

Articles of Association “AGO Alliance”

1. Name and seat of the association

„AGO Alliance“ is the name of an association in accord with Art. 60ff. of the Swiss Civil Code, and has its seat in Zurich. The association is politically and religiously independent.

2. Purpose of the association

The association aims to improve the quality of life of patients with Argonaute syndromes associated with mutations in the Argonaute genes AGO1, AGO2 (Lessel-Kreienkamp syndrome), AGO3 or AGO4, and their families. For this purpose, activities are implemented in the following areas:

- a) Promotion of the quality of life of patients and their relatives, in particular by increasing interconnectedness and improving knowledge on the illness and treatments,
- b) Support research of the syndrome and the development of therapies,
- c) Public relations work to raise awareness of the syndrome and facilitate access to diagnosis, information, therapy, care, support and inclusion,
- d) Creation of information material for professionals,
- e) Cooperation with national and international rare disease organizations.

The association AGO Alliance is a non-profit association.

3. Financial matters

To pursue the objectives of the association, the association has the following resources:

- a) Membership fees, which are determined annually by the General Assembly,
- b) Voluntary donations from natural or legal persons,
- c) Public contributions,
- d) Income from events, bequests, gifts, legacies.

The association's assets are exclusively liable for the association's liabilities. A personal liability of the members is ruled out.

4. Members

Association membership is open both to natural and to legal persons. Registration for membership must be made in writing to the board of directors, which makes the final decision on admission. There is no entitlement to admission.

Due to the global issue of mutations in AGO genes, membership of interested members from outside Switzerland is explicitly welcome.

Membership can be terminated through resignation, exclusion, death of the natural person or dissolution of the legal person.

Declarations of resignation are to be sent in writing to the board of directors. Withdrawal, subject to a notice period of 3 months, is possible by the end of each calendar year.

The board of directors decides on the exclusion of members by majority voting. Exclusion is possible without statement of reasons. The member can refer the exclusion decision to the general assembly, which then makes the final decision. Membership rights are suspended until the final decision.

5. Organs of the association

The bodies of the association are:

- a) The general assembly
- b) The board of directors
- c) The auditor

5.1. General meeting

The general assembly is the supreme body of the association.

A regular general meeting takes place annually. Further general meetings are called as often as business requires. The meeting is convened by the President at the decision of the Board of Directors or upon written request by at least one fifth of the members. In the latter case, this must be convened within 2 months of receipt of the application.

The general assembly decides on:

- a) Approval of the minutes of the last general meeting, and acceptance of the annual report of the board
- b) Approval of the annual accounts after taking note of the auditor's report
- c) Discharge of the board of directors
- d) Election of the board of directors and the auditor
- e) Amendment of the Articles of Association
- f) Determination of the membership fee
- g) Treatment of the exclusionary recourse
- h) Varia and other previously announced agenda items
- i) Dissolution of the association

The general assembly can take place physically or online, as the association works in Switzerland and abroad. Every properly called general meeting has a quorum regardless of the number of members present. The voting on changes to the statutes and the dissolution of the association are regulated under Articles 7 and 8.

5.2. Board

The board consists of at least two members and is usually composed of:

- a) President
- b) Vice President
- c) Treasurer

Office accumulation is permitted. With the exception of the President, the board is self-constituting. The board is elected for four years. Re-election is possible without limits.

Decisions are made in the context of a board meeting or a circular resolution and require a simple majority of the board members present, and the majority when passing resolutions via e-mail respectively. The presence of at least two board members is required for resolutions at meetings. In the event of a tie, the President can cast the casting vote. Board meetings can also take place online.

The responsibilities of the board include in particular:

- a) Preparation of the general meeting
- b) Implementation of the resolutions of the general meeting
- c) Decision on the admission and possible exclusion of association members
- d) Handling of suggestions, applications and complaints from the members of the association
- e) Preparation of budget and annual accounts
- f) Administration of the association's assets
- g) Activities related to the fulfillment of the association's purpose

The board of directors is entitled to all powers that are not expressly transferred to another body of the association. The board can delegate project-specific tasks to working groups, but retains responsibility and the final decision-making process.

The board of directors works on a voluntary basis, which means that compensation that goes beyond the reimbursement of expenses and reasonable remuneration for performing special orders is excluded.

The board can be expanded at any time by further board members, provided this is decided unanimously by the current board.

5.3. Auditor

The general assembly elects an auditor annually, who controls book keeping. The financial year coincides with the calendar year. The auditor reports on the audit of the annual accounts to the general assembly.

6. Scientific Advisory Board

The board of directors appoints a medical and scientific advisory board. Members should be proven experts who are committed to the concerns of AGO Alliance. In particular, they can assess scientific projects or contribute to the creation of information material.

7. Dissolution

The general assembly can, provided that at least two thirds of members are present and a majority of three quarters of the members present approve the expressly announced dissolution request, resolve the dissolution of the association.

In the event of the dissolution of the AGO2 association, all capital and assets are to be donated to another tax-exempt institution with the same or similar purpose with a seat in Switzerland. A distribution among the members is excluded.

8. Amendment of the Articles of Association

The present statutes can be changed if three quarters of the voting members present at the meeting approve the proposed change.

9. Representation and authority to sign

The board represents the association externally with the collective signature of the president together with another member.

10. Final provisions

These statutes were adopted at the founding meeting on June 14, 2021 and revised on September 13, 2021 and June 15, 2023.

The masculine formulation of the present statutes also applies in full to women.

Zurich, June 15, 2023

The board of directors

Dr. Nora Leonardi

President

Prof. Dr. Christoph Basten

Vice-President