

Voting Members Accreditation and Code of Conduct Document

Accountability: Global Alliance of Sickle Cell Disease Organizations

Responsibility: Membership Committee

Approver: Board of Directors

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Last Revision date:

Review:
as necessary

Overview

The Global Alliance of Sickle Cell Disease Organizations (herein referred to as "GASCDO") is primarily an alliance of national and regional sickle cell organizations. It is formed to reduce the global incidence of Sickle Cell Disease (SCD) and ensure equitable access to optimal care and treatment by all people with SCD worldwide. To achieve this vision, it is imperative that GASCDO's national member organizations (NMOs) and regional member organizations (RMOs) and their representatives align with GASCDO's vision and display a high level of professionalism, collegiality and cohesiveness that will foster GASCDO's growth and positively impact GASCDO's image at all times.

Voting Membership

According to article 4 of GASCDO's bylaw, the Voting membership is also referred to as Class A membership and...

Clause 4.1 stipulates that this class of membership will be provided to sickle cell disease focused organizations that are national and/or regional in scope except the founding organizations grandfathered to GASCDO. The class A members shall be entitled to receive notice of, attend and vote at all meetings of the organization.

Benefits of Voting Membership

NMO and RMO benefits include:

- ✓ Participation in GASCDO congresses;
- ✓ Participation in skills training workshops and webinars;
- ✓ The right to vote at GASCDO's Annual Meeting of the General Assembly;
- ✓ Listing on GASCDO's website linked directly to NMOs/RMOs' website;
- ✓ Access to GASCDO's online community where our members can connect, share information and work together;
- ✓ Access to publications, statistics, fact sheets updates as they become available.

Accreditation Program

The Accreditation Program will be the official vehicle by which patient associations are guided through the process of becoming NMOs/RMOs of the GASCDO. The program oversees the status of NMOs/RMOs, making sure that the goals and aims of the

organizations align with those of the GASCDO. In order to be accredited by the GASCDO, the patient association must represent the best interests of the majority of people with SCD and their families in a country. It must demonstrate that it has a good record, credible and recognized in their country.

Only one patient association may represent a country as an NMO of the GASCDO except the founding organizations grandfathered into GASCDO. Accreditation as an NMO shall be decided by the voting members of the GASCDO based on the criteria set out in this document and in the bylaw.

For accreditation purposes NMOs and RMOs must satisfy the requirements listed below in addition to abiding by GASCDO's code of conduct terms:

- ✓ Provide proof of legal registration as a national and/or regional SCD focused organization with non-profit status;
- ✓ Provide its most recent Annual Report ; the Statutes/ By-laws; list of Board of Directors or Executive members and contact information of member organizations if regional in scope;
- ✓ Bylaws and statutes must not be in conflict with GASCDO's

- ✓ Must be patient driven (governing boards must include patients and / or caregivers)
- ✓ Disclose source of funding
- ✓ Must show professional commitment to work for GASCDO
- ✓ Participate actively in GASCDO's events
- ✓ Satisfy GASCDO's code of conduct requirements at all times.

Where there is no established NMO in a country, GASCDO may accept the most effective local organization or the regional association (whichever exists). The governing body of GASCDO will take decisions on a case-by-case basis and exceptions to the eligibility criteria can be made under special circumstances.

Code of Conduct

The Code of Conduct (Code) for voting members of the GASCDO sets out fundamental principles and practices for avoiding conflicts of interest, upholding ethical conduct, ensuring the highest standards and maintenance of integrity, and protecting the reputation of GASCDO.

The Governance Committee shall oversee compliance with this Code, provide advisory guidance, and investigate potential breaches. This Code is neither all-inclusive nor exhaustive

Application of Code of Conduct

The provisions set forth in the Code apply to each NMO or RMO, and their representatives both in their respective countries/regions and at GASCDO's meetings including board meetings.

