

# **EACD Newsletter**

June 2023

# **EACD Ljubljana 2023**

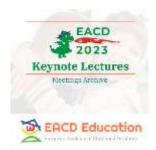
## Thank you for joining!



EACD 2023 has been a blast! We hope you have enjoyed it as much as we did. Almost 900 participants joined in person the 35th EACD Annual Meeting in Ljubljana, the vibrant and green capital city of Slovenia, from 24-27 May 2023. EACD Ljubljana 2023 offered the delegates an excellent opportunity to share experiences, exchange scientific ideas, and foster interactions between all professionals, people with lived experience and their families. The motto of this EACD annual meeting was "Smarter Goals for Better Future", with the intent to emphasize the importance of goal setting in all processes of care in the rehabilitation of children and youth.

And finally a special thanks to our sponsors and partners for sharing our mission to promote research and education for the benefit of people with childhood-onset disabilities. Without their support, EACD 2023 would not have been possible.

# **EACD 2023 Keynote Lecture Recordings**



EACD Ljubljana 2023 was proud to present a number of excellent keynote lectures from prestigious professionals in the field of childhood-onset disability, including: Prof. Helene Polatajko, Emma Livingstone, Dr. Minna Ståhl, Prof. Laurent Servais, Prof. Muharrem Yazici, Prof.Izzeldin Abuelaish, Dr. Ruslan Vasyutin, Prof. Sylvain Brochard and Niek De Taeye! These <a href="EACD 2023 keynote lectures are now available to (re-)watch on our EACD Education website">EACD Education website</a> for EACD members only.

# **EACD 2023 Meeting Award Winners**

The EACD would like to congratulate all Award Winners once more and thank them for their contributions for the benefit of people with childhood-onset disabilities!

### Mac Keith Press Best Abstract Award

1st place - 'Motherese phonation style during interactions with pre-linguistic infants at high risk of Cerebral Palsy'

By Fabrizia Festante, Okko Räsänen, Manu Airaksinen, Viviana Marchi, Olena Chorna, Andrea Guzzetta

## **EACD Best Poster Awards**

1st place – 'Children with Cerebral Palsy Improve Affect Recognition After Completing a Home-Based Computerized Cognitive Intervention'

by <u>María García-Galant</u>, Montse Blasco, Marc Herrera, Olga Laporta-Hoyos, Júlia Ballester-Plané, Júlia Miralbell, Xavier Caldú, Xènia Alonso, Esther Toro-Tamargo, Mar Meléndez-Plumed, Francisca Gimeno Esteve, Roslyn N. Boyd, Roser Pueyo

2nd place – 'A systematic review of interventions promoting physical, psychological and socioeconomic well-being of parents of children with neurodevelopmental disabilities'

by Monika Novak-Pavlic, Peter Rosenbaum, Debbie Hughes, Briano Di Rezze, Luciana Macedo

## EACD Early Career Researcher Awards

1st place - Alexandra Palmcrantz, Sweden

'Muscle strength, muscle volume and functional mobility in children with spastic cerebral palsy'

2nd place - Liza van Dijk, The Netherlands

'Pre-operative gait pattern seems to influence the effect of selective dorsal rhizotomy on gait in children with spastic diplegia'

3rd place (equal) - Mari Naaris, Belgium

'Effectiveness of a four-week powered wheelchair training intervention in children and young people with severe cerebral palsy'

3rd place (equal) - Jacqueline Ding, Australia

'Exploring young adulthood: Experiences and perceptions of participation for adolescents and young adults with cerebral palsy'

### Nestlé Health Science Clinical Research Award

1st place – 'Effect of a community-based intervention (FitSkills) for young people with disability on physical activity participation: a stepped wedge cluster randomised trial'

by <u>Nora Shields</u>, Yeshna Bhowon, Claire Willis, Nicholas Taylor, Shalika Bohingamu Mudiyanselage, Jenny Watts, Christine Imms, Luke Prendergast

# **EACD Bruges 2024**

# Deadline approaching for Mini-Symposia Abstracts: 30 June 2023



The abstract submission deadline for **Mini-Symposia** is approaching for EACD Bruges 2024! The scientific committee of the 36th Annual Meeting of the European Academy of Childhood Disability (EACD) invites you to submit your abstracts for mini-symposia, be aware that only abstracts following the Guidelines for Abstract Submission (see here) will be accepted.

The deadline for Mini-Symposia abstract submissions is June 30th, 2023, 23:59h Central European Time (CEST). After undergoing the review process, all authors will be informed by September 4th, 2023 at latest on the formal acceptance or rejection of the submitted

abstract(s) for a mini-symposium.

Thank you for submitting an abstract for EACD2024. Do not hesitate to encourage your colleagues and those from other fields working on developmental disability to do so as well, in the spirit of the theme of the meeting: 'Composing a new symphony'.

