

EACD Newsletter

December 2021

Message by the Executive Committee

Dear colleagues and friends,

As the evenings become progressively shorter and we snuggle deeper into the raised collars of our jackets in the northern hemisphere, it is that time of the year when we sit down with a hot cuppa and look back over the year that's just been. And what a year it has been! A proper rollercoaster!!

During last year's festive message if anyone had predicted that we would be looking again at a global lockdown this December, we probably would have laughed at them. We were full of hope, the vaccine had arrived and we thought we had a way out of the pandemic. This time we know it is different. The pandemic is here to stay, and with it stays the huge challenges it brings for children with disabilities, their families and all the professional groups caring for them. Our planning needs to change as this is not a sprint, it is a marathon. To do this, the EACD as a professional organisation needs to join hands with families and users to identify how we can do this best, together.

Though this has been a hard year, when looking back, it has not been all bad. We have achieved much in the last year. From becoming an European International Not-for-Profit Association from a British charity, to hosting a successful web conference, supporting the Early Career Researchers to come together, supporting new Academies in Ireland & Ukraine, fostering various networks and partnerships....We could go on. However, the most important and the most pleasing has been the realisation of the ambition to create the means to have an equal and meaningful relationship with families of disabled children/young people, their families, users and all those who have an interest in their lives. We have many to thank for their hard work in developing the Family and User Forum over the years. In particular we would like to thank Alain Chatelin who work tirelessly to bring this forum to life. Alain has now handed over the co-ordination of this important work and we are proud to welcome our first two elected Family and User Forum Co-ordinators, Teresa Mano da Costa and Niek De Taeye, who have lost no time in getting to work with all Forum members on the priorities the Forum has identified.

The upshot of all that is that the EACD is changing as an organisation, and we are changing fast. We want to seize the opportunities that we see and which we know can make a difference. Now more than ever the rapid advances of technology can transform participation opportunities. We need to bring scientists, engineers, industry, clinicians to the same virtual table as young people and their families. We need to think together and find innovative solutions. First, though, we need to know what is out there. That is exactly what the newly commissioned EACD Technology and Innovation Task Force are doing. Look out for their [RehaTech4Child survey](#) call just published. We also need to shout loudly about the great work going on in the research settings and bring it to forums open to all. The first of our webinar series launched earlier this month on The Power of New Technologies. Look out for more such exciting stuff to come.

Networking has been a priority for the EACD. Forming stronger bonds with existing partners like the Elsass Foundation, Mac Keith Press, La Fondation Paralysie Cerebrale and joining hands with new friends with a common interest, like the ERN-RND Neurorehabilitation, GRDDC (Global Research on Developmental Disabilities Collaborators group, to mention a few. Our National Co-ordinator networks are growing in strength, bolstered by increasing numbers and regular meetings. Fostering stronger ties with all our international partners at the International Alliance of Academies of Childhood Disability (IAACD), taking advantage of the better virtual connectivity that the pandemic has enabled. We have been able to experiment successfully with a new web conference model in EACD2021, focusing on the four most important themes

of the day: the impact of COVID-19, partnership with users/families, global networks and future technologies. This has given us a lot of food for thought and possible directions for us to explore.

Changing organisational structures and increasing activities bring on new challenges. We had the good fortune to find a window for the General Management Committee to meet in person in beautiful Ljubljana, our venue for EACD 2023. It allowed us the opportunity to reflect on our priorities and also consider broader issues of policy development, diversity and ethics. We engaged in robust discussions on engagement rules with one another, with other organisations and industry. We have constituted the EACD ethics committee and agreed the fundamental values of equality and diversity that we stand for. We took the opportunity of the committee meeting to connect, check on how we were doing and shared food and laughter. The chance to meet made it clear to us that the in-person meetings add so much more. We do hope we all can connect and continue the conversation in person at Barcelona for EACD 2022.

