Dear EACD-members,

The final preparations for the Annual EACD Meeting in Brussels are under way.

My duty has been to prepare the agendas for different committee meetings and Annual General Meeting. One of the main topics open for discussion will be the progress reports of the EACD Task Force Groups. In order to give you a bit of “taste” of the latest news, there will be reports from Task Force leaders in this issue. Related to the progress in the Task Force “Central and Eastern Europe Countries”, I am very pleased to inform that we have recently received announcements of new National Coordinators from Albania, Bosnia-Herzegovina, Bulgaria, Macedonia and Ukraine, respectively. Furthermore, we will have a topic of “Information and Communication” in the agenda of the Annual General Meeting. It is said in Finland (promised country of Nokia), that the organization does not exist in this modern world if one cannot transfer information and communicate effectively. Indeed, we would urgently need the feedback and suggestions from our members, how to develop the EACD website and Newsletter. In addition to the Annual General Meeting taking place on Friday 28.5., you can easily come and discuss with EACD representatives during the meeting by the EACD stand. Hope to see you in Brussels!

Leena Haataja
EACD Secretary
STARTS AT THE EUROPEAN PARLIAMENT

The 22nd Annual Meeting of the European Academy of Childhood Disability has been placed under the patronage of Her Royal Highness Princess Astrid of Belgium, the City of Brussels and the European Parliament. Mr. Freddy Thielemans, the Mayor of the City of Brussels, will welcome the delegates on Wednesday 26 May at the 15th century town hall, which is the jewel of the Grand Place, arguably “one of the most beautiful town squares in Europe, if not in the world”. Mr. Thielemans sent us a poignant address (http://www.eacd2010.com/component/content/article/62.html), in which he states the following: “As the father of a wonderful daughter with a disability, I wish to express my gratitude for the help, the hope and the knowledge we may share thanks to you. In the hope that her life, and the life of all children with disabilities, may still be full of happiness, beauty and especially of the greatest freedom.” The opening scientific session of the 22nd Annual Meeting of the EACD will take place at the European Parliament in Brussels on Thursday 27 May 2010, at the invite of Mr. Jerzy Busek, President of the European Parliament. We will be welcomed by Mrs Roberta Angellili, Vice-President of the European Parliament, who has been particularly active in designing European Union strategies on the Rights of the Child. The full programme of the meeting “Measures of Progress – Evaluating management outcome in childhood disability” can be found on the website www.eacd2010.com. Abstracts published in the May supplement of Developmental Medicine and Child Neurology are available on-line on the Journal website (http://www3.interscience.wiley.com/cgi-bin/fulltext/123400168/PDFSTART). Keynote lectures cover a wide range of subjects from stem cell research, animal models and genetic pathways underlying behaviour, to evidence-based practice, quality of life, and European policy-making. Themed sessions also address various issues including nutrition, education, neuromuscular disorders, ADHD, sleep, and visual perception. Two of the sessions are organised by the American Academy for Cerebral Palsy and Developmental Medicine (AACPDM) and the European Paediatric Neurology Society (EPNS), providing an excellent
occasion for exchanging views and further work on common projects. There are workshops on partnership between parents and professionals and on EU perspectives. There is also a symposium on orphan drugs organised by the European Medicines Agency (formerly EMEA) and other satellite symposia on intrathecal baclofen, comorbidities in epilepsy, and biofeedback, and no less than 14 instructional courses. There will be three sessions of one-hour courses given in parallel, addressing a variety of important subjects. Issues relating to assessment of motor disorders will be the focus of didactic, well-illustrated courses emphasising either clinical aspects, such as those on dyskinetic cerebral palsy, the manual ability classification system (MACS) or the neuropsychological and psychiatric profile of children with movement disorders, or technology-assisted approaches, such as basic interpretation of gait analysis or 3D analysis of upper limb movements. Tools for early evaluation and intervention will be the subject of courses on powered-mobility and autism. One course will present guidelines for the management of osteopenia, which is increasingly recognised in children with disabilities. Various aspects of the functioning of multidisciplinary team will be addressed in courses on fostering communication skills, formulating therapeutic goals, managing disability in patients with tuberous sclerosis or the notion of the knowledge broker. And one course will address parenting issues. The abstracts of these courses can be found following a link from the scientific programme section of the website (www.eacd2010.com). Another important aspect of the meeting concerns work on guideline consensus under the leadership of Rainer Blank, chairman of the EACD scientific committee). Rainer stresses that “This is the first time in EACD history that we meet to consent and make decisions on European standards in assessment and treatment.” There will be a European interdisciplinary guideline consensus on the assessment and management of children with Developmental Coordination Disorder. Another expert group will work on international interdisciplinary evidence-based practice guidelines on the assessment and management of children with cerebral palsy. The meeting has also a cultural dimension emphasising participation and transitions to adulthood, with a special plastic art exhibition entitled ‘Measures of Bodies’ presents original work from the Rocket Artists, a group of artists with developmental disabilities who work alongside art students from the University of Brighton, and the « Extra & Ordinary People ! » Film Festival (EOP!), featuring short-feature films on children and (dis)abilities.