#### Presentation type:

Mini-Symposium

Mini-symposia provide a state-of-the-art overview of research evidence and clinical application of a theme that is relevant and innovative. At least 3 presenters with a multidisciplinary background will present in a 60-min session that includes 15 minutes for discussion with the audience. Mini symposia that have scheduled (family members of) persons with childhood-onset disabilities presenting their perspectives on the discussed theme will be prioritised.

Please structure your abstract for a mini-symposium using the following headings:

- Objectives
- Summary
- · Outline of the symposium

## Abstract Submission deadline for Mini-Symposia: 30 June 2023

Submit your abstracts now!

Go to the EACD Bruges 2024 Abstract Submission page!

Visit the EACD Bruges 2024 website

# **Update from France**



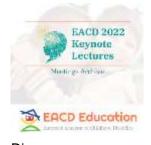
We are happy to inform you about our new national coordinator for France: Dr. Guy Letellier!

As a pediatrician and physical medicine & rehabilitation specialist he practices in a rehabilitation hospital for children, and he is very happy to commit himself to the EACD as a representative of France in connection with SFERHE, the French-speaking society of study and research on

childhood-onset disabilities. Within SFERHE, Dr. Letellier is as vice-president in charge of communication and international relationships. Dr Letellier has a deep attachment to our profession and a renewed commitment to clinical and research projects. The values carried by the EACD are dear to him and he will gladly be in contact with all European colleagues. His first experience with EACD was in 2019 during the EACD Annual Meeting in Paris and has positively marked him, and he would like to make the necessary link between European expertise and the local (French) concerns. In his experience, empathy, research, innovation and training are closely linked, and his very much looking forward to learn more on this via his role as National Coordinator.

On behalf of the EACD General Management Committee we are happy to welcome Dr. Guy Letellier on board, and would also like to express our sincere gratitude to Dr. Carole Vuillerot for her work as National Coordinator for France in the past years!

# **EACD Barcelona 2022 - Keynote recordings**



The EACD Barcelona 2022 keynote lectures are now available to be (re-)watched for everyone on our EACD Education website! EACD Barcelona 2022 was proud to present a number of excellent keynote lectures from prestigious professionals in the field of childhood-onset disability, including: Prof. Christopher Newman & Prof. Bernard Dan, Prof. Mijna Hadders-Algra, Prof. Iona Novak, Prof. Peter Rosenbaum, Prof. Tom Novacheck & Prof. Wade Shrader, Prof. Roslyn Livingstone, Claudia Tecglen & Miguel López Zúñiga, and Prof. Mara

Dierssen.

Please visit: https://edu.eacd.org/34th-eacd-annual-meeting-barcelona-may-2022-archive

# **EACD General Management Committee** update



The posts of **Treasurer** (Term 2023-2026) and **GMC Member + Education** & **Training Officer** (Term 2023-2026) were up for election at the most recent EACD Annual General Meeting (May 25th, 2023) during the EACD Ljubljana 2023 Meeting. Following the outcome of the elections, EACD would like to welcome Dr. Anina Ritterband-Rosenbaum (Treasurer) and Prof. Giuseppina Sgandurra (GMC Member + Education & Training Officer)

as elected members of the EACD General Management Committee! Furthermore, the General Management Committee is glad to welcome Prof. Annemieke Buizer (Chair of the Scientific Committee), Prof. Rainer Blank (Future Meeting President), Dr. Arnab Seal (IAACD Representative), and Prof. Bernard Dan (Chairperson) in their new role!

# **EACD Families & Users' Forum update**



Deirdre Fitzgerald, a parent and a clinician in Ireland, shares an overview of her research findings to date, investigating the relationship between parents of children with complex disabilities and professionals. She illustrates the importance of professionals recognising the role 'love', as provided by these parents, has to establishing a truly collaborative partnership.

Love as a catalyst

The importance of family in a child's life is well documented. Parents particularly hold expert knowledge of their children, understanding subtle nuances and emotions that are often missed and less understood by the experts tasked to assist the child's development. This tension is heightened in the case of the child with a diagnosis of a complex disability. Evidence of increased focus on and scrutiny of family life is sharpened when a child requires support outside of the family circle. Access to experts is often required to seek physical, emotional and intellectual support for the child, which in turn can lead to diminishing confidence in parental decision making processes. My research looks at one aspect of parental decision making. It seeks to examine the interactions and discourses that occur between parents and professionals in the decision making process around the first educational placement for a child with complex disability. As both a parent myself, and a professional, the approach to the methodology I used had to be both considered and appropriate. Using a constructivist grounded theory approach I was able to reflect and appreciate my influence on the data as it was analysed.