So, looking back, it has been a year of mixed blessings. A year in which we have faced up to the pandemic, we have seized opportunities to push forward where possible and as a result, we are stronger as an organisation. Let us hope that the coming year brings better times. More cheer, more smiles, more time with family, friends and close colleagues. We hope you and your families stay safe. On behalf of the EACD we wish you a very merry festive season and a wonderful year ahead!

Arnab Seal, Chair EACD

Elegast Monbaliu, Secretary EACD

Therese Millar, Treasurer EACD

EACD Barcelona 2022

Special Calls for Abstracts: Deadline Today (Dec 17th)!

'Innovative Products and/or Technologies' abstracts

EACD Barcelona 2022
Special Call for Abstracts:
Innovative Products & Technologies
Extended abstract submission deadline:
17 Dec 2021, 23:59h CET

EACD 2022
84th ANNUAL MEETING
European Academy of
Disability Research
Barcelona 2022

Innovative product and/or technology abstracts should describe a new, innovative product, tool and/or technology relevant to the area of childhood disability. 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.

'User & Family Needs' abstracts

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Special Call for Abstracts:
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The views of the individuals with a childhood-onset disability, their families, friends and carers are extremely important to EACD. We want to work together with service users and their families to make sure that we are meeting individual needs and providing the treatment, care and support that people rightly expect and deserve. Users and families can provide invaluable insight and information about their current needs, challenges and barriers they experience in their lives, and identify relevant areas and/or challenges for researchers to explore. The template of a 'User & Family Needs' Abstract is less formal than a scientific abstract. Furthermore, at least one of the authors should be an individual with a childhood-onset disability, a family member, or a close other concerned.

[Click here to go directly to our EACD Barcelona 2022 - Special Calls for Abstracts page](#)

EACD RehaTech4Child Survey

RehaTech4Child Survey

Aim: To explore the barriers and facilitators in the use of new digital technologies

Why:

To identify the digital technologies that are used, or not used, in clinical practice in the area of childhood-onset disabilities

To help future innovators in designing new digital technologies for the benefit of people with childhood-onset disabilities

How:

A Cross-European Survey

When:

Now!



On December 7th, the [RehaTech4Child Survey](#) has been launched! EACD has prepared this Europe-wide survey with a number of partners to identify the digital technologies (e.g., robotic devices and treadmill systems, virtual reality and gaming systems, telehealth) that are used in clinical practices throughout Europe, and to explore the barriers and facilitators in the use of these new technologies in clinical practice. In order to reach out to as many people as possible, the survey has been translated into 20 different languages due to the invaluable support of our RehaTech4Child Steering Group, our EACD National Coordinators and many others. 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.

This survey is one of ongoing actions performed by our [Technology & Innovation Task Force](#). EACD has set

up this Technology & Innovation Task Force in May 2020, and is currently led by Prof. Sylvain Brochard and Dr. Christelle Pons. Technology and innovative solutions are making more and more a difference in our society as well as in paediatric rehabilitation, and in some cases technologies and innovative solutions could improve rehabilitation practices in complementary with traditional approaches. However, most initiatives in this area relevant to our community are still mostly from local/regional initiatives, and which kind of technologies and innovations exactly are used, or not used, in paediatric rehabilitation at the moment is still rather unknown. Therefore, the EACD Technology & Innovation Task Force aims to develop a vision at the European level by making visible the needs for people with childhood-onset disabilities and by promoting innovation targeted on this group.

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](#).

Family and User Forum



An important step has been taken recently to enable meaningful engagement of people with childhood-onset disabilities, their families and important others in EACD activities and governance procedures by the (provisional) instalment of the EACD Family and User Forum! There are many to thank for their hard work in developing the Family and User Forum

over the years. In particular the EACD would like to thank Alain Chatelin who work tirelessly to bring this forum to life. Alain has now handed over the co-ordination of this important work and we are proud to welcome our first two elected Family and User Forum Co-ordinators, Teresa Mano da Costa and Niek De Taeye, who have lost no time in getting to work on the priorities the forum has identified. We already have 20 forum members. We welcome more interest. The arrangements for the forum will be presented at the AGM in Barcelona in May 2022, so please join us then to hear more and have your say.

