Series was very well received! Thank you to our speakers and to all those who attended our 8 IPBIS Webinars. You can access recordings of these fantastic sessions and obtain CME credits by [clicking here](#). Enjoy! Stay tuned for more virtual presentations and sessions coming soon.

Next, do come and join us in New York City (USA) from September 21 to 24, 2022 at the Joint Conference on Brain Injury! We can't wait to gather together once again to celebrate exciting and important paediatric brain injury work being conducted around the world. See the 'IPBIS Board Updates and Events' section below for more and see you in NYC!

We hope you enjoy this newsletter. Please share with your colleagues and [click here to subscribe](#).

Find out more about IPBIS by visiting our [website](#) 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

IPBIS Board Updates and Events

1. 2022 Joint Conference on Brain Injury

Organized by the [International Paediatric Brain Injury Society](#) and the [North American Brain Injury Society](#), the 2022 Joint Conference on Brain Injury will take from September 21 to September 24, 2022 in New York City (USA). 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. The conference will feature internationally-renowned plenary speakers, platform lectures, workshops and panels. Find out more about the conference by [clicking here](#)! In addition, brain injury professionals from around the world will have the opportunity to share their research and clinical findings through the peer-reviewed abstract submission process – [submit your abstract today](#) (Abstract submission deadline is April 11, 2022). See you in New York City!

2. 2021 Virtual World Congress on Brain Injury

The 2021 Virtual World Congress on Brain Injury took place in July 28-30, 2021! Brain injury professionals from around the world gathered virtually to share, learn and connect. IPBIS specific content included pre-conference symposia, a paediatric track throughout the conference and a keynote presentation. We thank all presenters and attendees for making this event a great success. Content from the event, including recorded symposia, presentations and posters remain available online. Find out more and register by [clicking here](#).

3. IPBIS Ambassador Role – Open for applications!

Ambassadors of the International Paediatric Brain Injury Society play a crucial role in supporting and promoting the work of the IPBIS through engaging local networks, supporting learning and developing connections between those with an interest in ABI. Find out more and apply by [clicking here](#).

4. IPBIS Toolbox

The IPBIS Toolbox is now available in an interactive format – this makes it much easier to search and download the tool or programme that you want. The toolbox, produced together with The [Eden Dora Trust for Children with Encephalitis](#), contains summaries of a wide range of tools and programmes free to use for professionals in the field of paediatric brain injury. Find out more by [clicking here](#).

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International Developments

International (United Kingdom-South Africa) research collaboration

The prevalence of neurodisabilities among young offenders and non-offenders and associated cognitive, behavioural and emotional outcomes in a South African context.



A/Prof Leigh Schrieff, Nina Steenkamp, Prof. Huw Williams

Who We Are

Professor [Huw Williams](#) (Exeter University, United Kingdom) and Associate Professor [Leigh Schrieff](#) (University of Cape Town, South Africa (SA)) have been developing a collaborative research program investigating the prevalence of neurodisabilities (mainly traumatic brain injuries and learning disabilities at this stage) and associated neuropsychological outcomes among young offenders in Cape Town, South Africa, based on Professor Williams' extensive work in this research area in the United Kingdom.

Our long term research goals

1. To advocate for greater awareness of and screening for neurodisabilities in the criminal justice system in South Africa;
2. To develop and conduct research evaluations of interventions for those with neurodisabilities who end up in the criminal justice system to curb recidivism

Reasons for Development

- South Africa has one of the highest crime rates in the world
- Broadly speaking, a young offender is a person younger than 18 years who has been accused of committing a crime³
- Approximately 3,432 young offenders sentenced every year in South Africa
- Increasing evidence from epidemiological and

neuropsychological studies suggests there is a strong association between criminal offending behaviour and traumatic brain injury (TBI)^{1,2}

- Many incarcerated adolescents having sustained one or more TBIs throughout their lifetime³
- Furthermore, sustaining a TBI also appears to be associated with earlier onset of criminal behaviour.
- Although extensive work on this topic exploring neurodisabilities in the criminal justice system has been done in high income countries (e.g. UK)³ there is a dearth of work in this area in South Africa, which is surprising, given the high rates of both neurodisabilities and crime in the country.

