COPPER(LESS) COMMITTEE

APPROVED
RULES OF PROCEDURE (as of 1 December 2024)

1. Definitions

1.1 Menkes International is the patient organization founded to fight rare diseases, particularly those related to copper.

1.2 The Copper(less) Committee (hereinafter, the Committee), is an open-ended scientific advisory board of Menkes International (MIa).

1.3 The Core is a subcommittee of the Copper(less) Committee, being the clinical and functional body of the Committee. Its main task is to facilitate access to the available treatments to patients, including elesclomol-copper, to monitor the treated patients and to give clinical advice to families and doctors. The Core coordinates exceptional treatments for Menkes disease and provides clinical advice to external medical teams that treat Menkes patients.

2. Membership

2.1 General scope

The Committee comprises scientists, researchers, medical doctors, biochemists, pharmacometricians, pharmacologists, chemists, biologists, therapists, and families all recognized for their fairness, expertise, and integrity. Members work pro bono, participating as private individuals rather than as representatives of any specific organization or institution.

2.2 New Members

Any current Committee Member may propose a new candidate after informing the Chair and the Secretary. The Secretary will inform the Committee about the proposed Member and give one-week objection period. The new member will not be accepted if one-third of the Members make an objection.

2.3 Members to leave

2.3.1 No individual Member can decide the entry or exit of another member. A prior proposal and vote will always be required. If the proposal is for a member to leave, at least two-thirds of the members must vote in favour.

2.3.2 Members of The Committee must be biannually revised. After a year, inactive Members will be asked if they want to continue being part of the team; if they remain inactive, the Chair may request voting on whether or not they should continue as members.

2.3.3 Inactive Members will be those who don't attend meetings nor provide any advice at the request of the Secretary or the Chair.

2.3.4 The Core Members shall be proposed from the members of the Committee, and its coordinator should be chosen by vote of the Committee to be officially appointed by Menkes International.

2.3.5 Menkes International will act as a supervisor and final decision making-body, particularly in case of conflict, also making sure any changes follow the Rules of Procedure.

3. Scope

3.1 The Committee´s primary role is to advance research, provide clinical guidance and collaboration with others to improve patient treatment outcomes for Menkes and other rare diseases, particularly copper-related.

3.2 Some of the main objectives are:

a) Exceptional treatments: Elesclomol-copper for patients duly authorised
b) Diagnostic Protocols: Early diagnosis protocols/guidelines and others.
c) Research Initiatives: Ongoing research projects on Menkes and other rare copper disorders.
d) New related initiatives and related projects.
e) Advocacy: Activities to raise awareness and improve treatment accessibility. Visibility.
f) Training and education: aimed at families, clinicians, community, etc.

4. Officers

4.1 The Committee shall elect a Chair and the Core leader among its Members for a three-year term. The Committee will also appoint a Vice-Chair. A member of the Core should occupy one of the positions mentioned; ideally, the other member should not be part of the Core.

4.2 In the absence of consensus or if multiple members are running for any of the positions, the Chair and the Vice-Chair shall be elected by a majority vote of the members of the Committee. In the event of a tie, the final decision will be made by consensus between the Chair, Vice-Chair, and the MIa management team. A period of one week would be given for the group to make a secret vote online that would be sent to the Secretariat.

4.3 Menkes International shall act as a supervisor and facilitator during the election process and ensure any changes or votes follow the procedure rules, and the authority to appoint the officers.

4.4 The Chair, or in his/her absence, the Vice-Chair, shall preside at meetings of the

Committee, intervene on behalf of the Committee based on the Committee´s discussions at any external meeting, such as conferences, workshops, etc., delegate his/her functions and representation of the Committee, and exercise any other functions as may be required to facilitate its work.

4.5 Menkes International provides the Secretary and necessary staff that compose the Secretariat. The Secretariat shall perform such duties as the Committee may require. Such responsibilities include but are not limited to supporting the meetings of the Committee, maintaining the webpages, documentation of research, traveling arrangements, maintaining a list of active members, and any other supporting work.

5. Voting

5.1 Voting will be secret. Votes will be sent to the Secretariat by electronic correspondence. Voting will only be valid if half of the Members take part of the voting.

5.2 Decisions of the Committee shall be non-binding and adopted by majority of vote.

5.3 Decisions shall be made by members present at the face-to-face or virtual meeting or by electronic communication two days before or after the meeting.

5.4 Any final recommendations must be written and distributed among the members.

6. Meetings

6.1 The Committee shall hold regular meetings at least every 2 months and will have an in-person meeting at least every two years. Meetings may be postponed if necessary.

6.2 Meeting notices shall generally be circulated at least 15 days before online meetings and (2) months before any in-person meetings.

6.3 The Committee can establish, when deemed appropriate, ad hoc working groups to review or examine specific issues and report back to the Committee.

7. Non-Members

7.1 Meetings of the Committee shall not be open to public participation.

7.2 Non-Members may after Member invitation and Chair approval attend Copper(less) Committee meetings.

7.3 Any Non-Member invited Guest who is invited to attend a meeting of the Committee may submit information and, subject to the direction of the Chair, participate in the discussions.

8. Agenda and documents

8.1 The Chair, in consultation with the Secretary and the Core, shall prepare a provisional agenda and, according to Article 6, shall normally circulate it at least 15 days or two (2) months in advance of in-person meetings to all Members and Non-Members invited to attend the meeting.

8.2 Members may request the Chair to insert an item in the provisional agenda. The Chair shall thereupon circulate the proposed item to all Members of the Committee, together with any accompanying documents.

8.3 The first item on the provisional agenda shall be the adoption of the agenda. The Committee, in its meeting, may, by general consent, amend the agenda by the deletion, addition, or modification of any item.

8.4 Any document requiring prior review by the group should be sent by one week in advance of the meeting.

9. Communications

9.1 All communications shall be circulated by the Secretariat to ensure that the Officers and all Members are dully informed.

9.2 Chats may be open directly among members after informing the Chair. The Secretariat will compile all responses in one document and circulate them to the Committee to ensure that all Members are aware about the ongoing matters.

10. Reports of meetings

A draft meeting minutes will be prepared after the meeting when Non-Members attend and will be validated by the Chair.

11. Amendment of Rules

The Committee may, by two-thirds of the formal members, amend its Rules of Procedure. Proposals to amend the Rules of Procedure must be circulated to all members through the Secretariat at least four (4) weeks before the meeting at which they will be considered.

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