Compliance with Laws, Rules and Regulations, and Ethical Conduct

Each NMO/RMO and their representatives shall:

- ✓ Comply with the letter and spirit of all laws, rules and regulations of the GASCDO;
- ✓ Comply with all governance policies and procedures relating to personal and professional conduct of the members of GASCDO; and
- ✓ Display the highest ethical standards in the GASCDO's business, personal and professional dealings and reputation.

Expectations of Voting Members and their representatives

- ✓ NMO/RMO representatives shall vote on all motions put up at the AGM and/or Board meetings (if representative is also on the board of GASCDO) unless a conflict of interest has been declared;
- ✓ NMO/RMO representative is expected to: attend all scheduled meetings; be fully prepared to participate; listen to the opinions of others with respect; encourage robust discussion and constructive dissent; and share the workload.
- ✓ NMO/RMO shall act with professional integrity and honesty in their dealings with GASCDO, including proper use and treatment of GASCDO's resources and information, and shall comply with the provisions of the GASCDO's Finance and Expense Policies;
- ✓ The Governance Committee will periodically review and make recommendation respecting any changes to the Voting Members' Code of Conduct.

Monitoring and Enforcement of the Members' Code of Conduct

- ✓ This Code of Conduct (Code) will be reviewed and signed by each NMO/RMO representative annually.
- ✓ Any allegation about, or perceived breach of, this Code by a representative will be discussed by the Board Chair, Chair of the Governance Committee, and Chief Executive Officer with the representative. The Chair of the Governance Committee shall report the discussion to the Governance Committee In Camera, and, at the discretion of the Governance Committee, to the Board In Camera.
- ✓ GASCDO's Governance Committee may recommend to the Board of Directors the removal of a dissenting representative and/or the NMO/RMO where it is perceived to be in the best interest of the GASCDO.
- ✓ In the event that the Board of Directors determines that an NMO or RMO should be suspended or terminated from membership in the GASCDO, the Chair, or such other officer as may be designated by the Board of Directors, shall provide sixty (60) days' notice of suspension or termination to the NMO/RMO and shall provide reasons for the proposed suspension or termination. The NMO /RMO may make written submissions to the Chair or such other officer as may be designated by the Board of Directors, in response to the notice received within such sixty (60) day period. In the event that no written submissions are received by the Chair, the Chair, or such other officer as designated by the Board of Directors, may proceed to notify the NMO/RMO that the NMO/RMO is suspended or terminated from membership in the GASCDO. If written submissions are received in accordance with this section, the Board of Directors will consider such

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submissions in arriving at a final decision and shall notify the NMO/RMO concerning such final decision within a further sixty (60) days from the date of receipt of the submissions. The Board's decision will be confirmed by the General Membership Meeting at the next meeting. The decision shall be final and binding on the NMO/RMO, without any further right of appeal.

NMO/RMO Certificate of Compliance with the Code of Conduct (Certificate)

Each NMO/RMO's representative shall sign this Certificate and Declaration annually.

To the best of my knowledge, information and belief:

- ✓ I have read the Voting Members' Code of Conduct (Code);
- ✓ I understand this Code, each of its sections and all of its Paragraphs;
- ✓ I have sought clarification from the Governance Committee or CEO, Board Governance, with respect to this Code's sections, meanings, interpretation, and application to my circumstances, as the case may be;
- ✓ I have been, presently am, and agree to be prospectively, in compliance with the letter and spirit of each and all provisions within this Code;
- ✓ If I come to acquire knowledge, information or belief that I am not, or may not be seen to be, in compliance with the letter and spirit of a provision within this Code, I shall promptly bring such knowledge, information or belief, as the case may be, to the attention of the Governance Committee in a prompt, full and true manner;
- ✓ I know of no other NMO/RMO representative that is not, or may not be seen to be, in compliance with the letter and spirit of each of the provisions within this Code.
- ✓ I understand that the Code is subject to change from time to time, and that I will be given adequate notice of such changes.

I, _____, hereby accept the terms described in the GASCDOs' Voting Members' Accreditation and Code of Conduct Declaration

dated this day of (month), (year): _____

Signature of Representative: _____

Name of Voting Organization: _____