

# EACD Newsletter

August 2022

## Message by the Treasurer

Dear Colleagues and Friends,



We hope that everyone has had time off over the summer to have a chance to relax and recharge. Although it has been quiet over the Summer for the committee, there is a lot to achieve in the next 4-8 months, which you can read about below. We are looking forward to meeting as a committee in Brussels in November to strategically think about the next 3 years. As mentioned, any thoughts, ideas or suggestions would be most welcome.

The Treasurer's role will become vacant at the next Annual General Meeting in May 2023. It has been a great nearly 6 years and I would really recommend applying for the post. The opportunity to be an integral part of the EACD Executive Committee, becoming more financially savvy and working with a fantastic team is definitely worth considering!

Plans are being finalised to dissolve EACD as a British charity, to transfer the majority of the assets to Europe, and to be fully functional as an INPA (International Non-Profit Association) by the end of the financial year. We remain financially stable, however we will be working to improve our income from a variety of sources to cover the costs of becoming a more professional organisation.

Finally welcome to Jackie Casey, our new GMC Members & Communication Officer, responsible for these newsletters as the Newsletter Editor! And of course also a warm welcome to Bernard Dan as Chair-Elect, and Niek De Taeye and Teresa Mano da Costa as the EACD Families & Users' Forum Coordinators! Very much looking forward to work with you on our mission to promote and support education and research in Europe for the benefit of people with childhood-onset disabilities!

*Therese Millar, Treasurer EACD*

## EACD 2023: Get to know Ljubljana!



The 35th EACD Annual Meeting is going to take place in Ljubljana, Slovenia from 24-27 May 2023 under the Meeting's theme "Smarter Goals for Better Future"!

Centrally located in Europe, Slovenia is a boutique European country of two million inhabitants coiled up by mountains, surrounded by Austria, Italy, Hungary and the Adriatic Sea on the one side, and Croatia on the other. Although it's only half the size of Switzerland, it surprises most first-time visitors with the array of its landscapes and the rich cultural and natural heritage, which the locals treasure. Slovenia has joined the European Union in 2004 and introduced the Euro as its official currency in 2007. The same year, it also joined the Schengen Zone. Slovenia is also the first country in the world to be declared a green destination based on the Green Destinations Criteria (2016).

Ljubljana, referred to as the hidden gem of Europe, is Slovene's small, yet vital, green and vibrant capital. With 286,000 residents, Ljubljana is a compact and relaxed walking city built to the human scale, whose Old Town quarter is often depicted as a welcoming lounge by meeting planners and delegates alike, ideal for socialising after the sessions. The Slovenian capital features a wealth of history, style, arts and culture, excellent gastronomy and an atmosphere that is both Central European and Mediterranean. Many would add it is a safe, green, multilingual and hospitable city, with most venues, hotels and sights of interest within

walking distance. The city's architecture is a harmonic blend of medieval Old Town, Baroque, Art Nouveau and newer styles, most notably the heritage of architect Jože Plečnik (1920s–1950s). Ljubljana's feeling of youthful energy can be attributed to 50,000 university students. Lonely Planet editors have listed Ljubljana among destinations most worth visiting, describing it as "one of Europe's greenest and most liveable cities, boasting a friendly cafe culture by day and vibrant nightlife after the sun sets". They also pointed out that Ljubljana makes the perfect base to discover the rest of Slovenia due to its central location. In terms of accommodation, Ljubljana provides a good range of quality options, with over 2,700 hotel rooms, two thirds of which are in the 4-star category. More than half are found in the downtown area, in the radius of max. 15 minutes walking to the Congress Venue. Additional accommodation is available in other types of structures (bed & breakfast, youth hostels, etc.) and more than 1.800 Airbnb units are available in the city, with a very good choice in the central part.

The Organising Team (led by Asst. Prof. Katja Groleger Srsen, President of EACD Ljubljana 2023) is working hard on the preparations for EACD 2023, and looks forward to welcome you to Slovenia, the only country with the word LOVE in its name!



**ABSTRACT  
SUBMISSION**  
Deadline:  
**21 Nov 2022**

**Save the dates: 24-27 May 2023**



Check out [www.eacd2023.org](http://www.eacd2023.org) regularly for the latest information and updates!

## Update on EACD's Activities

The EACD General Management Committee (GMC) is glad to give you a brief update on some of the exciting and important developments within EACD following its GMC Meeting and the Annual General Meeting during EACD Barcelona 2022, which brought together over 900 people from over 50 different countries, who joined us either in person or virtually.

