

EACD Newsletter

August 2021

Message from the EACD Treasurer

Dear EACD members, friends and colleagues,



Welcome to August's newsletter! Summer is nearly over and hopefully most people have had time to have a had a break. We are delighted to share the news of the inaugural meetings of two new academies in September. The Ukrainian Academy of Childhood disability is having their first webinar on the 16th and 17th of September. The Irish Academy of Childhood Disability is following hot on their heels, and their inaugural webinar is on the 24th of September. We wish both academies every success with their meetings and a long and fruitful future.

We are also looking forward already to the EACD conference being held in Barcelona next year. The conference organisers are working incredibly hard to provide a full and varied programme in a fully hybrid format. More information on the EACD2022 Call for Abstracts and Registration will follow soon! In the meanwhile, planning for the EACD 2023 programme (being held in Ljubljana, Slovenia) is now fully underway too.

Finally, we would like to inform you that recently we have been made aware of scammers who have sent emails, supposedly from our Chair, with the request to send funds to him. In this respect, we would like to emphasize that no one from the EACD committee will EVER ask for money from anyone, so if you would have received such email please do not send money, and block the emailer.

As you know, we always welcome feedback, thoughts and suggestions from our membership, please feel free to email us at admin@eacd.org.

I hope you and your family stay safe, and well.

Therese Millar, Treasurer EACD

EACD Early Career Researchers' Forum – Networking Event



EACD Early Career Researchers' Forum
Networking Event
21 September 2021, 18:00-19:30h CET

This event is open for all EACD members who identify themselves as early career researchers. Registration is open until September 7th, 23:59h CET.

→ Sign up now for this networking event via the following link:
<https://eacd.typeform.com/to/qZavwpz4>



We are very happy to welcome you to the first event hosted by the EACD Early Career Researchers' Forum, which will take place at **Tuesday September 21st, 18:00-19:30h CET (Brussels time)**! In response to the priorities identified during the EACD Early Career Researchers' Forum launch at the EACD 2021 conference this first event will focus on networking. This will be a virtual event where we will all get to know each other better with the aim of becoming a supportive community for early career researchers! Please be prepared to interact with

each other discussing topics ranging from your research challenges and advice to your food preferences. This event is open for all EACD members who identify themselves as early career researchers

Sign up now for this networking event via the following link: <https://eacd.typeform.com/to/qZavwpz4>
Registration is open until 7 September 2021, 23:59h CET.

New National Co-ordinator: Portugal



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

Dr. Alexandra Oliveira is the new National Co-ordinator for **Portugal**. She is a neurodevelopment paediatrician and a Board member of the Portuguese Neurodevelopmental Society (Sociedade de Pediatria do Neurodesenvolvimento da Sociedade Portuguesa de Pediatria; SPND-SPP). She is eager to have a more active role in providing the best possible care to children with disabilities and their families, and highlights the importance of making them feel appreciated and supported by our communities. Having a genuine interest in this field, it has been Dr. Alexandra Oliveira's goal to improve the knowledge in children care, for example by taking specialized training in neurodevelopmental paediatrics, where I will gather the best knowledge in different fields (genetics, metabolic diseases, physical recovery, cerebral palsy, paediatric neurology, child psychiatry). And by sharing experience through lectures, scientific work in meetings and others. She applied for the position for Portuguese National Co-ordinator of the EACD, believing she has the skills to thrive and to help EACD to accomplish its purpose of developing high care to people with a childhood-onset disability and their families!

Spotlight: Sweden

Several research projects related to cerebral palsy are ongoing in Sweden. The unique access to National registries in Sweden makes it possible to increase our understanding of the development of individuals through their life. Diagnose specific follow-up programmes with regular systematic and uniform assessments assure high accountability. The ongoing studies of total populations allows for differentiation and comparisons between functional levels, sexes and age groups. The cerebral palsy follow up programme in Sweden originally started in 1994 as a hip surveillance of children and over the years it has developed into a multiprofessional health-care programme and quality registry. The programme involves orthopaedic surgeons, hand surgeons, neuropaediatricians, physiotherapists, occupational therapists, speech and language therapists, psychologists and certified prosthetists and orthotists.



Erika Cloudt, PT and co-founder of the EACD Early Career Researchers' Forum, is a PhD-student in Orthopaedics at Lund University. [Her research](#) will increase our understanding of the prevalence, risk factors and sequence of contracture development in the lower limbs. Erika's focus is primarily on [knee contractures](#), which are frequent as well as being the first contracture to develop in children classified at GMFCS levels III-V. She is also collaborating with the Orthopaedic and Rehabilitation Centre in Poznan lead by Professor Marek Jozwiak.



