Extracorporeal Life Support Organization (ELSO)

CHARTER

I. Mission Statement

The Extracorporeal Life Support Organization (ELSO) is an international consortium of health care professionals and scientists who are dedicated to the development and evaluation of novel therapies for support of failing organ systems. Crucial is the promotion of a broad multidisciplinary collaboration. The primary mission of the Organization is to maintain a registry of, at least, use of extracorporeal membrane oxygenation in active ELSO centers. As appropriate, registries of other novel forms of organ system support are within the purview of ELSO. Registry data is to be used to support clinical research, support regulatory agencies, and support individual ELSO centers. ELSO provides educational programs for active centers as well as for the broader medical and lay communities.

II. Activities of ELSO

1. Maintain a Registry of a Limited Data Set to be used for Quality Assurance and other studies to improve the delivery of care.
2. Promote use of Registry data for scholarly studies.
3. Provide for interchange of information on devices and techniques used for novel organ system support.
4. Provide logistical guidelines and education for the above devices and techniques.

5. Provide information and communication regarding techniques used for organ system support to active ELSO centers, the medical community, professional societies, industry, regulatory and granting agencies, third-party payors and the lay community.
6. Organize an annual conference focused on novel techniques used for organ system support.

III. Organization

1. Membership

ELSO is an international consortium of active clinical programs. Each ELSO program that contributes all appropriate cases to the registry is considered to be an active member. In any action of the organization, which is determined by vote, each member program (whose dues are paid in full) has one vote. Each program may designate an unrestricted number of individual representatives to participate in the activities of the organization.

Interested individuals who are not affiliated with an active ELSO center may hold individual membership (clinicians, scientists, industry members and members of regulatory and public health institutions). Individual members may participate in all the activities of the organization, but do not vote. Application for individual membership must be sponsored by a member center and be reviewed and approved by the Steering Committee.

Corporate membership may be held by corporations who are active in research and development of techniques used for novel organ system support. Each corporation may designate as many individual representatives as it wishes to the various activities of the organization. Corporate members do not vote.

2. Steering Committee

Activities of ELSO will be direct by a Steering Committee comprised of a chairman (serving a four year term), the chairman of the six standing committees, the President of the European Extracorporeal Life Support Organization (EESO), and one to six members at large (serving a three year term, renewable once). One at-large position is reserved for a non-North American center and one position is reserved for a member site Clinical Coordinator. Non-voting Steering Committee members will be liaisons to other appropriate professional societies and the Director of Grants and Development.

The responsibilities of the Steering Committee are:

a. To determine the priorities of ELSO and implement activities consistent with the priorities
b. To determine the responsibilities of each standing committee and coordinate committee activities
c. To administer the finances, including dues, registry fees, and grants
d. To communicate the activities of the Organization both inside and outside the group

3. Standing Committees

a. Registry & Data
b. Conference
c. Protocols & Research
d. Communications
e. Devices and Techniques
f. Logistics and Education

IV. Director of grants and Development Responsibilities

1. Identify sources of funding (e.g. industry, government) to maintain core Registry activities
2. Write and submit grants
3. Procure funding
4. Share, in conjunction with the Protocols Committee, possible studies which other ELSO members may submit for consideration of funding
5. Assume strong leadership for all related activities

V. Standing Committee Responsibilities

1. Registry & Data

a. Oversee the design of all data collection mechanisms
b. Oversee the definition of all individual data elements
c. Oversee the data maintenance procedures
d. Liaison with other registries that may have similar interests and data elements to promote standardization of data definitions
e. Generate bi-annual reports of the registry activities
f. Evaluate, and approve when appropriate, all data requests
g. Notification, specifically to the Protocols Committee Chairman and involved centers, when centers are classified as inactive for failure to submit data to the Registry for six months
h. Generation and maintenance of policies and procedures which apply to Registry data requests
i. Facilitate collaboration between sites requesting overlapping data sets for publication
j. Track use of all data sets and review annually progress toward publication
k. Notify centers of failure to submit datasets for abstract presentation and/or publication within one year
l. Report at least annually Registry data set usage and status of tracking in "j"
m. Develop and maintain a form to be used for Registry data requests which also indicates the rules of Registry data use as in "h"

2. Conference

    a. Plan and execute the annual conference
    b. Determine the format and the questions to be addressed at the conference
    c. Determine the program including invited and competitive presentations
    d. Prepare a syllabus for the conference
    e. Prepare a written summary suitable for publication

3. Protocols & Research

    a. Coordinate ELSO sponsored or managed multicenter trials, regarding data collection, study evaluation and reporting
    b. Coordinate applications for grants and/or projects on behalf of ELSO and its centers participating in cooperative studies
    c. Liason for Research requests from non-ELSO organizations for cooperative studies utilizing ELSO data
    d. Coordinate the collection and utilization of data in conjunction with the Devices Committee regarding new devices or materials
    e. Maintain bibliography of publications based in whole or part on Registry data
    f. Maintain a copy of all Registry related abstracts and manuscripts submitted for publication

4. Communications

    a. Publish and update a directory of ELSO programs
    b. Publish and update a newsletter for the organization
    c. Publish and update the ELSO bibliography for the organization
    d. Publish and update management protocol information
    e. Develop a system to facilitate patient referral, including guidelines for various patient groups and a network system to assist with bed location and transportation

5. Devices and Techniques

    a. Determine the priorities for improvements in technology
    b. Develop protocols for the testing and reporting of devices
    c. Serve as liaison between ELSO and the medical industry
    d. Serve as liaison between ELSO and the Food and Drug Administration
    e. Develop protocols for multicenter testing of new devices and techniques (in conjunction with the Protocols Committee and the Director of Grants and Development)
    f. Ensure rapid distribution of information regarding major improvements or potential safety risks regarding devices (in conjunction with the Communications Committee)

6. Logistics and Education

    a. Develop guidelines for use of techniques and/or technologies within the purview of the Registry
    b. Develop guidelines for training certification requirements and professional standards for use of techniques and/or technologies within the purview of the Registry
    c. Develop standardized, multidisciplinary education programs for techniques and/or technologies within the purview of the Registry
    d. Collect and report information about the socioeconomic impact of the techniques and/or technologies within the purview of the Registry
    e. Supervise activities of the Follow-up Committee

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