

EACD Newsletter September 2023

Message by the Secretary

Dear Friends, Members, and Colleagues,



As a researcher, clinician, industrial partner, or policy maker, you want your work to make a difference. You want to make a **positive long-term impact**, in the domain you work in, but also for the people you are working with and their community. We as EACD of course also have to think about this. It is important to consider how can we make our EACD Annual Meeting more than just a scientific congress that comes to an European city and leaves again.

That is, international conferences are an important means of stimulating debate, disseminating knowledge and developing informal networks. But does our Annual Meeting really makes a difference for people with childhood-onset disabilities and their families from the region?

This asks us to think about **what legacy we want to create** at a local level for the hosting country of our event? In this respect, we have seen in the past that EACD Annual Meetings have played a big role in bringing people and networks together at National level, leading to stronger and better collaborations in the subsequent years. This is great of course, but how do we measure this impact on the local community? And how can we ensure these changes from activities linked to our Annual Meeting live on in a sustainable way?

Coming from this, for the first time in the history of our Academy, a separate unit has been set up for our EACD Bruges 2024 Meeting in addition to the "traditional" Local Organising Committee and Scientific Congress Committee: the **EACD 2024 Impact Task Force**. The purpose of this Task Force is to set a pathway to generate and measure broader societal impact around the EACD2024 congress in a systematic and sustainable way. Based on the Theory of Change, and in close collaboration with experts from VisitFlanders and Meet4Impact International, this group is working on defining, managing, measuring and communicating the societal impacts of the planned activities in a stepwise approach:

1) Defining the **intentions to generate impact** for the benefit of people with childhood-onset disabilities through the EACD Annual Meeting;

2) Building and engaging a wide group of stakeholders around this vision;

3) Use the momentum of the Annual Meeting to plan **legacy** project **activities** around the congress;

4) Assess the value created by the event and report on the impact generated.

Impact intentions have been defined on the desired change linked to the topics **Accessibility**, **Research**, **and Technology**, and will be communicated to you in the upcoming months. And we hope to see you in Bruges of course at the end of May 2024 to witness the planned legacy activities around our EACD 2024 Annual Meeting!

Elegast Monbaliu, Secretary EACD

EACD Bruges 2024

General Call for Abstracts deadline is approaching!



The general Call for Abstracts deadline for EACD Bruges 2024 is approaching! The scientific committee of the 36th Annual Meeting of the European Academy of Childhood Disability (EACD) invites you to submit your abstracts for instructional courses, oral communications and/or poster presentations.

The deadline for abstract submissions is October 20th, 2023, 23:59h Central European Time (CET). After undergoing the reviewing process, all authors will be informed by December 11th, 2023 at latest on the formal acceptance or rejection of the submitted abstract(s). Be aware that only abstracts following the Guidelines for Abstract Submission (see here) will be accepted.

Thank you for considering submitting an abstract for EACD2024. Do not hesitate to encourage your colleagues and those from other fields working on developmental disability to do so as well, in the spirit of the theme of the meeting: 'Composing a new symphony'.

Oral communication

Oral communication sessions consist of a group of talks within a theme by individual participants. Presentations of 7 minutes each will be scheduled in concurrent sessions of 60-minutes with space for live discussion/Q&A with all speakers of the session, led by a scientific/clinical moderator.

Please structure your abstract for an oral communication using the following headings:

- Introduction
- Patients and methods
- Results
- Conclusion

Scientific Poster

Scientific Posters provide the opportunity to present novel methods and findings and include discussion on-site. Scientific Posters will be sorted by theme. Scientific Posters will be on display during the conference and dedicated poster sessions will be organised.

Please structure your abstract for a scientific poster using the following headings:

- Introduction
- · Patients and methods
- Results
- Conclusion

Technology & Innovative Product Poster (NEW)

Technology & Innovative Product Posters provide the opportunity to present new, innovative products, tools and/or technologies relevant to the area of childhood-onset disability and include discussion on-site. Ideally, these should be solutions that can be quickly implemented in routine practice and/or in daily life. Products, tools and/or technologies that have been piloted or implemented are encouraged. These abstracts should include information that allows session attendees to evaluate the usability and effectiveness of such a product, tool or technology. This category is intended for descriptive abstracts as well as products with more rigorous evaluations. Technology & Innovative Product Poster will be sorted by theme.

Each Technology & Innovative Product Poster will be on display during the conference and dedicated poster sessions will be organised.

Please structure your abstract for a Technology & Innovative Product Poster using the following headings:

- Statement of problem
- · Description of the product or technology
- Findings to date
- Practical applications

Instructional Course

Instructional courses are didactic sessions of 75-min in the morning with at least 2 instructors addressing a focused theme or method with appeal to a targeted audience. Examples are new assessments, investigations, techniques, treatments etc. The courses shall be interactive and practical.

Please structure your abstract for an instructional course using the following headings:

- Objective
- · Learning objectives of the course
- Summary
- Outline of the course

Abstract Submission deadline: 20 October 2023

Submit your abstracts now!

Go to the EACD Bruges 2024 Abstract Submission page!

Visit the EACD Bruges 2024 website

EACD 2024 Bursary Application deadline is today!



To support professionals from low income countries who may otherwise not be able to attend EACD Bruges 2024, the EACD Bruges 2024 Organizing Committee is providing a number of bursaries for both professionals and families for on-site participation. The EACD Bruges 2024 Organizing Committee seeks out applicants who are highly motivated, and who are ready to disseminate knowledge acquired at the meeting to others in their home country once they return. Particular emphasis is placed on assisting those from <u>Hinari countries</u>.

Bursary recipients receive:

- Waived on-site registration to EACD Bruges 2024;

- Valuable networking opportunities;

- Opportunity to learn from multi-disciplinary experts in the field of childhood-onset disabilities.