Jackie Casey, OT and facilitator of the EACD Family and User Forum is also a PhD-student in Orthopaedics at Lund University. [Her research](#) area is posture and mobility in children with cerebral palsy. She has a special interest in children and adults with severe motor impairments who are at risk of developing severe deformities such as windswept hip deformity and scoliosis. Her research contributes to the evidence base and understanding of the relationship between having postural asymmetries, inability to move or change position and pain. This has an impact upon the child's ability to maintain an upright sitting position and subsequently participate or engage in daily activities. Her work has also identified risk factors interfering with independent wheelchair mobility such as hand function, spasticity and upper extremity range of motion.

Mac Keith Press update

New publication: Gross Motor Function Measure (GMFM-66 & GMFM-88) User's Manual 3rd Edition



We are delighted to announce Mac Keith Press' latest publication: Gross Motor Function Measure (GMFM-66 & GMFM-88) User's Manual 3rd Edition by Dianne J Russell, Marilyn Wright, Peter L Rosenbaum and Lisa M Avery.

About the book

The third edition of the GMFM User's Manual has built upon the important work of the original 2002 and 2013 publications. This edition provides insight on estimating GMFM-66 scores using the GMFM-66-Item sets (GMFM-66-IS) and the GMFM-66-B&C (Basal & Ceiling), and updates are included on the Challenge module and the Quality FM, translations, and the use of the GMFM in populations other than cerebral palsy and Down syndrome. The new edition also includes information and an Appendix on the updated version of the Gross Motor Ability Estimator scoring program (GMAE-3), which is available through the GMFM App+

Please see this link for more information about the book as well as the opportunity to download the first chapter for free: [Gross Motor Function Measure \(GMFM-66 & GMFM-88\) User's Manual 3rd Edition – Chapter 1 \(free ebook\) \(mackeith.co.uk\)](https://mackeith.co.uk/Gross-Motor-Function-Measure-GMFM-66-GMFM-88-User-s-Manual-3rd-Edition-Chapter-1-free-ebook)

New DMCN Publication Highlights



[Barriers and facilitators of physical activity participation for young people and adults with childhood-onset physical disability: a mixed methods systematic review](#) by Mckenzie et al.

[Repeated onabotulinum neurotoxin A injections for drooling in children with neurodisability](#) by Bekkers et al.

[The long-term effect of COVID-19 on disabled people in low- and middle-income countries: the situation in Yemen](#) by Jonathan Delchambre

[Organizational perspectives and diagnostic evaluations for children with neurodevelopmental disorders](#) by Cloet et al.

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

Listen to the *Developmental Medicine & Child Neurology* podcasts:

Recent DMCN podcast highlights include:

'Should Doctors Work with the Pharmaceutical Industry? An Ethical Miasma' | Hank Chambers | DMCN | Watch on [YouTube](https://www.youtube.com/watch?v=VYKqc8Oj7u4) <https://www.youtube.com/watch?v=VYKqc8Oj7u4>

'Withdrawal of Antiseizure Medication and Seizure Recurrence in Epilepsy' | Julia Patrick Engkasan | DMCN | Watch on [YouTube](https://www.youtube.com/watch?v=d-0qPu7CxAw) <https://www.youtube.com/watch?v=d-0qPu7CxAw>

'Precision Medicine for Genetic Childhood Movement Disorders' | Audrey Soo & Arianna Ferrini | DMCN | Watch on [YouTube](https://www.youtube.com/watch?v=RcBSbH2L_7o) https://www.youtube.com/watch?v=RcBSbH2L_7o

'Sit-to-stand Training Self-care/Mobility in CP Children: Randomized Controlled Trial' | Nick Taylor | DMCN | Watch on [YouTube](https://www.youtube.com/watch?v=HOwpSqsRiDc) <https://www.youtube.com/watch?v=HOwpSqsRiDc>

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

Short updates

EACD Barcelona 2022

The 34th EACD Annual Meeting is going to take place in Barcelona, Spain from 18-21 May 2022! The EACD 2022 Organising Team is working hard to bring you an inspiring, high-quality programme under the Meeting Theme: "Networking Knowledge into Actions". The Meeting will be in hybrid format. Save the date and join us next year in Barcelona! For the latest updates on the EACD Barcelona 2022 Meeting, please visit regularly: <https://eacd2022.com/>


Irish Academy of Childhood Disability - Inaugural webinar

The theme of the Webinar launching the Irish Academy on 24 Sept 2021, 1pm-5pm (local time), is the F-Words and we are delighted that one of the Keynote Speakers is Peter Rosenbaum. Please keep an eye on the Twitter handle @IrishDisability for more updates and information on this event!

SAVE THE DATE: EACD Barcelona 2022

Join us at the 34th Annual Meeting
Meeting theme: "Networking knowledge into actions"
18-21 May 2022, Barcelona (Spain)

www.eacd2022.com



EACD 2022
34th ANNUAL MEETING
European Academy of Childhood Disability
"Networking knowledge into actions"
BARCELONA
18-21 MAY
www.eacd2022.com