

EACD Newsletter

December 2022

Message by the Chair

Dear Friends and colleagues,



Recently we had a little bit of EACD history in the making. On 25/26 November this year the EACD General Management Committee held its first Strategy Meeting at the Palace of Academies in Brussels. An apt setting for such a momentous occasion! We debated and agreed on EACD policy priorities for the next three years. You might ask why now, why not earlier? This has been planned to coincide with a new Chairperson taking over the reins of the organisation next summer. This historical Strategy Meeting marks something important for the EACD, which is that we have progressed from a

reactive organisation to a proactive one, where we set our priorities based on clear vision and ambition. This reflects a mature and confident organisation, an organisation that is looking forward to the future. Our vision is that the EACD will be the 'go to' organisation in Europe for matters relating to childhood onset disabilities.







The other bit of positive news to share with you is that we have had an amazing response to the call for abstracts for the EACD Annual Meeting in beautiful Ljubljana, with over 600 submissions. This promises a great meeting this summer, with lots of science and lots of social opportunities (https://eacd2023.org). Your Meeting President, Dr Katja Groleger Srsen, is working hard to ensure a very warm welcome for everyone. Ljubljana is a wonderful place, and the congress venue is magnificent. Be sure not to miss it!

Talking of a warm welcome, we are constantly aware of the hardships that this winter brings for many children with disabilities and their families this winter. The challenge is even greater for those in Ukraine, where vast parts of the country have had energy supply disruptions. Here in UK, I was pleased to see a Warm Welcome (https://www.warmwelcome.uk) and a Warm Spaces (https://www.warmspaces.org) initiative where organisations and businesses were opening their doors for people to spend some time getting warm, having a warm drink and some company. We hope more of such innovative ideas will bring some warmth over the festive season for those who need support.

One event to look forward to in the coming year for our community is the EACD Summer School for Early Career Researchers from across Europe. The aim is to bring together around 30 young researchers from across Europe for a week to provide opportunities for training and networking. The process is highly competitive, and we anticipate a great demand. Look out for more information on our website. The Summer School will be hosted by Professor Marek Jozwiak in Poznan, Poland. Unlike our last 'visit' to Poznan for our Annual Meeting which we had to hold virtually, this time we will definitely be there in person. More information on this will follow soon!

As the year draws to a close, I am very thankful. Thankful that we can all meet in person, whether it be in Barcelona or Brussels or Ljubljana or Poznan. The pandemic has taught us this, to be thankful for all things that we take for granted like getting together with family, friends and colleagues. I hope you have a happy and peaceful festive season surrounded by your near and dear ones. On behalf of the EACD I wish you a wonderful year ahead full of peace, hope, joy and fulfilment.

Arnab Seal, Chair

EACD Ljubljana 2023

Benefit from the early bird registration fees!





Register now!

Early Bird Registration
Deadline:

20 Feb 2023

Check out www.eacd2023.org regularly for the latest information and updates!

It is a great privilege and pleasure for the EACD Ljubljana 2023 Team to welcome you to Ljubljana, Slovenia from 18-21 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. The programme in Ljubljana will be divided into five main thematic modules: (i) The importance of timely intervention; (ii) Advances in the management of orphan diseases; (iii) Management of pain in children with developmental disorders and pain syndromes in otherwise normally developing children; (iv) Goal setting: active role of the

child and parent in (re)habilitation process; (v) Advances in technological support of the rehabilitation process. It is also our great pleasure to announce several excellent keynotes for EACD Ljubljana 2023 with prestigious professionals in the field of childhood-onset disability: Helene Polatajko, Emma Livingstone, Minna Ståhl, Laurent Servais, Muharrem Yazici, Izzeldin Abuelaish 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 benefit from the early bird fees!

Go to the EACD Ljubljana 2023 Registration page!

