Contents

Foreword............................................................................................................ IX

List of participants............................................................................................ XII

Entrance criteria and outcome measures in pediatric epilepsy clinical trials
  Deborah Hirtz ................................................................................................ 1

Is it possible to predict the outcome of childhood epilepsy?
  Peter Camfield, Carol Camfield ...................................................................... 17

Prognostic factors for recurrence after a first unprovoked seizure in childhood
  Shlomo Shinnar .............................................................................................. 25

Newly diagnosed epilepsies:
  clinically relevant conclusions from global studies on outcome
  Willem F. Arts ............................................................................................... 33

Does treatment with antiepileptic drugs influence the long-term outcome
  of newly diagnosed epilepsies?
  Alexis Arzimanoglou ...................................................................................... 45

The influence of convulsive status epilepticus on outcomes of childhood
  epilepsy
  Richard Chin .................................................................................................. 53

Mortality in children with epilepsy
  Oebele F. Brouwer ........................................................................................ 61

Immune-related mechanisms of seizures: insights from experimental models
  Teresa Ravizza, Silvia Balosso, Valentina Iori, Federica Frigerio,
  Annamaria Vezzani........................................................................................ 71
# Outcome of Childhood Epilepsies

Febrile infection-related epilepsy syndrome (FIRES): pathogenesis, treatment, and outcome  
A large cohort and update  
*Uri Kramer* ........................................................................................................ 83

Are idiopathic epilepsy syndromes in neonates always “benign?”  
*Federico Vigevano, Maria Roberta Cilio, Domenico Serino, Lucia Fusco* .......... 91

Neonatal epilepsy and underlying aetiology (other than idiopathic): to what extent do the seizures and the EEG abnormalities influence outcome?  
*Georgia Ramantani* ........................................................................................ 99

Infantile spasms: what matters more?  
Seizures, EEG, underlying aetiology, or treatment?  
*Andrew L. Lux* ..................................................................................................... 109

Lennox-Gastaut syndrome: nosographic limits and long term outcome  
*Giuseppe Capovilla, Alberto Verrotti* .................................................................... 121

Dravet syndrome  
What matters more: seizures or the underlying aetiology?  
*Ingrid E. Scheffer* .................................................................................................. 133

Epileptic encephalopathy with continuous spike-waves during slow-wave sleep including Landau-Kleffner syndrome: what determines the outcome?  
*Patrick Van Bogaert* .............................................................................................. 141

Outcome of idiopathic generalized epilepsy and the role of EEG discharges  
*Elaine C. Wirrell* .................................................................................................... 149

Refractory childhood epilepsy: comparing the outcome of medical versus surgical treatment  
*Michael Duchowny* .............................................................................................. 163

Adult outcome of childhood-onset, cause unknown (cryptogenic), MRI-negative, focal epilepsy  
*Carol Camfield, Peter Camfield* ........................................................................... 173

Focal non-idiopathic epilepsies: does outcome after epilepsy surgery depend on the localization of the epileptogenic zone in frontal and temporal lobe epilepsy?  
*Ingrid Tuxhorn* ...................................................................................................... 179

Outcome after epilepsy surgery of MRI-negative non-idiopathic focal epilepsies  
*Thomas Bast* ......................................................................................................... 191
Contents

Outcome when malformations of cortical development (MCD) are the cause
Hans Holthausen, Tom Pieper, Manfred Kudernatsch, Ingmar Blümcke .......... 203

Timing of antiepileptic drug withdrawal after pediatric epilepsy surgery
Kees P.J. Braun, Kim Boshuisen ..................................................................... 217

Anxiety and depression in children with epilepsy
Julianne Giust, David W. Dunn ........................................................................ 225

Health perception and socio-economic status of childhood onset epilepsy
Ada T. Geerts ................................................................................................ 237

What if quality of life better expressed outcomes for epilepsy?
Kathy Nixon Speechley ................................................................................... 253
Foreword

From 15 to 18 November, 2012, 49 experts in the field of childhood epilepsy convened in The Hague, The Netherlands, for a workshop entitled: Outcome of Childhood Epilepsies. The workshop was held within the framework of the “Progress in Epileptic Disorders” workshops, organized by the journal Epileptic Disorders. The 2012 workshop was held in The Hague on the occasion of the 25th anniversary of the Dutch Study of Epilepsy in Childhood, and the members of the Dutch study group felt indeed very honoured to host so many distinguished guests.

