

EACD Newsletter

April 2023

Message by the Secretary

Dear friends and colleagues,



In less than a month, we will be meeting each other again in Ljubljana for the 35th EACD Annual Meeting. I want to congratulate the EACD 2023 Scientific and Organising Committee for putting together an excellent scientific programme, with many interesting lectures, presentations, debates & deliberations over coffee breaks being planned! The motto of this EACD annual meeting is "Smarter Goals for Better Future", highlighting the importance of goal setting in the rehabilitation context. But also for EACD as an organisation, goal setting is a very important. It allows the Academy to set directions, evaluate our progress and facilitate initiatives for the benefit of people with childhood-onset disabilities to move forward.

The EACD General Management Committee has been working hard on this in the past months to continue the work on the strategies to take us forward for the next three years. In this respect, six strategic key areas have been identified for the period 2023-2026: 1) To promote Excellence in Research in the area of childhood-onset disability in Europe and beyond; 2) To facilitate Knowledge Transfer from research to (clinical) practice and to deliver state-of-the-art educational material and events; 3) To facilitate adoption and application of Technology & Innovation with respect to childhood-onset disability practices; 4) To co-advocate for their rights with people with childhood-onset disabilities, and their families, throughout Europe and beyond; 5) To foster the development of International, Regional and National Networks; and 6) To continue to build a stable, sustainable organizational and financial structure.

These ambitious plans promise a lot for the future of EACD. But just as in research, being in the position to set these ambitious goals, is only possible by standing on the shoulders of giants. And therefore I would like to use this opportunity to formally and sincerely express my gratitude for the amazing work accomplished by my fellow colleagues in the Executive Committee during their terms as Chair (Arnab Seal) and Treasurer (Therese Millar). Both their terms are getting to an end in Ljubljana next month, and you are going to be strongly missed. Although I am sure you both will keep to be involved in the work of EACD in the next years to come in one way or another. Your continued commitment and enthusiasm has been inspiring and you have shown an exceptional dedication to the EACD and our mission to promote education and research for the benefit of people with childhood-onset disabilities. It has been a pleasure to work so closely with you during the many weekly online meetings on Tuesday to discuss the daily management and operations of the Academy. And I want you to know that I value the amount of effort you have put into the EACD. Thank you very much!

Elegast Monbaliu, Secretary

Message by the Treasurer



The last 6 years as EACD Treasurer has been a real journey. I have learnt such a lot and the privilege of being on this committee, with people who are passionate about improving the lives of children (and their families) with disability, has been enormous. There are so many people to say thank you to; but a special thanks goes to Jenny Carroll, Giovanni Cioni, Elegast Monbaliu, Arnab Seal, Bernard Dan and Marco Konings, as well as the rest of the General Management Committee who have served over the last 6 years. It has had its moments (especially wrangling with a certain bank), but it has always been stimulating and exciting. I wish the incoming Treasurer gets as much out of it as I have!

Therese Millar, Treasurer

EACD Ljubljana 2023

EACD 2023 Meeting Programme



CONGRESS
DATES:
24-27 May
2023

EACD Ljubljana 2023



Check out www.eacd2023.org regularly for the latest information and updates!

The EACD Ljubljana 2023 Team is very much looking forward to welcome you to Ljubljana, Slovenia from 24-27 May 2023! The motto of this EACD annual meeting is "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 - Check also the [invited editorial](#) in DMCN on this by EACD 2023 Meeting President Katja Groleger Srsen! - You can check out now the [preliminary programme](#) for EACD Ljubljana 2023! The EACD 2023 programme contains several excellent keynote lectures with prestigious professionals in the field of

childhood-onset disability: Helene Polatajko, Emma Livingstone, Laurent Servais, Muharrem Yazici, Minna Ståhl, Izzeldin Abuelaish, Sylvain Brochard, Niek De Taeye and Ruslan Vasyutin. Also don't forget to visit on Thursday May 25th, 13:40-14:25h the Nestlé Health Science Lunch Satellite Symposium on 'Nutritional Management of Children with Neurodisabilities' and/or the Clinigen Lunch Satellite Symposium!

