



European Academy of
Childhood Disability



EACD News.



EACD Newsletter **September 2021**

Message from the EACD Secretary

Dear EACD members, friends and colleagues,



Although there are obviously a lot of individual differences between individuals with a childhood-onset disability in respect to their required level of support, many of them are to a certain extent dependent on health care services to facilitate their participation to everyday life activities, especially in areas such as mobility, communication, control of movement, and equipment. How best to meet the needs of these individuals with a childhood disability, and their families, was

already a challenge prior to COVID-19 in a climate of apparent increasing demand and constrained resources for health care provision. And as we have all experienced, this became even more of a challenge after the outbreak of the COVID-19 pandemic. Yet we have also gained a lot of insights about what is actually important in order to meet the needs of individuals with a childhood-onset disability, two of which I would like to highlight:

1) We have become more and more aware of **the importance of technology and innovative solutions** in this day and age for providing the best possible care for people with a childhood-onset disability. In recognition of this, you may be aware that we have set up a special **EACD Technology & Innovation Task Force**, currently led by Prof. Sylvain Brochard and Dr. Christelle Pons. This Task Force has already led to the new EACD Technology & Innovation Award, highlighting excellence in the development of new tools and technologies relevant to individuals with a childhood disability. And an important next initiative by this Task Force is on the horizon: the **RehaTech4Child survey!** This European-wide survey by EACD will aim to identify to learn more about how rehabilitation professionals use, or not use, digital technologies in motor rehabilitation practices within the paediatric population, and to explore the barriers and facilitators in the use of these new technologies in clinical practice. This knowledge would eventually help in designing the future technological developments based on the feedback of rehabilitation

professionals, reason why responses from you will matter once this survey will be launched in the upcoming period!

2) We have experienced also a **renewed appreciation for informal meetings**, with a much greater degree of spontaneity, relaxedness and no set agenda, where many great ideas and plans for research and clinical practice find their origin. Those moments to discuss work- and less work-related issues with colleagues and other stakeholders which may not have an appropriate place in a formal meeting. In this perspective, we are very much looking forward to a **fully hybrid EACD Barcelona 2022!** To facilitate both formal and informal gatherings in the area of childhood disability, EACD and the EACD Barcelona 2022 team are committed with the return to the classic "on-site" format of our EACD Annual Meeting, although the worldwide development of COVID-19 will of course be carefully monitored. At the same time, after the good experiences from previous editions, EACD 2022 will continue to offer the opportunity of virtual participation for people who cannot attend in Barcelona physically due to travel restrictions or any other reason. **Our Call for Abstracts and the Registration tool for EACD Barcelona 2022 have recently been opened**, and I would strongly encourage you to check <https://eacd2022.com/> regularly for the latest updates!

Finally, in this newsletter we are also happy to provide you an update from The Netherlands, an introduction to our new National Coordinator from Denmark, testimonials from EACD Europe 2021 bursary recipients, and the Mac Keith Press update.

I hope you and your family stay safe, be well and I thank you for the important work you are doing.

Elegast Monbaliu, Secretary EACD

EACD Barcelona 2022

Call for Abstracts



The scientific committee of the 34th Annual Meeting of the European Academy of Childhood Disability (EACD) **invites you to submit abstracts for a mini-symposium, instructional course, oral communication and/or poster presentation.** Be aware that only abstracts following the Guidelines for Abstract Submission (see [here](#)) will be accepted.

With our motto "**Networking knowledge into actions**" we invite authors from all fields and professions surrounding children and adults with disabilities to submit their topics. With improving networks of care and better web connectivity, collaborative working across boundaries has prospered within Europe and across our global community. We would welcome submissions where such collaborations has led to a change in practice, influenced outcomes, offered benefits or thrown up some challenges. All abstracts related to childhood-onset disabilities are welcome, including those on treatment, prevention, early detection, early intervention, transition and lifespan

issues, parents' and siblings' experiences, adult research, health systems, engineering in disability, basic sciences, social science research and ethics.

Key dates:

Mini-symposia & Instructional courses:

18 October 2021: Abstracts Submission deadline

12 November 2021: Notifications to submitting authors

Oral communications & Poster presentations:

15 November 2021: Abstract Submission deadline

17 January 2022: Notifications to submitting authors

[Click here to go directly to our EACD Barcelona 2022 - Call for Abstracts page](#)

Celebrate new European Academies launch events



Ukrainian Academy of
Childhood Disability
(UACD)

The **Ukrainian Academy of Childhood Disability** celebrated their inaugural meeting this week. Look out next month for a review of their webinar event.

IACD

[Irish Academy of Childhood Disability](#)

The **Irish Academy of Childhood Disability** are due to hold a launch webinar 25th September 2021. Registration is still open [here](#). Follow the Irish Academy on Twitter: [@IrishDisability](#).

