

EACD Newsletter

March 2023

Message by the Chair

Dear friends and colleagues,



It is only 2 months before we all meet in Ljubljana for the EACD 35th Annual Meeting and I know this time will pass quickly. There is an excellent main scientific program, plus the coming together of various Special Interest Groups (SIGs) & committees, debates & deliberations over coffee breaks and taking forward many European and international initiatives. Katja Groleger Srsen, Meeting President, and her team have tried their best to accommodate every request which have come their way to make sure we are meeting

everyone's needs. The organising team have my gratitude for such generosity.

I am looking forward to this meeting with excitement and a tinge of sadness. It is the sadness of letting go of something close to my heart. I have had the privilege of serving as your Chair for the last 3 years and my EACD colleagues, along with managing EACD matters, have become an integral part of my life. I certainly will miss that.

I am very proud of what the EACD has achieved during these past few years. The achievements span across science and education to policy, governance and much more. We are changing as an organisation, redefining parts of our identity and making our voice heard about all the issues we care about.

As part of these changes we now have established Education and Training Committee, in addition to the Scientific Committee, which ensures that we have an educational and research programme throughout the year in addition to the Annual Meeting. Elisabet Rodby-Bousquet has led this team and given it strong leadership. She steps down this year and the election for this post will soon commence. Christopher Newman has served brilliantly as our Scientific Committee Chair for two terms and hands over the role to Annemieke Buizer from the Netherlands. We also have active Task Forces and Working Groups addressing important questions in our field, from Technology & Innovation, Life course approach and Cerebral Visual Impairment.

The EACD now has an established Families and Users' Forum with members representing the family and users' voice in everything that we do. Under the able leadership of Niek De Taeye and Teresa Mano da Costa the group has already contributed hugely to the Annual Meeting and our Education & Training priorities. My gratitude also to Alain Chatelain who has over the years guided us in this direction.

Another great achievement has been the regular activities and programmes of our National Co-ordinators, led by Jeroen Vermeulen. There are regular meetings to discuss scientific issues, updates on local academies and identification of needs of different communities across Europe. The bonds of collaboration and friendship across the various European networks have been greatly strengthened through the activities of this group and we also have a greater understanding of each other's needs.

Our Communication Committee, led by Jackie Casey, has increased our presence in social media. Jackie is also taking on the leadership of the Ethics & Compliance Committee whose work is becoming increasingly relevant as we increase our activities and presence in all spheres. The EACD website remains an amazing resource, all thanks to the enormous work of Oleh Kachmar, who in spite of the current situation in Ukraine continues to provide his invaluable services.

The EACD Early Career Researchers' Forum has matured rapidly into a strong group with a good governance structure. There are many who have made this possible including the current executive team

of Erika Cloodt, Inti Vanmechelen and Teresa Joyce. The group now has representation in all the EACD committees and has contributed to the Strategic Plan for the next three years.

While these activities are very significant, of no less importance is the huge change we have achieved in our governance structure of the EACD, moving from being a UK charity organisation to an EU based INPA. This has required an enormous amount of work and I thank particularly Marco Konings, our EACD Administrator, for his huge contribution. My huge thanks also go to Elegast Monbaliu, Secretary, and Therese Millar, Treasurer, who as part of the Executive Committee have been an active part of all decisions big and small. They have given their time, expertise, support and friendship generously, and there are no words I have which could thank them enough.

It has been a time of turbulence through my term as Chair, with the challenge of the pandemic lockdowns, the conflict in Ukraine, major economic pressures and environmental disasters. It has adversely affected the children and families who are at the centre of all the EACD is about. The EACD has come through these challenges and are stronger for it. As I get ready to hand over the reins of this organisation, I know that I could not find any better pair of hands than that Bernard Dan. Bernard has been part of the EACD and its various committees for many years. He not only knows this organisation well but also has a brilliant understanding of the European and global priorities in our field. The EACD has strong foundations and is ready to be even bigger and better. I know Bernard's wisdom will lead us to fulfil these ambitions. Most importantly, I thank you, the membership, for your continued support for this wonderful organisation and sharing in its mission and values.

