

**Standard Operating**

**Procedures**

**Executive Committee**

**and**

**Consortium Members**

**Version Date:**

**Approved by:**

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# Amendments:

# 1.0 The Executive Committee

## 1.1 Role of the Executive Committee

The Executive Committee provides overall leadership and guidance to the Consortium by regular meetings and publication of minutes of those meetings. The Executive Committee will consist of an Executive Chair, Scientific Chair, and Clincal Chair plus a representative from the Genetic Aortic Disorders Association (GADA) Canada Board. Members leading the data coordinating centers for MAC will be appointed for the Executive Committee.

The Executive Committee will:

1. seek input from members of the, Consortium in order to define the overall goals and objectives of the Consortium.
2. work with a variety of entities to establish and maintain the best possible economic support of the Consortium.
3. Ensure development and currency of standards and procedures from all the consortium activities.
4. Ensure rapid dissemination of results and resources to the research and clinical communities.
5. Set the tone for cooperation.  Sometimes Consortia members do not freely cooperate.  In some cases sites compete for the same funding resources. It is the purpose of the executive committee to rise above this competition and make sure sites cooperate in completing the shared vision and goals.
6. Ensure equality in decision-making.  The Executive Committee will ensure that suggested projects meet the needs of as many participants as possible, fairly weigh all requests and act impartially.
7. Act as the ultimate decision maker in handling strategic, legal, organizational, technical, cost, management, cultural and personnel issues.

## 1.2 Role of the Executive Chair

The Executive Chair provides direct leadership for all governance, administrative, legislative, and ethical activities and implements these activities. In addition, the Executive chair acts as the leader for overall coordination of activities, meetings and agendas.

## 1.3 Role of the Scientific/Research Chair

The Scientific/Research Chair provides direct leadership and guidance for all research and scientific activities.

## 1.4 Role of the Clinical Chair

The Clinical Chair provides direct leadership and guidance for all activities related to collection of phenotype data.

## 1.5 Role of the Genetic Aortic Disorders Association (GADA) Canada

The GADA Canada will function as Administrative support to the Executive Committee and the Consortium members. A Director from the GADA Canada Board will serve on the Executive Committee.

## 1.6 Role of the Publications and Communications Committee

The Publications and Communications Committee provides direct leadership for all considerations of dissemination of Consortium activities and implements production of publications. In addition, the Committee publishes guidance documents for all relevant activities of the Committee, notably establishing principles of authorship and arbitrating authorship issues. Members of the Publications and Communications Committtee will be appointed by the Executive Committtee.

## 1.7 Executive Committee Appointments

The first appointed – Executive Chair will serve a term of 3 years, Scientific/Research Chair will serve a term of 4 years and Clinical Chair will serve a term of 5 years. Following the first term completion, the length of terms for each of the Chairs will be 3 years. Members of the Executive Committee can be reappointed by majority vote of the Consortium members for one additional term.

New members can be appointed to the Execituve Committee by a current member of the Executive Committee plus a majority vote by the Consortium members at its next meeting. On appointing new members to the Executive Committee, the quorum will comprise of the majority of members.

# 2.0 Criteria for Membership

Researchers or clinicians will be eligible for enrollment if they fulfill the following criteria.

## 2.1 Inclusion Criteria for Enrollment

Inclusion criteria for entry into the MAC are:

1. The individual is associated with a recognized educational institution or hospital
2. Has shown exemplary contributions to the field of aortic disorders through clinical practice, research, and/or publications.
3. Support the Consortium’s mission and activities
4. Suggest potential sources of funding and work to generate funding.

## 2.2 New Member Appointments

New Consortium members can be nominated by any member of the Executive Committee and approved by majority vote of the Executive Committee. New members will receive a welcome package from GADA Canada.

# 3.0 Criteria for Study Enrollment

Principal Investigators will be eligible for enrollment if they fulfill the following criteria.

## 3.1 Inclusion Criteria for Enrollment

Inclusion criteria for entry into the Registry are:

1. Agreement to contribute subjects to a given study
2. Completion of local institutional review board approval
3. Agreement to the publication policy of the Consortium

# 4.0 Methods of Enrollment

Information about Consortium projects will be disseminated to potential study subjects using a number of sources. The principal means of enrollment will be Consortium members.

## 4.1 Enrollment Procedures

Eligible patients will be solicited during clinic visits or through retrospective review of medical records followed by direct contact according to protocols approved by the local IRB.

Signed informed consent will be obtained prior to any data or sample collection. Patients will receive a hard-copy of the consent form to keep.