More news on these two events in next month's newsletter...!

New National Coordinator: Denmark



This month we would like to introduce our new national co-ordinator of Denmark who has taken on this role in September 2021.

Jonas Jensen is the new National Co-ordinator for Denmark. He is an occupational therapist with over 8 years of clinical experience, plus Project Manager for Practice and Innovation at The Elsass Foundation with a focus on knowledge transfer from research to practice. Jonas is also currently following a Master of

Science in Management Development at the Copenhagen Business School, and is looking forward to represent professionals in the area of childhood disability from Denmark within EACD!

A word from the Netherlands



Dutch
Academy of
Childhood
Disability

Since there is a decline in the COVID-19 infection rate, we are looking at the consequences for the care for our patients. Although there is an increase of waiting lists, most therapies run at normal capacities, and schools are reopened with some

restrictions. For healthcare professionals the positive side is that we can organize some live-meetings again. Despite the great success and efficacy of the digital meetings, we have the need of meeting in person to talk and inspire each other. From the Dutch-ACD we organize a hybrid meeting on collaborating in the care for children with profound multiple disabilities. We focus on parental support, stimulation of movement and various other aspects in the care of these patients and their families. For the Dutch-speaking friends of the EACD, I welcome you to our website and symposium, see www.dacd.nl.

Another great news is that in the Netherlands, after some years of absence after Prof Jules Becher retired, we now have two wonderful professors in pediatric rehabilitation in the Netherlands. Professor Jan Willem Gorter started in the Utrecht University Medical Center, and Professor Annemieke Buizer will have her inaugural speech at the VU University and Amsterdam University Medical Centers. Having these two professors is a great inspiration for the Dutch rehabilitation community and helps in the further development of our professions!

We hope to see you all in Barcelona at the EACD, and look forward to meet in person!

Kind regards,

Mattijs Asem, EACD National Coordinator - The Netherlands

Dutch Academy of Childhood Disability - Symposium, October 15th

The Dutch Academy of Childhood Disability (DACD) is organizing on 15 October 2021, 09:30-16:00h (local time) a symposium at the RadboudUMC Experience Center in Nijmegen, The Netherlands. The theme of this day will be: 'Rehabilitation or Stimulation? Together for children with severe multiple disabilities'. For more information, please visit: [DACD Congres - DACD](#) (in Dutch).

EACD Bursaries enabled attendance at EACD Europe 2021

Milena's testimony

As a recipient of the bursary, I have attended all four thematic days of the EACD Europe 2021 congress. The EACD Europe 2021 bursary has provided me with an opportunity to present my research work and earn international recognition. Since I come from Serbia, a low-income Western Balkan country, this has been a support for me to make connections needed to continue with my

academic achievements. Researchers from this region have rarely participated in this prestigious conference. Through the generous support of the EACD 2021, I got in touch with cutting-edge research on childhood-onset disabilities and best practice interventions, which I have actively promoted on social networks. It was a privilege to listen first-hand, directly, to the presentations of the most famous names in the field of disability studies. Inspirational discussions followed informative lectures, which is my strongest impression and observation shared with colleagues and co-workers who did not get the chance to participate in this scientific meeting.

Milena Milicevic

Institute of Criminological and Sociological Research, Belgrade, Serbia

Anna's experience

Hello everyone! My name is Anna, and I am an early career researcher and paediatrician from Ukraine. This year I was among the bursary nominees to attend the EACD Europe 2021. This opportunity was a great honour for me, since EACD meetings are one of the most exciting and beneficial annual events for those who work in the field of childhood disability. Additionally, I submitted an abstract, and my team was happy to be awarded with the 3rd place of the Mac Keith Press Best Abstract Award.

Nowadays, we are coping with tough times due to the COVID-19 pandemic. It was important that many EACD 2021 sessions were dedicated to the challenges that pandemic brings and possible solutions to how we can overcome these problems. In our facility, we started to apply remote consultations, and it was helpful to hear about the experience in using telemedicine from colleagues from other countries.

We are confronting a period when effective collaboration is vital, and I was happy that the special event of the recent EACD meeting was the [EACD Early Career Researchers' Forum](#). I am pleased to be a part of this networking and expect to meet and plan some collaborative projects with young researchers and practitioners from different parts of Europe.

Therefore, I am deeply grateful to the EACD Organizers for the excellent scientific events and opportunities for early-career researchers. I wish you all the best in your ideas and plans!

