

SINDROME E.E.C. INTERNATIONAL

Net. work word communication

Association ONLUS

Statues

Article 1- Constitution

A Foundation named “SINDROME E.E.C. INTERNATIONAL net. work word communication”, non-profit organization of social usefulness (ONLUS) is incorporated.

In its name and for any kind of mark addressed to the public the Association is required to use the wording “non-profit organization of social usefulness” or the acronym “ONLUS”.

Article 2- Head Office

The Association has its head office in Tencarola di Selvazzano Dentro35030, Padova, Italy, Via Buccari 14

Article 3 – Logo

The Association’s logo portrays a stylized world with a coloured butterfly enveloped in a spiral, along with the writing SINDROME ECC INTERNATIONAL net.work communication

Article 4- Goals

The Association is an apolitical and non-profit organisation. It intends to pursue social, civil, cultural, scientific and ethical research goals pursuant to the purposes and the rules contained herein.

The Association is a non-profit organisation and can not allocate earnings, profits or surpluses, even on an indirect basis.

The Association has a non-limited duration. Members have equal rights. Only the Association is entitled to establish new delegations and offices.

The Association intends to purse the followings:

- to acquire and disseminate information, both nationally and internationally, concerning the so called RARE DISEASES, including what is to them connected - clinical data, R&D etc. -. To pursue goals of social solidarity. To promote social support and assistance as well as civil rights protection in favour of people affected by rare diseases and their families, with particular attention to the orphan diseases
- to collect information about rare diseases characteristics, creating an international database connected to other associations and public agencies websites
- to encourage and promote medical research

- to collect and share reliable data regarding rare diseases' treatment and therapy development, as well their actual results obtained nationally and internationally
- to set up a database listing names of national and international experts with medical background, along with names of centres of excellence established according to the laws
- to form, within the Association itself, a scientific committee whose members will be medical doctors in the field of genetics and other experts in the field. The committee's composition, structure and organisation shall be governed according to the law
- to disseminate relevant information, via Web or brochures, among the Association's members and people seeking for information
- to develop at local, regional, national and international level a proper information service able to provide ordinary citizens, patients and their families with legal advice on significant and applicable laws and regulations
- to spread appropriate information in schools and public agencies by way of public communication services or via a new communication network
- to organize meetings, congresses, round tables focused on the topic of "rare diseases"
- to create a multilingual website describing in details the Association's activities
- to publish Web pages and leaflets concerning rare diseases
- to encourage awareness in the general public as to: knowledge on rare diseases and pertinent laws, assistance to people affected by rare diseases, scientific projects intended to study and treat rare diseases. To this purpose the organisation will employ natural persons, and/or public or private agencies operating even on a voluntary basis
- to find citizens, institutions, public/private/national and international agencies willing to sponsor the Association's activities and goals. Sponsors' financial support to the Association may be unlimited
- to improve time, costs and resources allocation in the rare diseases' management
- to apply for public funds to support the achievement of the Association's institutional goals
- to carry out any activity related to the abovementioned purposes
- to establish offices both in Italy and abroad with their own press office, internal organisation and experts in the field of rare diseases in order to give information and psychophysical support to the persons affected and their families
- to cooperate with other organizations and/or agencies sharing the same goals

Article 5- Members

Any natural and/or legal person, public or private agency, enterprise or association sharing the Association's goals, and abiding by its Statutes and its possible internal management rules may become a member of the Association.

Members are admitted by decision of the Members General Meeting. Refusal must be justified. No appeal is admitted against the Assembly's decision. Applicants shall submit an application indicating their personal data. Members must expressly commit themselves to pay the annual subscription dues, to respect these Statutes and any regulation adopted. Inscription shall have effect from the Assembly's deliberation of admission.

Membership is divided into four categories:

Founders (members who have incorporated the Association according to the law)

Ordinary Members (members paying the annual membership dues to the extent determined by the Members General Meeting)

Sustainers (members contributing to the Association's life with voluntary monetary donations in addition to the annual membership dues)

Honorary (members appointed by the Members General Meeting on account of their services to the Association)

Temporary membership is not allowed. Membership's subscription dues can not be assigned or transferred.

Article 6- Members rights and duties

Any member is entitled to take part to the Members General Meeting, to elect (personally or by proxy) and to be elected in the Association's bodies and offices.