Arnab Seal, Chair

EACD Ljubljana 2023

Regular Registration Deadline



It is a great privilege and pleasure for the EACD Ljubljana 2023 Team to welcome you to Ljubljana, Slovenia from 24-27 May 2023! Following the outstanding line of previous EACD annual meetings, we will do our best in offering an excellent opportunity to share experiences, exchange scientific ideas, and foster interactions between all professionals, children and their families. 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. 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 childhoodonset disability: Helene Polatajko, Emma Livingstone, Laurent Servais, Muharrem Yazici, Minna Ståhl, Izzeldin Abuelaish, Sylvain Brochard, Niek De Taeye and Ruslan Vasyutin!

Slovenia, your host country, tells its green story. Everything is green no matter which direction you turn – towards the Alpine peaks and extensive forests, the Adriatic Sea, the mysterious Karst and nearby vineyards, and the Pannonian Plain. Ljubljana, the capital city, is a vibrant city with thousands of years of history. The European Green Capital 2016 has in a short time become a model of livability and ecosustainability for all medium-sized cities in Europe. Our conference venue is in the city centre, which is closed to traffic. The local Scientific and Organizing committee hopes to greet you in person. Plan your schedule to make the most of your Ljubljana visit. Build your clinical skills with scientific and educational sessions, satellite symposia, oral presentations, in-person networking opportunities, and much more!

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!

EACD Summer School 2023



The European Academy of Childhood Disability is proud to announce the 2nd EACD Summer School! The **EACD Summer School 2023** is a 5-day training course for early career researchers from a Monday morning to Friday afternoon, organized by the European Academy of Childhood Disability together with the Poznan University of Medical Sciences from 17-21 July 2023 in Poznan, Poland.

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.

At the end of the course the participants will be (i) familiar with the recommended methods for all stages of the research process, including identifying the research question, methodological considerations, good clinical practices, and how to write, publish and communicate your research findings; (ii) able to choose and develop the appropriate instruments and measurements tools for conducting research in the area of childhood-onset disability; (iii) aware of the specific challenges related to conducting clinical care and research with people with childhood-onset disabilities and their families, and be equipped to anticipate and overcome them; (iv) able to integrate the newly acquired knowledge to advance their practice clinical and research career; (v) able to build on their knowledge to foster regional and international partnerships.

Application Deadline: 31 March 2023, 23:59 CET

Click here for more information on how to apply for the EACD Summer School 2023!

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 <u>link here</u>.

Technology & Innovation Task Force Update

Digital technologies such as robotics, virtual reality or telehealth can be used as part of paediatric motor rehabilitation to remediate impairment, promote recovery and improve function, activities and participation. However, the uptake of digital technologies in this clinical field may be limited in clinical practice. Therefore, the EACD Technology & Innovation Task Force performed the European-wide survey



"RehaTech4Child" with the aim to assess digital technology use for paediatric motor rehabilitation. Thanks to your contribution and support, more than 1350 answers have been gathered from 34 EACD-member countries: thank you very much for your answers! The main survey results will be presented during the EACD 2023 Congress in Ljubljana during the Technology & Innovation session on Friday 26 May 2023 between 4:30 PM and 5:45 PM (local time).

Update from Spain



In Spain, an international congress was held in Seville on 16 and 17 February 2023 under the slogan: "Cerebral palsy affects us all, an interdisciplinary approach". Different disciplines (orthopaedic surgeons, rehabilitation doctors, physical therapists, occupational therapists, speech therapists, neuropaediatricians, etc.) as well as users and families with children with cerebral palsy participated in this scientific event. The congress was organized by the "Antonio Guerrero Foundation", founded by the

grandparents of a child with developmental disorders. These grandparents as presidents of this foundation have achieved many accomplishments in the Andalusian community and many of these achievements were made known at this event.

