



March 2023

Message from the Chair



IPBIS Chair

Welcome to the fourth issue of the International Paediatric Brain Injury Society (IPBIS) Newsletter. Thank you for your interest in IPBIS and all things paediatric brain injury. We have some exciting content to share with you across three themes – Hot Topic, International Developments, and our Researcher Spotlight. We hope you enjoy this newsletter – please share with your colleagues and click here to

subscribe.

This Newsletter is published in alignment with the 14th World Congress on Brain Injury that will be held March 29-April 1, 2023, at the Convention Centre Dublin, in Dublin, Ireland. Representatives of the IPBIS leadership have developed educational sessions for paediatric brain injury professionals that will take place throughout the Congress. Organized by the International Brain Injury Association (IBIA), the <u>World Congress on Brain Injury</u> is the largest gathering of international professionals working in the field of brain injury. The 2023 World Congress is being held in partnership with <u>Acquired Brain Injury Ireland</u>. Find out more by visiting the official Congress website by <u>clicking here</u>.

A reminder that our two future International conferences will be held in Glasgow, UK, in 2024 and Calgary, Canada, in 2026. Find out more <u>here</u> and stay tuned for additional information as we get closer to the events.

See the 'IPBIS Board Updates and Events' section below to find out more about IPBIS including our <u>Ambassador Role</u> and our active Subcommittees. These are opportunities for you to get involved in IPBIS and to contribute to our international platform to help improve the lives of children, adolescents and young adults with ABI, and to promote prevention of brain injuries on a worldwide scale.

Find out more about IPBIS by visiting <u>our website</u> and by following us on Twitter @IPBIS. Become a <u>member</u> 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: Sport Injury Prevention Research Centre



Dr. Carolyn Emery (Sport Injury Prevention Research Centre, University of Calgary, Canada)

Why sport injury research matters?

Sports are a natural and beneficial part of childhood and adolescence. For many of us, sports and play help create some of the most lasting memories of childhood; the friends we've made, successes, near successes, and a multitude of experiences that build personal character. However, every day, youth are at risk of injury through sport; often without awareness of risk or the simple things that could protect them from

injuries and their consequences.

Based on the recent <u>Raising Canada 2022</u> report, unintentional injuries are the number one threat to child and adolescent health in Canada. Injuries are the leading cause of disability in adolescents (ages 10-19) and more than 50% are sport-related. Further, concussions are common in youth and can have devastating impacts on individuals and families. It is estimated that adolescents have a 1 in 10 risk of sustaining a concussion each year. In some collision sports (e.g., ice hockey, rugby, football) concussions are the most common injury. Vulnerable youth living in rural and Indigenous communities and those with disabilities are no exception.

The Sport Injury Prevention Research Centre (SIPRC)

At the Sport Injury Prevention Research Centre (SIPRC), our research and passion for research impact in reducing the burden of sport-related injuries will promote healthy lifelong physical activity participation. SIPRC's home is in the Faculty of Kinesiology, University of Calgary (Canada). SIPRC is one of 11 International Research Centres for Prevention of Injury and Protection of Athlete Health supported by the International Olympic Committee. SIPRC has committed to achieving a 25% reduction in youth sport-related injuries in Alberta by 2025. We will achieve this by conducting world leading research on injury prevention in youth sport, with a focus on prevention of concussions and their consequences. SIPRC builds sustainable and collaborative partnerships with community stakeholders including sport associations, schools, government, coaches, teachers, referees, parents, and most importantly youth.

Led by Dr. Carolyn Emery, PT PhD, Chair of the Sport Injury Prevention Research Centre, the SIPRC research team prioritizes student and postdoctoral scholar training to support the next generation of researchers focused on sport-related injury and concussion burden, risk factors, prevention strategies, and consequences to reduce the public health burden for youth and support lifelong physical activity.

SHRed Concussions

One of SIPRC's primary research programs is "SHRed Concussions: Surveillance in High School and Community Sports to Reduce Concussions and their Consequences." SHRed Concussions is a pan-Canadian longitudinal cohort study aimed to evaluate concussion prevention, detection, diagnosis, prognosis, and management in youth (ages 11-18) sport.

SHRed Concussions' four research aims are:

- To establish a concussion surveillance program nationally in schools and the community to inform concussion burden, mechanisms, risk factors and predictors of recovery
- 2. To develop and validate multifaceted models for concussion detection, diagnosis, and recovery prediction
- 3. To evaluate the implementation, effectiveness, and sustainability of novel sport-specific and school-based strategies

4. To provide a platform for recruitment to treatment studies aimed to prevent long-term consequences of concussion

The work of SHRed Concussion research will have important public health implications in informing best practice and policy for youth concussion prevention, detection, diagnosis, management, and treatment to promote health through safe lifelong participation in sport.

