

# ILAE Consortium on Genetics of Complex Epilepsies

## Governance Structure Charter December 2011<sup>1,2</sup>

### Guiding Principles

The driving principle behind the Consortium is that through collaboration and synergy, collectively we will make more rapid progress towards fully understanding the inherited components of epilepsy than can be achieved individually.

It follows that membership of Consortium carries advantages for which some sacrifices of autonomy are considered to be a reasonable price – the collective benefits considerably outweighing the individual restrictions.

While this does not mean that all individual epilepsy research efforts should be subsumed into a single Consortium effort, we do aspire to a community of ideas some of which will be best realized using a cooperative approach.

For any research that would rely wholly or in significant part on Consortium data or resources, Members are required to discuss their ideas within the Consortium. This principle of “no surprises” extends to all new analyses, poster and oral presentations, manuscripts and other tools of the trade.

Members are further encouraged, but not required, to share relevant ideas that do not require use of Consortium data or other resources.

Amongst other advantages, benefits of this cooperative approach are expected to include the strengthening and improving of preliminary ideas via discussion with fellow experts, the possibility of attracting additional resources in support of proposed projects, access to larger sample and data sets, better analytical tools, and sharing of complementary skills.

### Structure and Rules

#### 1. Size and Shape of the Consortium

The Consortium has developed from an initiative of the Commission on Genetics of the International League Against Epilepsy (ILAE).

The *Consortium* is the authoritative coordinating body.

The *Commission* is the facilitating body.

Commission members are not necessarily in the Consortium if they are not contributing.

Many non-Commission scientists will be involved in the Consortium.

The Consortium consist of four parts:

- Governance Committee

- i. A small, stable group of experienced individuals who work well together and can be trusted to do what is best for epilepsy genetics. This group has responsibility for setting the long-term agenda, tone and principles behind the Consortium. It is also

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<sup>1</sup> Modeled with permission on the Charter of the International Multiple Sclerosis Genetics Consortium (<https://www.imsgc.org>) and the ENIGMA Consortium Memorandum of Understanding

<sup>2</sup> Charter updated in December 2018 to increase number of samples for Strategy committee representation from generally 200 to 500

charged with ensuring members have obtained appropriate approval from their local Ethics Committees, settling disputes and ultimately has the final word.

- ii. Four members (in alphabetical order, Sam Berkovic, Alastair Compston, Anna-Elina Lehesjoki, Dan Lowenstein) will meet ad hoc.
- iii. Term limit of three years, renewable.

- Strategy Committee

- i. Larger group (10-20) within which most of the work of the Consortium is done. It is anticipated that most strategic decisions will be made by this group.
- ii. Composed of principal (independent) investigators, each appointed by the Governance Committee.
- iii. Each member of the Strategy Committee must either bring a substantial number of epilepsy DNA samples or a key skill set or technical capacity of value to the Consortium. (See below for details.)
- iv. Meets ~ monthly or bi-monthly by telephone and occasionally in person.
- v. Reaches decisions by informal consensus of those participating in calls, not by formal vote.
- vi. Term limit of three years, renewable. (Renewals are the decision of the Governance Group.)
- vii. Disputes or impasses are settled by the Governance Committee.
- viii. Subcommittees of the Strategy Committee will include:
  - Phenotype Subcommittee (n ~ 5)
  - Analysis Subcommittee (n ~ 5)

- Working Groups

- i. Temporary ad hoc groups established by the Strategy Committee to pursue specific and time limited projects that are better handled by smaller, specialist groups.
- ii. A chair is appointed for each Working Group.
- iii. Working Groups report progress and findings to the Strategy Committee.
- iv. Working Groups meet by teleconference according to a timetable established by each Working Group chair.

- Regular Members

- i. A large group with no strictly defined membership criteria.
- ii. Regular Members can only be added under the auspices of individual members of the Strategy Committee.
- iii. Regular Members are added to the email listserv.
- iv. Regular Members can listen in and participate in teleconference calls, and can join Working Groups, if approved by their Strategy Committee representative.

## **2. Strategy Group in More Detail**

- **Members:**

To be appointed after application.

New Members must be independent investigators who are able to submit a substantial number (generally more than 500) of patients (or controls) with GWAS data:

- a. Sample analyzed on an acceptable platform and data available for reanalysis by contributing centre.
- b. Ethical approval will allow use of analysis (although not necessarily primary data) by the Consortium.
- c. Taken from well-characterized patients.
- d. New Consortium members will sign this Charter document indicating that they agree with the policies listed here and that they have obtained the required ethical

clearances to participate or send data.

- All Strategy Committee investigators are equal contributors and are encouraged to participate in the regular teleconference meetings.
- All Strategy Committee investigators are allowed to involve a small number of their students, staff and close colleagues into the group as Regular Members, but all such Regular Members will remain under the guidance and sanction of their Strategy Committee representative.

### **3. Project Decisions**

- Any project (large or small) using unpublished Consortium data must be formally proposed to the Strategy Group.
- Each proposal to include:
  - a. A description of what data is required.
  - b. A description of the analysis to be performed.
  - c. A timetable.
  - d. The name of the Strategy Committee member who will be responsible for the project and a list of others who will be involved.
  - e. A publishing/authorship plan (see section 5.)
- All proposals will be distributed to all Strategy Committee and Governance Committee members.
- Each proposal will be discussed during Strategy Committee meetings and either approved or declined by consensus.
- If a project is approved, no data will be used without the express permission of the investigators who contributed that data.

### **4. Publishing/Authorship**

- All project proposals must include a specific publishing/authorship plan.
- Typically the plan will be one of the following three options taken from the MS model:
  - a. A full consortium paper: The Consortium is listed as the author with a list of individual contributors made according to the journal's style preference. (This option must include a suggestion for corresponding author(s).) See NEJM 357, 851-862 (2007) for example.
  - b. A partial Consortium paper: Individual authors listed. The Consortium name is included in the author list. (This option must include a list of authors.)
  - c. A local paper: Simply acknowledges the Consortium. (This option to state who will take responsibility for the paper.) See HMG, 15, 2813-2824 (2006) for example.
- Consortium members will be reasonable and self-critical in their claims for authorship.

I AGREE:

1. To consider participation in meta-analyses and secondary analyses proposed by the Consortium, subject to constraints or limitations that I can impose in each case.
2. To abide by the guidelines for authorship and publication, and other guidelines described in this document.
3. Not to distribute or communicate any privileged information to individuals who are not members without consent of the entire Consortium. This includes any other existing collaborators who are not members of the ILAE Consortium. Privileged

information includes results of any unpublished analyses completed by members of the Consortium.

4. Not to distribute or copy any data collected by the Consortium without prior written consent of all Strategy Committee and Governance Committee members.

5. That the Consortium Strategy Committee will review and evaluate future scientific opportunities, and will make recommendations regarding the needed expertise and research program to maximize those opportunities in the best possible way.

7. That failure to uphold this agreement may result in my expulsion from the Consortium (but I will still be bound by publication moratorium on Consortium work, as described above).

Signature

Date

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Please print name

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