



**ipbis**

international paediatric  
brain injury society

*Official Newsletter*

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## Message from the Chair

Welcome to the inaugural issue of the new International Paediatric Brain Injury Society (IPBIS) Newsletter.



Beth Wicks  
IPBIS Chair

This newsletter will be distributed to brain injury researchers, clinicians and professionals from around the world. We will use three issues each year to bring you the latest

news from the IPBIS and keep you up to date on international initiatives related to paediatric brain injury research, education and clinical care.

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

Further, to make the newsletter the best it can be, we want to hear from you! Please share any feedback or ideas for newsletter stories by [emailing us](#).

Find out more about IPBIS by visiting [our website](#) and by following us on Twitter @IPBIS and Facebook.

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. 2021 Virtual World Congress on Brain Injury

Join us at the 2021 Virtual World Congress on Brain Injury (July 28-30, 2021)! This multidisciplinary event will offer a broad and varied program spanning cutting-edge research to practical and applied techniques for improving outcome for persons with brain injury. The conference is a joint initiative of the International Brain Injury Association, ABI Ireland, the International Paediatric Brain Injury Society, the North American Brain Injury Society, PINK Concussions, and the IBIA Special Interest Groups. IPBIS specific content includes pre-conference symposia, a paediatric track throughout the conference and a keynote presentation. Find out more and register by [clicking here](#).

### 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 [clicking here](#).

### 3. IPBIS Webinar Series

Learn about paediatric brain injury research and initiatives from around the world by attending our virtual webinar series. Our next broadcast will focus on 'Using apps to develop Executive Function Skills' (Sept 9, 2021). Find out more and register 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](#).

### 5. Welcome new IPBIS Board Members and Ambassadors

IPBIS would like to send a very warm welcome to our newest Board Members and Ambassadors. Thank you for your contributions to paediatric brain injury! Dr. Miriam Beauchamp (Canada – Board Member), Dr. Rajendra Prasad (India – Board Member), Dr. Rebecca Slykerman (New Zealand – Ambassador), Dr. Enrico Castelli (Italy – Ambassador).

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# National Guidelines for Rehabilitation after Paediatric ABI, The Netherlands



## Who We Are

In the Netherlands, the HEJ (Hersenletsel En Jeugd – Braindamage And Youth), a nationwide network of professionals and researchers, has been advancing health-care services for youth with brain injury.

To our knowledge, the Netherlands is the first country with national guidelines for rehabilitation after paediatric ABI. This work was presented by Dr Peter de Koning, Heliomare, during the 2017 IPBIS conference in Rome.

## The National Guidelines

The national guidelines recommend the following three steps:

- The type of rehabilitation to be provided after paediatric ABI is documented in the national standard of care.
- The implementation of rehabilitation in terms of practice and units are determined in local care programs.
- Decisions about the location of rehabilitation services and members of the multidisciplinary team are made in a care plan with each patient and the parents.

These advancements are important, increasing the accessibility of qualitative early and long-term rehabilitation services for children and youth with ABI.

## Reasons for Development

The need for improved:

1. Recognition and monitoring
2. Assessment
3. Transfer of care
4. Coordination of care
5. Information and communication
6. Informal care and (self) management

## What Has Been Done

The HEJ group has done several projects which resulted in:

## National guidelines

- Mild TBI, acute phase
- Neuropsychological assessment
- Follow-up after acute phase
- Toolkit for long-term care and family support
- Procedures in education for pupils with ABI
- PCS assessment and treatment (in progress)

## Standard of care

- Minimal requirements for good care, from patient perspective (revision starts after the pandemic)

## Research and development

- National joint research projects resulted in several PhD theses

## Knowledge transfer

- Annual symposium for patients, parents and professionals
- Psychoeducation app for children/youth



## How It Was Done

Contributing factors: Dutch Brain Foundation, HEJ, Funding  
Work conferences: Experts with patient

representation

Writing: Professional writer, e-mail consultations

Ensure: Endorsement by national health organizations, make an implementation plan

## Results

*Regional networks:* Awareness, referral, assessing local sticking points, knowing each other

*Handover:* Information from Emergency Room (ER) to General Practitioners (GP), schools are also informed

*Regional care programmes:* formal agreements, management commitment, coordinated care

*Knowledge transfer:* to families, to schools, toolboxes, book, app.

*National:* national knowledge center for recovery phase and longtime-care for children/ youth with severe ABI.

## Contact information

Dr Peter de Koning  
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## Dr. Anna Adlam



### Current role and location

Associate Professor (Reader)/Clinical Psychologist  
Research Lead for the Child and Adolescent Neuropsychology Group & Co-Director of Postgraduate Research, Psychology, University of Exeter, UK

### Key research interests

My research focuses on developing and evaluating neurocognitive interventions for children with acquired brain injury (ABI). This research is guided by the Medical Research Council (2006; 2019) framework for developing and evaluating complex interventions. I

use quantitative (randomized controlled trials, RCTs; single case experimental designs, SCEDs) and qualitative (focus groups, semi-structured interviews) methods. My research is very much a team endeavor and involves collaborations with national and international clinical-researchers, healthcare providers, and charities.



