Setting Standards: International Collaboration for Pediatric Epilepsy Surgery Through the ILAE

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On Behalf of the Pediatric Epilepsy Surgery Task Force of the ILAE
Task Force for Paediatric Epilepsy Surgery

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William D. Gaillard (New Chair)
Renzo Guerrini
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Hans Holthausen
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Philippe Kahane
Gary Mathern
Brian Neville
Alexis Arzimanoglou
Carmen Barba
Eduardo Barragan
Christine Bulteau
Sarat Chandra
Arthur Cukiert
Deepak Gill
Adam Hartman
Nathalie Jette

Philippe Kahane
Jack Kerrigan
Pavel Kresk
Mark Libenson
Guoming Luan
Liisa Metsahonkala
Taisuke Otsuki
Bertil Rydenhag
Manjari Tripathi
Angus Wilfong
Jo Wilmshurst
Nandan Yardi
Giordano Flavio

Eija Gaily
Armen Melikyan
Sergey Ayvazyan
Frank Ritter

Nico Moshe
Perrine Plouin
Doug Nordli
Fernando Cendes
Disclosure

NeuroPace, Inc.  Member of the Data Management Committee

American Epilepsy Society  |  2013 Annual Meeting
Learning Objective: Trace the History, Accomplishments & Challenges for the Pediatric Epilepsy Surgery Task Force of the ILAE

• Chapter 1: “In the beginning . . .”
• Chapter 2: What is pediatric epilepsy surgery? Dordogne, 2003
• Chapter 3: International survey of pediatric epilepsy surgery programs
• Chapter 4: Guidelines for presurgical assessment- Florence, 2011
• Chapter 5: What we have learned and where next?

American Epilepsy Society | 2013 Annual Meeting
Chapter 1: “In the beginning . . .”

Commission of Neurosurgery created Pediatric Epilepsy Surgery Sub-commission in 1998

Tasked to report on the role of palliative procedures for pediatric epilepsy surgery

Initial meeting AES Orlando 1999, Cleveland in 2000, and AES Los Angeles 2000

American Epilepsy Society | 2013 Annual Meeting
Chapter 2: What is pediatric epilepsy surgery?

• Are the unique characteristics of children with epilepsy and their syndromes sufficiently different to justify dedicated pediatric epilepsy centers?
• Is adequate information available to propose guidelines regarding patient selection and surgical treatment for pediatric epilepsy surgery patients?
## Invited participants (*present at St. Avit de Vialard*)

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<tr>
<th>Name</th>
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<td>Sarah Aylett*</td>
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<td>Christine Bulteau*</td>
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<td>Rochelle Caplan</td>
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<td>Catherine Chiron*</td>
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<td>Harry Chugani</td>
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<td>Yousef Comair</td>
<td>Beirut, Lebanon</td>
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<td>Thierry Dionna*</td>
<td>Lausanne, Switzerland</td>
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<td>Olivier Dulac*</td>
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<td>Martine Fohlen*</td>
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<td>William Harkness*</td>
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<td>Isobel Heyman*</td>
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<td>Philippe Kahnau*</td>
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<td>Solomon L. Moshe*</td>
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<td>Perrine Plouin</td>
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<td>Don Shields*</td>
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<td>Shlomo Shinnar</td>
<td>New York, U.S.A.</td>
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<td>Carter Sneed</td>
<td>Toronto, Ontario, Canada</td>
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<td>Tatsuya Tanaka*</td>
<td>Tokyo, Japan</td>
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<td>Patrick Van Bogaert*</td>
<td>Brussels, Belgium</td>
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<td>Eileen Vining*</td>
<td>Baltimore, Maryland, U.S.A.</td>
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<tr>
<td>Harry Vinters</td>
<td>Los Angeles, California, U.S.A.</td>
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Original Research

Proposed Criteria for Referral and Evaluation of Children for Epilepsy Surgery: Recommendations of the Subcommission for Pediatric Epilepsy Surgery

Why are children different?

