

By-Laws

Art. 1: Name, legal stipulations, fiscal year, domicile

Art. 1.1

The non-profit association will be named “Sjögren Europe” – European Federation of Sjögren’s Syndrome Patient Associations – and will be established according to § 60 and following of the Swiss civil code book.

Art. 1.2

The working language of Sjögren Europe shall be English.

Art. 1.3

The reference text for judicial interpretation of the By-Laws shall be English text.

Art. 1.4

The fiscal year is equivalent to the calendar year.

Art. 1.5

The domicile of Sjögren Europe is in Switzerland.

Art. 2: Purpose and Objectives

The purpose of Sjögren Europe is to increase visibility, attention and solutions for Sjögren’s Syndrome by promoting the advancement of knowledge, research, information, treatment and care, by fostering patient involvement and participation in scientific research, medical, health, political institutions, pharmaceutical industry and social areas, and by increasing awareness about Sjögren’s Syndrome at all levels.

The objectives of Sjögren Europe are to:

- Empower national organisations
- Coordinate efforts and actions and work together to have a better impact
- Collaborate with all stakeholders
- Share knowledge, experience and best practices among national organisations and with any other appropriate entities
- Gather people with Sjögren’s Syndrome in Europe
- Represent patients at a European level and be their voice
- Be involved in decisions, programs, strategies etc. which affect patients with Sjögren’s Syndrome in Europe

- Foster and/or undertake surveys and research projects related to the disease and the publication of the results of any such research
- Collect and distribute information on all aspects of the disease
- Assist, promote and encourage the improvement of knowledge about Sjögren's Syndrome and raise awareness about the disease and all its aspects among national Sjögren's Syndrome and health-related organisations, patients, members of the health, welfare and medical professions, governmental bodies, pharmaceutical companies and the public
- Work to achieve an optimal care system, medical treatment and follow-up, psychosocial support and quality of life for all the Sjögren's Syndrome patients in Europe
- Support the creation of national patient organisations for Sjögren's Syndrome and informal support groups if appropriate
- Promote patient advocacy for Sjögren's Syndrome and support the new generations of advocates
- Implement any appropriate action or project related to the disease and the purpose of Sjögren Europe
- Practice our values of collaboration, democracy, independence, impartiality, transparency and openness.

Art. 3: Means of Action

Sjögren Europe will use all means authorized by law, which may contribute to the achievement of its objectives, notably:

- All legitimate means of communication
- Provision of services
- Provision of fellowships for attendance at meetings or events
- Signing of partnership agreements
- Creation of any legal entity or participation in any already existing legal entity directly or indirectly related to Sjögren's Syndrome
- Reliance on volunteers for specific actions
- Membership of other organisations
- Financial and logistic support to any project related to Sjögren's Syndrome
- Contact, collaboration and partnership with other entities inside or outside Europe sharing common interests
- Award grants.

Art. 4: Resources

The income of the Federation consists, amongst others, of

- Membership fees
- Donations and legacies
- Sponsorship
- Public and private subventions
- All other resources authorized by law.

Funds of Sjögren's Europe can only be used for purposes stated in these By-Laws. Its members do not, as members, receive any financial benefits from the Federation's funds.

Art. 5: Membership

Art. 5.1

Sjögren Europe has the following membership categories:

- **Members** (also called Full Members): Formal national patient organisations for Sjögren's Syndrome in Europe
- **Associate Members**: Individuals running or actively involved in an informal patient group in Europe for Sjögren's Syndrome

Members are volunteers and do not receive any salary from Sjögren Europe. Adequate compensation may be arranged for legitimate authorized expenditure.

Art. 5.2

Membership of Sjögren Europe is open to all the formal non-profit national patient organisations in Europe providing support for people living with Sjögren's Syndrome.

Sjögren Europe may also consider admission to organisations from countries outside Europe.

At all meetings, each member has one vote, with the proviso that not more than two organisations may join from any one country.

