

## Charter of the Ataxia Global Initiative

Version	Date	Changes
2	18 September 2024	

### Background

The Ataxia Global Initiative (AGI) is a worldwide public-private partnership as defined in article II that has the goal to facilitate the clinical development of therapies for ataxias. AGI’s activities are based on the principles of openness, transparency, flexibility, and fairness.

Specifically, the AGI

- provides services that support trial readiness,
- promotes sharing of data and biomaterials,
- contributes to the definition of worldwide accepted common standards for clinical research and interventional trials,
- provides information that is relevant to prepare and conduct clinical trials,
- organises and hosts international meetings and conferences to update and educate the field on key issues,
- offers training and education programmes, and
- provides information about clinical research to people with ataxia and the public.

### Article I – Organisation and Affiliation

- 1.1 This network is known as the Ataxia Global Initiative (AGI).
- 1.2 AGI is organised as an independent, non-profit network of interested individuals who work together to support therapy development for ataxias.
- 1.3 The views of the AGI do not necessarily represent the views of the institutions and organisations with which members are affiliated.
- 1.4 There are two ways to engage with AGI, via individual membership or by organisations being partners (see Article II and III below).

### Article II – Membership

- 2.1 AGI members are ataxia researchers (academic or industry-based), ataxia clinicians, representatives of patient organisations or individuals or organisations with an explicit interest in ataxia therapy development.
- 2.2 Members of the AGI agree to work with AGI to further advance the aims and objectives of AGI.

- 2.3 To apply for membership a membership application should be submitted to the AGI Office. Membership applications will be approved by the Steering Committee.
- 2.4 AGI membership will be valid for three years and can be renewed. To renew an expired membership a request should be sent to the AGI Office.
- 2.5 On becoming a member, members will receive a membership certificate and will be listed as a member on the AGI website (name and location), unless requested otherwise.
- 2.6 Members who wish to terminate their membership must contact the AGI Office via e-mail. Membership will cease after 30 days from receiving the termination request and the members' information will be removed from the website within this period.
- 2.7 Members will have the right to participate in the working groups and projects of AGI.
- 2.8 Members will have access to reports, including financial reports, newsletters, work plans and updates on activities.
- 2.9 Members must not, whether knowingly or negligently, act in a way which could bring AGI into disrepute, lead to a possible loss of public confidence or legal actions.
- 2.10 If a member is found to have brought, or could possibly bring, AGI into disrepute then the member will be contacted by the Chair of the Steering Committee in writing to request an explanation of the reasons for their actions and how this can be resolved. The member will be given a period of 30 days to resolve the issue(s) or explain why they feel they have not contravened the obligations in article 2.7. If the member does not comply then they will be asked to remove the AGI logo and any other association from any publishable materials, i.e., websites, newsletters, etc and their membership will be terminated forthwith following a two thirds vote of the Steering Committee members.
- 2.11 Members will not claim to be a member of AGI without first having received the membership certificate.
- 2.12 Members must comply with all relevant known national and international data protection, privacy and ethical laws and guidelines.

### **Article III – Partnership**

- 3.1 AGI partners are organisations including industry and patient organisations. AGI partnership is not limited to legal entities and may include companies, patient organisations, patient support groups, foundations, academic institutions and research consortia.
- 3.2 A Partner of the AGI agrees to sign a partnership application and agrees to work with AGI to further advance the aims and objectives of AGI. AGI partnership will be valid for three years and can be renewed.
- 3.3 To apply for partnership a completed partnership application should be filled out by an entitled representative of the respective organisation and submitted to the AGI Office. Partnership applications will be approved by the Steering Committee.
- 3.4 AGI partnership will be valid for three years and can be renewed. To renew an expired partnership a request should be sent to the AGI Office.
- 3.5 On becoming a Partner, Partners will receive a partnership certificate and will be listed as a partner on the AGI website (name and location), unless requested otherwise.
- 3.6 Partners who wish to terminate their partnership must contact the AGI Office in writing at any time. Partnership will cease after 30 days from receiving the termination request and the members' information will be removed from the website within this period.

- 3.7 Partners have the right to nominate representatives to AGI Working Groups. These nominations will have to be approved by the chairs of the AGI Working Groups.
- 3.8 Partners will not claim to be a partner of AGI without first having received the partnership certificate.
- 3.9 Partners must comply with all relevant known national and international data protection, privacy and ethical laws and guidelines.
- 3.10 Partners must not, whether knowingly or negligently, act in a way which could bring AGI into disrepute, lead to a possible loss of public confidence or legal actions.

