

EACD Newsletter

April 2022

Message by the Secretary

Dear colleagues,



We are living in challenging times: The importance of international collaboration is learned to all of us in Europe again the hard way via the war in Ukraine. As the greatness of a society can be judged by how it treats its most vulnerable, there is a great responsibility for all of us to provide any possible help we can to children with a disability and their families from Ukraine. As stated in our [Open Letter](#) earlier this month, a number of actions for children with disabilities from Ukraine are urgently needed and require a joint effort from all key players. From the health boards within different countries, non-governmental organisations, patient organisations, to local authorities and many other important players, including EACD.

We are living in collaborative times: From its foundation, EACD has always believed in the principle that via collaboration and building bridges we can do more for the benefit of people with childhood-onset disabilities. EACD has always been a multidisciplinary organisation with the people with a childhood disability as its central focus rather than a specific profession. And I'm happy to say that collaboration is alive and kicking within EACD, and it is ever expanding! In the last year, EACD has welcomed two new countries (Estonia and Iceland) within our [network of National Coordinators](#), bringing the total to 32 countries. These National Coordinators are essential in the work we do as organisation by building collaborative networks within a country and to build bridges between regions! EACD is also trying to build bridges between clinicians and engineers via our [Technology & Innovation Task Force](#), by identifying the currently used technologies, and by stimulating collaborative efforts towards finding new solutions for the benefit of people with childhood-onset disabilities.

We are living in networking times: As the first EACD Congress which allows in person participation again since 2019, [EACD Barcelona 2022](#) next month 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! On top of this the 34th EACD Annual Meeting in Barcelona will mark a very important milestone in the history of EACD. In recent years, the participation of users and families within our activities has become more and more, but in May 2022 the EACD Families and Users' Forum will be finally launched officially, to ensure representation of the voices of individuals with a childhood-onset disability, their families and close others concerned across Europe in the decision-making of all of EACD's organized plans and actions.

We are living in future-oriented times: We are proud on our [EACD Early Career Researchers' Forum](#), led by Early Career Researchers (ECRs) for the ECRs community across Europe active in the area of childhood-onset disability. Launched less than a year ago, they already feel as an indispensable part of EACD and they have created with their infectious enthusiasm a place for ECRs to find and discuss opportunities, learn from others, share experiences, get to know your colleagues, mentor peers, and create impact through community engagement! And I highly encourage all early career researchers (and clinicians) who are planning to be at EACD Barcelona 2022 to join the planned sessions of the EACD Early Career Researchers' Forum!

Finally, we are living together and we should be ambitious! This is the time to reach out our hands out to each other. This is the time to build bridges. This is the time to strengthen our collaboration with longstanding and new partners. And lets invite you all to join in this ambition. Because every step we are able to take together towards a better society, and for EACD specifically for the benefit of people with childhood-onset disabilities, is a victory for us all.

Best wishes and take care!

Elegast Monbaliu, Secretary EACD

Support to Ukraine & neighbouring countries



The war in Ukraine due to the invasion by the Russian Army is having a devastating impact on the country's children with disabilities and the implications for this vulnerable group cannot be underestimated. In response to the situation EACD has published among other an Open Letter in April 2022 with an appeal for actions for children with disabilities inside Ukraine and refugee-host countries.

To read our full Open Letter with our appeal for actions, in English or in Ukrainian, please visit: <https://www.eacd.org/openletterukraine>

In addition, many health care centres for people with a disability in Ukraine and neighbouring countries are currently facing several challenges, including the need for correct treatment advice, access to the right medicine, equipment, and medical devices. In order to bring efforts together from across Europe to support these professional organisations, the European Academy of Childhood Disability has created two questionnaire tools to facilitate inter- and intra-regional cooperation and support initiatives between professional organisations across Europe. Based on the responses, the EACD and its partners will attempt to coordinate all efforts from across Europe for the benefit of people with a childhood-onset disability.

