



EWGGD Working Groups

I. STATEMENT OF PURPOSE

- To promote high-quality science within the Gaucher community and identify and promote new innovative areas for research
- To promote best patient care through the development of guidelines and policy statements
- To initiate and create scientific networks and international registries that serve under the umbrella of EWGGD
- To standardize nomenclature, methods and biological materials in collaboration with international partners
- To disseminate knowledge relevant to the mission of the EWGGD through educational fora and publication

II. GOVERNANCE

A. EWGGD Board

The EWGGD Board will be responsible for confirming the initiation and dissolution of WGs, reviewing the work of the WGs and making decisions on structure and function of the WGs.

B. Working Groups

WGs may be created for a set period of time for a particular project.

Proposals for new WGs must be submitted to the EWGGD board. Approval requires a simple majority vote.

Each WG is represented by a Chair with a term of 3 years. The WG Chair is an EWGGD member. Five co-chairs will be voted for the same term. A board member will serve as an additional co-chair.

In each clinical WG, an additional co-chair will be nominated from the international Gaucher Association (IGA)

The EWGGD policy requires that every WG chair and co-chair discloses their relevant financial relationship every year and sign a form outlining any conflict of interests.

Membership of a WG is open to anyone with a professional interest in the area of the working group. Members of EWGGD-WGs are strongly recommended to apply for EWGGD membership. Membership of a WG is not limited.

Each WG will provide a project plan with proposed timeline and an annual report on its activities that is published online on the EWGGD website. The WG chair will be held accountable to the EWGGD board for the performance and progress of their group

The WG chair will propose a budget which will be ratified by the EWGGD board.

All financial expenses will be submitted to the board in line with the budget and accompanied by receipts

The term of each WG is 3 years. After this period, the WG may re-apply for their status. In the new term new chair and co-chairs will be elected.

Chair/co-Chair cannot serve as chair/co-chair on two WGs at the same time

WGs may apply to hold a public meeting during the EWGGD meetings.

The WG's publication need to be reviewed and approved by EWGGD board prior to publication. The WGs will acknowledge the EWGGD in all publications issued by the WGs.