Members shall be informed of the Association's activities; they have the right to ask for the reimbursement of costs occurred by reason of their activities in favour of the Association.

Members shall pay the annual membership dues, and shall respect these Statutes and any regulation adopted.

Any service provided by a member in favour of the Association is to be considered done mainly on a personal, voluntary, non-profit and without retribution basis.

Article 7- Membership dues

Memberships dues are determined by the Members General Meeting. They are annual, non-divisible in case of withdrawal or exclusion.

Failure or delay to pay the annual membership dues shall prevent the member from taking part to the Members General Meeting, performing the Associations activities, electing and being elected.

Article 8- Member's withdrawal and exclusion

Any member may withdraw from the Association at any time by written notice to the Members General Meeting. The withdrawal will have effect from its acceptance by the Executive Council.

Any member failing to comply with his/her obligations as required by these Statues may be excluded by the Assembly with justified deliberation. The Assembly shall vote the exclusion by secret ballot; the member may present his position and arguments. The Assembly's deliberation may be appealed before the Board of Arbitrators, whose decision will be irrevocable.

Article 9- Bodies and Offices of the Association

The following are the bodies of the Association:

1. The Members General Meeting or Assembly;
2. The Executive Council;
2. The President;
3. The Board of Auditors;
4. The Board of Arbitrators;
6. The Scientific Committee
5. The Board of Trustees.

All offices are carried out without salary.

A Press Committee and a Public Relations Committee may be established at local, national, international level. The Members General Meeting will appoint their members and determine their functions.

Article 10- Members General Meeting or Assembly

The Association has its sovereign authority in the Members General Meeting, or Assembly.

It is made up of all the Association's members.

The Assembly shall be called by the President, or his substitute, once a year by written notice sent at least 10 days in advance of the day the Assembly takes place. The notice shall contain the agenda of the meeting.

The Members General Meeting can be called either upon request of at least one tenth of members (in this case the President shall call the Assembly by written notice to be sent at least 15 days after the members' request; the Assembly shall take place within 30 days from the call. The notice shall contain the agenda of the meeting) or when it is deemed necessary by the Executive Council or by the President.

The Members General Meeting can be held in ordinary or extraordinary session. Meetings are chaired over by the President of the Executive Committee or, when absent or impeded, by the Vice-President.

The extraordinary meeting shall be called to decide on Statues' amendments and Association's dissolution. In any other case the Members General Meeting can be held in ordinary session.

Article 11 – Powers of the Members General Meeting

The Members General Meeting, in addition to what expressly stated herein, is required:

- to approve the final account and the proposed annual budget for the forthcoming year
- to determine the annual membership dues and members' monetary contributions
- to decide the Association's activities general guidelines
- to approve the possible internal rules
- to decide irrevocably on the members' admission and
- to decide on members' exclusion
- to elect the President and the Executive Council
- to exercise its competences according to the law and these Statues, as well as to decide on the issues submitted by the Executive Council
- to elect the members of the Board of Auditors
- to approve or reject Statues' amendments
- to decide on the Association's dissolution

Article 12- Members General Meeting validity

The Members General Meeting called in ordinary session is considered valid on the first convention if one half plus one of qualified voters members are present, in person or by proxy; on the second convention, held even on the same day, it is considered valid whatever the members' number, in person or by delegation.

Each member is entitled to a single vote; he may, in addition, cast no more than one proxy votes on behalf of absent members.

Deliberations of the Members General Meeting called in ordinary session are taken by simple majority of members, present in person or by a delegate. Votes are cast publicly, except when they concern persons and their characteristics or when it is deemed necessary by the Assembly itself.

The Assembly shall indicate when votes shall be cast by a show of hands, by roll-call, by secret ballot. In case of secret ballot the President shall appoint a commission of three members in order to scrutiny the votes.

The Members General Meeting called in extraordinary session shall validly approve the Statutes' amendments when 2/3 of members are present and the amendments are approved by the majority of members.

The Members General Meeting called in extraordinary session approves the Association's dissolution and its asset allocation with the quorum of 3/4 of members,.

Article 13- Minutes of the meeting

Minutes of discussions and deliberations of the Assembly shall be kept. They are written by the Secretary, or by a delegate of him, and signed by the President.