EACD 2023 Pre-Congress Session: *Pediatric dystonia, a rare disease, needing a multidisciplinary future resistant European approach*



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EACD Ljubljana 2023



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Dystonia is a rare disease that often starts its first symptoms in childhood. The burden for patients not only concerns the movement disorder symptoms but often the consequences for participation in society. The ICF framework provides an excellent frame work to address diagnostics and treatment for the individual patient. Proper clinical diagnosis is needed, including clinical characterization of the movement disorder and strategies for genetic analysis. New treatment developments include training programs, oral medication, and neurosurgical intervention.

In this preconference we will address and discuss the above topics. In addition, we will have an extensive round table discussion about ethical issues about treatment in rare diseases.

Chairpersons: Jeroen Vermeulen (Netherlands), Annemieke Buizer (Netherlands)

Topics to discuss:

- 13.05 > Welcome (Jeroen Vermeulen)
- 13.05-13.25 > Patient view on dystonia (Amybel Taylor, UK)
- 13.25-13.45 > General introduction of the ERN (Carola Reinhart, Germany)
- 14.05-14.25 > Paediatric Dystonia: clinical and genetic diagnostics (Wieke Eggink, NL)
- 13.45-14.05 > ICF structure applied on rare diseases (Annemieke Buizer, Netherlands)
- 14.25-14.55 > Tea/Coffee break
- 14.55-15.15 > Outcomes in dystonia/paramedic treatment (Hortensia Gimeno, UK)
- 15.15-15.35 > Evidence for treatment including botulinum toxin and intrathecal baclofen (Laura van de Pol, Netherlands)
- 15.35-15.55 > DBS treatment (Belen Pérez, Spain)
- 15.55-16.15 > Dystonia care pathway (Elegast Monbaliu, Belgium)
- 16.15-16.55 > Ethical issues round table discussion (Bernard Dan)
- 16.55-17.00 > Closure

EACD Early Career Researchers' Forum

ECR session with Giuseppina Sgandurra & Roslyn Boyd: 'Mistakes makes and lesson learned over the course of a research career'



In this session, Professor Giuseppina Sgandurra and Professor Roslyn Boyd will share their insights in what they learned over their extensive research careers about making mistakes in research. Making mistakes is something we will all do, and often the consequences are minor. In some cases, however, consequences of specific decisions may not be minor. How do we handle such cases? How do we make sure each individual feels safe enough to admit that something has gone wrong? Are the perceptions of these processes different in Europe and Australia?

Which steps could we undertake to try and catch mistakes before they become worrisome? These and other questions will be handled in a discussion-like format between the speakers and the attendees. Apart from the insights of Professors Sgandurra and Boyd, we would love hear the contributions of the early career researchers in this discussion.

EACD 2023 Post-Congress Workshop: CO-OP



CONGRESS DATES:
24-27 May 2023



Cognitive Orientation of daily Occupational Performance (CO-OP) is a client-centered, performance-based, problem-solving approach aimed at improving performance and participation for people with performance difficulties. Originally created to enable children with Developmental Coordination Disorder (DCD) to learn to perform the everyday activities they find challenging, the Approach has now been shown to be effective with both children and adults with a variety of other conditions, e.g., Acquired brain injury, ADHD, Cerebral Palsy, Autism Spectrum Disorder (high functioning), dystonia, stroke, traumatic brain injury, and chronic

mental illness. The CO-OP Approach has been demonstrated not only to enable the acquisition of a large variety of skills ranging from bicycle riding to wedding planning but also the generalization and transfer of learned skills and performance solving strategies to everyday life. The Overview is an introductory workshop offering three hours of interactive lectures and learning exercises designed to provide participants with a basic introduction to the Approach, its theoretical foundations and the evidence supporting its use with a variety of populations. The course provides an overview of the seven Key Features of CO-OP and how they are implemented in practice. At the end of this course, participants will be able to determine the applicability of the CO-OP Approach to their work, be it practice or research. Note: This course does not provide any practice competencies.