Application process

To apply for an EACD 2024 Bursary, please visit <u>https://eacd2024.org/bursaries/</u> and submit your application via the Bursary Application tool by at latest **Friday 29 September 2023**. Please note incomplete applications will be rejected.

Submit your application now!

Go to the EACD 2024 Bursary Application page!

Visit the EACD Bruges 2024 website

Update from the Early Career Researchers' Forum:

Welcome to the new board members!



On September 28th, the first Early Career Researchers' (ECR) Forum Annual Meeting took place. This online Annual Meeting started with an inspiring lecture by Prof. Christopher Morris, further exploring the theme of family and patient involvement. Prof. Chris Morris leads PenCRU (the Peninsula Childhood Disability Research Unit), which undertakes a programme of applied health research aimed at identifying ways to improve the health and wellbeing of disabled children and their families. PenCRU involves families of disabled children as partners in all the activities of the unit through our Family Faculty. In the session, Prof. Morris provided a brief overview of the Patient and Public Involvement and Engagement (PPIE)

landscape, where it has come from and its rationale. He shared also his experience of how PenCRU have partnered with families across a range of studies to drive and shape their research, and outlined examples of good practice in childhood-onset disability research and reporting guidelines for PPIE so we can learn together. This lecture has been recorded and will be published on Edu.EACD.org in due course.

After this lecture, around 19.30h CET, the formal ECRF online Annual Meeting started, during which the ECRF Board presented their planned activities, and acknowledged the outgoing ECRF Board members for their work (Thank you Inti Vanmechelen, Teresa Joyce, Anna Kushnir, Karen Lennon, and Selamenesh Tsige!). Following the application and selection procedure, the ECRF announced and welcomed the newly incoming ECRF board members: Dilara Bozgan, Irene Gonzalez Eiroa, Montse Blasco, Mari Naaris, Annemarie Knijnenburg, and Meltem Celik!

If you want to know more about the Early Career Researchers' Forum, please have a look at: <u>https://www.eacd.org/EACD-ECR-Forum</u>

Update from Moldova & Romania



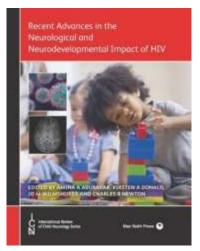
On September 20th, 2023 the EACD (together with IAACD) supported an online event in Moldova & Romania. This online event involved an interactive presentation from Prof. Peter Rosenbaum on among other things the F-words and the importance of a lifespan perspective. The event, organised by Liana Nagy & Ecaterina Gincota, was joined by 250-300 attendees from Romania and Moldova with simultaneous translation from English into Romanian, and was a starting point for further collaboration in the region.

Mac Keith Press update

Available for pre-order: Recent Advances in the Neurological and Neurodevelopmental Impact of HIV

International Review of Child Neurology Series

Edited by Amina A Abubakar, Kirsten A Donald, Jo M Wilmshurst & Charles R Newton



Recent Advances in the Neurological and

<u>Neurodevelopmental Impact of HIV</u> brings together worldleading experts in the field of HIV, to provide new and critical insights into HIV treatment and management for children and adolescents. Those infected with HIV are living longer thanks to antiretroviral drugs, and HIV-related neurological and neurodevelopmental disorders therefore require urgent attention, particularly complications which arise from long-term medication use .The authors summarise key findings in these important areas, as well as gaps in research and implications for paediatric HIV work. Readers will discover ways of optimising the neurological health of children and adolescents living with HIV through better care provision and earlier intervention.

- Outlines the important clinical neurological issues facing children and young adults with HIV infection

- Presents up-to-date diagnostic and treatment approaches

- Provides practical clinical strategies to improve the care of children and adolescents with HIV

An essential resource for all clinicians involved in the care of children and adolescents with HIV and their families, including doctors, paediatricians, psychologists, and other health practitioners and researchers.

--20% off for EACD members--

(Simply enter the <u>EACD discount coupon code</u> when pre-ordering)

DMCN Podcasts

Developmental trajectories of SLC and functional communication in children with CP

Author Podcast with Emma Vaillant

HipScreen mobile app for the measurement of hip migration % in children with CP

Author Podcast with Vedant Kulkarni

Measuring grip strength in adolescents and adults with CP in a clinic setting

Author Podcast with Ed Hurvitz

F-words and early intervention ingredients for non-ambulant children with CP

Author Podcast with Carol de Campos

DMCN - Key papers this month

Prevalence and incidence of chronic conditions among adults with cerebral palsy: A systematic review and meta-analysis By Jennifer Ryan and colleagues

Consensus on level descriptors for a functional children's eating and drinking activity scale By Emily Hanks and colleagues

Cognitive behavioral therapies for individuals with cerebral palsy: A scoping review

By Tamar Silberg and colleagues

Pain and neurodevelopmental outcomes of infants born very preterm By Vito Giordano and colleagues

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

Other Meeting Updates

DACD 2023 Congress

On 24 November 2023, the Dutch Academy of Childhood Disability (DACD) will be organising its Annual Symposium in Nijmegen, The Netherlands on 'Transition to Adulthood' (in Dutch). For more information, please click <u>here</u>.

IDPA 2023 Congress

From 28 November to 1 December 2023, the International Developmental Pediatrics Association (IDPA) will be organising its 5th Congress in Johannesburg, South Africa on 'Our children our future, from vulnerability to resilience'. For more information, please click <u>here</u>.

SACD Research Day 2024

On 25 January 2024, the Swiss Academy of Childhood Disability (SACD) will be organising its 3rd Research Day in Bern, Switzerland. Abstract submission is open until 31 October 2023. For more information, please click <u>here</u>.