All ingredients for an excellent meeting. We hope to see you there.

Bernard Dan, President of the 2010 EACD Meeting
EACD 22nd ANNUAL GENERAL MEETING
Friday 28 May 2010 at 16.30 – 18.00
at the Erasmus campus in Brussels

AGENDA

1. Minutes of previous meeting held in Vilnius 5.6.2009
2. Matters arising from the Minutes
3. Chairman’s report
4. Secretary’s report
5. Treasurer’s report
6. Election of new members to General Management Committee (KG)
7. Election of new National Coordinators
8. Report of Task Force Group “Guidelines and Best Practice” (RB)
11. The future prospects for Task Force Group “Family” (HF)
12. Information/Communication (Newsletter/Website)
13. Rome Meeting 2011 (EC)
14. Istanbul Meeting 2012 (Dr Günel)
15. Election of Candidate for Annual Meeting 2013
16. Collaboration with EPNS, AACPDM, ESPAC
17. Any other business
18. Date of the next Annual General Meeting
In December 2008, the EACD GMC decided to initiate a task force to develop Clinical Practice Guidelines in common childhood disorders that are assessed and treated by different professional groups in Europe. It was intended to develop and adapt high-quality national guidelines to European and interdisciplinary standards.

Such guidelines are of interest for all professional groups and they may be an important basis for future research in the area of childhood disability.

As there is no European registration for clinical practice guidelines, we decided to develop registered guidelines following the criteria of national medical scientific associations for guidelines but to include international (European) experts in the guideline development in order to achieve a pan European professional influence and consensus. Such guidelines could then be adapted easily to national requirements of different countries.

The first guideline on Developmental Coordination Disorder developed for German speaking countries with international participation will be consented at the next EACD meeting in Brussels.

The work on a complex guideline on cerebral palsy will also be started at the EACD meeting in Brussels.

For practical reasons, the CP guidelines will be registered with AWMF (Germany) or/and NICE (Great Britain). The guideline process will include nominal group consensus processes for relevant key questions and recommendations, systematic literature searching, analysis of evidence, implementation strategy, involvement of all relevant professional groups and involvement of patient representatives.

The CP guideline will be started with three core groups located in Germany, Great Britain and Sweden. International experts from other countries are to take over an active part of the process. The guideline work would aim for a European Consensus in different areas of CP. Due to the complexities of the organisational background mentioned above it will not be possible to include experts from all European countries from the beginning. However, national experts from all countries represented in the EACD will be encouraged to develop adaptations of these future European guidelines taking into account their national requirements.

Rainer Blank
Chair Scientific Committee
A main aim for the EACD is to “ensure […] quality teaching in the field of childhood disability; […] to raise professional standards throughout Europe” (www.eacd.org 2009).

We will soon meet at the annual scientific meeting in Brussels to accomplish this aim. But could it also be reached in other ways? So far the Task Force has explored basic standards of education and training and how advanced competencies are described in Europe. At the annual meeting in Groningen 2007 questions on basic standards and advanced competencies were raised and later followed up at the meeting in Zagreb and Vilnius. Martin Bax contributed with material from previous workshops and discussions, for example the “Syllabus for Neurodisability training” for paediatricians in the UK. Ulrich Haug, the NC of Germany thoroughly explored basic training of OTs, PTs and SLTs in Germany. And Pirkko Nieminen, member of the GMC and psychologist from Finland, described an extensive survey of the training of psychologists in Europe.

From the work undertaken to date we could draw the conclusion that a majority of basic educations for the various professions in Europe reach Bachelor’s degree and that further education and training in neurodisability would be at an advanced level according to the Dublin descriptors connected to the Bologna process. It seems as if this framework is well anchored in most European countries and also outside Europe. Mintaze Kerem Günel, NC from Turkey, described the implementation of the Bologna process in her country at the meeting in Zagreb.

Where could we go from here? Could defining learning outcomes for various professions and making descriptions of competencies contribute to the overall aim of the EACD? Such descriptions have been made previously but have not become “living” documents. An exception might be the Syllabus for Neurodisability. The NC’s and the Task force could make update the Syllabus for Neurodisability that could be anchored in each country and with all professions involved. At best it could serve as a framework for education and training.