Instructors:

Dr. Sangster Jokić is an occupational therapist and lecturer in Occupational Therapy Studies at the University of Applied Health Sciences in Zagreb, Croatia. Her clinical and scientific experience is focused in the areas of occupational and social participation, cognitive approaches in neurodevelopmental rehabilitation, and developmental coordination disorder. She has over 20 years of practical and research experience with the CO-OP approach and delivers CO-OP education to practitioners as a certified CO-OP instructor. **Helene Polatajko**, PhD, Professor Emeritus, University of Toronto: Dr. Polatajko, PhD, is an internationally respected occupational therapy scholar and educator. Her work has focused on occupation and its enablement. Prominent among her contributions are co-authorship on the internationally acclaimed Canadian Occupational Performance Measure and the two Enabling Occupation books, and leading the creation and development of the Cognitive Orientation to daily Occupational Performance approach. Dr. Polatajko has been granted numerous top awards and distinctions including the Muriel Driver Lectureship, election to The American Occupational Therapy Foundation's Academy of Research and being named as a Fellow to the Canadian Academy of Health Sciences.

Date and time:

Saturday May 27th, 2023
14:00 - 17:00h, E1 Hall

Register now to join us at EACD 2023:

[Go to the EACD Ljubljana 2023 Preliminary Programme page!](#)

[Go to the EACD Ljubljana 2023 Registration page!](#)

IAACD Knowledge Hub Survey



On behalf of the Global Professional Education Committee of the IAACD (International Alliance of Academies of Childhood Disability), we would like to invite you to complete their Knowledge Hub Survey! The IAACD Global Professional Education Committee began their work in 2016 and one of the first things this IAACD committee did, to help guide their activities, was to undertake a survey of professionals working in the field of childhood-onset disability. This helped to

understand people's needs and aspirations and to link together those in the field able and willing to support the work of IAACD and its member academies. Over 1,000 professionals from across the globe replied to the survey back then, providing really useful information. Now 8 years on, the IAACD Global Professional Education Committee would like to update this information and use it to guide the next phases of work and priorities, so a new, updated survey has been prepared. This survey is for everyone who works in the field of childhood-onset disability, regardless of whether you are currently member of one of IAACD member academies or not. Please fill in the survey and forward the link to your colleagues as we would like to collect as many opinions and views as possible!

The IAACD Knowledge Hub Survey will take less than 5 minutes to complete and can be accessed via the [link here](#).

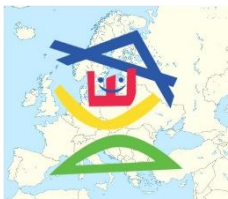
IAACD COVID-19 Task Force Survey Paper



EACD is glad to share the [IAACD COVID-19 Task Force surveys paper](#). This paper synthesizes existing evidence describing the impact of COVID-19 on people with disabilities, derived from surveys conducted across the globe. This project was conducted as part of the IAACD COVID-19 Task Force. Information from more than 17,230 participants around the world was collected. Globally, the surveys highlight that COVID-19 has negatively impacted several areas of functioning - including

mental health, and human rights of people with disabilities and their families. For more information, please check out also this [podcast](#)

Update from Croatia



On the 12th of January 2023, the Croatian Academy for Developmental Habilitation organized its Annual General Meeting in Children's Hospital Zagreb. This meeting had a great importance because our long-time president, prof. Vlatka Mejaški-Bošnjak, MD, PhD, ended her last mandate as a president and from now on be with the Croatian Academy as the honorary president. We thank prof. Vlatka for her indescribable contribution in the development of the Croatian Academy's activities

at the domestic and international level. Together with colleagues, she has been building the Croatian Academy for decades, numerous world-renowned experts came to Croatia, and over the years some of the professionals from Croatia were trained to independently lead some of the professional training courses. The work of the Croatian Academy is recognized and supported by numerous centers, institutions and experts around the world. The new president of the Croatian Academy for Developmental Habilitation is Goran Krakar, MD, PhD. We wish Goran a lot of success in his future work!

