



European Academy of
Childhood Disability



EACD Newsletter.



EACD Spring Newsletter 2019



Chairman's report

Dear EACD members, dear friends,

I would like to start this short report by addressing again, on behalf of our Academy, the warmest thanks to Nana Tatishvili and her team for the splendid organization of our 2018 Meeting in Tbilisi. The high scientific quality of invited lectures, workshops and free papers and posters, not to forget the parallel workshop organized with the International Alliance of Academies of Childhood Disability (IAACD) Global Professional Education Committee (GPEC), met with the hospitality of our Georgian friends. Moreover, we felt to be observers and hopefully significant contributors to the noticeable change on the approach and the treatment of childhood disabilities in this part of Europe. The motto of EACD 2018 "Together we are stronger" could not have been more appropriate.

Paris EACD 2019 is rapidly approaching and Sylvain Brochard, President of the meeting and Christopher Newman, chair of the EACD scientific committee, are working intensively on the scientific and social programs. More news about this event can be found in this newsletter. The high quality of the scientific program and the majestic beauty of the city of Paris are the best guarantee of success for this event.

After Paris, Poznan in Poland will host the 32nd EACD meeting in 2020, organized by Marek Jozwiak, as President, and Magdalena Chrościńska-Krawczyk, as National Coordinator of Poland. They will inform us about the preparation of the event in Paris.

According to our constitution, the venue of the annual meeting has to be selected three years in advance. Therefore, during the AGM in Tbilisi we selected Bruges (Belgium) as the venue for the 2021 32rd EACD Meeting, under the organization of Elegast Monbaliu, the current Secretary of EACD.

It is now time to start thinking of the European city that will host the 34th EACD Meeting in 2022. For that we invite our national coordinators and all members that might be interested, to write very soon to Elegast and myself, and to prepare for the GMC a first draft of their proposal by the end of this year. Some potential candidates have already come forward. To select the venue for EACD 2022, all proposals will be firstly examined by the GMC and then voted, during the AGM in Paris.

According to the amendments in our constitution that we approved in Amsterdam to make the Academy more efficient and flexible, the Chair term is now limited to 3 years, and is not renewable, but with an overlap "elect" position for one year. Therefore, in Paris we

need also to vote for our new Chair. Our nomination Committee will inform the members about the procedure at due time.

As you know, in Tbilisi we confirmed our main lines of EACD activity in the triennium 2017-2020.

The first is to develop a “global perspective”, as part of the ongoing work with the IAACD, and with the existing links to the AACPDm and the AusACPDM. According to the signed Constitution, a number of subcommittees, essential for the work of the IAACD have been established or are going to be nominated within the next few weeks. Among the committees already activated, I would like to mention the Global Professional Education Committee (GPEC) led by Arnab Seal, that has several important goals: i) to promote a common global standard of knowledge, training and multi-disciplinary practice; ii) to improve the life chances and participation of disabled children and young people in their communities; iii) to develop and maintain a core curriculum for health professional training in childhood onset disability; iv) to encourage measures that make the educational material easily accessible and locally available. A training program, coordinated by an international staff of members of the IAACD indicated by EACD, AACPDm and AusACPDM, was held during the Georgia meeting. The program was well attended and had a great success. It will be the ideal framework for future similar initiatives in Europe, as already requested by some countries, and elsewhere. These projects will be discussed during the midterm GMC meeting in Poznan, in December.

In the same occasion, the other important new EACD project in the field of training and education, decided in Tbilisi, will be discussed and finalized, i.e. the first edition of a Summer School to be held in Pisa (Italy) next July 15-19, 2019, devoted to “Evidence based medicine and research in rehabilitation of childhood disabilities”. It will be a full-immersion course, both theoretical and practical, covering the models, the procedures and the instruments and information that are internationally requested to plan and conduct evidence-based researches in rehabilitation of childhood disabilities.

Attendees will be young clinicians and researchers working in the disciplines related to rehabilitation of childhood disabilities with interest in performing research in this field. A maximum of 30 participants will be selected on the basis of their CV and of selection criteria that will be elaborated, as well as the final teaching program with the list of docents, in Poznan. Attending grants will be available according to the budget decided by the AGM in Tbilisi.

All information about the Summer School will be send to EACD national coordinators and all members by a special mail soon in January and will be at the same time in the EACD education web page. Registration will be available via the University of Pisa, that will be responsible for the school and will attribute European University Credits for it.

