



ECHDO STATUTES

European Congenital Heart Disease Organisation is registered in Belgium (registration number 821.091.637). It was established by collaboration of 26 Congenital Heart Disease organisations all over Europe.

Constitute of the European Congenital Heart Disease Organization

Article 1. NAME AND REGISTERED OFFICE

1. The name of the Association is: European Congenital Heart Disease Organization.
2. The abbreviated name is: ECHDO.
3. ECHDO's registered office is Elzenlaan 20, 2390 Westmalle
4. The Association is governed by the provisions of Instrument III of the law of 27 June 1921 on not-for-profit organizations international not-for-profit organizations and foundations.
5. All legal proceedings will be according to Belgian Law, the place of court will be Antwerp. Official documents will be in Flemish or French as required by law.
6. The working language of ECHDO and all members is English.

Article 2. STATEMENT OF PURPOSE

1. The purpose, aims and objectives of ECHDO are to
 - improve the treatment and quality of life of patients with Congenital Heart Disease (CHD) by information on appropriate medical, surgical and psychosocial therapies, in particular regarding long-term outcomes and unifying statistical methodology;
 - integrate paediatric and adult cardiac treatment, and in particular to install and provide a smooth "transition" for adolescents from paediatric to adult;
 - promote and sustain scientific and medical research in all fields of CHD;
 - represent the interests of CHD patients in national and European health policy;
 - raise public awareness of CHD and to instill in the public an understanding of the concerns of people with CHD;
 - improve the safety of treatments for children and adults;
 - advocate European regulations for off-label use and special treatment needs (i.e., paediatric).
2. A cross-European standardized and appropriate CHD therapy is needed. A European, if not worldwide, exchange of scientific information based on multicentred, multinational research (i.e., to prevent repetitive studies) is needed to avoid stress and suffering for people with CHD. Therefore, ECHDO may offer training and information and arrange programs with the goal of an exchange of experiences for people with CHD and specialists, such as doctors, nurses, teachers, etc. In order to reach its objectives, ECHDO works in close co-operation with other national, European and worldwide organizations, groups and institutions.

2.1. ECHDO promotes unprejudiced presentation of CHD-related issues in public and aims to improve their situation in society.

2.2. ECHDO is politically and religiously neutral.

2.3 (A). ECHDO will solely pursue charitable aims according to Belgian taxation regulations.

2.3 (B). ECHDO is a charitable, non-profit organization.

2.3 (C). All proceeds and possible profits of ECHDO will be spent solely according to these Statutes.

2.4. Upon termination of ECHDO, all proceeds will go to a charity organization with similar aims to ECHDO, determined by the General Assembly (see Article 17).

Article 3. ASSOCIATION YEAR

The Association year coincides with the calendar year.

Article 4. MEMBERSHIP

1. Members of ECHDO will usually be national or regional legally-recognized Associations of people with CHD, parents, patients' organizations and related healthcare organizations represented by persons chosen locally (hereinafter referred to as Representatives), and are committed to the vision of ECHDO as set out in **Article 2** of these Statutes. The Board will make decisions on membership issues including new members during the year.

a) Member organizations need to be national or regional.

b) Member organizations need to have access and cooperation with the main health centers in the relevant country.

c) Member organizations should reflect the numbers of people with CHD in the country.

2. Membership of ECHDO is of three kinds:

A. Active Membership (a patient or family CHD organization),

B. Associate Membership (other NGOs),

C. Honorary Membership (Doctors and other professionals who can contribute to the richness of the debate).

3. The right to vote in a General Assembly is limited to the Active Members. The right to vote in the General Assembly is suspended if a Member association fails to pay membership fees for more than a year.

4. The Board of Directors will keep a register showing the names and addresses of the Representatives of the Members of ECHDO. Each Member must appoint one person as its permanent representative and must inform the Board of Directors of this in writing. The Member must notify the Board of Directors immediately in writing of a change of Representative.

5. The right to vote can be transferred in written form, including by email or fax.

6. All Members have the right to propose motions to the General Assembly in written form. Associate and Honorary Members have the right to speak and to introduce motions at a General Assembly, but they do not have the right to vote.

7. All Members have the right to participate in internal communication of ECHDO, unless information from third parties is restricted by confidentiality agreements.

8. Members shall not share in any fiduciary profit and shall not be otherwise compensated for their capacity of being a Member, from any proceeds of ECHDO. No person shall be reimbursed for any expenses that do not meet the aims of ECHDO, or are disproportionately large.