## EACD Families & Users' Forum

At the Annual General Meeting in Barcelona in May 2022, the EACD Families & Users' Forum has been formally installed. The Families & Users' Forum (FUF) will be the body through which persons with lived experience, their family members, and close others participate in the organised plans and actions of EACD. The aim of the Families & Users' Forum will be to foster cooperation between people with lived experience, their family members, and close others with professionals and researchers in the field of childhood-onset disabilities in matters related to science, education and the development of better responses to the needs of people with lived experience, their family members, and close others. The Families and Users' Forum shall be consulted by the EACD General Management Committee and/or Local Organisers regarding the EACD Annual Meeting and other EACD Events, and any change in the aims, values, and ethos at EACD will be done in partnership with the Families and Users' Forum. For more information on the FUF please visit: <https://www.eacd.org/families-users-forum>.

## EACD Education & Training Committee

We are happy to inform you about the launch of our new Education & Training Committee. The aim of the Education & Training committee is to facilitate initiatives in the field of training and education across Europe. For this objective, the Education & Training committee will aim as a first step to identify gap/needs for education and training, and as a second step create a strategy to meet the identified needs. These steps may relate to among other the following aspects: (i) Knowledge translation, research and evidence into practice; (ii) How to find and access information and guidelines; (iii) EACD's knowledge hub for families and clinicians; (iv) Creation / organisation of e-courses, webinars, workshops, summer schools and/or other education material, either by EACD itself or in partnership with others. This Committee is chaired by GMC Member Prof. Elisabet Rodby Bousquet.

## Support for Ukraine Advocacy Group

Following the war in Ukraine due to the invasion by the Russian Army, EACD has set up a Support to Ukraine advocacy group which has brought together involved stakeholders from the region and partners. This working group has provided a platform for information gathering on the need for equipment and provision of healthcare for people with a childhood-onset disability from Ukraine, and has facilitated the co-ordination of provision of equipment and healthcare via our network of National co-ordinators and with other organisations (related to childhood-onset disability) across Europe. Traditionally, EACD has not been involved in non-academic advocacy work. However, there is a strong feeling in the General Management Committee (GMC) that EACD should be involved in advocacy matters affecting children with disabilities and their families across Europe. The GMC agreed to see how EACD could learn from the support to Ukraine work and how this could be implemented for future crises or regular practices.

## EACD Strategic Planning Meeting - Nov 2022

The EACD GMC approved a two-day GMC Strategic Planning Meeting in November 2022, to set out EACD's strategic vision for the next three years (2023-2026). If you have any ideas, suggestions or questions, please do not hesitate to reach out to us, your input to EACD is highly appreciated and we would like to hear any thoughts or suggestions you may have for us to consider!

## EACD Early Career Researchers' Forum

### Upcoming Online Event with Prof. Imms



The graphic features the ECR logo at the top, followed by the text 'ECR SESSIONS'. Below this, it states the time '08:00-09:15 am CET (Brussels time)' and the topic: 'Participation in childhood disability. How to create networks to improve the implementation of research findings in clinical practice?'. The speaker is identified as 'Christine Imms'. A photo of Christine Imms is shown on the right. At the bottom left, it says 'Thursday, September 1st' and provides a QR code and a link to subscribe: 'subscribe via https://eacd.org/event-4926051'.

As one of the objectives of the Early Career Researchers' (ECR) Forum is to support knowledge exchange, we are very happy to invite you to our first online educational session! In this session, Prof. Christine Imms will talk about her work on participation in childhood disability and how to create networks to improve the implementation of research findings in clinical practice. Since Christine's session at the EACD 2022 conference in Barcelona took place at the same time as the ECR Forum session, we would like to use this opportunity to allow early career researchers who were unable to attend Christine's session to learn more about participation. This online session will take place on **Thursday, September 1st, 08:00-09:15 am CET** (Brussels time).

## EACD RehaTech4Child Survey

Closing date approaching: 30 Sept 2022!



The [RehaTech4Child Survey](#) is still open, and EACD invites all health care professionals active in the area of childhood-disability to participate in the survey! The knowledge gained from this survey is foreseen to help eventually in designing the future technological developments based on the feedback from professionals active in the area of childhood disability.

We would like to emphasize that also **the voices of non-users of digital technologies are really important** for the survey and the results we'll get from it!

Click here to go to the survey: [A Cross-European Survey «RehaTech4Child»](#)

### Available languages:

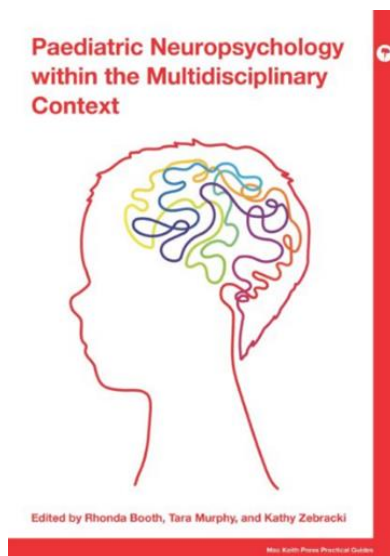
[English](#), [German](#), [French](#), [Spanish](#), [Italian](#), [Portuguese](#), [Turkish](#), [Polish](#), [Dutch](#), [Swedish](#), [Finnish](#), [Danish](#), [Romanian](#), [Ukrainian](#), [Georgian](#), [Croatian](#), [Serbian](#), [Slovene](#), [Lithuanian](#) and [Estonian](#).