The Dutch Study of Epilepsy in Childhood (DSEC) started in 1987 as a prospective cohort study of children with newly diagnosed epilepsy. The children were recruited from four hospitals in three adjacent cities in The Netherlands and the almost 500 children recruited over a period of four years were considered to contain roughly 70–80% of all incident cases in the referral area of the participating hospitals.

The original study group consisted—in alphabetical order—of Willem Arts, Oebele Brouwer, Ada Geerts, Boudewijn Peters, Hans Stroink and Cees Van Donselaar, and, sticking together as a group despite changes in the respective careers, we were able to continue the follow-up of the cohort until quite recently. Altogether, the DSEC produced about 50 papers in peer-reviewed journals, six theses, and countless contributions to international congresses and meetings. Most of this output concerned research on the outcome of the epilepsy of these children. Without aiming for completeness, we can mention the outcome after a single unprovoked seizure (Stroink), the outcome of newly diagnosed epilepsy (Arts, Geerts), the outcome after withdrawal of AEDs (Brouwer, Peters, Geerts), mortality (Brouwer, Callenbach), quality of life and psychosocial outcome (Carpay, Geerts), cognitive outcome (Geerts, Oostrom, Peters, Schouten), outcome predictability (Arts, Boerrigter, Geelhoed, Geerts), and intractability (Arts, Geerts).

Many of the contributions were realized only after intensive collaboration by and discussions with experts in the field like Carol and Peter Camfield, Anne Berg, Shlomo Shinnar, Matti Sillanpää, David Chadwick, Richard Appleton and many, many others. The 25th anniversary of the DSEC for us marked an excellent occasion to acknowledge their contributions and express our gratitude for it.

The background of the workshop was on the one hand the availability of many outcome data from cohort studies, trials and other studies on (treatment of) childhood-onset epilepsy. We felt that a state-of-the-art survey of the available data was now timely. On the other hand, it had already become clear that our knowledge on outcome of childhood epilepsy in general and of specific types of epilepsy and of treatment modalities in particular is as yet by far insufficient to base sound, evidence-based treatment strategies on. The workshop therefore also aimed to identify the lacuna’s in our knowledge and define research topics in this area for the years to come.

We really enjoyed three days of exciting discussions, and we hope that the readers of this book will agree with us that altogether, this is a state-of-the-art review as good and as up-to-date as one can get.
We are very grateful for having had the opportunity to organize this workshop. Our thanks go especially to Alexis Arzimanoglou, editor-in-chief of *Epileptic Disorders*, who opened up the possibility to embed the workshop within the “Progress in Epileptic Disorders” series, and was of great help with the content and organization, and to the other two members of the scientific committee, Carol and Peter Camfield. And of course, this also gives us the opportunity to gratefully acknowledge the enduring friendship, trust and hospitality we experienced from “The Camfields” during many years!

We thank all speakers and discussants who did such a great job, especially those who wrote a chapter and later revised it, incorporating the remarks and suggestions made during the sometimes heavy discussions. Special thanks go to Mrs. Florence Marsy from ANT Congress who did all the practical organizational work and to UCB Pharma for their continuing support for the “Progress in Epileptic Disorders” workshops. We gratefully acknowledge their unrestricted educational grant.

Finally, we also wish to thank John Libbey Eurotext Editions and their editor, Mrs Anne Chevalier, for their help in publishing this book soon after the workshop, eliminating our textual and linguistic mistakes.