At all meetings, delegates must be authorised by their own organisation to make decisions for Sjögren Europe.

Art. 5.3

Associate Membership of Sjögren Europe is open to persons running or actively involved in an informal group in Europe providing support for people living with Sjögren's Syndrome. They are not allowed to vote at meetings.

If a formal organisation already exists in a country and is a Full or Associate Member in that same country can only apply for membership if they positively collaborate with that association.

Art. 5.4

Members and Associate Members are expected to offer full support to Sjögren Europe.

Art. 5.5

Applications for membership are to be submitted to the Board by post or e-mail. Any organisation applying for membership automatically accepts these By-Laws.

The Board decides on membership application. It is not obliged to give reasons if it rejects an application.

Once the Board approves the membership and the payment of the registration fee is processed, the membership process is completed.

Each organisation prior to acceptance shall be required to satisfy the Board that it is correctly set up and accepted as a bona-fide organisation within its own country.

The Board shall maintain and publish a list of Sjögren Europe's members.

Art. 5.6

Membership ceases through resignation, exclusion or failure to pay the membership fee.

Termination of membership, for whichever reason, results in the loss of all rights associated with the membership.

Art. 5.7

Notice of termination of membership is to be submitted in writing to the Board. The period of notice is three months and is effective at the end of the calendar year. At the express wish of the member, termination of the membership can be effective immediately, however full fees for the current fiscal year are still due.

Art. 5.8

The Board may expel a Full Member with immediate effect for serious cause if the member acts in a manner disrespectful of the rules, regulations and statutes or the interests of the Federation. A two-third majority vote in the Board is required to expel a member. Before the Board vote, the member must receive a two-week period in which they may respond to the accusations. Expelled members may appeal the decision within 30 days of receiving notice of expulsion. The appeal is to be submitted to the Board and brought to attention at the following General Assembly, at which the Board, the person or the organisation who lodged the initial complaint and the person or the organisation under disciplinary action can state their positions, either verbally or in written form. The General Assembly then votes on the issue. Simple majority rules.

The Board may expel an Associate Member with immediate effect if it considers that they no longer meet the requirements for the application, do not respect these By-Laws or do not share the Federation's values. No appeal will be allowed.

Art. 6: Membership Fees

The annual membership fee for each membership category is set by the General Assembly. The Board can decide to exempt any member from paying the membership fees for a given year in case of financial hardship.

The liability of members is limited to the membership fee.

Art. 7: Organisation of the Federation

The Federation consists of the following bodies:

- 1) The General Assembly
- 2) The Board
- 3) The Medical Advisory Board
- 4) The Financial Audit Committee

Art. 8: General Assembly

Art. 8.1

The General Assembly is the Supreme Body of the Federation. The overall control of Sjögren Europe shall be administered by the General Assembly.

One nominated delegate from each Full voting Member organisation shall serve on the General Assembly and shall carry one vote. Each Board Member shall also serve on the General Assembly and shall carry one vote. If a Board Member is also a nominated delegate from her/his member organisation, she/he will hold 2 votes. Board Members do not vote on discharging of the Board.

It is possible to vote by proxy under the following conditions:

- Proxy must be established by a written document
- The person who holds the proxy must also be a delegate of a Full Member of the Federation
- Both parties must be up-to-date with their membership fees.

Each member present may hold no more than five proxies.

Every General Assembly called in accordance with the By-Laws has a quorum.

The General Assembly passes motions by simple majority of those votes present. A tied vote is considered a denial of the motion.

For motions to be passed regarding changes to the By-Laws or the dissolution of the Federation, a two-thirds majority of those votes present is required.

Art. 8.2

The General Assembly has the power to decide on fundamental questions and issues of Sjögren Europe. The following competences are assigned to the General Assembly:

- Electing the Board members
- Receiving and approving the previous General Assembly's minutes
- Receiving and approving the annual report
- Accepting the Financial Audit Body report and approving the annual financial report
- Discharging the Board
- Approving the budget for the following year
- Setting the annual membership fee for each membership category
- Approving the By-Laws and any changes thereto
- Consulting and deciding on current motions and any other point or issue on dealings brought forth by the Board

Deciding on the eventual dissolution of the Federation.