- One questionnaire tool allows any professional organisation **who is able to provide any form of support** to people with a childhood disability affected by the war to indicate what kind of support they are able to provide.

This may include among other the provision of equipment (e.g. wheelchairs/assistive devices), provision of essential medicine, provision of treatment to children who fled the country, and/or provision of medical devices needed in medical institutions.

- The other questionnaire tool allows any professional organisation **who needs support** to indicate what kind of support they need exactly.

This may include among other the provision of equipment (e.g. wheelchairs/assistive devices), provision of essential medicine, provision of treatment to children who fled the country, and/or provision of medical devices needed in medical institutions, etc..

The two questionnaire tools and more information about this Support to Ukraine initiative can be found at: <https://www.eacd.org/supportukraine>

EACD Barcelona 2022

Full Preliminary Programme Now Online!



The [full 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 are also happy to inform that that **simultaneous translation into Spanish** will be provided for all the #EACD2022 Keynotes, plus a full Spanish track throughout the entire congress programme!

- Please click here to learn more about the [full EACD Barcelona 2022 Programme!](#)

- Please click here to learn more about the [EACD Barcelona 2022 Keynote Speakers!](#)

- Please click here to learn more about [in person and/or virtual registration for EACD 2022!](#)

Early Career Researchers' Forum Special Interest session



The EACD Early Career Researchers' Forum (ECR) are very pleased to invite you to the ECR session at the EACD Barcelona 2022 congress - Room 3 on Thursday May 19th!

ECR Session programme:

07:30am – Welcome & ECR Introduction

07:35-08:10 am – "How to write a good manuscript in childhood disabilities" by Prof. Bernard Dan, Editor in Chief of Developmental Medicine & Child Neurology

08:10-08:45 am – "How to write a good funding application" by Dr. Cristina Simon-Martinez, Marie-Curie postdoctoral fellow at HES-SO Valais-Wallis.

All interested EACD 2022 delegates may [register for this session via the link here!](#)

Did you know the EACD Early Career Researchers' Forum is also active on Twitter now? Follow [@EACD_ECRF](#) and stay updated!

ECR SESSIONS

7.30 am. Welcome & ECR introduction
7.35 - 8.10 am. "How to write a good manuscript in childhood disabilities" – Bernard Dan
8.10 - 8.45 am. "How to write a good funding application" – Cristina Simon-Martinez

THURSDAY,
MAY 19TH
ROOM 3

SUBSCRIBE VIA
<https://eacd.org/event-4796485>

The Elsass Foundation Research Prize



Every second year 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

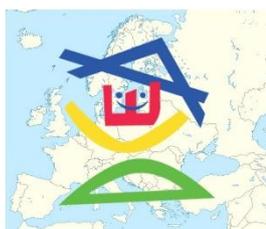
at the foundation's premises in Charlottenlund, Denmark. The prize recognizes researchers that have - and continue to make - an exceptional contribution within the field of cerebral palsy (CP).

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 [via the link here](#) in English in confidence before June 1, 2022!

New National Co-ordinator: Denmark



We are happy to inform you about our new national co-ordinator for Denmark: Line Zacho Greve! Mrs. Zacho Greve has been working with children with neuro-disabilities for the last 16 years as an occupational therapist both with a focus on practice and development of the field. One of her main interests is how knowledge is being translate into practice and implemented in the life of families with children with neuro-disabilities, and her main role at the Elsass foundation is to facilitate the knowledge of children with Cerebral palsy and neurohabilitation, into practice across Denmark. Furthermore,

as an occupational therapist working with children with CP it is important for her to have a family-centered focus. As such, Mrs. Zacho Greve anticipates the role of Danish National Coordinator for the EACD to be a natural extension of this work. She is hoping to be able to strengthen the local network in Denmark, and she looks forward to contribute with her colleagues to promote mutual learning, communication and support between professionals in Denmark and beyond!

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.

We would like to emphasize that also **the voices of non-users of digital technologies are really important** for the survey and the results we'll get from it!