Any member may have access to the minutes and make copies.

Article 14- Executive Council

The Executive Council is made up of 5 members, appointed by the Assembly and chosen among its members. The Executive Council is summoned at least once every three months by the President. The Executive Council shall be called by written notice sent at least 10 days in advance of the day the meeting takes place. The notice shall contain the agenda of the meeting.

The Executive Council is considered valid on the first convention if one half plus one of members are present (should be the Executive Council made up of 3 members, it is considered valid if all its members are present). On the second convention, the Executive Council is considered valid if 1/3 of members are present. Deliberations are taken by simple majority of members; in the case of an equality of votes, decisions shall be determined by the casting vote of the President or his delegate.

The Executive Council is required to manage the Association's general and special affairs not reserved to the General Meeting of Members; it prepares and submits to the Assembly the annual report concerning the Association's activities; it prepares the final account and the proposed annual budget for the forthcoming year; it appoints the President and the Vice-President; it hires employees; it appoints the Secretary; it decides the Association's governing rules; it draws up programmes and targets of the Association within the framework of the Association's goals and

activities as approved by the Assembly; it authorizes and approves expenses; it ratifies decisions taken by the President as a matter of urgency and falling within its powers and competencies; it appoints the members of the Board of Arbitrators.

The Executive Council appoints within its structure:

- one President
- one Vice-President
- one Secretary General
- one Treasurer

Article 15- President

The President is the legal representative of the Association in its relationship with third parties. The President chairs the Executive Council and the Assembly. He summons, both in ordinary and extraordinary sessions, the Members General Meeting and the Executive Council.

In case of necessity and urgency, the President takes the decisions reserved to the Executive Council. The decisions shall be ratified by the Executive Council at its first meeting.

In case of absence, impediment or withdrawal of the President, the Vice-President shall exercise his functions.

Article 16- The Secretary General

The Secretary General acts together with the President and is responsible for the following:

- to maintain and update the members' register
- to maintain contacts with all of the members
- to present to the Executive Council new applications for membership
- to deal with correspondence
- to write and keep the minutes books
- to keep the Association's account book, as well as documents pertaining to revenues and expenditures specifying the names of payor/donor and payee/donee
- to collect revenues and to pay costs according to the Executive Council's decisions

Article 17- Board of Auditors

The Board of Auditors is made up of three regular auditors and two substitutes appointed by the Assembly. The Board of Auditors appoints its President within its members.

The Board of Auditors is entrusted with the powers and functions provided by articles 2403 and the following of the Code of Italian Civil Law.

The Board of Auditors exercises its control on its own initiative, or at request made by one of the Association's bodies, or when a fact is reported with a written and signed communication by one of the Association's members.

The Board of Auditors reports to the Assembly once a year through a signed written account handed out to the Association's members.

Article 18- Board of Arbitrators

The Board of Advisors is made up of three arbitrators, whose irrevocable decisions are taken “*ex bono and equo*” . No rules of procedure shall apply.

The Board of Advisors is require to deal with the controversies concerning the Statutes' interpretation and execution arising between the Association's bodies and members or among the Association's members.

Article 19- Treasurer

The Treasurer is require to oversee the Association's ordinary affairs, to prepare the final account and to present it, signed by the President, to the Members General Meeting. Along with the President, the Treasurer has authorization to perform and sign any bank transaction on the Association's bank/postal accounts including money withdrawal.

The Treasurer reimburses actual expenditures previously authorized by the President and the Executive Council, and, upon their authorization, purchases what is necessary to the Association's activities.

Article 20- Scientific Committee

The Executive Council may establish a Scientific Committee whose members shall be notable experts in scientific, editorial, legal, judicial, legislative, psychological fields.

The Scientific Committee is required to present proposals regarding the Association's scientific activities; to support contacts and relations between the Association and technical-scientific agencies at national and international level; to act in order to support organization of meetings, congresses, round tables, seminars, courses.

Article 21- Working Groups

Working Groups are establish to develop action plans and to formulate strategies in relation to the Association's activities.

The President or the Executive Council set up the Association's Working Groups; they may possibly assemble volunteers.

Working Groups are a democratic forum for cooperation and action. Members of each working group appoint within themselves a coordinator entrusted with the organization of the group activities along with the maintenance and harmonization of collaboration among the various groups according with the Association's goals.