Anna Kushnir, M.D., Ukraine

EACD RehaTech 4Child Survey



Last year, EACD has set up a Technology & Innovation Task Force as it recognises the importance of technology and innovative solutions in this day and age for providing the best possible care for people with a childhood-onset disability. In this respect, we are happy to inform you about an upcoming initiative led by this EACD Task Force: **the European survey RehaTech4Child!**

This survey aims to identify the digital technologies (e.g. robotic devices and treadmill systems, virtual reality and gaming systems, telehealth) that are used in clinical practices throughout Europe and to know more about how rehabilitation professionals use or not use digital technologies in motor rehabilitation practices within the paediatric population, and to explore the barriers and facilitators in the use of these new technologies in clinical practice. This knowledge would eventually help in designing the future technological developments based on rehabilitation professional feedbacks, reason why responses from you and your colleagues matter!

A multidisciplinary steering group consisting of EACD members from Belgium, France, Romania, Spain, and Switzerland have built a first draft of the survey in English, and surveys are currently translated in many of the European languages. With one lead on this project for every European country, a committed team to conduct the survey has been created, leading hopefully to a truly a pan-European survey. As you could imagine, the input and contribution of professionals from all over Europe is essential to create a European voice around these crucial questions that would help in building the right place for these technologies in the future of rehabilitation. This information will help us to be better prepared to provide the best possible care and support individuals with a childhood disability, not only during future pandemics or serious global events, but also during their everyday lives.

The RehaTech4Child survey by EACD **is anticipated to be launched in October 2021**, and more information on this will follow soon!

Mac Keith Press update

Accredited Online Learning Courses



Mac Keith Press and the European Paediatric Neurology Society (EPNS) present two European Accreditation Council for Continuing Medical Education (EACCME®) accredited online learning courses that provide authoritative advice on managing neurological disorders presenting in infancy. Completion will enable you to better support families, assess young children and work in an interdisciplinary way with other professionals and caregivers to assess, diagnose and manage neurological and neurodevelopmental problems in the first two years of life.

[Principles of Child Neurology in Infancy Course 10 EACCME® credits](#)

[Clinical Practice of Child Neurology in Infancy Course 11 EACCME® credits](#)

20% Discount for EACD members!

EACD members are eligible for a 20% discount on these courses - contact the EACD office admin@eacd.org for the code to use when booking!

New DMCN Publication Highlights

- [Parents of children with disabilities and the COVID-19 pandemic](#) The latest Invited Editorial in DMCN is by Her Majesty Queen Mathilde of Belgium. It looks at the impact COVID-19 has had on parents and children with disabilities, with a focus on reduced access to services and increased awareness of fatigue and mental health issues. The Editorial has been translated into [Dutch](#), [French](#), and [German](#)

- [Is the search for cerebral palsy 'cures' a reasonable and appropriate goal in the 2020s?](#) Honan et al. explore the contentious notion of 'cures' in cerebral palsy, combining perspectives acquired during community consultations with those published in the literature.

- [Consensus clinical management guideline for beta-propeller protein-associated neurodegeneration](#) this excellent review by Wilson et al. is informed by an evaluation of the literature and expert opinion and provides recommendations for the evaluation and management of individuals with beta-propeller protein-associated neurodegeneration.

- [Functional development in children with cerebral palsy in Uganda: population-based longitudinal cohort study](#) Andrews et al.'s study found limited access to health care and rehabilitation likely contribute to children with cerebral palsy in Uganda developing motor skills at a slower rate than peers in high-income countries.

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

Listen to the Developmental Medicine & Child Neurology podcasts:

- Discussion of the paper 'Effects of Extreme Weather Events on Child Mood and Behavior'. Watch on [Youtube](#)

- Discussion of the paper 'Patient Perspectives in Pediatric Neurology: A Critical Shift in the Paradigm of Outcome Measurement'. Watch on [YouTube](#)

- Discussion of the paper 'Quality of Life Measures in Pediatric Multiple Sclerosis: A Systematic Review and Meta-analysis'. Watch on [YouTube](#)

Check out more podcasts on the [DMCN YouTube channel](#).

Short Meeting updates

AusACPDM / IAACD Melbourne 2022 goes fully virtual!

Because of the current COVID-19 outbreaks throughout Australia and accompanied uncertainties, the Better Together 2022 | AusACPDM/IAACD 2022 Organising Committee, in consultation with the AusACPDM Board and IAACD Steering Group, have made the decision to move to a fully virtual Conference in March 2022. The Better Together 2022 Organising Committee would like thank everyone for their support and understanding in this decision, and we are all very much looking forward to a day when we can all safely come together again. The registration for this

meeting has now been re-launched for the fully Virtual Conference. For more information, please visit: <https://bettertogether2022.org/>.



SAVE THE DATE: EACD Barcelona 2022

Join us at the 34th Annual Meeting
Meeting theme: "Networking knowledge into actions"
18-21 May 2021, Barcelona (Spain)

www.eacd2022.com



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European Academy of Childhood Studies
"Networking knowledge into actions"
BARCELONA
18-21 MAY
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