New National Co-ordinator: Israel



We are happy to inform you about our new National Co-ordinator for Israel: Dr. Inbar Hartmann. Dr. Hartmann graduated Sackler School of Medicine at Tel Aviv University and specialized in Pediatrics and Pediatric Neurology at Asaf-Harofe Medical Center, Israel. "Today, I work as a senior neurologist at the Childhood Epilepsy and Developmental Disorders Clinic, the child development center, the neuromotor and the newborn clinics. I define myself as a hard working doctor who is dedicated to my patients and their parents. I also do my best to participate in several researches in our hospital nowadays. As a resident I was elected as chief resident, a complex role, which led me to take part in an exquisite fellowship, partly in the USA, and was chosen to oversee the child abuse and neglect issues at my hospital. At present, I serves as the head of the Child Protection Services of the hospital, and lectures around the country about this delicate issue, especially on the subject of mal-treatment of children with special needs. More important than that, I'm happily married to a great musician and have 3 beautiful children at the ages of 15, 11 and 5. I myself love to sing, photograph and run or swim as a hobby. I am excited to be the EACD National Co-ordinator for Israel as child development is my passion and my profession as well. I love performing and teaching about developmental evaluation, educate residents and most of all the teamwork."

On behalf of the EACD General Management Committee we are happy to welcome Dr. Hartmann on board, and would also like to express our sincere gratitude to Anat Lahav for all her work as National Co-ordinator for Israel in the past years.

Successful EACD Webinar Event: The Power of New Technologies in Childhood Rehabilitation - December 7th

EACD Webinar Event

**The Power of New Technologies
in Childhood Rehabilitation**

 **Prof. Elegast Monbaliu**
EACD Secretary

 **Mr. Rowan Johnson**
Winner EACD 2021 Technology & Innovation Award

 **Ms. Saranda Bekteshi**
Winner EACD 2021 Early Career Researcher Award

**7 December 2021,
19:30-21:30h CET**



Thank you very much for everyone who joined us at the first webinar event hosted by the European Academy of Childhood Disability on December 7th. We hope you found it as stimulating as we did. This is the first of many of our webinar series. So please look out for them. The recordings of the Webinar Event will become available at the [EACD Education website](#) in due course. We would also like to express once more our sincere gratitude to the speakers Elegast Monbaliu (EACD Secretary), Rowan Johnson (Winner of the EACD 2021 Technology & Innovation Award), Saranda Bekteshi (Winner of the EACD 2021 Early Career Researcher Award) for their great presentations and discussion. We would like to also thank our longstanding partner [Mac Keith Press](#) for their support in the organisation of the webinar event. We hope you enjoyed the experience, and we look forward to having you again with us soon!

EACD Early Career Researchers' Forum Online Event: 'Christmas Quiz & New Year's Research Resolutions!' - December 13th



The first year of the EACD Early Career Researchers' Forum is coming to an end and this has been celebrated with an online meeting full of Christmas spirit on December 13th. Thank you to all Early Career Researchers who joined this meeting for sharing your amazing accomplishments of this year and your exciting new year's research resolutions for next year! And on behalf of EACD we are happy to pass on our congratulations to 'team Quiz Kringle' for winning the first EACD Early Career Researchers' Forum - Christmas Quiz Trophy!

Mac Keith Press update

New Book: Children with Vision Impairment: Assessment, Development, and Management

Naomi Dale, Alison Salt, Jenefer Sargent, and Rebecca Greenaway.



Vision impairment is a long-term condition caused by disorders of the eye, optic nerve, and brain. Using evidence-based knowledge, theory, and research, this book provides practical guidance for practitioners who are involved in the care and management of children with long-term vision impairment and disability.

