



Project Mercury Global Task Force Member Charter

The Global Task Force (GTF) will provide advice, support, and guidance to the Country Working Groups to identify optimal strategies and pathways that address and accomplish our primary goals. In addition, Members of the GTF will define global projects as needed to support the goals of Project Mercury. The preferred courses of action will reflect consideration of various FSHD community goals, issues, concerns, and find the appropriate balance among competing interests.

I. Global Task Force Goals

- Advise the Country Working Groups about key aspects of Project Mercury, provide a global perspective on key considerations, and be a sounding board for program projects and deliverables.
- Work towards consensus among GTF Members on the desired program goals, alternatives, phasing, and mitigation measures.
- Identify key resources amongst the GTF Members themselves that can be contributed toward Project Mercury's objectives. Note, this does not mean or imply financial support for this program from GTF Members.

II. Project Mercury Outcomes

The process will be considered a success if:

- The GTF establishes clear, consensus-based recommendations on the best strategies and pathways to include in Project Mercury's strategies and tactics (globally and locally via the Country Working Groups);
- The stakeholders in the FSHD global community are engaged in a meaningful way in evaluating the proposed project programs and initiatives and in reviewing and commenting on the project;
- The project schedule takes the least amount of time and makes the most effective use of project resources;
- Appropriate regulatory and government agency(s) are involved and understand the outputs of Project Mercury to avoid surprises that lead to delays.

III. Terms of GTF Membership

Members agree to volunteer through the process and contribute expertise and resources where feasible and relevant to the member.

A member's position on the GTF may be declared vacant if the member:

- Resigns from the GTF (this should be in writing to the GTF Chair)
- Fails to attend more than two meetings without prior notice
- In a case where a member's position is declared vacant, the Chair may appoint an alternative representative from the same interest group to fill the position.

IV. GTF Operating Guidelines

Convening of Meetings

- Meetings will be held at the time and place chosen by GTF Members during their meetings or at the Chair's discretion.
- At the inaugural GTF meeting, the GTF will determine meeting frequency for the remainder of 2023 and 2024.
- Members will be informed of meetings through email, depending on their preference, at least six weeks prior to the meeting.

Communication

- Meetings will be posted in a special project section of the Project Mercury website (projectmercuryFSHD.org)
- Project documents and notices will be posted on the project website.
- The Chair (or the Secretariat) should be copied on all Member email or written correspondence. Members will be provided the contact details of the Chair and Secretariat.

Conduct of meetings

- Meetings will be open to all Members.
- Meetings will be facilitated virtually and/or in-person.
- The Chair will moderate meetings.
- We will comply with the Global Federation of Pharmaceutical Manufacturers and Associations' (IFPMA) EFPIA Code to ensure ethical and transparent interactions with the healthcare, patient and biopharma community. See <https://www.efpia.eu/relationships-code/the-efpia-code/> for more information.
- Informed alternates are acceptable and encouraged if the Member cannot attend.
- All meeting participants will be afforded opportunities for open discussion throughout the meeting and all members in attendance to voice their opinions.
- Meetings will end with a clear understanding of expectations and assignments for next steps.
- In-person meetings are expected to be no more than one full day in length (8 hours). Virtual meetings are expected to be no more than 3 hours in length. Extension of time in either case will require the consent of the majority of members attending that meeting.

- Secretariat will keep a record of meeting attendees, key issues raised, and actions required.
- The previous meeting record and a meeting agenda will be forwarded to Members at least one week before every meeting. Any changes to the record of the past meetings shall be in writing and forwarded to the Secretariat prior to the next meeting.

Meeting Ground Rules

- Speak one at a time – refrain from interrupting others.
- Wait to be recognized by moderator before speaking.
- The Chair will call on people who have not yet spoken before calling on someone a second time for a given subject.
- Share the oxygen – ensure that all Members who wish to have an opportunity to speak are afforded a chance to do so.
- Maintain a respectful stance toward towards all participants.
- Listen to other points of view and try to understand other interests.
- Share information openly, promptly, and respectfully.
- If requested to do so, hold questions to the end of each presentation.
- Remain flexible and open-minded, and actively participate in meetings.

Member Roles and Responsibilities

The GTF is an advisory group for Project Mercury and the Country Working Groups.

There are two types of Members:

Voting Members: Are representatives of organizations in the World FSHD Alliance.

Non-Voting Members: Are representatives from various organizations.

GTF Voting Members and Non-Voting Members agree to:

- Provide specific expertise, including identifying emerging issues;
- Where feasible and relevant, provide resources to the project;
- Review project reports and comment promptly;
- Attend all meetings possible and prepare appropriately;
- Complete all necessary assignments prior to each meeting;
- Relay information to their constituents after each meeting and gather information/feedback from their constituents as practicable before each meeting;
- Articulate and reflect the interests that Members bring to the table;
- Maintain a focus on solutions that benefit the entire program;
- Identify and participate in Global Projects together, pursuant to mutually agreeable terms that the participating Members of that project will specify in a written Statement of Work between them.

The Chair agrees to:

- Provide GTF Members the opportunity to collaborate with other agencies and groups on making recommendations for the project;
- Effectively manage the scope, schedule, and budget;
- Keep GTF Members, partners and the FSHD global community informed of Project Mercury progress;
- Provide documentation to support recommendations;
- Provide domain and other technical expertise;
- Brief decision makers and produce briefing materials and reports;
- Provide early notification of GTF meetings and provide ten business days to review and comment on reports and other documents;
- Manage planning for meetings

V. Decision Making

The GTF is primarily advisory. In those areas where it has decision-making authority, only Voting Members will vote. Voting Members will strive to reach agreement by consensus at a level that indicates that all Members are willing to “live with” the proposed action. All Members will strive to work expeditiously and try to avoid revisiting decisions once made.

VI. Conflict Resolution

When an issue arises that cannot be easily resolved, Members agree to:

- Remember that controversial projects are unlikely to receive funding, so the intent of all parties is to resolve issues so the project can be funded.
- Determine if the issue should be resolved within or outside of the GTF and participate however is appropriate.
- Ensure the appropriate decision makers are at the table to resolve the issue.

Charter Agreement

This Charter is effective immediately upon signature and shall remain in effect until amended or otherwise revoked. This Charter shall be reviewed annually, or as needed, to ensure currency and relevance.

Agreed to and accepted by:

Chair, Project Mercury Global Task Force

(signature)

Your Name:

Your Organisation:

Date:

-----End of Global Task Force Member Charter-----



The Global Initiative to Speed the Delivery of Therapies for FSHD