9. Representatives can be paid standard compensation and fees for services rendered if these services are not directly related to their quality as Member Representatives (i.e., counseling, advising).

10. Members or their representatives do not receive shares from any proceeds of ECHDO on termination of membership or of ECHDO.

Article 5. MEMBERSHIP FEE

1. The Members are obliged to pay a membership fee to ECHDO. The level of the membership fee is determined by the General Assembly once a year.

2. The Board of Directors has power in special cases to grant full or partial exemption from the obligation to pay a membership fee.

3. Membership fees will be based on an adjustable sliding scale according to the financial limits of the local organization. In some cases (when there is a new group or an especially financially limited one) the Membership fee can be waived by the BOD while maintaining full voting rights.

Article 6. TERMINATION OF MEMBERSHIP AND SUSPENSION

1. Membership ends:

- a. on resignation by the Member group;
- b. on dissolution of the Member group;
- c. by termination by ECHDO;
- d. by disqualification;
- e. suspension.

2. Resignation by the Member Group is subject to four weeks' written notice.

3. Termination of membership in ECHDO is effected by the Board of Directors. This can be done if a Member has ceased to fulfill the requirements for membership or if they otherwise do not comply with obligations towards ECHDO. Termination of membership by the Board of Directors takes place with immediate effect.

4. Disqualification from membership is imposed by the General Assembly. This can only happen if a Member acts contrary to ECHDO's Statutes, regulations or resolutions, or harms ECHDO's interests in a purposeful manner. Disqualification causes membership to end immediately.

5. The Board of Directors can suspend a Member due to any of the above-mentioned reasons. A suspension that is not followed within three (3) months by a decision to terminate the membership ends on the expiry of that period.

6. With termination of membership all claims resulting from the membership relation are withdrawn.

7. Any Representative who becomes a contracted employee of ECHDO will automatically be replaced as Representative by the local organization or association from which they come for the duration of their period of employment.

8. No Representative shall vote on any financial matter that involves a potential advantage to themselves, their family, or Association they are member of. Any such Representative (or Member) must declare their interests in advance of such a vote. Failure to declare interests may result in the vote being invalidated.

9. Any change of membership status must be notified to the Member within one month by registered post. The Member has the right to object to the change and demand a hearing at the next GA.

Article 7. THE BOARD of DIRECTORS (BOD)

1. Members of the Board of Directors (hereinafter referred to as Board Members) are elected by the General Assembly. Member organizations are not elected. Only physical persons representing them can be elected. The number of Board Members is determined by the General Assembly, but the Board consists of no fewer than five and no more than nine persons. The BoD will at all times be composed of at least one parent and one GUCH (Grown Up).

2. Candidates for the Board can be nominated by any Member or Member organization, including Board Members.

3. Membership to the Board is limited to one per country. In the case of co-optation (Art's 9.10 and 9.11), this article 7.3 is suspended.

Article 8. END OF BOARD MEMBERSHIP, SUSPENSION OF BOARD MEMBER

1. A Board Member stands down:

- a. on giving notification of resignation in writing;
- b. as a result of the expiry of the term for which they were appointed; or
- c. as a result of loss of capacity on the basis of which they were elected or appointed.

2. In the event of a Board Member's absence or inability to act, the other Board Members are charged with carrying out the absent Board Member's duties. If one or more Board Members are absent, the remaining Board Members form a competent Board. Vacancies must be filled no later than the next General Assembly.

3. A Member of the Board may be suspended from the Board by a unanimous vote of all other Members of the Board of Directors upon failing their legal and/or constitutional duties. All ECHDO Members must be informed of such a move promptly.

4. The Board or a Member of the Board may be replaced during the period of office by simple majority of the General Assembly, provided notice of such a motion has been given at the time of invitation. If a motion to replace the Board of Directors or a Member of the Board of Directors arises spontaneously during a General Assembly a 2/3 majority of votes of those present is necessary for the motion to pass.

Article 9. BOARD FUNCTIONS AND DECISION-MAKING

1. The Board of Directors must keep an updated database containing the names and addresses of all Board Members. Board Members are obliged to inform the Board immediately of any relative changes.

2. All Board resolutions will be adopted by a simple majority of the votes cast. Abstentions, although recorded, are not counted. The Board is at quorum when at least half of its Members are present. In case of a tie vote, the vote of the President of the Board is decisive.

