

# EACD Newsletter

February 2022

## Message by the Chair

Dear colleagues,



Over the last few weeks I have had the luxury of spending time with a colleague whose judgement I value highly. We have been thinking about current and future priorities for the EACD. A statement we discussed was 'Adults are not big children'. Though this sounds obvious, it is a bit more nuanced than that, and especially so in our field of childhood onset disabilities.

In recent years the importance of taking a lifespan approach has been better recognised. We now have evidence that interventions early in life can have profound impact on life course and life chances for children with disabilities. A simple example is the opportunities that open up for exploration, socialisation and participation for an immobile child who is provided with powered mobility...and of course, the earlier the better. Similar examples can be offered across other functional domains covering hand use, communication, aids for vision and hearing.

What is less known about is the life course patterns of adults with a range of childhood onset disabilities. This is an evolving field, and it is very important that we systematically collect and disseminate this data to improve clinical care and provide better outcomes. We need to carefully document effects of gender, ethnicity, geographical regions causing variations of outcome, to be able to personalise our care.

Another worry is the huge knowledge gap that still exists in adult services about childhood onset disabilities. Most EACD members and colleagues we work with focus our care on the childhood disability population. We have designated services, specialist teaching/training courses, established academies and a thriving community of practice. There is expanding knowledge and healthy debate among interested people, driving forward better outcomes. Sadly, this is lacking for the same population when they become adults. Their care is often delivered by professionals trained in adult rehabilitation or by generalists who have sparse knowledge about these childhood onset conditions and their life course as adults. It is time to close this gap. Our responsibility to the children we serve extend beyond childhood, thus closing this gap should be one of the future priorities of the EACD. If you are interested and want to get involved, please get in touch. Adults are not big children, and we should strive to meet the needs of adults with childhood-onset disabilities better.

Best wishes and take care!

*Arnab Seal, Chair EACD*

## EACD Barcelona 2022

### Pre-conference symposia



The [full preliminary programme](#) for EACD Barcelona 2022 from 18-21 May 2022 is now online. EACD Barcelona 2022 promises to offer a wonderful opportunity to share experiences, to exchange scientific ideas, and foster interactions between all professionals involved in the field of Childhood Disability! We would also like to draw your attention the three exciting pre-conference symposia which will be organised by the EACD Barcelona 2022 Organising Team on Wednesday 18 May 2022, 13:00-17:00h CET!

Please click on the links below to learn more about these pre-conference symposia:

- 1) [Advances and new approaches for children with Autism Spectrum Disorders and their families](#)
- 2) [New insights in early detection and intervention in Preterm Infants](#)
- 3) [Controversies in Neuro-Orthopedics](#)

In order to register for the congress and/or one of the pre-conference symposia, please visit: <https://eacd2022.com/index.php/registration>

## Update from the EACD Newsletter Editor



It's coming to the end of my time as EACD newsletter editor. I thought I would take the opportunity to reflect on the last 6 years of holding this position. The communication landscape has changed significantly over the time of my tenure. EACD now has an active social media presence with 1,696 Twitter followers ([@EACDtweet](#)) and 806 [EACD Facebook group](#) members. Social media is a great way to connect clinicians and academics across Europe and beyond, in order to support the mission of EACD. Having both media platforms means that individuals can choose which one has most uptake in their individual countries. Social media has a key role in directing individuals back to the EACD website with targeted direction to blogs and lecture archive content.

I also want to celebrate how the professionalisation and family focus of EACD has developed. Much progress has been made in the last 6 years. Alongside other EACD committee members, my contribution has been to pull together a communication strategy and an action plan to increase visibility across professional groups, and develop partnerships with families.

Although COVID-19 has curtailed our travel across Europe, I feel honoured to have spent time both personally and virtually with a great group of people in all committees, and across so many countries. Thank you all very much and best wishes for the future.

*Dr. Lorna Wales, EACD GMC Member & Newsletter Editor*

## New National Co-ordinator: Iceland



We are happy to inform you about our first national co-ordinator for Iceland: Guðný Jónsdóttir! Mrs. Jónsdóttir is a certified specialist in Neurophysiotherapy and Posture Management with a M.Sc. in Health Sciences with a PGC in posture management from Oxford Brookes University. Her main speciality is prevention of secondary impairments, finding mobility, seating and positioning solutions with emphasis on participation, and she has specialized in habilitation, consultation and research of individuals with complex disabilities and long term care needs. Mrs. Jónsdóttir founded Endurhaefing, Rehabilitation-Centre of Excellence in 2004 when she was asked by the Minister of Health in Iceland to improve the overall rehabilitation for individuals with disabilities, and is one of the founders of the follow up program of people with cerebral palsy in Iceland (CPEF). Furthermore, she also serve as the national coordinator of the follow-up program for adults with cerebral palsy in Iceland, and is part of the multi-professional specialist team responsible for the national follow up of adults with CP in Sweden (CPUP). Finally, Guðný Jónsdóttir does part-time teaching at the University of Iceland and has lectured widely at home and abroad.