- International team of experts present up to date vision and neuroscience research and assessment and management approaches.
- Multidisciplinary approaches for improving function, learning and activity in children with vision impairment.
- New approach to childhood vision impairment with a focus on assessment, function and participation.
- Covering all vision disorders and levels of vision impairment, including eye disorders, cerebral vision impairment and complex disability.

[Click here to find out more and order the book!](#)

EACD Members get 20% off all books and courses published by Mac Keith Press! Click [here](#) to find the EACD Member discount code.

The Mac Keith Press International Awards

The International Alliance of Academies of Childhood Disabilities (IAACD) is joining with Mac Keith Press to recognize outstanding contributions to advancing the health and wellbeing of individuals with child-onset disabilities through two awards. The **'Outstanding Contribution to Childhood Disability Globally' Award** recognizes and highlights an individual or an organization who has made an outstanding contribution to the field of childhood disability with actual or demonstrated potential for global impact. This work may represent any combination of leadership, education, collaboration, mentoring, knowledge translation, or advocacy to improve the health and wellbeing of children, youth and adults with childhood onset disability around the globe. The **'Outstanding Contribution to Childhood Disability in a Low Resource Country' Award** recognizes and highlights an individual or organization whose work has had a significant impact on advancing service models, education, research or advocacy related to children, youth and adults with childhood onset disability in a country where resources are limited. The Mac Keith Press International Awards support an increased focus and attention to the worldwide issues related to the needs of children and their families and the enormous disparity in opportunity that currently exists.

Nominations may be made up until **January 8th, 2022**. To nominate please write a letter to [Prof. Roslyn Boyd](#), Chair IAACD Conference Planning Committee, of no more than 400 words, that outlines the significant contributions made by the person or organisation. Please include the contact information of the nominator/s and nominee. These inaugural Mac Keith Press International Awards will be presented at the joint AusACPDM/IAACD Conference in Melbourne, Australia in March 2022.

New DMCN Publication Highlights

[ICF Core Sets for the assessment of functioning of adults with cerebral palsy](#)

Suzie Noten, Melissa Selb, Lorenzo A A Troenosemito, Deborah E Thorpe, Elisabet Rodby-Bousquet, Wilma M A van der Slot, Marij E Roebroek, on behalf of the ICF Core Set for Adults with CP Consensus Group

[Prognostic value of transient pattern visual evoked potentials in children with cerebral visual impairment](#)

Jessica Howes, Dorothy Thompson, Alki Liasis, Ngozi Oluonye, Naomi Dale, Richard Bowman

[Development of gross motor capacity and mobility performance in children with cerebral palsy: a longitudinal study](#)

Andrea Burgess, Sarah Reedman, Mark D Chatfield, Robert S Ware, Leanne Sakzewski, Roslyn N Boyd

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

Other Meeting Updates

BACD 2022 Annual Scientific Meeting

The 2022 Annual Scientific Meeting of the British Academy of Childhood Disability will focus on Managing Pain in Childhood Disability and will take place on Thursday 17 March 2022. Abstract submission will close on Sunday 19 December 2021. Early Bird Registration closes on Sunday 9 January 2022. Find out more here: <https://www.bacdis.org.uk/pages/ASM2022>

EPNS 2022 Registration Now Open

You can now register for Onsite or Virtual participation to the 14th Congress of the European Paediatric Neurology Society (EPNS) from 28 April – 2 May 2022 in Glasgow, United Kingdom here: <https://epns-congress.com/registration/>

IAACD / AusACPDM 2022 Scholarships

You may be eligible for a IAACD / AusACPDM #BetterTogether2022 Scholarship! Virtual Scholarships are available for individuals from low resource communities or workplaces, and can support you in attending the Conference. View the criteria and full details at: <https://bettertogether2022.org/scholarships.php>



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

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