

International Headache Society (IHS) International Classification of Headache Disorders IV Meeting Thursday 14 September 2023 at 08:00 IHC 2023, Conference Room 209B, COEX, Seoul, South Korea

In attendance: Peter Goadsby (PJG) Richard Lipton (RL) via Zoom Amy Gelfand (AG) Cristina Tassorelli (CT) Todd Schwedt (TS) Shuu-Jiun Wang (SJW) Patricia Pozo-Rosich (PPR) Gisela Terwindt (GT) Alison Worth (PJG PA; AW)

- 1.0 Apologies:i) Arne May (AM), Stefan Evers (SE), Jean Schoenen (JS)
- 2.0 Consent agenda:

i) PJG put together an agenda.
ii) Documents will be approved by committee.
iii) Items will not be discussed unless on agenda.
iv) There will be an assumption that all material is read prior to the meeting.

3.0 Minutes of previous meeting:i) Not applicable

4.0 Process aspects:

a) Minutes- to be taken by AW

(i) Committee felt it was a good idea to keep a record as a curated summary of discussion.

(ii) Draft minutes would be presented to the committee with one month given for edits.

(iii) Once agreement on minutes they would be sent to the secretary of IHS (PPR) for information then on to the IHS Executive and Board.

(iv) The Committee requested, through PPR, that IHS allocate a webpage available to members for information/transparency; not for comment.

b) Committee membership (initial): Stefan Evers (SE; secretary), Amy Gelfand (AG), Richard Lipton (RL), Arne May (AM), Patricia Pozo-Rosich (PPR), Jean Schoenen (JS), Todd Schwedt (TS), Cristina Tassorelli (CT), Gisela Terwindt (GT), SJ Wang (SJW), Peter Goadsby (PJG; chair). The committee contains extensive clinical and research experience, and may require enlargement as the process develops. Sub-committees to be diverse and inclusive, including geographical considerations and junior members.

c) The Issues:

i) There will be errors in ICHD-3. PJG has written about errors in Cephalalgia. PJG encourages committee members to point out errors and bring to the committee for discussion. Factual errors need to be resolved.

ii) Beta process: The Committee discussed whether to wait five years and then publish, or publish Beta versions of particular planned changes.

- Beta papers will be published in Cephalalgia and we would liaise with media committee for media outreach to ensure new versions are cited.
- We would make members aware of new releases.
- We would only release beta versions we consider are, in essence, final and would likely be published in the final ICHD-4.
- Any versions would be published early in the year for citation purposes.
- We would only publish if there is a committee consensus on the change and nothing would get published without full consent of the committee.
- Outcome: The committee broadly agreed with the process. It was decided to write an editorial for Cephalalgia to cover this and other matters.

Action: PJG to draft an appropriate editorial

iii) Timelines: Agreed that it would take 5-6 years to complete ICHD-4. It was noted that 2028 would mark the 40th Anniversary of ICHD-1.

- iv) Process summary:
- Agreed to keep minutes and record of what is going on.
- Broad input careful of sub-committee selection mindful of diversity and inclusivity.
- Any errors in current classification to be collated.
- Beta process to be an ongoing work.
- In general, data should be provided for classification changes.
- Timeline 5-6 years.
- 5.0 Areas in need of consideration:

a) Role of appendix: The committee were asked to think hard about what the appendix does. Most appendix criteria seem not to be used except for migraine.

- b) Areas to discuss:
 - Classification of attacks versus disease
 - Episodic vs chronic migraine
 - Menstrual migraine

- Accounting for both primary and secondary headache, such as primary headache phenotypes such as in CADASIL or MELAS

- Role of Biomarkers in classification

- Secondary headaches

-associated criteria to algorithm

-classify attacks or disease

- Mathematical modelling

-Digital version – PJG has spoken to statistician Jim McGinley at Cephalalgia who has said he would be happy to help.

- Headache features – include psychiatrists – regional differences around classification across the globe e.g. photophobia not a big thing in

Taiwan/Korea/China; osmophobia more severe in certain regions

- Dimensions of features or diagnostic criteria to be selected for diagnosis: how to decide, any rule, e.g. DSM-5

- Tension-type headache

- New Daily Persistent Headache

- Medication Overuse Headache

- Debate needs to be had for when it makes sense to have sub-types of migraine – guidance on what makes sense.

- Terminology – clarify what we mean – photophobia offered as an example

- Handling of age and sex as it effects headache disorders.

6.0 Any other business:

i) PPR commented the approach was contemporary.

ii) PJG noted the process is an evolution not a criticism of what has gone before.

iii) Typesetting errors and proofreading – the Committee needs to take ownership of the final product.

iv) TS supports increased transparency.

v) It was noted that committee members would become sub-group leaders – this allocation is for another meeting.

vi) A photograph of the committee was taken for electronic meeting committee.

7.0 Next meetings:

i) aim for two meetings in 2024 in April and September, with more meetings if felt necessary.

ii) All meetings will be hybrid to maximize attendance.

iii) Editorial for Cephalalgia required to set out the aims and direction which will be drafted when minutes are agreed.