The development of a communication strategy is another one of the main points of EACD program 2017-2020, in order for the “voice” of the EACD to be heard and outstand as a significant “third sector” in Europe. A first important example and test for this strategy will be the dissemination of the results of the Austerity Survey conducted across Europe in 2017, under the direction of Karen Horridge, to identify the enablers and barriers to inclusion following the significant economic austerity in the last decade. As you know the results of the Survey, recently published in *Developmental Medicine Child Neurology*, indicate a very large variation in funding and access to all services for children with disabilities between countries across Europe and a direct impact on families of austerity cuts, in terms of reduction of the services, increased waiting times, worse working conditions, less time per patient. Again, in Poznan we will discuss on how to disseminate effectively these results, both at national and European level.

As you can see, our Academy is full of initiatives whose results will be surely presented in Paris, next May.

Best wishes again to Sylvain, Christopher and their team for the Paris meeting and thanks for their commitment. Surely, it will be a great success.

It is a great pleasure to devote the last words of this newsletter to Arnab Seal, who has concluded in Tbilisi his mandate as EACD Secretary, a duty that he accomplished for many years with great competence, passion for the work, for his talent and gentile touch. It is of great comfort for us that he will continue to be active in the EACD with other duties, now as head of the joint GPEC with the IAACD.



GRAZIE Arnab! And best wishes to Elegast Monbaliu who has accepted the difficult task of replacing you.

Giovanni Cioni

Chair of the EACD

Award for EACD Chair

Congratulations to Professor Giovanni Cioni, EACD Chair on receipt of the inaugural Karel and Berta Bobath award for an outstanding lifetime contribution to improving the lives of children who have cerebral palsy.



Changes in Committee membership



Thank you Arnab

At the 2018 EACD AGM Giovanni Cioni thanked Arnab Seal who has served two terms as EACD secretary. As Giovanni notes in his newsletter above, Arnab is an active member of the IAACD and I am sure we will continue to benefit from his ongoing endeavours for children with neurodisability.

New Secretary



At the 2018 EACD AGM in Georgia, the members voted unanimously to appoint Elegast Monbaliu as the next Secretary

C.V.

Elegast has been senior paediatric physical therapist (PT) since 1999 at Dominiek Savio Institute, a rehabilitation school for children with motor disabilities (Gits, Belgium), where he is currently Staff Member Medical Service. Additionally, in 2000, he started a private practice for paediatric rehabilitation, which is located in Ostend (Belgium). In 2013, Elegast completed his PhD and started a teaching and lecturer position at the Department of Rehabilitation Sciences KU Leuven (University of Leuven, Belgium). In 2017 he was appointed as assistant professor in a tenure track at the KU Leuven (Campus Leuven – research unit neuromotor rehabilitation). His research primarily focuses on the evaluation, characterization, understanding and management of dystonia and choreoathetosis in dyskinetic CP, which is one of the most severe forms of CP.

Motivation

Since 2015, Elegast has been chairman of the Belgian Academy of Childhood Disability and since May 2017 member of the GMC. He subscribes the clinical, scientific and educational objectives of the EACD. He believes that intensified activities towards societal inclusion for individuals with childhood disabilities will enrich our society. But therefore our community needs a continuing effort and professional structure. Elegast is convinced that the secretary has a very important role in the EACD organisation to help in structuring and catalyzing new initiatives to challenge the present and future difficulties... The recent EACD Austerity survey underlined the difficulties... The Belgian Academy of Childhood Disability is already actively searching openings to bring the EACD Austerity survey on the political agenda. People with childhood disabilities and their families are living in challenging times. In an accelerating innovative and often increasingly expensive care, austerity in inclusion and service widens the gap between the families who can afford the service and those who cannot. Notwithstanding the fact that communication, mobility, custom accommodation, healthcare etc are basic rights, persevering cost savings negatively impact daily life and are often a one-way ticket to poverty and loss of independence in adulthood.

In the role of secretary, Elegast wants help to lift this challenges to the highest levels of national and European stakeholders. Therefore, in these challenging times new collaborations are needed.. over several levels in order to keep quality of health service for people with childhood disabilities high but also affordable for everyone!

31st EACD Annual meeting, Paris, May 23-25, 2019



31st Annual meeting of the European Academy of Childhood Disability in Paris (France) will take place at the conference centre of la Cite des Sciences et de L'Industrie (City of Sciences and Industry) of La Villette, from **May 23rd to May 25th, 2019**.

eacd2019.org

Keynote speakers

[Jan Willem Gorter, MD, PhD, FRCP \(C\)](#)

CanChild Centre for Childhood Disability Research
Department of Pediatrics, McMaster University, Hamilton, ON Canada.

Title: Turn the Tide on Transition to Promote Participation

[Bryce Johnson](#), Inclusive Lead, Product Research & Accessibility
Microsoft Corporation, Microsoft Devices, Seattle, USA

Title: The Xbox Adaptive Controller, Intentionally including gamers with limited mobility

[Sue Fletcher Watson](#), Senior Research Fellow
Patrick Wild Centre, University of Edinburgh

Title: Merging psychological theory with a neurodiversity framework for better autism interventions.