3. The Board must appoint a

- President (portfolio includes the conduct of the Board of Directors),
- Vice President (The President may delegate their powers in written form to the Vice-President for a defined period in case of their temporary absence (i.e., illness or vacation. The VP takes over the powers of the President in case of the President's inability or termination of membership of ECHDO),
- Secretary (portfolio includes general administration, communication systems, as well as duties towards the Register of Associations at the Court of Commerce),
- Treasurer (whose portfolio includes financial administration, book-keeping according to the law and tax regulations, and collection of memberships fees), and other such officers as it considers desirable, from the other Board Members.

4. Minutes of the proceedings of each meeting must be taken by the Secretary or some other person designated by the Board, and signed by the President and Secretary after they have been approved by the Board.

A. The first meeting of the newly elected Board must be held within four weeks of the election and minutes taken and presented in Flemish or French as well as English. These minutes will include the results of the internal elections and must be offered for registration to the Register of Associations at the Court of Commerce.

5. An officer may be represented at a meeting by a fellow officer, if agreed in writing by both officers.

6. The Board can adopt resolutions and make decisions in writing without holding a face-to-face meeting, providing all officers have expressed their views on the motion concerned in writing, including electronically, if all Members declare to agree to this procedure.

7. Invitations to a meeting of the Board must be given verbally, by phone, or in writing by post, fax or email at least one week in advance, and must include an agenda. If it seems necessary during a meeting of the Board, a subsequent meeting can be called for within 48 hours, if all Members of the Board agree to this procedure.

8. Members of the Board are elected by the General Assembly according to an approved protocol. The period in office for Members of the Board of Directors is three years. They stay in office until their successors have been duly elected. A Member of the Board of Directors may be elected for a maximum of two consecutive periods in office. There must be a period of 6 months out of office before being re-elected as a Member of the Board of Directors.

9. In order to provide overlapping periods, the General Assembly may extend the period in office of one-third of the Members of its first Board once to 4 years and one-third of them to 5 years.

10. In the case of extraordinary circumstances, where no existing Member of the Board of Directors is able or willing to assume special duties not previewed at election time, the Board may co-opt any Member for the express purpose of fulfilling these duties. This co-optation ends at the next General Assembly.

11. If Directors withdraw from office between two General Assemblies the Board will be allowed to reconstitute itself to the original number of members elected at the General Assembly (i.e., co-optation as described above). All Member Associations will be informed of such a move promptly. The period in office of a substitute director will end with the next General Assembly. When over 50% of the Members of the Board of Directors are replaced in this way, a General Assembly must be called within 6 months.

12. The Board is in charge of all affairs of ECHDO unless stated otherwise in the Statutes, or by decision of the General Assembly. All powers not assigned by law or these Statutes to other bodies are vested in the Board.

13. The Board must decide on their own rules of operation, including the rules needed to enable employment contracts. These must be in writing (in the by-laws) and notified to the Membership.

16. Minutes are to be taken of all meetings of the Board. These minutes are to be communicated to the Membership within 1 month.

Article 10. BOARD'S ROLE AND POWERS

1. Testamentary dispositions may only be accepted with the benefit of ECHDO's inventory.

2. Provided it has the approval of the General Assembly, the Board has power to enter into contracts to acquire, dispose of and encumber property subject to registration and to enter into agreements by which ECHDO binds itself as surety or joint and several debtor, warrants performance by a third party or provides security for a debt of a third party.

3. A Board Member will not receive payment for his or her Board work.

4. A Board Member's expenses will be reimbursed, unless the Board decides otherwise in specific cases.

Article 11. LEGAL REPRESENTATION

1. ECHDO is represented by the Board in and out of Court. It can also be represented by the President and/or Vice President along with any one of the other officers. No BoD member may legally represent ECHDO alone. Individual Members of the Board may act on their own, respecting the decided limits imposed in the boundaries of their responsibilities and agreed budgets within the Financial Protocols of ECHDO. These powers are not transferable.

2. The Board may delegate the representation of ECHDO either in defined and explicit areas, or in all areas, to other Board Members, a designated employee or Member or Representative, or to third parties under the responsibility of a specific Member of the Board. The Secretary of ECHDO will inform the Register of Associations at the Court of Commerce about this appointment in written form.