Article 22- Board of Trustees

The Board of Trustees is made up of five members elected among members and non-members by the Members General Meeting called in ordinary session. The Board's members remain in office for five years and can be re-elected.

The Board of Trustees gathers at least once a year, and upon request of the Executive Council.

The Board of Trustees shall oversee the function and management of the Association, ensuring that its core values and purposes are reflected in the operation process.

Every year the Board of Trustees reports to the Assembly in regard to the legality of the Association's accounts and management . As an advisory body the Board of Trustees may intervene at the Executive Council meetings. Notice of the meeting shall be sent to the Board of Trustee

Article 23- Offices term

Every person holding an office within the Association's bodies serves a five-year term and can not be re-elected, with the exceptions specifically provided for in these Statutes

Article 24- Incompatibility

Persons holding a public office at local/regional/national level (e.g. mayor, member of regional council, president of regional council) may not serve as a member in the Executive Council, the Board of Arbitrators, the Board of Auditors.

The Executive Council, the Members General Meeting and the President are entitled to consider circumstances of incompatibility on an individual basis and may grant exemption with justified decision.

Persons holding public offices incompatible may be part of the Association as ordinary members, members of Working Groups, members of bodies other than the Executive Council, the Board of Arbitrators, the Board of Auditors.

Article 25- Asset

The Association's asset consists of:

- a) membership dues and private contributions;
- b) donations, inheritance and legacy;
- c) funds assigned to the Association by the national and regional governments, by private or public, local/national/international/European agencies and entities;
- d) revenues gained from transferring of movable and immovable goods and services to members and third parties. Services may include economic activities such as commercial, artisan, agricultural activities intended to pursue the Association's goals;
- e) contributions of members and third parties;
- f) earnings obtained through promotional campaigns and instrumental activities, for instance parties, subscriptions etc;
- g) revenues compatible with the Association's goals of social usefulness;
- h) any other revenue pursuant to the law n. 383/2000.

The Association shall employ its revenues, profits and surpluses to the carry out its institutional activities or those directly connected to them.

Every distribution of earnings or surpluses, funds, reserves or capital, even on an indirect basis, is forbidden as long as the Foundation exists, unless the destination or distribution are required by Law or addressed to other non-profit organisations that by rule of law, statutes or regulation, belong to the same united structure.

The Executive Council shall deposit the Association's funds with a bank it has previously selected. Any bank transaction shall be signed both by the President and the Secretary.

Documents pertaining to the bank transactions, along with the names of payors and payees, shall be kept for three years.

Article 26- Financial statement

The Financial year begins on 1st January and ends on 31st December every year.

The final account includes the Association's revenues and expenditures over the last year. The budget for the forthcoming year contains estimate of revenues and expenditures for the running year. The final account contains the Association's current and fixed asset and equity.

The financial statement is drawn up by the Executive Council and approved by the Members General Meeting according to the procedures and majorities set forth in these Statues. It shall be kept at the Association's head office at least 20 days before the Assembly meeting and put at members' disposal.

The final account shall be approved within 120 days after the end of the financial year. It shall be put at the Board of Auditors' disposal at least 20 days before the Assembly meeting. Furthermore, it shall be kept at the Association's head office at least 15 days before the Assembly meeting and put at members' disposal.

Article 27- Amendments to the memorandum of associations and to the Statutes or article of associations

One of the bodies or at least five members of the Association may propose to the Assembly amendments to the Association's memorandum and articles of associations.

The Assembly shall approve the amendments with an absolute majority of its members.

Article 28- Disciplinary sanctions

Against the Association's members the following disciplinary sanctions may be taken: censure, in case of behaviour prejudicial to the Association, its bodies and members; suspension up to three years in case of behaviour more prejudicial than that deserving censure; expulsion, with regard to members suspended several times or responsible of extremely serious misconduct.

Article 29 – Dissolution and assets allocation

The Members General Meeting is the Association's body vested with the power to decide the dissolution of the Association. It shall deliberate according to the procedures set forth in article 12. The Association's assets shall necessarily be allocated to similar goals of public usefulness by deliberation of the Assembly and according to its programme

Article 30 - Reference Clause

Issues not covered by these Statutes shall be judged under the provisions of the Italian Code of Civil Law and other applicable laws in force.