Contact us

Members of SIPRC would love to hear from you. For questions and comments, please contact Carolyn Emery, Chair Sport Injury Prevention Research Centre at caemery@ ucalgary.ca or Mark Agius, Manager of SIPRC Communications and Partnerships at mark.agius1@ucalgary.ca.

Twitter @SIPRC_ and @SHRedConcussio1 and @SHRedMobile1 Instagram @SIPRC

Published SIPRC Papers

 Emery CA, Eliason P, Warriyar V, Palacios-Derflingher L, Black AM, Krolikowski M, Spencer N, Sick S, Kozak S, Schneider KJ, Babul S, Mrazik M, Lebrun C, Goulet C, Macpherson A, Hagel BE. <u>Body checking in non-elite</u> <u>adolescent ice hockey leagues: it is</u> <u>never too late for policy change aiming</u> <u>to protect the health of adolescents</u>. Br J Sport Med 2022;56:12-17.

- Eliason PH, Hagel BE, Palacios-Derflingher L, Warriyar VKV, Bonfield S, Black AM, Mrazik M, Lebrun C, Emery CA. <u>Body checking experience and rates of injury among 15 to 17-year</u> <u>old ice hockey players</u>. CMAJ June 2022;194(24):E8334-E842.
- Shill IJ, West SW, Sick S, Schneider K, Hagel BE, Pasanen K, Wiley JP, Emery CA, Black AM. <u>Injuries and Concussions in Female High School Rugby:</u> <u>Prevention is Worth a Try</u>. Clin J Sport Med November 2021.
- Black AM, Meeuwisse DW, Eliason PH, Hagel BE, Emery CA. <u>Sport participa-</u> tion and injury rates in high school: A <u>Canadian survey of 2029 high school</u> <u>students</u>. Journal of Safety Research 2021;78:314-321.
- Emery CA, Warriyar V, Black AM, Palacios-Derflingher L, Sick S, Debert C, Brooks BL, Yeates KO, Mrazik M, Lebrun C, Hagel BE, Dukelow S, Schneider KJ. <u>Factors Associated with Clinical</u> <u>Recovery After Concussion in Youth Ice</u> <u>Hockey Players</u>. Orthop J Sports Med 2021;9(5).





International Developments



Who We Are

Dr. Rajendra Prasad, FRCS, FRCS (SN) Senior Consultant Neurosurgeon, Apollo Hospital, New Delhi, has more than 40 years

Dr. Rajendra Prasad, FRCS, FRCS (SN)

experience in brain and spine surgery with work experience in Ireland, United Kingdom, Saudi Arabia and in India since 1996. His main fields of interest include spine surgery, prevention of injury, neurorehabilitation and assistive technology in Neuro-rehabilitation.

Dr Prasad is the Medical Director of the Indian Head Injury Foundation, Trustee of Kara Medical Foundation and Board Member of IPBIS.

Activities of the Indian Head Injury Foundation

- Reducing mortality and morbidity of road traffic accidents through advocacy with the Government, public awareness programs on road safety and helmet distribution programs.
- 2. Improving Pre-hospital care by conducting Primary Trauma Courses for doctors, Nurses, Paramedics and First Responders
- Improving hospital care of the trauma victim by conducting Neuro critical care courses for Anaesthetists, Intensive care staff and neurosurgeons.
- Improving access to neuro rehabilitation in India which is at present almost non-existent. This is through conducting workshops, training courses for therapists and running three state-of-the art neuro rehab centers in India.

Activities of Kara Medical Foundation

Promoting access to Assistive Technologies for Persons with Disabilities through " Skills lab for Mobility and Vision" located in Patna, India.

Long Term Goals

- To make Neurorehabilitation and Assistive Technologies accessible to more people with disabilities in larger parts of India, particularly to those below the poverty line
- To validate the findings of our pilot project on "Tele assessment of assistive technology devices for mobility" through a larger study, which will have a wider impact in other states in India and subsequently in other low and middle income countries (LMICs).

What Has Been Done

1. Set up three Neurorehabilitation centers in India that are situated at

Jodhpur, Delhi and Patna and training of its neuro rehab professionals.

- Set up an "A T Skills Lab for Mobility" in Patna where custom built wheelchairs are donated free to beneficiaries and given necessary peer training.
- Set up a "Vision Skills Lab for the Visually Impaired" at a school for blind girls from low-income families. Through orbit readers and writers, and special software, computer education makes these children follow the National Curriculum and be more inclusive.
- 4. "Children's Ride with Safety Program" in Delhi Government Schools, wherein road safety awareness is carried out and children's helmets are distributed. More than 40,000 children's helmets have been distributed free to children of low income families. The campaign has won the Indian Head Injury Foundation the Prince Michael Road safety Award in 2020 and the BMJ South Asia Award in 2017.