- Age dependent presentation
- Heterogeneous presentation of focal epilepsy in childhood
  - Generalised presentation
  - Imaging during brain development
- Effect of epilepsy on brain development
- High prevalence of comorbidities (not contraindication for surgery)
- Potential for neuroplasticity
Proposed criteria for referral and evaluation of children for epilepsy surgery

- ‘Paediatric Specialist Epilepsy Unit’
- No minimal expertise/infrastructure requirements
- Certain subgroups should be referred to unit with experienced multidisciplinary personnel, access to advanced technologies
  - Infants and toddlers
  - Hemispherectomy
  - Multilobar resection
  - Paediatric aetiologies

Cross et al Epilepsia 2006;47:952-959
Concepts agreed
• strategies for specific syndromes of childhood
• need for evaluation of children in dedicated centres
• need to assess surgical success
  – Seizures
  – Developmental
  – Psychosocial

Concepts for further evaluation
• minimal criteria for defining surgical unit
• need for epidemiological data
• data on role of additional investigative techniques
• standardisation of outcome measures

Cross et al Epilepsia 2006;47:952-959
Chapter 3: International survey of pediatric epilepsy surgery programs
Aims

• overview of epilepsy surgery being undertaken currently in children around the world
  - what ages & epilepsy syndromes
  - what preoperative investigations
  - what surgical procedures

• partially overcome the syndrome/ procedure/ centre related biases of published paediatric surgical series

• examine generalisations made about paediatric surgery

• identify issues that might arise a multicentre, prospective study of epilepsy surgery in children
Survey Data Collection

• all epilepsy surgery performed during 2004 in ≤ 18 yrs:
  - resections, disconnections, reoperations etc.
  - intracranial EEG monitoring
  - VNS and radiosurgery

• on-line survey in March and June 2005 using GlobalSCAPE® Web Survey (internet data entry with rigorous data verification and correction)

• data collected on:
  - age at seizure onset, seizure frequency, syndrome
  - preop investigations performed, MRI findings
  - age at surgery, surgery performed, histopathology (not seizure types, development/behaviour, outcomes)
<table>
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<th>CENTRES (20)</th>
<th>PATIENTS (543)</th>
<th>PROCEDURES (742)</th>
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<td>UCLA, Los Angeles, USA (Mathern, Koh, Shields)</td>
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<td>GOSH, London, UK (Cross, Harkness, Dunkley)</td>
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<td>Karolinska, Stockholm, Sweden (Amark)</td>
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<td>Region</td>
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| Asia/Oceanic (233 Patients) | Australia, Melbourne, Royal Children’s Hospital  
                      | Australia, Sydney, Westmead & Sydney Children’s  
                      | China, Beijing, Sanbo Brain Institute  
                      | China, Hong Kong, Prince of Wales  
                      | India, New Delhi, AIIMS  
                      | Japan, National Nagasaki Medical Center  
                      | Japan, Shizuoka National Epilepsy Center  
                      | Japan, Tokyo National Center of Neurology & Psych.  
                      | Korea, Yonsei, Severance Children’s  
                      | Korea, Seoul, Samsung Medical Center  
                      | Taiwan, Taipei Veterans General Hospital |
| Europe (259 Patients) | Belgium, Brussels, ULBH-Hôpital Erasme  
                      | Finland, Helsinki, University Central Hospital  
                      | France, Lyon, IDEE (HCL)  
                      | France, Paris, Foundation Rothschild  
                      | Germany, Bonn, University Clinic Bonn  
                      | Germany, Vogtareuth, BHZ  
                      | Italy, Milano, Ospedale Niguarda  
                      | Italy, Rome, Catholic University  
                      | Netherlands, Wilhelmina Children’s Hospital  
                      | Sweden, Goteborg, Sahlgrenska University Hospital  
                      | Sweden, Stockholm, Karolinska, Children’s Hospital  
                      | United Kingdom, London, Great Ormond Street |
| North America (533 Patients) | Baltimore, John’s Hopkins  
                      | Boston, Children’s Hospital Boston  
                      | Cleveland, Cleveland Clinic Foundation  
                      | Chicago, Children’s Memorial Hospital  
                      | Denver, Denver Children’s  
                      | Los Angeles, UCLA  
                      | Miami, Miami Children’s Hospital  
                      | St Paul, Minnesota Epilepsy Group  
                      | New York, New York University  
                      | Phoenix, Barrow Neurological Institute  
                      | Seattle, Seattle Children’s Hospital  
                      | St Louis, St Louis Children’s  
                      | Houston, Baylor, Texas Children's  
                      | Toronto, Sick Kids  
                      | Washington, DC, Children’s National  
                      | Milwaukee, Wisconsin Children’s Hospital |
| Latin America (87 Patients) | Argentina, Buenos Aires, Garrahan  
                      | Brazil, Ribeirao Preto  
                      | Brazil, Sao Paulo  
                      | Chile, Santiago, Instituto de Neurocirugía Asenjo  
                      | Mexico, Hospital Infantil de Mexico |
| Eastern Med (12 Patients) | Egypt, Cairo, Ain-Shams University |
Etiology for Pediatric Epilepsy Surgery Patients
ILAE 2004 Outcome Survey - Resection Cases (n=797)