Other activities of the EACD concerning education and training could be to provide lectures on the EACD Website like the ones we can find at AACPDM called Grand Rounds Lectures. Here different researchers present a lecture of about one hour on a range of interesting topics. Thirdly, collaboration between European universities could be an interesting option. Web-based courses, regarding various aspects of neurodisability, are given today at many universities. Could such courses be announced at the EACD Website? Let us continue the discussion when we meet in Brussels!

Kind regards from Eva Brogren Carlberg and a cold Stockholm (April weather!)
An important goal for EACD is to reach out to countries in Central and Eastern Europe and to include colleagues in our Pan-European community for professional interaction. Apart from the annual meeting last year in Vilnius, we have had little interaction with countries belonging to the former USSR. In Truskavets, outside Lviv in Western Ukraine, Professor Volodymyr Kozyavkin has built a modern Rehabilitation Centre for children with cerebral palsy and developed a multimodal training programme. The training programme has become popular among parents far outside Ukraine, and about half of the patients are coming from other countries, e.g., Germany and Kuwait. The treatment includes correction of the vertebrae of the spine, mobilisation of joints, physical exercise, and massage and several other activities. It is based on Ukrainian and Russian tradition but has not been tested according the criteria of Evidence Based Medicine (EBM).

In order to discuss the role of EBM in cerebral palsy Volodymyr Kozyavkin in collaboration with Volodymyr Maryniuk, Kiev and Hubertus von Voss, Munich organised an international symposium on “Cerebral Palsy Syndrome: Treatment Methods and Research on Effectiveness“, April 8-10, at the International Clinic of Rehabilitation in Truskavets. Among the invited speakers were Hans Forssberg and Vlatka Mejaski Bosnjak from the EACD and several distinguished professors from Russia, Ukraine, Belarus and Kazakhstan.

The first day comprised a presentation of the Rehabilitation Clinic and a demonstration of one of the central components of the intervention programme practised at the Clinic, i.e., the polysegmental correction of the spine, on several patients with diplegic cerebral palsy. The second day included several lectures in which the different treatment methods practised in Ukraine and Russia were presented and the principles of EBM as applied in the western part of Europe were discussed. Details about the programme and invited speakers are published at the web page http://www.reha.lviv.ua/index.php?id=233&L=0. The symposium exposed that the tradition and the intervention principles for cerebral palsy are very different in the Eastern and Western parts of Europe, respectively. At the same time, the discussions at the meeting showed a big respect from both sides and a willingness to learn from each other and to collaborate in the future. Vlatka Mejaski Bosnjak informed the participants that EACD wants to invite professionals from Eastern European countries to join EACD. As a first step Dr Oleh Kachmar from the Rehabilitation clinic in Lviv, was proposed as national coordinator for Ukraine, and he will, at first, also act as representative for Russia and Belarus. It was also suggested that a regional Academy for Childhood Disability should be formed as a platform to exchange knowledge and experience between EACD and the Eastern region. We think this was an important and promising first step in what we hope will be a fruitful collaboration between EACD and Ukraine, Russia, Belarus and Kazakhstan and welcome some delegates already to the meeting in Brussels.

Hans Forssberg and Vlatka Mejaski Bosnjak
Dear members of EACD,

The Nomination Committee is in search for two new members of Executive committee (EC). Carmen Matey, who joined the EC two years ago, has to resign due to personal reasons.

We would like to find a person from a southern part of Europe to have diverse content of the EC. Up until now, we have one new candidate, Prof. Giovanni Cioni, Italy. Since many years of committed work in the EC, he is not needed to be introduced to the members of EACD. Still we invite you to suggest some other candidates.

Paul Gorham is soon ending his second mandate period as a treasurer and cannot be re-elected. Paul has done a magnificent job during the last 6 years and it will be hard to succeed him. It is a demanding job to be the treasurer, but also very exciting and challenging. For now there is no candidates yet, so we ask you all to consider if there is anyone that would be able to take over. Please send your suggestions or nominations as soon as possible to: katja.groleger@mf.uni-lj.si

New member of EC and Treasurer should be starting after the Annual Meeting in Brussels 2010, and with a mandate period of 3 years.

Katja Groleger

Nominations Committee
Practical Guide from Mac Keith Press

Physiotherapy and Occupational Therapy for People with Cerebral Palsy
A Problem-Based Approach to Assessment and Management

Edited by: Karen Dodd, Christine Imms and Nicholas F. Taylor

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