Art. 8.3

- The Board must call a General Assembly once per year
- Invitations must be sent out by post or e-mail at least eight weeks prior to the meeting date and include an agenda and a list of any known current motions.
- Objections to the agenda and proposed elections as well as any new motions from the members must be submitted to the Board at least four weeks prior to the General Assembly.

Art. 8.4

The President shall preside over the General Assembly. If this is not possible, a Board Member shall preside.

Art. 8.5

Excluding changes to the By-Laws, late motions (those submitted later than 4 weeks before the meeting) and emergency motions (those submitted during the General Assembly) may be considered if the majority of voting members agree.

Art. 8.6

The Board is obliged to call an immediate Extraordinary General Assembly if the interests of the Federation demand it, or if one-fifth of the members submit a written request together outlining the purpose and reasons for the meeting to the Board.

Precise details of the grounds for the Extraordinary General Assembly are to be included in the invitation.

Art. 8.7

Minutes of the General Assembly recording all decisions are to be taken during the meeting and made available in draft to all members within 90 days after the General Assembly.

Art. 9: Board

Art. 9.1

The general administration of Sjögren Europe shall be undertaken by the Board – should be the Board acting as a single entity, not individual Board Members.

The Board consists of the Executive Committee (President, Vice-President, Secretary, Treasurer) and the Advisors. All have one vote when voting during meetings.

The Executive Committee shall represent different countries.

The number of Board Members shall be at least 4 and not more than 12.

The Board Members are elected by the General Assembly by simple majority vote from authorised nominated individuals. Terms of office are 3 years and repeated re-election is permitted.

Any Full Member can nominate 1 to 3 individuals to be elected to the Board by the General Assembly.

Art. 9.2

Associate Members can stand for election if they have the endorsement of 2 Full Members of Sjögren Europe. Any individual, affiliated or not to a formal organisation or an informal group, can stand for election if they have the endorsement of 2 Full Members of Sjögren Europe.

Art. 9.3

Executive Committee: the main positions on the Board are the President, the Vice-President, the Secretary and the Treasurer.

President

- The President is the legal representative of the Federation
- The President shall conduct meetings and represent the Federation in all civil proceedings. The Vice-President or another Board Member can deputize for the President if needed
- The President shall be responsible for taking any urgent action between the Board Meetings in consultation with at least one other Board Member

- The President shall be the principal officer of Sjögren Europe and shall in general supervise and direct the business and affairs of the Federation, subject to the direction and control of the Board. He/she shall preside at all meetings of the Board and of the General Assembly. The Vice-President or another Board Member can deputize for the President if needed.

Vice-President

- The Vice-President shall assist the President.

Secretary

- The Secretary shall be responsible for the communication and correspondence of the Federation (minutes, agenda, notifications and invitations to meetings)
- The Secretary shall prepare all official minutes, maintain a list of members of the Federation and their representatives, make annual reports to the Board and General Assembly in collaboration with the President, assist with, and coordinate the preparation and organisation of the annual General Assembly: she/he is responsible for ensuring meetings are effectively organized and minuted
- She/he is responsible for maintaining effective records and administration and upholding the legal requirements of governing documents.

Treasurer

- The Treasurer shall be responsible for the proper management of the funds including receiving dues and contributions on behalf of the Federation, preparing the financial report, and publishing the Financial Audit Committee report
- The Treasurer shall be responsible for all Sjögren Europe financial matters and shall report to the Executive Committee as well as to the General Assembly
- The Treasurer shall be responsible for the budget and the financial year-end statements, which shall be audited by an independent auditor. He/she shall present the budget for the following year to the Board; he/she shall provide to the Board and the General Assembly the audited financial year-end statements.