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Tele-rehab session



Wheelchair distribution



 Primary Trauma Care courses (PTC) and Disaster drill for doctors, nurses, paramedics and First Responders (80 courses have been conducted so far).

Impact

Through three neuro rehab centers setup by the Indian Head Injury Foundation, a lot of patients with brain and spine injury, stroke, congenital brain and spine disorders etc have had increased access to neurorehabilitation, particularly to those of the low socioeconomic group. More than 30,000 neurorehab sessions have been conducted per year. The introduction of tele rehabilitation during covid times has continued, hence allowing rehabilitation to people in rural and remote areas who would not otherwise have had access to such facilities. More than 1000 tele-rehab sessions have been carried out so far.

For the first time, through distribution of custom built wheelchairs, young people have had access to properly fitting sturdy wheelchairs enabling them to continue their education and employment. Paraathletes donated wheelchairs have won national para-games medals.

The recent successful intervention of teleassessment for wheelchairs has meant that people with disabilities living in rural areas have not had to make multiple trips for wheelchair assessment, delivery and subsequent training. 80 patients have had tele assessments for their wheelchairs. This pilot has been very successful in terms of beneficiary satisfaction.

Future Plans

To establish a comprehensive state-of-theart Neurorehabilitation and A.T Center in India.

Find out more

Website: Indian Head Injury Foundation Email: neurosurgeryindia@gmail.com

Join IPBIS for our next conference in Scotland!







Researcher Spotlight



Mélodie Vallée

Mélodie Vallée

• PhD student in the Department of Psychology at the University of Rouen Normandy, France, under the supervision of Dr. Anne Boissel (Associate Professor in the Department of Psychology at the University of Rouen Normandy), based in the Saint Maurice Hospitals, France.

Doctoral students' representative on

the Ethics Advisory Committee of the Centre de Recherches sur les Fonctionnements et Dysfonctionnements Psychologiques (CRFDP) laboratory in Rouen, France

• Lecturer in the Department of Psychology at the University of Rouen Normandy, France.

Clinical focus

The impact of childhood acquired brain injury (ABI) on siblings

Contact details

Email: melodie.vallee@univ-rouen.fr Website : <u>crfdp.univ-rouen.fr/melodie-vallee/</u> Twitter: @MelodieVallee1

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Key research interests

My current research focuses on the impact of a brain lesion sustained around birth (e.g., cerebral palsy) or later in childhood or adolescence (e.g., posterior fossa tumor, traumatic brain injury) on siblings. For this purpose, I use both qualitative (semi-structured interviews and thematic analysis using NVivo software) and quantitative (McMaster Family Assessment Device, Questionnaire sur les Relations avec la Fratrie, Symptoms Checklist-90-R) methods.

We aim to evaluate the impact of the occurrence of a brain lesion sustained during childhood or adolescence on siblings' experience in the short term and the long term, to discuss them in the context of international research on the topic, and to propose adapted support systems to siblings in each of the considered conditions.

This study is directed by Dr. Anne Boissel (Associate Professor in the Department of Psychology at the University of Rouen Normandy). It is linked to a larger research project on posterior fossa tumors led by Dr. Mathilde Chevignard (Medical Doctor specializing in Physical Medicine and Rehabilitation) at the Saint-Maurice Hospital, in collaboration with Pr. Mickael Dinomais at the Angers University Hospital, as part of the CERVIRM project. The CERVIRM project aims at assessing a number of language, cognitive, social cognition, and motor outcomes following childhood posterior fossa tumors, and factors associated with those outcomes. As such, the research is supported by the Saint-Maurice Hospitals and by the French Ministry of Higher Education, Research, and Innovation in the framework of a convention industrielle de formation par la recherche (CIFRE) doctoral contract.

Summary of recent research

There is little data in the literature on the specific impact of brain injury in children and adolescents on their siblings. Moreover, these data come only from English-speaking countries, in research with varied methodologies and sometimes insufficient samples. Finally, the participants in these studies are not always the siblings themselves, but sometimes their parents or other relatives.

We performed a scoping review on the topic of the impact of an ABI sustained during childhood or adolescence on siblings. The main results were presented at the IPBIS conference in New York in September 2022 and a manuscript is currently under review. (Vallée, M., Chevignard, M., & Boissel, A. In Press. The impact of childhood acquired brain injury on siblings: a scoping review, *Brain Injury*).