## Mac Keith Press update

### Book highlights

Now published! - [Paediatric Neuropsychology within the Multidisciplinary Context](#)

By Rhonda Booth, Tara Murphy, and Kathy Zebracki



Booth, Murphy, and Zebracki present exciting new critical insight on neuropsychological theory and its influence on clinical practice in this accessible and forward-looking publication. With new research and theory on brain-behaviour relationships supported by instructive case studies, this Practical Guide demonstrates how neuroscience and other important factors are driving clinical formulation in paediatric neuropsychology. Rather than being constricted by conventional pathology, this book invites the reader to consider typical and atypical development as nuanced processes. The content serves to inform readers on assessment and intervention for children with commonly occurring and rare conditions, which require close and complex multidisciplinary collaboration.

**Readership:** This book is an essential resource for early-career paediatric neuropsychologists, clinical psychologists, educational psychologists, occupational therapists, speech and language therapists, paediatric neurologists, neurodisability and community paediatricians, and specialist nurses.

**Author podcast:** [Paediatric Neuropsychology within the Multidisciplinary Context](#)

EACD Members get 20% off all books and courses published by Mac Keith Press! Click [here](#) to find the EACD Member discount code.

### DMCN Podcasts

[Motor development in infants with CCHD: a longitudinal study](#)

Author Podcast with Darlene Huisenga

[Cognitive Empathy Across the Lifespan](#)

Author Podcast with Liam Dorris

[Evidence-based practice: how is this conceptualized and applied?](#)

Author Podcast with Dido Green (with guests Gillian Saloojee and Nicole Buckley)

## New DMCN Highlights

### [Financial cost and quality of life of patients with spinal muscular atrophy identified by symptoms or newborn screening](#)

This article compares the societal financial costs and quality of life of untreated spinal muscular atrophy (SMA) patients and treated patients identified because they presented symptoms or were identified by early testing (sibling or newborn screening). Dangouloff et al. found that early identification and treatment offers the opportunity to reduce total societal costs of SMA where treatments are available for pre- and post-symptomatic patients.

### [Early intervention for very young children with or at high likelihood for autism spectrum disorder: An overview of reviews](#)

This overview of reviews by Franz et al. synthesizes early intervention literature for very young children with or at high likelihood for autism spectrum disorder to identify which interventions are supported by evidence and the quality of that evidence.

### [Lived experiences of adolescents with fetal alcohol spectrum disorder](#)

Through semi-structured interviews, Skorcka et al. explored the lived experiences of adolescents with fetal alcohol spectrum disorder (FASD) to understand the ways in which their challenges influence daily functioning and participation. They argue service providers should consider incorporating strengths-based approaches with an explicit focus on facilitating the development of positive self-identities to better support adolescents with FASD.

### [Paediatric epilepsy and cognition](#)

In this invited review, Stéphane Auvin discusses the importance of screening for cognitive impairment in children with epilepsy, to allow diagnosis and appropriate management. Underlying aetiology/syndrome, seizure recurrence, antiseizure medication, and interictal abnormalities are identified as risk factors.

Check out more on the [DMCN homepage](#) and the very latest releases on [Early View](#).

## Other Meeting Updates

### **AACPDM 2022**

The American Academy for Cerebral Palsy and Developmental Medicine (AAPDM) is thrilled to be planning an in-person congress in Las Vegas, USA, September 21-24, 2022! Visit the <https://www.aacpdm.org/events/2022> for more information.

### **PANDa 2022**

The Polish Academy of Childhood Disability (PANDa) will be organising its third National PAND-a Conference, which will take place in Warsaw, Poland, Sept 30th – Oct 1st, 2022. Please visit the [congress website](#) for more information.

### **EPNS 2023**

The 15th Congress of the European Paediatric Neurology Society (EPNS) will take place from 20-24 June 2023 in Prague, Czech Republic with the main highlight "From genome and connectome to cure". The Call for Abstract will be open until 31 December 2022. Learn more at <https://epns-congress.com/>, or check out this [video](#).



### European Academy of Childhood Disability

The European Academy of Childhood Disability (EACD) is an international not-for-profit association founded in 1989, whose members have a scientific and/or clinical interest in the area of Childhood Disability.

The mission of the EACD is to promote and support evidence-based education and research in Europe for the benefit of people with childhood-onset disabilities.

[EACD Website](#)

[www.eacd2023.org](http://www.eacd2023.org)



# EACD 2023

Ljubljana

SMARTER GOALS FOR BETTER FUTURE

24 – 27 May 2023

This message was sent to you by European Academy of Childhood Disability  
*International not-for-profit association*

(Registered company: 0757.731.534; Registered office: Spoorwegstraat 12, Bruges, Belgium)