## The Elsass Foundation Research Prize



The Elsass Foundation acknowledges a researcher, who is making a significant impact in the field of cerebral palsy. Call for nomination is open now! Once every second year the Elsass Foundation Research Prize is awarded by the protector of the Elsass Foundation, HRH Princess Benedikte at the foundation's premises in Charlottenlund, Denmark. The prize

recognizes researchers that have - and continue to make - an exceptional contribution within the field of cerebral palsy (CP).

It is preferably given to one person only, but it may also be shared by several researchers. Nomination of candidates within all areas of CP research and sciences, with any professional background are welcome.

The Elsass Foundation Research Prize was founded and given for the first time in 2019. The first recipient of the award was Belgium Professor Bernard Dan and the second in 2021 was Professor Iona Novak from Australia. You can nominate your candidate for the Elsass Foundation Research Prize 2023 now. To be considered, nominations must be submitted [Here](#) in English in confidence before June 1, 2022.

## EACD 2021 Keynote Lectures are now online!



We are happy to announce an addition to our popular [EACD educational webpage](#)! The keynote lectures from the EACD Europe 2021 Annual Meeting are now available in the Meetings Archive section of our Educational Page:

<https://edu.eacd.org/eacd-europe-2021-archive>

### Day 1: Childhood Disability in the Era of COVID-19 - May 20th, 2021

[Reflections from a European perspective by the first President of the European Council](#) - Herman Count van Rompuy

[COVID-19 pandemic and child and adolescent mental health](#) - Jörg Fegert

[COVID-19 and the infant brain](#) - Carl Stafstrom

[Home-based intervention in childhood: can technology help?](#) - Giuseppina Sgandurra

### Day 2: Care, research and innovation, the new landscape of user-professional partnership - May 27th, 2021

[Just do it! Creating opportunities where researchers and parents can connect and learn about one another's experiences](#) - Rachel Martens & Jan Willem Gorter

### Day 3: Global Partnerships in a Changing World: - June 3rd, 2021

[What is the chemistry for a successful partnership?](#) - Mary Jane Platt, Andrea Guzzeta, Veronica Schiariti & Bernadette Gillick

[Nurturing partnership, strengthening care for every child's development](#) - Kate Milner

### Day 4: The Future of Childhood Disability - June 10th, 2021

[Technology and disability](#) - Annegret Kern & Robin Christopherson

[The future of disability services, towards new models](#) - Hannah Kuper, Christine Imms & Julia Hanes

[Genetics, ethics and childhood disabilities: what the future holds](#) - Laurent Servais, Jonathan Roberts & Kristien Hens

[Children with disabilities: the future of rights and participation](#) - Beyza Ünal & Judith Heumann

Full access to the EACD Education Hub is a great ongoing benefit of your EACD membership as the lectures are only available for EACD members. To access members-only content on Edu.EACD.org you need to press "EACD Login" button on top of the page and enter your username and password. Anyone with a clinical and/or scientific interest in childhood-onset disabilities can join us as an EACD member by following the [link here](#).

EACD membership is more than only a list of benefits. EACD membership is about supporting our mission to relieve individuals with a childhood-onset disability throughout Europe by the promotion of education and research into Childhood Disability. Nevertheless, EACD membership is accompanied with a number of [member benefits](#)!

# Upcoming General Management Committee Vacancies



The posts of **Chair-Elect** (Term 2022-2026; 1 year as Chair-Elect, 3 years as Chair), **GMC Member & Communication Officer** (Term 2022-2025), and **GMC Member & National Networks Officer** (Term 2022-2025) will be up for election at the next EACD Annual General Meeting (May 19th, 2022) during the EACD Barcelona 2022 Meeting. Dr. Arnab Seal will finish his term as Chair in 2023. Dr. Lorna Wales will finish her second term as GMC Member in 2022 and is not eligible for re-election. Prof. Jeroen Vermeulen will finish his first term as GMC Member in 2022 and is eligible for re-election. These positions offer an exciting opportunity to shape and guide the activities of the EACD. Should you have any queries about any of the vacancies, or interest in applying for any of these positions, please contact [Prof. Elegast Monbaliu](#), EACD Secretary, or [Prof. Nana Tatishvili](#), Chair of the Nominations Committee.