Dr. Anna Adlam

### Summary of recent research

Due to the limited availability of specialist paediatric neuropsychological rehabilitation services in the U.K. (and the need for existing services to cover large geographical areas), my research focuses on developing effective low-cost, highly-accessible interventions to meet the needs of children with ABI and their families. Some of my recent externally funded studies include: a RCT evaluating the effectiveness of Cogmed Working Memory Training (CWMT) in children with ABI (British Academy and Action Medical Research, 2012-2017); a feasibility RCT to evaluate the clinical and cost-effectiveness of an online problem-solving intervention with adolescents with ABI (National Institute of Health Research, 2016-2019); and using intervention mapping to guide the development of an online problem-solving intervention for younger children with ABI (British Academy and National Institute of Health Research, 2016-2018). I was fortunate to be awarded a Mid-Career Fellowship from the British Academy (2016-2018) to learn about, and use, intervention mapping as a framework to guide the development of neuropsychological interventions. Intervention mapping enables me to work alongside

key stakeholders, including children with ABI and their families, healthcare and education professionals, and third-sector providers, throughout the entire research cycle ensuring that the interventions are co-designed and 'fit for purpose'. Intervention mapping is consistent with my values as a researcher and a clinician as it provides scientific rigor to the research approach, whilst simultaneously prioritizing the voices of the children and their families.

### The bigger picture...

This is an exciting time to be working in the field of paediatric neuropsychological rehabilitation – many of us around the world are working towards the same goal of developing effective interventions to support children with ABI and their families, and we are working together to achieve this goal. At the same time, the field is beginning to explore precision-medicine approaches. For example, I am collaborating with Dr Brad Kurowski (Cincinnati Children's Hospital, funded by the National Institute of Health, USA) on a study examining the genetic and environmental factors that can influence the variability in outcomes following paediatric ABI with the hope to be able to provide individualised interventions to optimise outcomes.

### Watch this space!

Continuing my work with Dr Jenny Limond (University of Exeter, UK), Prof Shari Wade (Cincinnati Children's Hospital), and our international collaborators, the intervention research will now move to the implementation phase - focusing on how we can 'scale up' interventions to be used in healthcare services and ensure their sustainability. Also, 'hot off the press' – I am very fortunate to work with a dedicated team of postgraduate students who are: i) adapting the Teen Online Problem-Solving intervention for use with younger children (9-12 years) with ABI; ii) developing an intervention to facilitate peer relationships in adolescents with ABI; and iii) evaluating the efficacy of brief behavioural activation to reduce depression in adolescents with ABI. We look forward to sharing the findings of these new studies with you soon!

To read more about my research and recent publications, please [click here](#).

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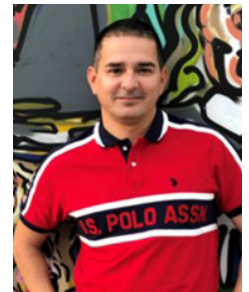
Kimberly Davis (USA)  
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## Developing Spanish Language Norms for Paediatric Tests, A Multi-Country Initiative



### Who We Are

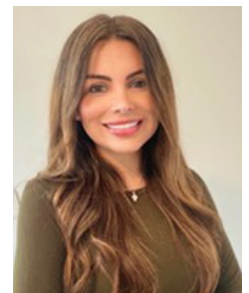
A neuropsychologist by training, Dr. Juan Carlos Arango-Lasprilla is a research professor of Biocruces Bizkaia Health research Institute in Bilbao, Spain. His areas of expertise include cross-cultural neuropsychology, brain injury and rehabilitation. Dr. Arango has over 20 years of experience working with individuals with brain injury and their caregivers in Latin America and Spain. Dr. Paula Karina Perez-Delgadillo is a paediatric neuropsychology postdoctoral fellow at New York University Langone Health/Rusk Institute of Rehabilitation Medicine. Her areas of specialization include bilingual neuropsychological assessment, paediatric neurological disorders, brain injury, and rehabilitation.



Dr. Juan Carlos Arango-Lasprilla

### What We are Doing

Paediatric Traumatic Brain Injury (pTBI) is one of the global leading causes of death and disability in Spanish-speaking individuals. Neuropsychologists and rehabilitation professionals frequently see these children and adolescents in their practices and are involved in the assessment and management of neurocognitive, emotional and behavioural dysfunction after injury. Still, there is a scarcity of research with regards to cognitive, behavioural and psychosocial assessment instruments for this population in Spanish speaking countries. As a result, most measures currently in use in certain Spanish speaking regions lack valid and reliable normative parameters to assess children and adolescents in their own country. To address this gap in the literature and improve the standard level of care, our research team decided to conduct a multi-country paediatric normative data study aimed at developing neuropsychological test norms for 10 Latin American countries and Spain. Paediatric normative data of all neuropsychological tests were published



Dr. Paula Karina Perez-Delgadillo

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in the monograph “Normative data for Spanish-language neuropsychological tests: A step forward in the assessment of paediatric populations.” The norms are available for free [here](#).

### **Impact on Children with Brain Injury**

As one of the first norming projects for Spanish speaking children and adolescents, this study laid the groundwork for additional research about paediatric outcomes and family dynamics trajectories over the first-year post pTBI in Mexico. Findings from this work highlights the need to develop and implement evidenced-based and culturally appropriate neuropsychological rehabilitation and family intervention programs to improve the overall functioning of children and their families. Papers stemming from the research cited above can be found in the following links:

[Trajectories of neuropsychological functioning in Mexican children with traumatic brain injury over the first year after injury](#)

[Longitudinal Growth Curve Trajectories of Family Dynamics after Pediatric Traumatic Brain Injury in Mexico](#)

### **Future Directions**

Presently, we are conducting research on paediatric TBI, developing rehabilitation interventions which aim to support these children and their families, and disseminating information on brain injury and rehabilitation through weekly training webinars and [postgraduate specialty courses](#) for trainees and professionals in these regions, in collaboration with Latin American-based organizations such as the [Colombian Society of Neuropsychology](#) among others.

Additionally, we participate and support continuing education activities such as the IV Iberoamerican [Neuropsychology Congress](#) recently held virtually (May 27-29, 2021).

### **Contact Info**

For questions about their research, Dr. Arango-Lasprilla and Dr. Perez-Delgado can be contacted at:

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We hope you enjoyed this newsletter!

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