[Yannick Bleyenheuft](#), PT, PhD
Professor at the Institute of Neuroscience, Université catholique de Louvain, Brussels, Belgium
Honorary attached to the Center for Cerebral Palsy Research of the Teachers College, Columbia University, NY, USA

Title: HABIT-ILE, an intensive intervention increasing autonomy and participation in children with cerebral palsy

[Lee Ridley](#) («Lost Voice Guy»),
Stand-up comedian
UK

We look forward to welcoming you to Paris!
On behalf of the organizing and scientific committees



Sylvain Brochard
President of the conference



Christopher Newman
Chair of the Scientific Committee

EACD Membership benefits

EACD has a special relationship with MacKeith Press. Developmental Medicine & Child Neurology is the official journal of EACD. Members receive **over 70% discount on the annual subscription charges** for Developmental Medicine and Child Neurology journal.



Training opportunities

IAACD training programme success in Georgia

The International Alliance of Academies of Childhood Disability (IAACD) ran the first Knowledge transfer and Training Programme in Georgia, parallel to the EACD annual meeting with regional representatives, stakeholders, clinicians and parents. This was led by their Global Professional Education Committee. EACD is represented on this

committee by Arnab Seal (Chair) and Jenny Carroll and Oleh Kachmar. Goals for the training program (as identified by participants in a pre-programme survey):

- Opportunities to learn new information, skills, evidence-based practice (n=32)
- Opportunities for networking with others (n=12)
- Opportunities for international collaboration and learning (n=6)
- To learn from parents and dialogue with them (n=4)
- Increased awareness of opportunities for future training (n=3)
- Opportunities for discussion, joint problem solving (n=3)
- To learn about GPEP (n=1)
- To observe and practice clinical skills (n=1)
- To learn goal setting (n=1)

Each session had co-presentation of each topic with international and local partners, thus ensuring equal partnership and a local voice making the training relevant to the local context. Nine sessions were provided over 2 days, each with learning objectives and on core topics (Introduction, ICF, F-words, Family Centred services, Evidence Based Interventions, Goal Setting, Functional Classification Systems, a Life course approach and Summary and Next Steps)

Post Programme Evaluation

A summary and reflections were drawn from the post-training questionnaire, completed by 48 participants (as for pre-conference evaluation) and reflections from GPEP members and programme organisers. **80% of participants reported their goals from the program were met**, 20% were uncertain. A report was produced for the Steering Committee of IAACD: A 6-month post-workshop participant survey to check what changes in practice has been implemented and what, if any, barriers people have faced is being carried out. Other regions have also requested similar programmes.

New EACD training initiative

A new training initiative has been approved by the EACD General Management Committee and AGM. This is a Summer School Model, the first of which is proposed in Pisa in July 2019. The aim is to bring together 30-35 young researchers from across Europe and to run a Summer School focusing on research skills. It is anticipated that this will lead to pan-European collaboration and research networks. There would be inclusion criteria advertised in the newsletters and the EACD would fund up to 10 bursaries.

Georgia report

The 30th EACD2018 conference in Tbilisi has finished. We think it was quite successful. Numbers are very impressive-5 continents, 45 countries and more than 500 participants.

The slogan of the conference was 'Together We are Stronger' and the meeting served as a platform for exchanging international knowledge and experience of all aspects of childhood disability and helped to spread these throughout the South Caucasian region and beyond. Participants from all neighbouring countries discussed ideas for developing standardized approaches to disability.

The committee suggested an open list of topics for free communications including epidemiology, screening and evaluation tools, study designs, outcome measures, integration of research and clinical practice, and best practice protocols – favoring the International Classification of Functioning, Disability and Health model. Topics also comprise social inclusion and participation, quality of life, family-centered care, nutrition, socio-economic and socio-cultural factors, coping with disabilities in resource poor countries, neurogenetics, epigenetics, multiple disabilities, ethical issues, innovations in technology, robotics, orthotics, surgery, interdisciplinarity, alternative versus conventional traditional treatment approaches, education, and service organization. As well as pain management, palliative care, mental health, sleep, epilepsy, motor control, hand function, mobility, gait, spasticity, dystonia, ataxia, bone health, feeding, intellectual disability, communication, vision, and hearing. The programme addressed a wide range of neurodevelopmental conditions.

The format of keynote lectures was new and interesting, including keynote speakers and discussants for highlighting debatable topics. The discussants include not only professional specialists, but also parents and decision makers. Topics were devoted to evidence-based approaches, new treatments, neuroplasticity, and changing the mode of thinking about childhood disability.