Willem F. Arts, Oebele F. Brouwer
Outcome of Childhood Epilepsies

Progress in Epileptic Disorders Workshop

The Hague, The Netherlands

November 2012

Scientific Committee

Willem F. Arts (The Netherlands), Alexis Arzimanoglou (France), Oebele F. Brouwer (The Netherlands), Carol Camfield (Canada), Peter Camfield (Canada)

List of participants

Willem F. Arts, Erasmus MC, Sophia Kinderziekenhuis, Rotterdam, The Netherlands, w.f.m.arts@erasmusmc.nl

Alexis Arzimanoglou, Epilepsy Sleep & Pediatric Neurophysiology Department, University Hospitals of Lyon (HCL), Lyon, France, aarzimanoglou@orange.fr

Stéphane Auvin, Neurologie Pédiatrique, Hôpital Robert-Debré, Paris, France, stephane.auvin@rdb.aphp.fr

Nadia Bahi-Buisson, Hôpital Necker-Enfants Malades, Université Paris-Descartes, Service de Neurpédiatrie et Maladies Métaboliques, Paris, France, nadia.bahi-buisson@inserm.fr

Thomas Bast, Klinik für Kinder und Jugendliche Epilepsiezentrums, Kehl-Kork, Germany, TBast@epilepsiezentrums.de

Thomas Blauwblomme, Service de Neurochirurgie Pédiatrique, Hôpital Necker Enfants-Malades, Paris, France, tblauwblomme@hotmail.com

Kees Braun, Rudolf Magnus Institute of Neuroscience, University Medical Center, Utrecht, The Netherlands, k.braun@umcutrecht.nl

Oebele F. Brouwer, Department of Neurology, University Medical Center Groningen, University of Groningen, The Netherlands, o.f.brouwer@umcg.nl

Peter Camfield, Department of Pediatrics, Dalhousie University and the IWK Health Centre, Halifax, Canada, camfield@dal.ca

Carol Camfield, Department of Pediatrics, Dalhousie University and the IWK Health Centre, Halifax, Canada, camfield@dal.ca

Giuseppe Capovilla, Child Neuropsychiatry Department, Epilepsy Center “C. Poma Hospital”, Mantova, Italy, pippo.capovilla@aopoma.it

Richard Chin, Neurosciences Unit, Child Life and Health, University of Edinburgh, Edinburgh, United Kingdom, R.Chin@ed.ac.uk

Helen Cross, Neurosciences Unit UCL, Institute of Child Health, London, United Kingdom, h.cross@ucl.ac.uk
Outcome of Childhood Epilepsies

Thierry Deonna, Unité de Neurologie et de Neuroréhabilitation Pédiatrique, Département Médico-Chirurgical de Pédiatrie CHUV, Lausanne, Switzerland, th.deonna@bluewin.ch

Mike Duchowny, University of Miami, Miller School of Medicine, Florida International University College of Medicine, Miami, USA, michael.duchowny@mch.com

David Dunn, Riley Child and Adolescent Psychiatry Clinic, Indiana University School of Medicine, Indianapolis, USA, ddunn@iupui.edu

Melissa Filippini, Child Neurology Unit, IRCCS, Neurological Science Institute of Bologna, Ospedale Maggiore “C.A. Pizzardi”, Bologna, Italy, melissa.filippini@libero.it

Annick Fonteyne, Revalidatiecentrum voor kinderen en jongeren Pulderbos, Zandhoven, Belgium, Annick.Fonteyne@revapulderbos.be

Stefano Francione, Centro per la chirurgia dell’epilessia “Claudio Munari”, Ospedale Niguarda Ca’ Granda, Milano, Italy, stefano.francione@gmail.com

Ada Geerts, Department of Neurology, Erasmus MC, Rotterdam, The Netherlands, mail@adageerts.nl

Giuseppe Gobbi, Child Neurology Unit IRCCS Neurological Science Institute of Bologna Ospedale Maggiore “C.A. Pizzardi”, Bologna, Italy, giuseppe.gobbi@ausl.bologna.it

Renzo Guerrini, Pediatric Neurology Unit and Laboratories Children’s Hospital A. Meyer-University of Florence, Florence, Italy, r.guerrini@meyer.it

Bruce Hermann, Department of Neurology, University of Wisconsin, Madison, USA, hermann@neurology.wisc.edu

Deborah Hirtz, National Institute of Neurological Disorders and Stroke, NIH, Bethesda, Maryland, USA, dh83f@nih.gov

