Update for IHS Council meeting
Clinical guideline committee
October 5, 2020
Clinical guideline committee

<table>
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<tr>
<th>Chair:</th>
<th>Gisela Terwindt</th>
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<td>Vice Chairs:</td>
<td>Chris Diener and Cristina Tassorelli</td>
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<td>Members:</td>
<td>Messoud Ashina</td>
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<td>Peter Goadsby</td>
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<td>Elizabeth Leroux</td>
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<td>Patricia Pozo-Rosich</td>
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<td>Shuu-Jiun Wang</td>
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<td>Juniors:</td>
<td>Daniele Martinelli (I)</td>
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<td>Thomas van den Hoek (NL)</td>
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<td>Marie Deen (D)</td>
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Previous deliverables

Guidelines of the International Headache Society for controlled trials of preventive treatment of chronic migraine in adults


Guidelines of the International Headache Society for controlled trials of preventive treatment of migraine in children and adolescents, 1st edition
Previous deliverables by junior members

The idea emerged that junior members prepare a manuscript on innovative trials designs, with the support of seniors.
Guidelines of the International Headache Society for controlled trials of preventive treatment of migraine attacks in episodic migraine in adults

Hans-Christoph Diener, Cristina Tassorelli, David W Dodick, Stephan D Silberstein, Richard B Lipton, Messoud Ashina, Werner J Becker, Michel D Ferrari, Peter J Goadsby, Patricia Pozo-Rosich, Shu-Juin Wang, Timothy T Houle, Thomas C van den Hoek, Daniele Martinelli, Gisela M Terwindt, on behalf of the International Headache Society Clinical Trials Committee
Health Technology Assessment for the Acute Treatment of Migraine Attacks and Prevention of Migraine: A Position Statement of the International Headache Society (IHS)
• All stakeholders have provided input. Almost finished.
Guidelines of the International Headache Society for Clinical Trials with Neuromodulation Devices for the Treatment of Migraine

(Cristina Tassorelli et al.)

- Primary/secondary endpoints will be used from 1
- Aimed for end of 2020
Guidelines of the International Headache Society for Controlled Trials for Idiopathic Intracranial Hypertension (Alexandra Sinclair and Rigmor Jensen et al.)

- Some key publications coming out over the next 6-9 months in this area that will impact this endeavour
- A practice changing international Good clinical Practice Guideline is due to be published in 2020
- Deliver in 2021, awaiting other consensus papers

Multidisciplinary team composition:
Lead / Chair Alex Sinclair
Susie Mollan, UK Ophthalmology Lead
Kathleen Digre, Utah, PROMS Lead
Chris Diener, Germany, Headache Lead
Rigmor Jensen, Copenhagen
Christian Luek, Australia
Mansoureh Togha, Iran
Mark Dinkin Stenting, US
Prem Subramanian, Ophthalmology, Denver
Valeria Biousse
Neurosurgery TBC
Statistic -, IIH specialist, Kristian Brock
Gisela Terwindt, Chair of Guideline committee, guideline expert / headache
Christina Tassorelli, Trial guideline expert.
Vivek Vijay, Secretary

Tele-meeting on 28th September
Guidelines of the International Headache Society for Registries on Real Life data (Todd Schwedt et al.)

Team composition:
- Todd Schwedt (Chair)
- Gisela Terwindt
- Chris Diener
- Cristina Tassorelli
- Messoud Ashina
- Stephen Silberstein
- David Dodick
- Tobias Kurth
- Patricia Pozo-Rosich
- Faisal Amin
- Christina Szperka (input for pediatric headache registry)
Guidelines of the International Headache Society for Registries on Real Life data (Todd Schwedt et al.)

- **Background**
  - What is a registry
  - Value of a registry
  - Specific goals for a registry
  - Existing guidelines/advice on registry development

- **Methods**
  - Process for developing a registry
    - Team members
    - Governance
    - Validated questionnaires and PROs
    - Registry specific questionnaires
  - Data Sources
    - Patient provided information
    - Clinician provided information
    - Electronic Health Records
    - Pharmacy/Insurance claims data
    - Biospecimens
    - Neuro-imaging
  - Data Harmonization
  - Ensuring data quality
  - Data and specimen protection
  - Human subjects protection
  - Patient/Participant selection and eligibility
  - Design (e.g. cross-sectional, longitudinal)
  - Patient engagement
  - Statistical considerations/guidance
  - Biorepository
  - Neuroimaging repository
  - Data Sharing
  - Dissemination policy (e.g. publications, presentations)
Guidelines of the International Headache Society for Controlled Trials on acute and preventive treatment (including neuromodulation) of Cluster Headache

(Jean Schoenen and Michel Ferrari)

• A committee and expectation for deliverable needs to be proposed
• Suggested members Rigmor Jensen, Julio Pascal, Arne May, Christoph Diener, Cristina Tassorelli, Gisela Terwindt, E Leroux & Patricia Pozo Rosich
• Juniors: Marie Deen (Denmark), Roberto De Icco (Italy), ? (NL)