Speakers from abroad and from different disciplines were invited such as Dr. Hank Chambers, Professor Iona Novak, Dr. Elke Viehweger, Dr. Turriago from Colombia, Dr. Ginny Paleg, Dr. Presedo, as well as national speakers also from different disciplines and involved to different scientific societies, such as the Spanish Association of Infantil Rehabilitation (SERI), the Spanish Pediatric Physical therapy Association (SEFIP), the Spanish Society of Paediatric Orthopaedics (SEO), Spanish Neuropaediatric Association (SENEP), and the Spanish association of speech therapists (AELFA). Hot topics of current orthopaedic surgical procedures were discussed with exchange of results among the attendees. Topics such as function should be a priority in the goals of children with developmental disorders, how mobility aids are a way to promote physical activity in children with severe developmental disorders with GMFCS levels IV and V; evidence on motor interventions, early intensive therapies in children with unilateral impairment, assessments prior to medical or surgical procedures, training and support of families, oropharyngeal dysphagia, etc. and many more topics including topics for discussion among professionals. I was also invited myself to speak about the topics of 'Standing upright', and 'From Hands-on to Hands-off in the clinical practice of physiotherapy in pediatrics', emphasizing here how in our discipline there has been an important change in clinical practice due to theoretical models that have changed in line with advances in neuroscience. In our country, as surely in others, some outdated therapeutic approaches developed in the last century are still used by some in clinical practice. And considering that scientific evidence is still low for many therapeutic interventions in cerebral palsy, it is important that we have a solid clinical reasoning according to current knowledge about: neuroplasticity, motor and control learning, muscle physiology, biomechanics and the ICF.

One of the most interesting moments was the roundtable at the end of the congress where professionals, users and families came to a summary of conclusions on how we should proceed to the future and how we all, especially professionals, should work, strive and improve our practices. This included a shared understanding to include families more and better in therapeutic, medical and surgical decisions, to work more as a (multidisciplinary) team between different disciplines, and to promote more and better family support.

Dra. Lourdes Macias, EACD National Coordinator of Spain

Upcoming GMC Vacancies



Training Officer (Term 2023-2026) will be up for election at the next EACD Annual General Meeting (May 25th, 2023) during the EACD Ljubljana 2023 Meeting. Therese Millar will finish her second term as Treasurer in 2023 and is not eligible for re-election. Prof. Elisabet Rodby Bousquet will finish her second term as GMC Member in 2023 and is not 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

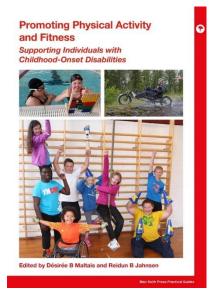
vacancies, or interest in applying for any of these positions, please contact Prof. <u>Elegast Monbaliu</u>, EACD Secretary, or Prof. Nana Tatishvili, Chair of the Nominations Committee.

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 by at latest March 31st, 2023 as part of the official election procedure.

Mac Keith Press update

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

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 <u>ALL BOOKS</u> from a collection of 150+ titles from Mac Keith Press. Please visit <u>this</u> <u>page</u> and log in as EACD member to find the **special discount codes** to apply at checkout)

DMCN Podcasts

<u>Single-case experimental designs for child neurological rehabilitation & developmental disability research</u>

Author Podcast with Agata Krasny-Pacini

<u>Chronic pain interference assessment tools for children/adults unable to self-report</u>
Author Podcast with Meredith Smith

<u>Neurodevelopmental profile and stages of regression in Phelan–McDermid syndrome</u> Author Podcast with Yumi Dille

DMCN - Key papers this month

How to make research accessible and meaningful for individuals with lived experience Invited Editorial by the AACPDM Community Council

Longitudinal development of hand use in children with unilateral spastic cerebral palsy from 18 months to 18 years

By Ann-Christin Eliasson and colleagues

<u>Psychological interventions targeting mental health and the mother-child relationship in</u> autism: Systematic review and meta-analysis

By Kavindri Kulasinghe and colleagues

Accelerometer-measured physical activity, sedentary behavior, and sleep in children with cerebral palsy and their adherence to the 24-hour activity guidelines

By Raquel Y. Hulst and colleagues

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

Other Meeting Updates

Handicaps et Mouvements 2023 Congress

On 12-14 April 2023, The French societies SOFOP, SFERHE and SOFAMEA will jointly organise the Handicaps et Mouvements (Disabilities and Movements) congress in Saint Etienne. <u>Click here</u> 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 super early bird registration and abstract submission close at Friday 31 March 2023, 23:59h 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



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

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