We would kindly like to ask members of EACD who would like to apply for any of the above-mentioned vacancies in the EACD General Management Committee to please send your Curriculum Vitae and Motivation letter to [admin@eacd.org](mailto:admin@eacd.org) by at latest March 31st, 2022 as part of the official election procedure.

## EACD RehaTech4Child Survey



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.

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

**Available languages:**

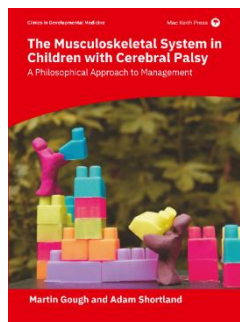
[English](#), [German](#), [French](#), [Spanish](#), [Italian](#), [Portuguese](#), [Turkish](#), [Polish](#), [Dutch](#), [Swedish](#), [Finnish](#), [Danish](#), [Romanian](#), [Ukrainian](#), [Georgian](#), [Croatian](#), [Serbian](#), [Slovene](#), [Lithuanian](#) and [Estonian](#).

## Mac Keith Press update

### Book highlights

**Now Published!** - [The Musculoskeletal System in Children with Cerebral Palsy: A Philosophical Approach to Management](#)

by *Martin Gough and Adam Shortland*



Do we need a paradigm shift in our approach to the assessment and management of the musculoskeletal system in children with cerebral palsy? This book encourages clinicians to reflect on how their thoughts and approaches are shaped by the clinical society. Using new perspectives and expertise, this book will inspire clinicians to rethink conventions about the child with cerebral palsy, consider how they communicate these new concepts to their fellow clinicians, and act to bring about positive changes in the management of children with cerebral palsy.

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

[SINDA: Standardized Infant NeuroDevelopmental Assessment](#)

Author Podcast with Mijna Hadders-Algra

[Classification of pain in children with cerebral palsy](#)

Author Podcast with Michael Vinkel

[Health service use among adults with CP: mixed-methods systematic review](#)

Authors' Podcast with Manjula Manikandan & Éabha Wall

## New DMCN Highlights

### *Editorial Services*

Mac Keith Press is delighted to launch the Mac Keith Press [Editorial Services](#)! The services are designed to help authors optimise their manuscript for publication. Language and/or technical support is provided for non-native English-speaking authors who plan to submit a paper to *Developmental Medicine & Child Neurology*, but will also help submissions to other journals. Authors are paired with an experienced professional who will provide valuable, quick, and efficient support, offering a better chance of the manuscript being accepted for publication.

Click [here](#) for more information.

### *New Virtual Issue: Epigenetics*

Epigenetics refers to complex mechanisms that regulate gene expression without changing the actual DNA sequence. DMCN's latest Virtual Issue, [Epigenetic mechanisms in human growth, development, and disease](#), has just been published and includes 10 papers that focus on varying aspects of epigenetics in neurodevelopmental disorders, from the epigenetics of fragile X syndrome to adverse childhood experiences, ageing and epigenetics to microbiome programming of brain development. New manuscripts will be added to this issue as the knowledge base for this important topic continues to grow, so keep your eye on the [page](#) for the latest developments!

### *DMCN Blogposts*

[Looking back on 2021: Books, courses, and more to come! – Mac Keith Press](#)

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

## Other Meeting Updates

### **IAACD / AusACPDM Better Together 2022**

The Combined 11th AusACPDM and the 3rd IAACD Conference 2022 will take place from 1-5 March 2022. It will be a fully virtual and accessible conference over four days with more than 100 sessions. All content will also be available for the delegates for three months after the conference. [Click here](#) to register for Better Together 2022.

### **BACD 2022 Annual Scientific Meeting**

The British Academy of Childhood Disability (BACD) has made the decision that its 2022 Annual Scientific Meeting on Thursday 17 March 2022 will be a fully virtual meeting. The 2022 BACD Annual Scientific Meeting will focus on Managing Pain in Childhood Disability, and registration fees for this event have been reduced by 50%. [Click here](#) to find out more.

### **EPNS Glasgow 2022**

The EPNS Congress from 28 April - 2 May 2022 is going ahead in-person in vibrant Glasgow, UK and virtually. In-person participants can dust off their passports and book with confidence for a unique chance to return to precious face-to-face networking whilst discovering Scotland in late Spring. Don't delay and register today! Visit the [congress website](#) to find out more.



## 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](#)

## SAVE THE DATE: EACD Barcelona 2022

Join us at the 34<sup>th</sup> Annual Meeting

Meeting theme: "Networking knowledge into actions"

18-21 May 2022, Barcelona (Spain)

[www.eacd2022.com](http://www.eacd2022.com)



This message was sent to you by European Academy of Childhood Disability  
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