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

Available languages:

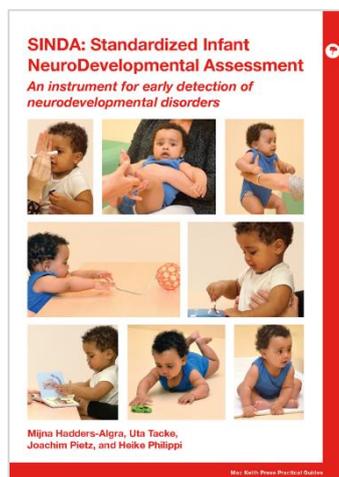
[English](#), [German](#), [French](#), [Spanish](#), [Italian](#), [Portuguese](#), [Turkish](#), [Polish](#), [Dutch](#), [Swedish](#), [Finnish](#), [Danish](#), [Romanian](#), [Ukrainian](#), [Georgian](#), [Croatian](#), [Serbian](#), [Slovene](#), [Lithuanian](#) and [Estonian](#).

Mac Keith Press update

Book highlights

Now published! - [SINDA: Standardized Infant NeuroDevelopmental Assessment](#)

Mijna Hadders-Algra, Uta Tacke, Joachim Pietz, and Heike Philippi



Is there a way to accurately predict neurodevelopmental disability within the first year of life? Standardized Infant NeuroDevelopmental Assessment (SINDA) has been developed as a screening instrument for infants aged 6 weeks to 12 months corrected age, to assist early detection of infants at high risk of neurodevelopmental disorders. It is the first developmental instrument to allow a comprehensive (360-degree) approach including “all” dimensions of development. With assessment in less than 10 minutes, SINDA can be used quickly in virtually any environment and requires only simple equipment.

Author podcast: [SINDA: Standardized Infant NeuroDevelopmental Assessment](#)

Blog post from the authors about how and why they chose the cover art: [Volcanoes in Iceland: How it all started with SINDA](#)

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

[What is cerebral palsy?](#)

Author Podcast with Martin Gough and Maeve Gough

[Paediatric Neuropsychology within the Multidisciplinary Context](#)

Author Podcast with Rhonda Booth and colleagues

[Eating and drinking ability and nutritional status in adults with CP](#)

Author Podcast with Elisabet Rodby Bousquet

New DMCN Highlights

[Conceptualization of quality of life in autistic individuals](#)

This study by Evers et al. reviews 174 articles examining the concept of quality of life in individuals with autism. The authors found that parents report a lower quality of life compared with autistic individuals themselves and argue that self-report should be the criterion standard for quality of life.

[Eye movements and stress during eye-tracking gaming performance in children with dyskinetic cerebral palsy](#)

The majority of children with dyskinetic cerebral palsy rely on eye-tracking technology for communication and computer access. In this study, Bekteshi et al. highlight the importance of early provision of eye-tracking technology to maximize its benefits in activities of daily living.

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

Other Meeting Updates

EPNS Glasgow 2022

The EPNS Congress from 28 April - 2 May 2022 is going ahead in-person in vibrant Glasgow, UK and virtually. Among other, the EACD is looking forward to the Joint Session EPNS-EACD on 'Fetal surgery for myelomeningocele' with Professor Jan Depreest! Visit the [congress website](#) for more information.

SFERHE 2022

The 13th Congress of the Société Francophone d'Etudes et de Recherche sur les Handicaps de l'Enfance (SFERHE) is being held this year in Reims on 13-14 June 2022, under the theme: "Support for child development. Which early interventions?". [Click here](#) to learn more about SFERHE 2022.

International Development Coordination Disorder (DCD-14) Conference

Building on the knowledge that has been gained over the past 3 decades, this conference will focus on understanding "DCD in the real world". The DCD-14 conference will be hosted as an in-person event from July 6th to July 9th in Vancouver, Canada. Please visit <https://dcd14.osot.ubc.ca/> 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](#)

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



This message was sent to you by European Academy of Childhood Disability
International not-for-profit association

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