Visit the EACD Ljubljana 2023 website

EACD Families & Users' Forum update



The EACD Families & Users' Forum met online on December 5th. The members of the Families & Users' Forum were updated here on EACD's activities and the ongoing integration of people with lived experience into the EACD organisation. In addition, following a presentation by one of the FUF members, Xenia Diaz, the topic of

nurturing style in child development was discussed. For example, there are several main concepts which were highlighted, such as the use of encouragement which notices effort and improvement (and not only success), the use of methods which help children feel a sense of belonging, significance and personal capability, and a focus on finding effective solutions in the long-term instead of depending on the use of punishment. Furthermore, the importance of relatedness and good connection between the therapist and the child were recognised.

The EACD Families & Users' Forum is the body through which persons with lived experience, their family members, and close others participate in the organized plans and actions of EACD. If you are a person with lived experience, a family member, or close other, interested in joining the Families & Users' Forum, please check https://www.eacd.org/families-users-forum or do not hesitate to contact us at: admin@eacd.org

4th Transatlantic Orthopedic Surgery Webinar: Treatment of Crouch Gait



It is a pleasure to inform you about the results of the 4th Transatlantic Orthopaedic Surgery Techniques Review of World Perspectives 2022, which was held online on Monday, 12th of December 2022, endorsed by the European Academy of Childhood Disability and supported by the Education & Training committee of the EACD. The Webinar's main theme was Treatment of Crouch Gait in Cerebral Palsy Children, directed by Prof. Marek Jozwiak and moderated by Dr. Lukasz Wozniak and Prof. Elisabet Rodby-Bousquet. The

webinar was prepared in cooperation with EACD and AACPDM, EPOS and POSNA as a combined educational event.

During this webinar, multiple recorded surgeries were broadcasted simultaneously from ten different operating theatres in München, Germany; Madrid, Spain; Istanbul, Turkey; Mumbai, India; Shenzhen, China; Melbourne, Australia; San Diego, California; Wilmington, Delaware; Saint Paul, Minnesota, and Poznan, Poland. Surgeries covered the wide spectrum of surgical techniques addressed for the treatment of crouch gait due to cerebral palsy as well as to present minimally invasive versions of operations used in flexed knee correction.

Thanks to this Webinar, participants had a unique chance to learn flexed knee correction surgery with special attention to the main indications and contraindications for the use of the techniques and to know how to avoid possible pitfalls during the surgery. The experts in neuropediatric orthopaedic surgery had a chance to share their experiences and surgery tricks among participants from all around the world as well as from low incomes countries as Colombia, Malaysia, Sri Lanka, Ukraine, and Uzbekistan.

This webinar was watched live by an audience of about 1600 people from 672 registered centres from 57 countries (see also the figure below), with the highest number of participants from Poland, United Kingdom, the USA, Norway, Sweden, and India. And we would like to inform you that the recorded broadcast will be published online from next Monday (December 19th) to the end of January 2023 at this webpage.

The <u>scientific committee</u> of the webinar would like to strongly thank all of the <u>faculty members</u> for their great work, presenting the lectures with no time zone limits - from early Monday morning in San Diego and Los Angeles, California, to late Tuesday night in Melbourne, Australia, and with no time limitations for discussion and question answers. We also are grateful to all participants whose number indicates the strong need of getting experience and surgery skills in such a modern and accessible way as online webinars.

Finally, we would like to thank all the sponsors of this event whose support was crucial for this successful event and look forward to inviting you for next year's webinars when we would like to expand our reach to developing countries from Africa, Asia, and South America.

With regards,

Prof. Marek Jozwiak

Prof. Elisabet Rodby-Bousquet Prof. Michael Wade Shrader

Dr. Peter Bernius Zaid Al-Shakarchi Dr. Lukasz Wozniak





EACD Early Career Researchers' Forum

Christmas Quiz and New Year's Research Resolutions!



On 13 December 2022, the EACD Early Career Researchers' Forum hosted for the second time its Christmas Quiz & New Year's Research Resolutions event! Now the year 2022 is coming to an end, the EACD Early Career Researchers' Forum invited all ECRs to join for an online meeting full of Christmas spirit and to talk about the past year's research experiences, wishes for coming year and much more. We would like to congratulate the Celebration Party quiz team, who managed to win this edition of the Christmas quiz after an intense, exciting, and hard fought battle. And we would like to thank all for sharing your achievements, experiences and challenges of the past year, and for letting us know your new year wish for more networking opportunities for Early Career Researchers!