What Has Been Done

Thus far, two postgraduate theses at Honours (4th year) and Masters levels have been completed. These initial research studies explored:

1. The prevalence of traumatic brain injury and an investigation of behavioural, emotional and executive functioning in a sample of male young offenders
2. Learning disabilities and access to education in custody, amongst young offenders and non-offenders in Cape Town, South Africa

Results

- Prevalence of TBI was higher in offenders (n = 18/25; 72%) than in non-offenders (n= 24/56; 43%). Young offenders reported experiencing more severe TBI, where the distribution of TBI with loss of consciousness was significantly different across offender and non-offender groups ($p < .001$).
- Analyses detected significant main effects of offender status on all outcomes; demonstrating poorer emotion regulation, increased aggression, and increased antisocial behaviour amongst young offenders.
- Results also showed significant differences in alcohol use, substance use, and reported possible learning disabilities, with higher scores and rates for these factors, indicating poorer outcomes, in the young offenders compared to non-offenders.

Next steps

Winnie Nkoana and Nina Steenkamp who completed the honours and Masters projects outlined above are continuing their Masters

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Winnie Nkoana

and PhD studies, respectively. In these ongoing studies on TBI and associated outcomes among young offenders and non-offenders in South Africa, we hope to investigate the degree of knowledge of and screening for neurodisabilities in youth centres for young offenders in South Africa. Further, we hope to include a neuroimaging component, and an intervention for executive dysfunction, in our research.

Find out more on this research

- View this session from the 2021 IBIA World Congress: [PEDIATRIC: What We Can Do to Stop Children and Young People with Neuro-Disabilities Ending Up in Prisons](#)
- View on You Tube: [World Congress on Justice with Children \(Southern Africa – workshop\)](#)
- Nkoana, W., Williams, W. H., Steenkamp, N., Clasby, B., Knowler, H., & Schrieff, L. (2020). [Understanding the educational needs of young offenders: A prevalence study of](#)

[traumatic brain injury and learning disabilities](#). International Journal of Educational Development, 78, Article 102261.

Contact information:

A/Prof Leigh Schrieff: leigh.schrieff@gmail.com

References

1. Clasby, B., Bennett, M., Hughes, N., Hodges, E., Meadham, H., Hinder, D., Williams, W. H., & Mewse, A. (2019). The consequences of traumatic brain injury from the classroom to the courtroom: Understanding pathways through structural equation modelling. *Disability and Rehabilitation*, 42(17), 2412–2421.
2. Kennedy, E., Heron, J., & Munafò, M. (2017). [Substance use, criminal behaviour and psychiatric symptoms following childhood traumatic brain injury: Findings from the ALSPAC cohort](#). *European Child & Adolescent Psychiatry*, 26(10), 1197–1206.
3. Williams, W. H., Chitsabesan, P., Fazel, S., McMillan, T., Hughes, N., Parsonage, M., & Tonks, J. (2018). Traumatic brain injury: A potential cause of violent crime? *The Lancet Psychiatry*, 5(10), 836–844. [https://doi.org/10.1016/s2215-0366\(18\)30062-2](https://doi.org/10.1016/s2215-0366(18)30062-2)

The International
Paediatric Brain Injury
Society and the
North American Brain Injury Society

Joint Conference on Brain Injury New York

New Yorker Hotel
September 21-24

2022

Abstract portal now open!

**Submissions due:
April 11, 2022**





Researcher Spotlight

Caron Gan

Registered Psychotherapist, Family Therapist

Current role and location

Registered Psychotherapist, Family Therapist – Private Practice
Adjunct Scientist – Bloorview Research Institute (BRI), Holland
Bloorview Kids Rehabilitation Hospital

Key research interests

Through the Bloorview Research Institute (BRI), my research has focused primarily on family interventions, family needs, and caregiver supports after pediatric brain injury. I am the co-developer of the Family Needs Questionnaire – Pediatric Version (FNQ-P) with Dr. Virginia Wright (BRI) and also the lead developer of the Brain Injury Family Intervention for Adolescents (BIFI-A). This is an empirically-based family system intervention for adolescents with acquired brain injury and their families. I have been actively involved in knowledge translation activities around strengths-based family system interventions after brain injury.