#### **Article IV – Membership Meetings**

- 4.1 Business meeting: The date of the Business meeting (either in person or virtual) will be set by the Steering Committee who will also set the time and the place. This will be announced at least two months in advance.
- 4.2 Special meetings: Special meetings (either in person or virtual) may be called by the Steering Committee.
- 4.3 Notice: Every effort will be made to provide meeting agendas and supporting documents for each meeting to each member, by email (as provided), not less than fourteen (14) days before the meeting.
- 4.4 Partners will be invited to participate in the membership meetings.

#### **Article V – Steering Committee**

- 5.1 The Steering Committee is responsible for providing overall policy and strategic direction to the AGI, oversees activities and progress, and delegates responsibility for day-to-day operations to the Office and Working Group leads. The Steering Committee will have no more than 15 and not fewer than 10 members. The Steering Committee members receive no compensation other than reasonable expenses.
- 5.2 The Steering Committee will meet at least annually, either in person or virtually, at an agreed time and place.
- 5.3 The AGI Steering Committee is representative in its composition of the key stakeholders in the ataxia field. Only AGI members can be elected into the Steering Committee. Up to three members of the Steering Committee will be elected from individuals representing patient organisations or advocacy groups and up to two members of the Steering Committee can be a non-academic (neither academic nor patient representative) members. At least one of the two places for non-academic SC members will be reserved for a member from industry. The remaining Steering Committee membership will be composed of academic members of AGI that represent all world regions – as defined by the Steering Committee - that participate in AGI.
- 5.4 Election of new Steering Committee members or election of current Steering Committee members to a second term will occur as the first item of business at the Business meeting. Steering Committee members will be elected by a ranked vote of the current AGI members. Separate ballots will be held for the patient organisation candidates, academic and non-academic candidates, as defined in 5.3.
- 5.5 All Steering Committee members will serve 3 year terms, but are eligible for re-election, with at least three Steering Committee positions up for rotation every 3 years.

- 5.6 A quorum must be met by at least two thirds of the Steering Committee members including at least one patient representative before business can be transacted or motions made or passed.
- 5.7 Every effort will be made to provide meeting agendas and supporting documents for each meeting to each Steering Committee member, by email, not less than seven (7) days before the meeting.
- 5.8 Steering Committee members will elect two of their members as a Chair and a Vice-Chair. The Chair and the Vice-Chair will serve a 3-year term of office. If the Steering Committee Chair or Vice Chair resigns before the end of the term, a new officer will be elected by the Steering Committee to fill the vacancy till the end of the term of resigned Chair/Vice Chair. The duties of the Chair and Vice Chair are as follows:
  - 5.8.1. The Chair will convene regularly scheduled Steering Committee meetings, will preside or arrange for the Vice-Chair or other members of the Steering Committee to preside at each meeting.
  - 5.8.2. The Vice-Chair will assume the role of Chair in case the Chair is not able to attend to his/her duties for one or another reason.
- 5.9 When a vacancy on the Steering Committee exists, self-nominations for the seat(s) may be received from present AGI members by the Office two weeks in advance of a Business meeting. These self-nominations will be sent out to the members to be voted upon and results announced at the next Business meeting. These vacancies will be filled only to the end of the particular Steering Committee member's term. A separate ballot will be held for the patient organisation candidates and the academic candidates, as required. Section 5.4 and 5.5 will need to be applied for filling vacancies.
- 5.10 All self-nominations have to be endorsed by the current Steering Committee. Only endorsed nominations will become candidates for the election.
- 5.11 Resignation from the Steering Committee must be in writing and received by the Office. A Steering Committee member may be removed from the Steering Committee if she/he has excess absences from regular Steering Committee meetings following a three-quarter vote of the remaining Steering Committee members following an appeal. A Steering Committee member may be removed for other reasons by a three-fourths vote of the remaining Steering Committee members following an appeal. All appeals must be submitted to the Chair of the Steering Committee on request.

#### **Article VI – AGI Office**

- 6.1 The AGI Office will be provided by University Hospital Tübingen, Germany, until such a time when this role is transferred to another organisation who can take over the administrative and financial responsibility for this role and whose role is agreed by a three-fourths vote of the Steering Committee. If University Hospital Tübingen cannot provide the AGI office for one or another reason any longer, notice will be given to the AGI Steering Committee at least one year in advance.
- 6.2 The Chair of the Steering Committee will be provided administrative support to ensure efficient communication between the Chair, other members of the Steering Committee, AGI members and the Office.
- 6.3 The AGI Office will provide an ongoing advisory role to the Steering Committee and members, as well as administrative support, communications support (website, newsletter, Twitter, etc.),

and project management support where required and is dependent on sufficient funding available to support these roles.

