

IMP Policy Plan Summary

Objectives for 2024/2025

1. To continue to support the international mitochondrial diseases (mito) community
2. To continue to support our members' work
3. To contribute to international research into mito
4. To raise awareness of mito
5. To secure adequate funding to support our objectives

Planned Activities for 2024/2025

Support

- Continue to offer support to people affected by mito in countries where there is no local patient organisation
- Continue to run the IMP private Facebook for people affected by mito
- Continue to connect people affected by mito with their local patient organisation
- Launch and continue developing a new website with information for the mito community

Members

- Continue to support our members
- Develop suite of resources for patient organisations
- Launch and continue developing a new website with information for members
- Support the development of new patient organisation in countries where none currently exist

Research

- GENOMIT: Continue development of Global Mitochondrial Disease Patient Registry as part of the GENOMIT Consortium
- SIMPATHIC: Contribute to the SIMPATHIC project as the patient representative group for Leigh Syndrome (type of mitochondrial disease)
- PMM Patient Journey: Contribute to the development of a Patient Journey for patients with Primary Mitochondrial Myopathies

- Diagnostic criteria and outcome measures in primary mitochondrial myopathies: Contribute to a European Neuromuscular Centre International Workshop

Awareness

- Host World Mitochondrial Disease Week, including sub events such as LHON Awareness Day, TK2d Awareness Day, Light Up for Mito and Faces of Mito
- Launch and continue developing a new website
- Manage Facebook channel

Fundraising

- Secure adequate unsecured funding for IMP's activities, primarily through grants and donations from the pharmaceutical industry, as well as secured (tied) funding for specific activities
- Manage and strengthen relationships with key funders