

Charter of the Ataxia Global Initiative

Version 1.0

Date

Version	Date	Changes
1	09 June 2021	

Background

The Ataxia Global Initiative (AGI) is a worldwide research platform 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

- 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,
- provides services that support trial readiness
- 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 organisation 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

2.0 AGI members are individual persons who could be ataxia researchers (academic or industry-based) and clinical investigators, ataxia clinicians, representatives of patient organisations or further persons with a proven interest in ataxia therapy development.

2.1 Members of the AGI agree to sign a membership form and agree to work with AGI to further advance the aims and objectives of AGI. AGI membership will be valid for three years and can be renewed.

- 2.2 To apply for membership (renewal) a completed membership application should be signed and submitted to the Office of AGI. Membership applications will be approved by the Steering Committee.
- 2.3 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.
- 2.4 Members who wish to terminate their membership must contact the Secretariat of AGI 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.
- 2.5 Members will have the right to participate in the working groups and projects of AGI.
- 2.6 Members will have access to reports, including financial reports, newsletters, work plans and updates on activities.
- 2.7 Members must not, whether knowingly or negligently, act in a way which could bring AGI into disrepute or lead to a possible loss of public confidence.
- 2.8 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.
- 2.8 Members will not claim to be a member of AGI without first having signed the membership application.
- 2.9 Members must comply with all relevant known national and international data protection, privacy and ethical laws and guidelines.

Article III – Partnership

- 3.0 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.
- 3.1 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.
- 3.2 To apply for partnership a completed partnership application should be signed by an entitled representative of the respective organisation and submitted to the Secretariat of AGI. Partnership applications will be approved by the Steering Committee.
- 3.3 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.
- 3.4 Partners who wish to terminate their partnership must contact the Secretariat of AGI 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.
- 3.5 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.
- 3.6 Partners will not claim to be a partner of AGI without first having signed the partnership application form.
- 3.7 Partners must comply with all relevant known national and international data protection, privacy and ethical laws and guidelines.

- 3.8. Partners must not, whether knowingly or negligently, act in a way which could bring AGI into disrepute or lead to a possible loss of public confidence.

Article IV – Membership Meetings

- 4.1 Membership meeting: The date of the membership 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 (electronic) mail, 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 first Steering Committee of AGI that is with this Charter coming into action will be composed of the members of the Steering Committees of SCA and ARCA Global, respectively. Those steering committees will cease to exist with the formation of the AGI Steering Committee.
- 5.2 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 Secretariat and chairs of the various Working Groups. 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.
- 5.3 The Steering Committee will meet at least annually, either in person or virtually, at an agreed time and place.
- 5.4 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) member. One of the two places for non-academic SC members will be reserved for a member representing 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.
- 5.5 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 annual 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 required.
- 5.6 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.
- 5.7 A quorum must be attended 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.
- 5.8 Every effort will be made to provide meeting agendas and supporting documents for each meeting to each Steering Committee member, by (electronic) mail, not less than seven (7) days before the meeting.
- 5.9 There will be two officers of the Steering Committee consisting of a Chair and Vice-Chair. Their duties are as follows:

- 5.9.1 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. The Chair will serve a 2-year term of office. This term can be renewed by a two-thirds vote of the Steering Committee members.
- 5.9.2 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.
- 5.10 When a vacancy on the Steering Committee exists, nominations for new members may be received from present AGI members by the Secretariat two weeks in advance of an annual meeting. These nominations will be sent out to the members to be voted upon and results announced at the next annual 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.
- 5.11 Resignation from the Steering Committee must be in writing and received by the Secretariat. A Steering Committee member will 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 of Tübingen, 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 of Tübingen cannot provide the AGI office for one or another reason any longer, notice will be given to the AGI SC 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 Secretariat.
- 6.3 The AGI Office will provide an ongoing advisory role to the Steering Committee and members, as well as administrative support, communications support (web site, 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 membership and Steering Committee members.

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 annual meeting.

Article VII – Working Groups and Advisory Boards

7.1 The Steering Committee may create Working Groups and Advisory Boards as needed.

7.2 Working Groups and Advisory Boards choose their representative chair. The newly elected chairs 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's chair.

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". 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 web site address as a footnote on the first page of the manuscript (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. Members of the Steering Committee and chairs of AGI Working Groups 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 – Date of Activation of Bylaws and Interim Officers

10.1 When approved by at least two-thirds of the votes cast by the Steering Committee, these bylaws will become active and adopted at the time of the annual meeting.

Article XI – Amendment of Charter Statement

11.1 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. Proposed amendments must be submitted to the AGI Office to be sent out with regular Steering Committee announcements.

Article XII – Dissolution of the Ataxia Global Initiative

12.1 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.

12.2 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 09.06.2021.