The EACD Early Career Researchers' Forum is a central platform run by Early Career Researchers (ECRs) for the ECRs community across Europe active in the area of childhood-onset disability. 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. Please click here to learn more!

Happy holidays and our best wishes for 2023,

EACD Early Career Researchers' Forum

Mac Keith Press update

DMCN 2022 Highlights: Celebrating excellence from European Researchers

Seven important academic papers authored by European researchers have been selected to feature in <u>the annual highlights of Developmental Medicine & Child Neurology</u>, a monthly peer-reviewed journal that ranks among the most prestigious paediatric-focused publication!

The first paper, Mini-EDACS: Development of the Eating and Drinking Ability Classification System for young children with cerebral palsy, is an original article authored by Diana Sellers and colleagues which developed and tested Mini-EDACS, a new valid and reliable system for classifying eating and drinking performance of young children with cerebral palsy under 3 years.

The second paper is an invited review from Sander Werkhoven and colleagues: Who benefits from diagnostic labels for developmental disorders? In this paper, the authors analysed the role labels can play in four different contexts (scientific, therapeutic, social and administrative) and identify what various stakeholders stand to gain or lose with continued, expanded, or abolished use of those labels.

The third paper, Rehabilitation after paediatric acquired brain injury: Longitudinal change in content and effect on recovery, is authored by Rob Forsyth and colleagues. This paper examined the content of neurorehabilitation provided to young people recovering after severe paediatric acquired brain injury.

The fourth paper is <u>Conceptualization of quality of life in autistic individuals</u> from Kris Evers and colleagues. This invited review looked in to what extent two core characteristics of the quality of life construct (its subjective nature; and its multidimensionality) were incorporated in the field of autism.

The fifth paper, <u>Functional development in children with cerebral palsy in Uganda: population-based longitudinal cohort study</u>, is an original article authored by Carin Andrews and colleagues. This paper followed the functional development of a population-based cohort of children with cerebral palsy in rural Uganda and indicated that children with CP in Uganda develop motor skills at a slower rate than peers in high-income countries.

The sixth paper by Janette Atkinson and colleagues, <u>Visual attention and dietary supplementation in children with perinatal brain injury</u>, investigated whether children with perinatal brain injury have impairments in specific components of visual attention, and showed receiving dietary supplementation from age 0 to 2 years improved attentional executive function.

The seventh paper is an invited review from Martin Kirkpatrick & Finbar O'callaghan: <u>Epilepsy and cannabis</u>: so near, yet so far. In this paper, the authors explore the science behind cannabis-based medicinal products in paediatric epilepsies, highlight the areas that warrant further research, and warn against children with epilepsy being at risk of being used as the 'trojan horse' for the cannabis industry.

The seven highlighted articles are just a sample of the important work done by European researchers this year for the benefit of people with childhood-onset disabilities.

Check out more on the DMCN homepage and the very latest releases on Early View.

DMCN Podcasts

Risk patterns associated with hearing loss & hearing impairment in infants born preterm Author Podcast with Wen-Hao Yu

Adapted bicycle riding outcomes for children and adolescents with disabilities Author Podcast with Abiramy Thevarajah

Other Meeting Updates

77th AACPDM Annual Meeting

On 10-13 September 2023, the American Academy for Cerebral Palsy and Developmental Medicine (AACPDM) will be organising its 77th Annual Meeting in Chicago, Illinois, USA. The abstract submission website is open and is set to close on Tuesday, January 31st, 2023 at 11:59pm EST. Click here for more information.

15th EPNS Congress

On 20-24 June 2023, the European Paediatric Neurology Society (EPNS) will be organising its 15th Congress symposium in Prague, Czech Republic. The main theme of the congress is "From genome and connectome to cure". Take a look at https://epns-congress.com/programme/ for more information. The registration will open in January 2023.

2nd Swiss Academy of Childhood Disability (SACD) Research Day

On 26th January 2023, the 2nd SACD Research Day will be held in Bern at the Unitobler. The goal of the SACD Research Day is to strengthen the transfer of knowledge from research into clinical practice and education and vice versa in Switzerland. 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