Dr. Caron Gan

Summary of recent research

1. Family Needs Questionnaire - Pediatric Version (FNQ-P)

The FNQ-P, a 40-item self-report measure, provides clinicians with a tool for systematic assessment of family needs after a child sustains an acquired brain injury (ABI). These needs may present during inpatient rehabilitation, outpatients, in the community, or anytime over the course of the child's development. Clinicians can use the FNQ-P to assess the degree to which the family's needs have been met at any point in time across six categories of need: Health Information, Emotional Support, Instrumental Support, Community Support, Professional Support, and Involvement with Care. This tool has been validated with international partners from UK, Sweden, Lithuania, and Australia. English and translated versions of FNQ-P in Swedish, Norwegian, and Spanish are available for free download from the FNQ-P website.

Published works

- Gan, C., Van't Hooft, I., Brookes, N., Prasauskiene, A., Wales, L., & Wright, V. (2020). [First stage international validation of the Pediatric Family Needs Questionnaire \(FNQ-P\)](#). *Brain Injury*, 34(8):1074-1083.
- Gan, C. & Wright, V. (2019). [Development of the family needs questionnaire – paediatric version \[FNQ-P\] – Phase I](#). *Brain Injury*, 33(5):623-632.

2. Brain Injury Family Intervention for Adolescents (BIFI-A)

BIFI-A is an empirically-based family system intervention designed for adolescents (13 to 19 years) with ABI and their family members. BIFI-A incorporates a broad curriculum, comprised of multiple components: education, emotional support and skill building. The BIFI-A intervention manual incorporates a detailed step-by-step protocol, treatment implementation procedures and guidelines for effective clinical implementation. The 250 page manual comes with activities, ready-to-use handouts, and resources for clinicians to use and replicate.

To address the limited resources around family intervention after pediatric ABI, we focused our efforts on knowledge translation activities to enhance capacity in the system. A two-day training program was developed for clinicians and rehabilitation professionals. This has now been completed by more than 430 rehabilitation professionals from Canada, US, Norway, and Sweden, and a Chinese version is also in development.

Published works

- Gan, C., Gargaro, J., Kreutzer, J., Boschen, K., & Wright, V. (2010). [Development and preliminary evaluation of a structured family system intervention for adolescents with brain injury and their families](#). *Brain Injury*, 24(4):651-663.
- Gan, C. & Ballantyne, M. (2016). [Brain injury family intervention for adolescents: A solution-focused approach](#). *NeuroRehabilitation*, 38:231-241.

3. Strengths-based family system assessment and intervention after pediatric brain injury.

As a clinical researcher and family therapist, I am a strong proponent of strengths-based approaches to care, specifically the Solution-Focused approach. This is a competency-based model that focuses on people's strengths, resources, and successes versus deficits and what needs to be fixed. Using this approach I have developed full-day training programs on Solution-Focused Brief Therapy (SFBT) and its application to individuals with ABI and their families. The Solution-Focused approach has also been incorporated into the empirically based Brain Injury Family Intervention for Adolescents (BIFI-A) and the resilience-based family systems framework, recently published with Dr. Roberta DePompei.

Published works

- Gan, C. & DePompei (2021). Family Assessment and Intervention. In N. Zasler, D. Katz, & R. Zafonte (Eds.) *Brain Injury Medicine*, 3rd edition, New York: Demos Medical Publishing (pp. 542-556). DOI: 10.1891/9780826143051.0037

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- Gan, C. (2020). [Solution Focused Brief Therapy \(SFBT\) with individuals with brain injury and their families. Invited submission](#) – Special thematic issue on Neuropsychological and Psychological Applications in *NeuroRehabilitation*, 46(2):143-155.
- Gan, C. & Ballantyne, M. (2016). [Brain injury family intervention for adolescents: A solution-focused approach](#). *NeuroRehabilitation*, 38:231-241.

The bigger picture

My work around family needs and family interventions after pediatric ABI underscores the central role that families play after a child sustains an ABI. As children with ABI often grow into their disabilities, it is important for families to learn tools to optimize coping and resilience over the life course. Moreover, given that every family is unique, it is important for clinicians to learn core theoretical and practical skills around family system assessment and intervention as a foundation to successful implementation of empirically based interventions. My clinician/researcher role has been instrumental to informing my clinical research priorities and to facilitating knowledge translation of research into the day-to-day realities of clinical practice. In collaboration with the [Ontario Brain Injury Association](#), a family engagement model was also employed to co-design [Caregiving After Pediatric Brain Injury](#) web-based supports using materials from the BIFI-A.