The Croatian Academy for Developmental Habilitation organizes many workshops, lectures, courses and other events related to childhood-onset disabilities every year. This year we will continue to give our best and provide new knowledge to our professionals, having more than 15 events, of which we would like to highlight the "Summer Academy" which has been organized for the last 24 years. The beautiful City of Zadar became host city in 2018. A long time ago, back in 1964, famous Alfred Hitchcock said: "Zadar has the most beautiful sunsets in the world", so we are glad to host professionals from Croatia and abroad every year, to learn together and enjoy walking through the beauties of Zadar. In August we will continue with professional courses on the 25th Summer Academy, with the main topics related to sleep disorders and quality of motor functioning in children with cerebral palsy.

Hrvoje Gudlin, PT, EACD National Coordinator of Croatia

Update from Norway



I am glad to update you on an ongoing national multicentre RCT study in Norway, the PIH Multi study, which started in 2021. It is a collaboration between departments of child (re)habilitation in all four Health regions in the country. The aim of the study is to evaluate the effects for both the child and their parents of participating in an intensive rehabilitation program for preschool children with early brain damage. The evaluation focus on the on the child's development, adaptive functioning and on parental stress and coping in order to treat and reduce the consequences of early brain damage. The study is headed from the Regional Center for intensive child rehabilitation (RIB), Sørlandet Hospital HF and the collaboration partners are the Child rehabilitation services at Haukeland University Hospital in Bergen, St. Olavs Hospital in Trondheim and University Hospital North-Norway in Tromsø. All the partners are offering the same intervention program and their children and their parents are evaluated three times with one year interval. We hope to include 90 children and their parents in the study, so far about 70 children have been included. There are PhD candidates involved in this research project. The study protocol and the method for implementation of the program, which has been developed and offered the last 20 years at Sørlandet Hospital, but not nation-wide, will be presented by two posters at the EACD congress in Ljubljana in May 2023.

Tordis Ustad, EACD National Coordinator of Norway

Invitation to the 35th EACD Annual General Meeting



We kindly invite all members of EACD to attend the 35th Annual General Meeting of the European Academy of Childhood Disability (EACD) on Thursday 25 May 2023 to be informed of previous and future activities, to vote on the important decisions regarding the organisation, and to let hear your voice! Please find below the agenda of the Annual General Meeting.

European Academy of Childhood Disability - Annual General Meeting

Date and Time: Thursday 25 May 2023

18.30 to 20.00 hrs

Location: EACD Ljubljana 2023 Annual Meeting - Cankarjev Dom, Cultural and Congress Centre, Prešernova 10, SI-1000 Ljubljana, Slovenia; **Room:** Kosovell Hall

AGENDA:

1) Chair's report

- Strategic Plan & Update on Key Areas

2) Secretary's report

3) Treasurer's report

4) EACD Organisational Structure

- End Transition period from UK Charity organisation to International Not-for-Profit Association;
- Dissolution of UK Charity organisation

5) Elections GMC Members

- Treasurer - term 2023-2026
- GMC member + Education & Training Officer - term 2023-2026
- Results of elections for GMC positions
- Transition of Chair post

6) Election EACD 2026 Congress Location

7) EACD Bruges 2024 Meeting

8) Any other business

Elections of GMC Vacancies & the EACD 2026 Meeting Location



The posts of **Treasurer** (Term 2023-2026) and **GMC Member + Education & Training Officer** (Term 2023-2026) is up for election. The election for the GMC Vacancies & the EACD 2026 Meeting Location is open for voting now until the 35th Annual General Meeting on Thursday 25 May 2023 in Ljubljana, Slovenia and we need your vote as a member of the European Academy of Childhood Disability! All active EACD members are entitled to cast their vote.

Election of Treasurer

term 2023-2026

There is one candidate who applied for the position of Treasurer:

- Dr. Anina Ritterband-Rosenbaum (applied for a 1st term)

Election of GMC Member + Education & Training Officer

term 2023-2026

There are four applications for the GMC Member + Education & Training Officer post. The applicant with the highest number of received votes will be elected as GMC Member + Education & Training Officer. The four applicants are listed below in alphabetical order:

- Dr. Dawn Pickering (applied for a 1st term)
- Prof. Giuseppina Sgandurra (applied for a 1st term)
- Prof. Kristine Stadskleiv (applied for a 1st term)
- Dr. Taras Voloshyn (applied for a 1st term)

Election of EACD 2026 Annual Meeting location

There is one bidding candidate for hosting the EACD 2026 Annual Meeting:

- A bid has been submitted to host the EACD Annual Meeting in 2026 in Galway, Ireland.