The main results of this review confirmed the lack of research on this topic and highlighted the negative impact of ABI on family functioning and relationships. The trajectory and quality of life of siblings of children with ABI are modified. ABI can lead to intense and mixed emotions, psychological distress, behavioural difficulties and social stigma. Siblings have varied ways of coping with ABI and express particular needs that should be assessed and addressed.

Given that few studies identified in this literature review directly gathered siblings' views, we chose to use a mixed (qualitative and quantitative) methodology including semi-structured interviews, analyzed with the thematic analysis method using NVivo software, as well as three questionnaires dealing with family functioning (FAD), sibling relationship (QRF 3) and psychological and psychopathological profile (SCL-90-R).

Given the specificities of ABI, we chose to include three groups: cancer (posterior fossa tumors) versus non cancer (traumatic) ABI, characterized by their sudden occurrence, and perinatal brain injury (cerebral palsy). This will allow better characterizing specificities of the impact of such injuries on siblings, according to different factors (e.g., some siblings witness the accident, or can be involved in the same accident; malignant brain tumors convey long-standing stress related to the possibility of relapse, while perinatal brain lesions have a different trajectory over time).

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In the Saint Maurice Hospitals, in collaboration with Anne Boissel, we also are currently conducting a "participative research" project (led by hospital, academic teams, with brain injury family associations, funded by the FIRAH, CCAH and Klésia), aimed at collecting data on the views of persons who sustained a childhood ABI and their parents and siblings, the impact of this ABI on their life, and the major themes they consider important for healthcare professionals (and for the larger public, including education professionals) to consider. They are also asked to mention obstacles they faced, as well as facilitating factors. The final aim of this collaborative project will be to provide documents, videos, motion designs, enabling better knowledge and awareness for the people affected by those conditions, as well as the general public, about the consequences of a childhood ABI on the life trajectory.

The bigger picture

The impact of brain injuries in children and adolescents on their relatives, in particular on their parents, is well known in literature. However, studies on the impact of these injuries on siblings remains limited to this day. Yet, the sibling relationship is one of the most significant relationships in terms of duration, attachment, and development in a person's life. Further, siblings, as part of the family context of a child with a brain injury, participate in the overall family functioning, that is a key component in childhood ABI rehabilitation and outcomes. Better understanding their needs will allow for better provision of help and adequate support when needed.

In fact, a number of interventions now focus on family problem solving, targeting the family unit. This leads us to think about setting up support systems inspired by systemic therapies, for example, or adapting the Teen Online Problem Solving (TOPS) program developed by Shari Wade and her team for the French public, with an extension of the section devoted to brothers and sisters.

Watch this space!

You can find out more about our work in our soon to be published article:

Vallée, M., Chevignard, M. & Boissel A. (in press). <u>The impact of childhood acquired brain injury on siblings: a scoping review</u>. *Brain Injury*.

Also keep an eye out for these other projects from our research groups:

- "Accompaniment of the young person, his siblings and his family after a brain injury acquired during childhood and consequences in adulthood"
- Project of French adaptation of the online problem solving program for teenagers : Teen Online Problem Solving -France (Fr-TOPS)
- XVIIIth SIICLHA Conference "A place of my own" (2023)

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IPBIS Board Updates and Events

1. IPBIS to Participate in the World Congress on Brain Injury

The <u>14th World Congress on Brain Injury</u> 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 pre-conference symposium led by Dr. Leigh Schrieff (South Africa), a symposium led by Dr. Peter Tucker (United Kingdom), and keynote lecture by Dr. Irwin Gill (Ireland).

Organized by the <u>International Brain Injury Association</u> (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 <u>Acquired Brain Injury Ireland</u>.

Visit the Congress website by clicking clicking here to access the full program and speaker information. Follow along on Twitter (@I_B_I_A or @IPBIS) and on <u>Facebook</u> to make sure you don't miss out on any of the action.

2. 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 <u>clicking here</u>.

3. 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. IPBIS is now seeking more entries for an updated version which will be online in 2024. The submission deadline is 30 November, 2023. Find out more by clicking here

4. IPBIS Subcommittees

IPBIS has a range of subcommittees made up of paediatric brain injury professionals from around the world. These subcommittees meet regularly to identify priority projects and take action. Currently, there are 7 IPBIS Subcommittees including: Communications, Toolbox, Research, Nominations, Early Career/Mentoring, Lower and Middle Income Countries, and Fundraising. For more information or to get involved, please contact IPBIS by <u>clicking here.</u>

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If you have any ideas for future stories or feedback for our newsletter, please let us know by emailing newsletter@IPBIS.org.

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If you are interested in becoming a member of IPBIS please <u>click here</u>.

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