The International Alliance of Academies of Childhood Disability prepared an interactive two days teaching programme with regional stakeholders, parents and team members.

We hope such a diverse spectrum of presentations made the conference very exciting and interactive. Also it gave possibility for informal communication and networking between participants from different parts of Europe and people with different professions.



On behalf of organizing committee.

Nana Tatishvili

President of the EACD2018 Conference

EACD Educational web page updates

We invite you to visit our educational web page edu.eacd.org.

Main keynote lectures from the Tbilisi 2018 meeting have been recorded and now are available at the Meetings Archive section of the page,



- [Opening ceremony](#)
- [Early childhood Intervention in Georgia \(film\)](#)
- [Peter Rosenbaum: How our thinking is changing in 21st century](#)
- [Federico Vigevano: Cognition and behaviour in epilepsy](#)
- [Diane Damiano: Evidence-based physiotherapy for children with cerebral palsy](#)
- [Rudolf Korinthenberg: A new era in the management of neuromuscular disorders in children and adolescents](#)
- [Roslyn Boyd: Enhancing participation for children with cerebral palsy: a paradigm shift](#)
- [Tamar Seperteladze: Parents point of view](#)
- [Hans Forssberg: Microbiota and brain development: Implications for autism spectrum disorder](#)

- [Giovanni Cioni: Neuroplasticity - the present and the future](#)
- [Closing ceremony](#)

To relive the best moments of the meeting visit photo gallery.

- [EACD meeting in Tbilisi. Day 1](#)
- [Day 2 of Tbilisi meeting](#)
- [Day 3 of Tbilisi meeting](#)

If you do not want your photo to be here - please write us webmaster@eacd.org and we will remove it.

Abstracts of the 30th Annual Meeting of the European Academy of Childhood Disability (EACD), Tbilisi, Georgia, 28–31 May 2018 are available in the [Supplemental Issue of the Developmental Medicine and Child Neurology \(2018, Volume 60 Issue S2\)](#).

EACD Meeting 2020 in Poznan

The 32nd Annual meeting of EACD is being planned! The conference organizing committee are busy planning a great programme for Poznan, Poland.

Austerity publication

This summer has seen the publication of the EACD sponsored project "Austerity and families with disabled children: A European survey". Many thanks to Karen Horridge and the team who carried out such a thorough project. The authors give sincere thanks to the EACD for funding Rosie Dew (£8000) to conduct the surveys and analyses for this project and to everyone who disseminated questionnaire links and all who responded. The authors would like to acknowledge Adam Gawne from the University of Sunderland Students Union for his help organizing student volunteers to assist with checking and translating surveys. Many thanks for Laszlo Kondacs, and the number of other student volunteers from the University of Sunderland, and EACD members for their help checking and amending translated surveys.

The article has been published in July 2018 issue of the Developmental Medicine and Child Neurology. We hope the results will have far reaching impact.

"Whilst this study set out to examine the impact of austerity on the experiences of families and professionals, one of the main findings was that regardless of austerity, families with disabled children and professionals caring for them across Europe reported that care has declined in recent years."

"The EACD joins UNICEF and others in the call for the needs of children to be specifically embedded in all policies at all levels in all countries, including the complex needs of those most vulnerable. Justice is required to fulfil our obligations to disabled children, enshrined in the United National Convention on the Rights of the Child and United National Convention on the Rights of Persons with Disabilities"

Read the Open Access full text article

Horridge, K. A., Dew, R. , Chatelin, A. , Seal, A. , Macias, L. M., Cioni, G. , Kachmar, O. , Wilkes, S. and , (2018), Austerity and families with disabled children: a European survey. Dev Med Child Neurol. . doi:[10.1111/dmcn.13978](https://doi.org/10.1111/dmcn.13978)

Update from Israel - Sarah Capelovitch, National Co-ordinator

January 7-9th, at the Israeli Child Development Centers- there will be a reorganization and an explanation of EACD, hopefully with new members registering. The Israeli Bobath tutors are continuing with presenting 6 day workshops on Typical and Atypical Development for PTs OTs and SLTs

Update from Austria - Ruth Amann, National Co-ordinator

Inspired from Tblisi, especially from the topics around ICF and the IAACD training programme a group meet after the congress. It seems that the IAACD training programme has had not just an impact in the Caucus but also further afield in Austria. The idea of a multiprofessional "concert" concerning ICF raised and will be put into concrete action in autumn 2019 in cooperation with the annual meeting of the paediatricians. They are open for a multiprofessional half-day around ICF. In that context we started to discuss the initiative to form an Austrian Academy!

If you have any questions or enquires you can contact the European Academy of Childhood Disabilities via secretary@eacd.org