Cortical Dysplasia: 33%
Tumor: 20%
Atrophy: 11%
Hipp Sclerosis: 9%
Hypo Hamartoma: 6%
Gliosis/Normal: 5%
HME: 5%
TSC: 4%
Rasmussen: 3%
Sturge Weber: 2%
Vascular: 2%

Harvey et al., Epilepsia 2006
Cases Per Center: 2004 ILAE Pediatric Epilepsy Surgery Survey

Number of Cases

Mean: 17±12
Median: 14

Unpublished Data; ILAE
Operation Types by Region: 2004 Pediatric Epilepsy Surgery Survey; P=0.05

![Bar chart showing operation types by region.]

Harvey et al., Epilepsia 2006
Presurgical Investigations by Region: 2004 Pediatric Epilepsy Surgery Survey

Harvey et al., Epilepsia 2006
Seizure Outcomes Pediatric Patients - Resective Cases; 2004 Outcome ILAE Survey

Number of Cases

1A 1B 1C 1D 2 3A1 3A2 3A3 3B 3C 4A 4B 4C

55% 3% 3% 3% 8% 4% 2% 2% 2% 8% 2% 8% 0.4%
Seizure Free & AED Use by Region: 2004 ILAE Pediatric Epilepsy Surgery Survey

Unpublished Data: ILAE
Chapter 4: Guidelines for Presurgical Assessment-Florence, 2011
Challenges

• The evidence base for investigations to be used is limited
  – Few exclusive paediatric studies
  – Range of pathologies/clinical presentation

• Country variability
  – Resource
  – Health care systems

• Centre variability
  – Investigation experience/availability
Can we now revisit?
J Helen Cross  London, England
William D. Gaillard  Washington, DC, USA
Prasanna Jayakar  Miami, Florida, USA
Renzo Guerrini  Florence, Italy
A Simon Harvey  Melbourne, Australia
Hans Holthausen  Vogtareuth, Germany
Philippe Kahane  Grenoble, France
Gary Mathern  UCLA, California, USA
Brian Neville  London, England
Alexis Arzimanoglou  Lyon France
Carmen Barba  Florence, Italy
Eduardo Barragan  Mexico
Christine Bulteau  Paris, France
Sarat Chandra  New Delhi, India
Arthur Cukiert  Sao Paolo, Brazil
Deepak Gill  Sydney, Australia
Adam Hartman  Baltimore, USA
Nathalie Jette  Calgary, Canada
Jack Kerrigan  Phoenix, USA
Pavel Krsek  Prague, Czech Republic
Mark Libenson  Boston, USA
Guoming Luan  Beijing, China
Liisa Metsahonkala  Helsinki, Finland
Taisuke Otsuki  Tokyo, Japan
Bertil Rydenhag  Gothenburg, Sweden
Manjari Tripathi  New Delhi, India
Angus Wilfong  Houston, USA
Jo Wilmshurst  Cape Town, South Africa
Nandan Yardi  Pune, India
Flavio Giordano  Florence, Italy
Yu-tze Ng  Oklahoma, USA
Methodology

• Members took responsibility for individual aetiologies

• Literature review,
  – expectation for outcome
  – recommendations for referral (minimal vs. optimal)
  – selection of candidates
  – Follow-up

• Presentation to group

• Vote on thoughts of requirements of individual presurgical evaluation
  – mandatory,
  – highly recommended,
  – optional
  – limited value)
# Investigations for Pediatric Epilepsy

**Surgery Patients: Florence 2011**

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<tr>
<th>Etiology</th>
<th>II EEG</th>
<th>Video EEG</th>
<th>MRI</th>
<th>3D EEG/MEG</th>
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M=Mandatory; H=Highly Recommended; O=Optional; L=Limited Value; U=Unnecessary
Chapter 5: What we have learned and what is next?
LEAVE YOUR EGO AT THE DOOR
What have we learned?

• You can do international collaborations that provide unique data
• These collaborations working together can lead to consensus agreements related to patient care
• Future: Leverage these collaborations to build toward high levels of care throughout the world