

# EACD Newsletter

February 2023

## Message by the Treasurer

Dear colleagues,



I am writing this on the anniversary of the beginning of the invasion of Ukraine, and in the aftermath of the devastating earthquake in Turkey and Syria. We continue to send our thoughts and prayers to the EACD members and their families who have been directly affected by these catastrophic events. There has been a lot of practical help offered by the EACD and its members to support families and young people who have childhood-onset disabilities, as well as our community who have been directly affected. The

European Academy of Childhood Disability has been, and still is, trying to facilitate inter- and intra-regional cooperation to support health care centers for people with a disability in Ukraine and neighbouring countries. Many of these centers are still facing several challenges, including the need for correct treatment advice, access to the right medicine, equipment, and medical devices. In this respect, professional organisations or individuals who are able to provide any form of support to people with a childhood disability affected by the war can still indicate what kind of support they are able to provide via the [link here](#).

The [preliminary programme](#) of the EACD 2023 conference has been published recently and it promises to be a very exciting and thought provoking conference with great speakers and topics! More information on EACD Ljubljana 2023 you can find later on in the newsletter. We invite all (family members of) people with lived experience who would like to attend the EACD 2023 conference in Ljubljana, but might have difficulty financing it, [to apply for a family bursary](#). The application deadline for these family bursaries is 28 February 2023!

The General Management Committee of the EACD met earlier this month to continue the work on the strategies to take us forward for the next three years. Six key areas have been identified in this respect: 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 advocate for the rights of people with childhood-onset disabilities, and their families, throughout Europe and beyond; 5) To foster the development of International, Regional and National Networks; 6) To continue to build a stable and sustainable organizational and financial structure.

An important first milestone, we hope to achieve already by the end of this financial year, when all business will be concluded as a UK based charity and the EACD will continue as an European INPA (International Not-for-Profit Association). This will be a brand new start for the new treasurer coming into post and I look forward to handing this over to someone who is enthusiastic and would like to take this role on ( full handover support will be given!) There is more information further on about the formal application process and I would be happy to talk to anyone who might be interested in this role!

*Therese Millar, Treasurer*

# EACD Ljubljana 2023

## Full Preliminary Programme Now Online!



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 childhood-onset disability: Helene Polatajko, Emma Livingstone, Laurent Servais, Muharrem Yazici, Minna Ståhl, Izzeldin Abuellaish, 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 eco-sustainability 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.

[Click here for more information about the EACD Summer School 2023 and how to apply!](#)

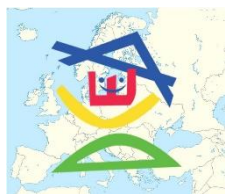
## Upcoming General Management Committee Vacancies



The posts of **Treasurer** (Term 2023-2026) and **GMC Member + Education & 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. [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, 2023 as part of the official election procedure.

## Update from Switzerland



On the 26th of January, the 2nd Research Day of the Swiss Academy of Childhood Disability took place in Berne (Switzerland). In this edition, we gathered about 50 researchers who presented their current, ongoing and future work in the form of 5-minutes talks. We had the pleasure to start with a keynote lecture given by Prof. Stephane Armand (University of Geneva), who talked about "Why our research must be collaborative and move towards Open Science". One of the take-home messages from this keynote was "Science is a common good".

The talks started with the study protocol session, which gives us the chance to take on advice from colleagues and improve your study before its start. We had many varied topics including participation, genetics, electrostimulation and neural correlates. The preliminary results and finalized studies sessions were filled by very high-quality research that impressed the scientific committee. The chosen format with short presentations allows the audience to listen to the main message of the study and allows more time for questions. Some Master and Bachelor students dared to share their work in these sessions, and some of them even won a prize – Congratulations to all the winners!

Finally, we got to the Early Career Researchers Forum, where we had networking group discussions (industry, participatory research and grant writing) and decided to use a bottom-up approach on the future of this group.

We are very grateful to the Anna Müller Grocholski Foundation for their kind support in the organization of the 2nd Research Day of the Swiss Academy of Childhood Disability.

More information about this SACD Research Day can be found at: <https://www.sacd.ch/de/researchday>

*The 2nd SACD Research Day Organization Committee: Petra Marsico, Cristina Simon-Martinez, Christopher Newman, Sandra Hunziker, Anne Tscherter and Sebastian Grunt*

# 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

### Promoting Physical Activity and Fitness

Supporting Individuals with Childhood-Onset Disabilities



Edited by Désirée B Maltais and Reidun B Jahnsen

Mac Keith Press Practical Guides

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.

**Publication date:** 28/02/2023; [Click here to pre-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

### [Interventions for children & young adults with non-ambulant CP](#)

Authors Podcast with Lynore McLean, Ginny Paleg & Roslyn Livingstone

### [Viewing disability: seeing the other side](#)

Authors Podcast with Anna Basu, Kathleen Friel, Bolajoko Olusanya & Mijna Hadders-Algra

## DMCN - Key papers this month

### [State-of-the-art therapies for Rett syndrome](#)

By Nicolas Panayotis and colleagues

What this paper adds:

- Recent advances shed light on the promises of gene replacement therapy with new vectors designed to control the levels of MeCP2 expression.
- New developments in DNA/RNA editing approaches or reactivation of the silenced X chromosome open the possibility to re-express the native MeCP2 locus at endogenous levels.
- Current strategies still face limitations in transduction efficiency and future work is needed to improve brain delivery.

## [Transition to adult services experienced by young people with cerebral palsy: A cross-sectional study](#)

By Jennifer Ryan and colleagues

What this paper adds:

- Many young people with cerebral palsy (CP) do not receive support that may improve the experience of transition.
- Appropriate protocols and training for health professionals may improve the provision of transition and reduce inconsistency in care between and within organizations.
- Young people and their families should be involved in service design, delivery, and evaluation related to the transition to ensure it meets their needs.

## [A core outcome set for lower limb orthopaedic surgery for children with cerebral palsy: An international multi-stakeholder consensus study](#)

By Hajar Almoajil and colleagues

What this paper adds:

- Eight core outcome domains were identified as important to measure in future clinical research.
- Key stakeholders perceived pain, balance and fall, and independence as very important outcomes.
- Six contextual factors were identified as essential in surgical decision-making.

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

## Other Meeting Updates

### National Symposium of the Belgian Cerebral Palsy Reference Centra

On Saturday 4 March 2023, the National Symposium of the Belgian Cerebral Palsy Reference Centra will take place at UZ Leuven, Belgium under the theme 'There is tension in the air'. [Click here](#) for more information.

### 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. [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](http://www.eacd2023.org)



**EACD 2023**  
Ljubljana

SMARTER GOALS FOR BETTER FUTURE

24 – 27 May 2023