Watch this space!

I have recently retired from my clinical role at Holland Bloorview Kids Rehabilitation Hospital and I am gradually winding down my research activities through the Bloorview Research Institute. However, as a group, we plan to continue disseminating our research findings and resources as widely as possible to support the families we have been very privileged to work with, and learn a lot from. Continued access to FNQ-P and BIFI-A (including training requests) will be available through the Holland Bloorview website. Web-based resources for caregivers are also available on the Ontario Brain Injury Association website. Tools can also be found in the IPBIS Toolbox.

Find out more on this topic

IPBIS Webinars: Internet Webinar Recordings - International Brain Injury Association [Authentic Partnerships: A Model for Building on Lived Experiences to Co-Design Caregiver Supports After Pediatric ABI](#) - Caron Gan & Brenda Agnew. In this webinar, co-presented by a family caregiver and clinician/researcher, we will trace the evolution of family involvement in pediatric rehabilitation care from: 1) doing FOR families, to 2) doing WITH families, and 3) learning FROM families.

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HOT TOPIC: Paediatric Disorders of Consciousness

Update on International Brain Injury Association's Disorders of Consciousness Special Interest Group in paediatrics

Dr. Beth Slomine (Kennedy Krieger Institute, Johns Hopkins University School of Medicine, USA),
Dr. Erika Molteni (King's College London, United Kingdom)



Dr. Erika Molteni

The International Brain Injury Association's (IBIA) 'Disorders of Consciousness Special Interest Group (DoC SIG) on diagnosis and prognosis' is completing a broad scoping review on the paediatric Disorders of Consciousness. A group of experts, coordinated by Beth Slomine (USA) and Erika Molteni (UK), have joined from ten countries to gather all the existing evidence on the topic: Marie-Michèle Briand (Canada), Liane Canas Dos Santos (UK), Anna Estraneo (Italy), Carolina Colomer (Spain), Rita Formisano (Italy), Katerina Fufaeva (Russia), Olivia Gosseries (Belgium), Robyn Howarth (USA), Paola Lanteri (Italy), Gimena Ines Licandro (Argentina), Wendy Magee (USA), Vigneswaran Veeramuthu (Malaysia), Pamela Wilson (USA) and Tomohiro Yamaki (Japan).



Dr. Beth Slomine

Over a two-year period, the experts have examined the existing peer-reviewed published literature in different languages, including data from children and adolescents manifesting a Disorder of Consciousness (DoC) for at least two weeks. They have focused on three main themes: diagnosis, prognosis and treatment, and the related assessment techniques: neurobehavioral, neuroimaging, and neurophysiological. Preliminary results were illustrated during a webinar organised by IPBIS, which can be [viewed here](#).

The search overall indicated that diagnosis and assessment of children with DoC is performed through the repeated employment of behavioural measures, and particularly through the evaluation of the auditory and visuo-motor abilities. The Coma Recovery Scale-Revised, a gold standard for the assessment of DoC in adults, was found to be increasingly applied in paediatrics, although still lacking robust validation for children. It was also highlighted that neurobehavioral assessment is often combined with magnetic resonance imaging of the brain and electrophysiological measures such as electroencephalography, event related potentials, and polysomnography.

A generalised lack of evidence was found about treatments for paediatric DoC, with reports mainly describing case studies, observational results from small cohorts, and pilot clinical trials. Amantadine, the unique pharmaceutical indicated for improving DoC after previous recommendation in broad guidelines for patients with DoC, is still lacking robust data in paediatrics, and the use of other drugs has low evidence in children.

The scoping review will soon be summarised in a manuscript, to the benefit of the community of DoC practitioners and researchers.

Find out more on this topic

[Coma recovery scale-revised](#) (training modules and manual)

[DOC Guidelines](#)

[Giacino, 2018](#)

[Giacino, 2020](#)

[Kondziella, 2020](#)

[UK, Royal College of Physicians, 2020](#)

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Until our next edition -

Thank you for all you do in the field of paediatric brain injury!