Art. 9.4

Applications for the position of Board Member must be addressed to the President of the Board four weeks before the General Assembly meeting by the authorized representative of the member organisation or by the individual with the required endorsement.

Art. 9.5

The Board decides on all matters which are not assigned to another body. The Board shall notably decide on:

- the strategic objectives of the Federation
- admission and exclusion of members
- the written annual report to be presented to the General Assembly
- the supervision and direction of the Federation, with reservations to the powers exclusive to the General Assembly
- representing Sjögren Europe vis-à-vis third parties
- appointing a Medical Advisory board and defining its specific functions
- appointing committees for specific tasks
- the activities of Sjögren Europe
- specific requirements for membership
- the conclusion of contracts, e.g. sponsoring agreements as well as cooperation agreements with other patient organisations.

Art. 9.6

The Board is quorate if at least half of its members are present at a meeting. It takes its decisions by a simple majority of those members present at the meeting. In the event of a tied vote, the President has the casting vote.

Art. 9.7

The Board must account to the General Assembly for its actions.

Art. 9.8

All negotiations of the Board are confidential. Confidentiality also applies in relation to personal information about all members of Sjögren Europe. This applies if a Board Member, because of his/her mandate, has access to such information.

The Board decides on the content and form of any information that is passed outside the Federation.

Art. 9.9

The liability of the Board is limited to intent and gross negligence.

Art. 9.10

Board Members are volunteers. They are not entitled to receive any financial compensation for their duties as Board Members, only reimbursement of expenses legitimately incurred on behalf of Sjögren Europe.

Art. 9.11

The Board may decide to dismiss a Board Member by simple majority in case of unjustified absence or if a Board Member acts in a manner disrespectful of the rules, regulations and By-Laws or the interests of the Federation.

Art. 10: Medical Advisory Board

Sjögren Europe shall establish a Medical Advisory Board to advise and support the Board on any medical or scientific question.

The exact composition, appointment, function and terms in office shall be determined by the Board.

The Board shall maintain and publish a list of the members of the Medical Advisory Board.

Art. 11: Financial Audit Committee

The Financial Audit Committee controls the financial management of the Federation and presents a report to the General Assembly. It consists of one auditor or a fiduciary company. The auditors can be members of the Federation but cannot be Board Members.

Art. 12: Representation

Sjögren Europe is considered to be validly represented by one member of the Executive Committee.

Except as otherwise provided in the articles or in these By-Laws, the Board by resolution may authorize any Board Member, representative, officer, officers, agent, or agents to enter into any contract or to execute any instrument in the name of and on behalf of Sjögren Europe. This authority may be general, or it may be confined to one or more specific matters. No officer, agent, employee, or other person purporting to act on behalf of Sjögren Europe shall have any power or authority to bind Sjögren Europe in any way, to pledge Sjögren Europe's credit, or to render Sjögren Europe liable for any purpose or in any amount, unless that person was acting with authority duly granted by the Board as provided in these By-Laws, or unless an unauthorized act was later ratified by the Federation.

Art. 13: Transparency

Sjögren Europe strives to preserve full transparency in all its activities. This concerns in particular all important documents, such as By-Laws, annual reports, annual accounts and minutes of the General Assembly, and where applicable, Ethics Charter, Code of Conduct concerning cooperation with other organisations or sponsors, contracts in this regard and sponsoring agreements.

Art. 14: Dissolution of the Federation

Art. 14.1

The dissolution of the Federation can be decided by the General Assembly with a two-thirds majority of those votes present.

Art. 14.2

Upon dissolution of Sjögren Europe, the remaining capital is to be donated to a tax-exempt entity with equal or similar aims based in Switzerland. The distribution amongst members is prohibited. Current Board Members are to act as liquidators unless the General Assembly votes otherwise.

Art. 15: By-Laws and Amendments to the By-Laws

These By-Laws were adopted by the Constituent Assembly of Sjögren Europe on February 23rd, 2019 and were not revised.