Article 12. ANNUAL REPORT, ACCOUNTS and RENDERING of ACCOUNTS

1. The Board is obliged to keep records of the financial position of ECHDO and of everything concerning its activities, in accordance with the requirements arising from these activities, and to keep the books, documents and other data to clarify ECHDO's rights and obligations.

2. The General Assembly elects one (or more) Internal Auditor/s and sets their Budget. The period in office of the Internal Auditor/s is 15 months from the start of the subsequent financial year, with 3 months overlapping with the incoming Internal Auditor/s.

2 (A). It is the task of the Internal Auditor/s to comment and advise upon all financial related matters of ECHDO.

2 (B). The Internal Auditor/s has the right to examine cash and books of ECHDO. They are responsible to the General Assembly. They are not subject to orders from the Board and cannot be employee(s) of ECHDO. They may not be a Member of the Board, nor may they be members of any Group appointed by the Board.

2 (C). The annual report of the Internal Auditor/s must be sent by post, fax or email to the Membership together with the invitation 4 weeks in advance of the General Assembly

2 (D). Relations between the Internal Auditor/s and the Board of Directors are subject of a separate protocol on Internal Auditing.

3. The Board appoints an external Auditor.

Article 13. THE GENERAL ASSEMBLY

1. The General Assembly of ECHDO shall consist of one Representative from each Member organisation (see Art. 4).

2. The General Assembly shall convene annually, which will be held not later than six months after the end of the ECHDO calendar year.

3. Each General Assembly must be recorded in minutes, signed by the minute taker. When required by law, minutes may be translated into Flemish and/or French.

4. The minutes have to be circulated to the Members within six weeks.

5. Changes to the Statutes have to be recorded in their original phrasing.

6. Changes to the Statutes, changes in the Board, as well as the Minutes of the first meeting of the Board of Directors after its election are to be offered in written Flemish within six weeks by the Secretary to the Register of Associations at the Court of Commerce.

Article 14. RIGHT TO VOTE AND MANNER OF ADOPTING RESOLUTIONS

1. The General Assembly is convened by the BOD. Meetings must be convened in writing by sending notices to the addresses of the Members as shown in the membership register. The notice period must be at least four (4) weeks before the event.

2. The items dealt with at the meeting must be specified in the convocation notice.

3. All Representatives of Members have the right to take part in meetings. Any Member can arrange for their vote to be cast by another Member authorized in writing ("proxy") to do so.

4. Resolutions are adopted by a simple majority of the votes cast, unless otherwise contravened in these Statutes. Blank votes, although recorded, are considered as not having been cast.

5. Active members (Art. 4.2 (A)) are the only members have full voting rights. Both Associate members and Honorary members, while being able to fully take part in the debates and issues, are not able to vote.

Article 15. BY-LAWS

1. The ECHDO By-Laws contain additional detailed arrangements for the regulation and the activities of ECHDO. By-laws must not contain any provisions contrary to Belgian law or the ECHDO statutes.

2. The By-Laws are adopted and altered by the General Assembly. The provisions of Article 16 concerning changes to the Statutes apply to the adoption of and changes to these by-laws.

Article 16. CHANGES TO THE STATUTES, MERGER, OR DIVISION OF ECHDO

- 1.** No change can be made to ECHDO's Statutes other than by a resolution of the General Assembly convened for that purpose with a notification that a change to the Statutes will be proposed at it.
- 2.** At least five days before the General Assembly a copy of the motion setting out the proposed change word for word will be available electronically, distributed by the BOD, for inspection by the Members and their Representatives until the GA.
- 3.** These provisions apply as well to any decision to merge or divide ECHDO.

Article 17. DISSOLUTION

- 1.** ECHDO can be dissolved by a decision of the General Assembly. The provisions of Article 16 apply.
 - 2.** ECHDO will continue to exist after dissolution to the extent necessary for the liquidation of its assets. Documents and announcements sent by ECHDO must contain the words: "in liquidation". Liquidation ends when the liquidators are unaware of the existence of any further assets.
 - 3.** The officers are the liquidators of ECHDO's assets. They continue to be subject to the provisions concerning the appointment, suspension, dismissal and supervision of the officers. During liquidation the other provisions of the Statutes also remain in force as far as possible.
 - 4.** The credit balance after liquidation will be used for those purposes to be determined by the General Assembly, which are in keeping with the objects of ECHDO.
 - 5.** Individual Members of the Board will not be held fiscally responsible and will be covered by titles of the Insurance Policy governing ECHDO.
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