- 6.4 The AGI Office is responsible for supporting the activities of the Steering Committee, coordinating the implementation of strategic priorities, fiscal procedures, support the development of donations/fundraising and grant plans and providing annual activity and financial reports to the AGI members. The Steering Committee must approve the annual reports.
- 6.5 The AGI Office will provide all supporting documentation and information to the Steering Committee at their regular meetings.
- 6.6 The AGI Office will be responsible for keeping records of Steering Committee actions, including overseeing the taking of minutes at all Steering Committee meetings, sending out meeting announcements, distributing copies of minutes and the agenda to the Steering Committee and members, and assuring that records are maintained.
- 6.7 The fiscal year will be the calendar year. Annual reports will be submitted and reported to the Steering Committee showing income, expenditures, justifications, and pending income. The financial records of the AGI are public information and will be made available to the AGI members and partners.
- 6.8 The AGI Office will also be responsible for planning and delivering all meetings (virtual and in person) of the Steering Committee, as well as any other meetings deemed necessary by the Steering Committee including the Business meeting.

#### **Article VII – Working Groups, Focus Groups, and Advisory Boards**

- 7.1 The Steering Committee may create Working Groups, Focus Groups, and Advisory boards as needed.
- 7.2 Working Groups, Focus Groups, and Advisory Boards choose their representative lead(s). The newly elected lead(s) should be approved by the Steering Committee. All Working Groups and Advisory Boards will report to the Steering Committee.
- 7.3 Members and representatives of partners are entitled to work in AGI Working Groups. Representatives of partners need to be approved by the respective AGI Working Group lead(s).
- 7.4 Advisory Boards will be required to report and provide recommendations to the Steering Committee based on the remit of the advisory board as defined by the Steering Committee.

#### **Article VIII – AGI Publication Policies**

- 8.1 All publications involving work by members that was supported by the AGI should be acknowledged by the main author as described in article 8.2 of this charter and a copy of the publication should be forwarded to the AGI Office. Members are encouraged to use open source journals for publication whenever possible.
- 8.2 The AGI should be duly acknowledged in the acknowledgements section of the manuscript with the following text: “This work has been supported by the Ataxia Global Initiative ([www.ataxia-global-initiative.net](http://www.ataxia-global-initiative.net))”. If a journal policy complies and AGI’s contribution is deemed significant in accordance with publication good practice, it is recommended that the author line conclude with the statement “in conjunction with the Ataxia Global Initiative\*”. The asterisk (\*) refers to

the AGI website address as a footnote on the first page of the manuscript ([www.ataxia-global-initiative.net](http://www.ataxia-global-initiative.net)).

#### **Article IX – Conflict of Interest Guidelines**

- 9.1 The Ataxia Global Initiative wishes to promote independence, objectivity and a fair balance of representation, in all its activities. AGI Steering Committee members and Working Group leads are expected to declare potential Conflicts of Interest upon appointment and with each renewal of AGI membership afterward. The AGI Office is responsible to provide a General Data Protection Regulation (GDPR) conform handling of this information.
- 9.2 Members of the Ataxia Global Initiative should maintain the highest personal and professional standards in conducting activities. Ataxia Global Initiative members have an obligation to act in the public interest and in the interests of the Ataxia Global Initiative.

#### **Article X – Amendment of Charter Statement**

- 10.1. These bylaws may be amended when necessary by a two-thirds majority of the Steering Committee. A quorum of at least three-fourths is required.
- 10.2. Proposed amendments must be submitted to the AGI Office to be sent out with regular Steering Committee announcements.

#### **Article XI – Dissolution of the Ataxia Global Initiative**

- 11.1. The dissolution of the Ataxia Global Initiative will be decided by an affirmative vote by written ballot of three-fourths of votes of the members of the Ataxia Global Initiative. The procedure on dissolution will follow that outlined for proposing amendments in Article XI.
- 11.2. If the Ataxia Global Initiative is dissolved, all of the AGI's assets which would otherwise be available to its members generally shall be transferred to another body with objectives similar to that of the AGI or to another body the objectives of which are the promotion of charity and anything incidental or conducive thereto (whether or not the body is a member of the AGI).

These revised Bylaws were approved following a meeting and vote of the Steering Committee of the AGI on 18.09.2024.