The essence of this research lies in the interaction between the parents and the professionals. It has uncovered the need for an approach of mutual respect and understanding of each other's expertise. That is, the parent's expertise in knowing their child best, and the expert's expertise in knowing the system and what is available for the child to access. Early findings have demonstrated how parents shift into uncertainty around their child's future following a diagnosis, followed by a determination in seeking an educational environment where their child can flourish. Following this the parent and professionals work together in positioning the child for the best possible outcome. However, the data has demonstrated that it is the parent with the clearest vision for the child's future that can move through these stages confidently. The professional expert does play a role, but ultimately it is the parent's decision, as expert parent.

These early findings demonstrate the necessity of collaboration and inclusion of parents in all aspects of a child's life and treatment. Families are best placed as experts on the child with complex disability. They are the unpaid experts, providing care and scaffolding the child with love. Love has often been cited as a soft and less scientific approach for many years. However, in the case of families of children with complex needs, love is the catalyst, love is the fuel, and love is what drives families to seek the best supports, interventions and

environments for their beloved child. As researchers, we cannot underestimate the driving forces behind the decisions made by parents. We need to respect, understand and collaborate with the parent experts, non-judgementally, gracefully and leaving ego aside ultimately contributing to the most productive research relationships.

Deirdre Fitzgerald, Member of EACD Family & User's Forum; PhD candidate University of Galway - Contact

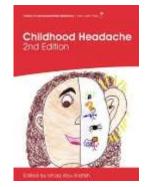
# **EACD Summer School 2023**

The European Academy of Childhood Disability will organise its 2nd EACD Summer School, together with the Poznan University of Medical Sciences from 17-21 July 2023 in Poznan, Poland! The EACD Summer School 2023 is a 5-day training course for early career researchers from a Monday morning to Friday afternoon. The 5-day course is a practical and immersive experience, covering the models, the procedures and instruments that are required internationally to plan and conduct research in rehabilitation of childhood-onset disabilities, guided by good clinical practice. The topics of the course sessions will cover a wide range of themes, representative of the multidisciplinary status of the EACD. Next to the course programme, the EACD Summer Schools entails a social programme including a visit to the laboratories at the hosting site during an afternoon, and a Social Dinner during one of the evenings.

# **Mac Keith Press update**

### **Books**

Special offer!



For Migraine and Headache Awareness Month, Mac Keith Press is offering a **50% discount** on the 2nd edition of *Childhood Headache*, edited by Ishaq Abu-Arafeh! EACD members can get a discounted copy of both the print AND digital version <a href="https://example.com/here/headache">here</a>.

### Buying Book Chapters

Lots of Mac Keith Press' books are available to buy by individual chapters, including such titles as Mijna Hadders-Algra's <u>Early Detection and Early Intervention in Developmental Motor Disorders:</u> <u>From Neuroscience to Participation</u>. EACD members can get **30% off individual chapters**, just as they can for Mac Keith Press complete

books, by using the EACD society coupon code at checkout. Mac Keith Press also offers a FREE digital copy of the introduction and first chapter for most of their titles. You can find more information via the Mac Keith Press books listing.

### **DMCN Podcasts**

How can medical professionals fulfil the rights of children with disabilities

Author Podcast with Zoe Picton-Howell

Community-based physical activity interventions for people with cerebral palsy Author Podcast with Prue Morgan

Mortality after spinal fusion in children with cerebral palsy: A 30-year study Author Podcast with Wade Shrader

Outcomes for children and caregivers attending a paediatric brain centre Author Podcast with Myrna Heydenrijk-Kikkert

## **DMCN - Key papers this month**

Global prevalence of intellectual developmental disorder in dystrophinopathies: A systematic review and meta-analysis

By Carlos Pascual-Morena and colleagues

<u>Long-term effects of transcranial direct current stimulation in the treatment of autism spectrum disorder: A randomized controlled trial</u>

By Paradee Auvichayapat and colleagues

<u>Supported-standing interventions for children and young adults with non-ambulant cerebral palsy:</u> A scoping review

By Lynore J. McLean and colleagues

Adaptive behaviour in adolescents and adults with Dravet syndrome

By Tommaso Lo Barco and colleagues

Check out more on the <u>DMCN homepage</u> and the very latest releases on <u>Early View</u>.

# **Other Meeting Updates**

### **AACPDM 2023 Congress**

On 10-13 September 2023, the American Academy for Cerebral Palsy and Developmental Medicine (AACPDM) will be organising its 77th Annual Meeting in Chicago, Illinois, USA. The early bird registration is possible until June 30th, 2023. Click <a href="https://example.com/here-browner-state-browner-

## **ESMAC Athens 2023 Congress**

On 18-23 September 2023, the European Society for Movement Analysis in Adults and Children (ESMAC) will organise its annual meeting in Athens, Greece! The ESMAC 2023 team plans an exciting scientific programme for a multidisciplinary audience, including inspiring keynote lectures and many oral and poster presentations, and a pre-conference ESMAC gait course. Click <a href="https://example.com/here-for-more-information">here-for-more-information</a>.



## **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



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

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