Hans Holthausen, Neuropediatric Clinic and Clinic for Neurorehabilitation-Epilepsy-Center for Children and Adolescents, Vogtareuth, Germany, hansholthausen@gmx.de

Philippe Kahane, Epilepsy Unit Neurology & Psychiatry Department Grenoble University Hospital, Grenoble, France, philippe.kahane@ujf-grenoble.fr

Uri Kramer, Pediatric Neurology Unit, Tel Aviv Sourasky Medical Center, Tel Aviv University, Tel Aviv, Israel, umkramer@netvision.net.il

Lieven Lagae, KU Leuven, Neuro-musculo-skeletal Research Unit, Leuven, Belgium, lieven.lagae@uzleuven.be

Andrew Lux, Bristol Royal Hospital for Children, Bristol, United Kingdom, andrew.lux@bristol.ac.uk

Wendy Mitchell, Childrens Neurology Hospital Los Angeles, Los Angeles, USA, WMitchell@chla.usc.edu

Brian Neville, Neurosciences Unit UCL, Institute of Child Health, London, United Kingdom, B.Neville@ich.ucl.ac.uk

John Pellock, Division of child Neurology, Virginia Commonwealth University, Richmond, USA, jpellock@mcvh-vcu.edu

Georgia Ramantani, Universitätsklinikum Freiburg; Epilepsiezentr um im Neurozentrum, Freiburg, Germany, georgia.ramantani@uniklinik-freiburg.de

Victoria San Antonio, Universitätsklinikum Freiburg; Epilepsiezentr um im Neurozentrum, Freiburg, Germany, victoriasanantonio@gmail.com
Ingrid Scheffer, Florey Institute and Department of Medicine and Department of Paediatrics, University of Melbourne, Royal Children’s Hospital, Melbourne, Australia, scheffer@unimelb.edu.au

Shlomo Shinnar, Comprehensive Epilepsy Management Center Montefiore Medical Center, Albert Einstein College of Medicine, New York, USA, sshinnar@aol.com

Matti Sillanpaa, Department of Public Health, University of Turku, Turku, Finland, matti.sillanpaa@utu.fi

Kathy Speechley, Schulich School of Medicine & Dentistry Western University, London, Ontario, Canada, kathy.speechley@lhsc.on.ca

Ulrich Stephani, Klinik für Neuropädiatrie Universitätssklinikum Schleswig Holstein Campus, Kiel, Germany, stephani@pedneuro.uni-kiel.de

Hans Stroink, Department of Neurology, St. Elisabeth Hospital, Nijmegen, The Netherlands, stroink.h@gmail.com

Petra Tijink-Callenbach, University Medical Centre Groningen, Department of Neurology, Groningen, The Netherlands, p.m.c.tijink@umcg.nl

Ingrid Tuxhorn, Pediatric Epilepsy Rainbow Babies and Children’s Hospital Case Western Reserve University, Cleveland, USA, Ingrid.Tuxhorn@UHhospitals.org

Patrick Van Bogaert, Université Libre de Bruxelles (ULB), Department of Pediatric Neurology, Hôpital Erasme, Brussels, Belgium, pvanboga@ulb.ac.be

Cees Van Donselaar, Maasstad Ziekenhuis, Rotterdam, The Netherlands, cees@vandonselaar.net

Onno Van Nieuwenhuizen, Rudolf Magnus Institute of Neuroscience, University Medical Center, Utrecht, The Netherlands, OnnovanNieuwenhuizen@umcutrecht.nl

Annamaria Vezzani, IRCCS-Istituto di Ricerche Farmacologiche “Mario Negri”, Milano, Italy, annamaria.vezzani@marionegri.it

Federico Vigevano, Neuroscience Department Bambino Gesù Children’s Hospital, Rome, Italy, vigevano@opbg.net

Patty Vinning, Department of Neurology, Johns Hopkins Hospital, Baltimore, USA, evining@jhmi.edu

Elaine Wirrell, Child and Adolescent Neurology, Mayo Clinic, Rochester, USA, Wirrell.elaine@mayo.edu