Voting will be open until two hours before the start of the 35th Annual General Meeting on Thursday 25 May 2023, 16:30h CET in Ljubljana, Slovenia. The results of the voting will be announced during the Annual General Meeting on Thursday 25 May 2023, 18:30-20:00h CET in Ljubljana, Slovenia.

[EACD members can click here to go the voting page to cast your vote](#)

Mac Keith Press update

New Book: Promoting Physical Activity and Fitness: Supporting Individuals with Childhood-Onset Disabilities

Promoting Physical Activity and Fitness

Supporting Individuals with Childhood-Onset Disabilities



Edited by Désirée B Maltais and Reidun B Jahnsen

Edited by Désirée B Maltais and Reidun B Jahnsen

Exercise and physical activity in all forms are an important part of life, and can have lasting mental and physical health benefits. Promoting Physical Activity and Fitness provides critical insights in the field through clear and evidence-based information on how to evaluate, train, and foster physical activity and fitness in individuals with childhood-onset disabilities safely across the lifespan. The authors respond to specific needs to enable many people to lead more physically active lives. Themes include physical fitness and activity assessment and training, safe engagement, measurement of activity levels and progress, responses to pain, and information relevant to specific diagnostic groups. Diverse, complex subjects are presented in an accessible and engaging way.

- Easy-to-understand, evidence-based information on fitness training and testing.
- Information on feasible types of physical activity for different diagnostic groups.
- Tables used to summarize test descriptions and training principles.
- Multidisciplinary and international team of co-authors: clinicians and academic experts with specialisms ranging from rehabilitation to oncology.

An essential resource for individuals with childhood-onset physical and developmental disabilities, and their families; rehabilitation clinicians; educators; coaches; specialists in sports medicine, sports science, or physical rehabilitation; health and exercise science students.

[Click here to order!](#)

(EACD Members receive 20% off [ALL BOOKS](#) from a collection of 150+ titles from Mac Keith Press. Please visit [this page](#) and log in as EACD member to find the **special discount codes** to apply at checkout)

DMCN Podcasts

[Pain and neurodevelopmental outcomes of infants born very preterm](#)

Authors Podcast with Vito Giordano & Philipp Steinbauer

[Cochrane SREs for rehabilitation interventions in individuals with cerebral palsy](#)

Author Podcast with Sara Liguori

[Exposure to endocrine-disrupting chemicals and implications for neurodevelopment](#)

Author Podcast with Fatih Özel

[Cognitive behavioral therapies for individuals with cerebral palsy: scoping review](#)

Author Podcast with Tamar Silberg

DMCN - Key papers this month

[Single-case experimental designs for child neurological rehabilitation and developmental disability research](#)

By Agata Krasny-Pacini

[User-perceived impact of long-term mechanical assisted cough in paediatric neurodisability](#)

By Brit Hov and colleagues

[The Dyskinesia Impairment Scale, Second Edition: Development, construct validity, and reliability](#)

By Inti Vanmechelen, Annika Danielsson and colleagues

[Sleep homeostasis, seizures, and cognition in children with focal epilepsy](#)

By Maria H. Eriksson and colleagues

[Long-term outcome of paediatric anti-N-methyl-D-aspartate receptor encephalitis](#)

By Lorraine Flet-Berliac, Nicolas Tchitcheck and colleagues

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

Other Meeting Updates

EPNS Prague 2023 Congress

On 20-24 June 2023, the European Paediatric Neurology Society (EPNS) will be organising its 15th Congress symposium in Prague, Czech Republic. The main theme of the congress is "From genome and connectome to cure". Take a look at <https://epns-congress.com/programme> for more information.

BACD Annual Scientific Meeting 2023

On Thursday 22 June 2023, the British Academy of Childhood Disability will meet for its first in-person conference for three years! The theme for the BACD Annual Scientific Meeting 2023 is Learning Disability in Children and Young People. The early bird registration and abstract submission close at Friday 11 May 2023, 09:00am GMT (London time). [Click here](#) for more information.



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



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)