International Mito Patients (IMP) Annual Meeting 2026

15 Years of IMP
29–31 May 2026 | Angers, France

Executive Summary

The IMP Annual Meeting 2026 brought together patient advocates, member organisations, researchers, clinicians and industry partners from across the globe. Celebrating 15 years of IMP, the meeting focused on strengthening international collaboration, advancing research, amplifying the patient voice and preparing the mitochondrial disease community for future therapeutic developments.

Key themes included growth of the IMP network, awareness initiatives, development of the Global Mitochondrial Disease Registry, engagement with European Reference Networks, international advocacy, governance improvements, and research readiness. Member organisations shared achievements and challenges from their respective countries, demonstrating both the diversity and commonality of experiences across the global mito

community.

The meeting reaffirmed IMP’s commitment to awareness, earlier diagnosis, access to care, patient-centred research, clinical trial readiness and international collaboration.

Attendance

Nineteen registered delegates participated in the meeting, including eighteen attending in person and one remote participant. Delegates represented IMP leadership and member organisations including AMMi, Mito Foundation, Mitocon, Mitocon Brazil, MioMito, The Lily Foundation, ASANOL, BOKS, CORD/Hope for Rare, Cure Mito Foundation, DGM, LHON Deutschland, POL-G Foundation, UMDF and Muscular Dystrophy UK.

The international representation reflected IMP’s role as a global umbrella organisation and provided valuable opportunities for collaboration and knowledge exchange.

Chair’s Report

IMP Chair, Paula Morandi, reflected on a year of growth, resilience and collaboration. IMP now unites 25 member organisations across five continents. The Chair highlighted the success of World Mitochondrial Disease Week, expansion of awareness campaigns, strengthening of governance, the development of the Scientific and Medical Advisory Committee, and increasing engagement in research and regulatory activities.

Paula spoke about the importance of developing a Global Mitochondrial Disease Patient Registry and of ensuring that patient voices remain central to healthcare policy, research design and drug development. The Chair thanked members, volunteers, researchers, clinicians and industry partners for their ongoing commitment.

Read Chair’s Report

IMP Project Updates

Director of Development and Operations, Jo de Bry, presented an overview of IMP’s projects. World Mitochondrial Disease Week 2026 will be delivered under the theme ‘Putting Mito on the Map’. Jo acknowledged and thanked The Lily Foundation who developed the theme and have successfully used it in their campaigns for the last few years.

World Mitochondrial Disease Week activities this year will include the Global Mito Map, Light Up for Mito campaign, TK2d Awareness Day and LHON Awareness Day. The members were invited to an Awareness Week webinar on 23 June where the campaign will be detailed, including the introduction of editable assets and information.

Updates were also provided on SIMPATHIC, a Horizon Europe funded initiative exploring drug repurposing opportunities; the creation of the Primary Mitochondrial Myopathy Patient Journey; GENOMIT and engagement with European Reference Networks including EURO-NMD, ITHACA, EpiCARE and MetaBERN.

The newly strengthened Scientific and Medical Advisory Committee was introduced, bringing together internationally recognised experts and patient representatives who will guide IMP's involvement in research.

Member Presentations

Member organisations shared updates on awareness, patient support, research participation, fundraising, education and policy engagement.

The Mito Foundation presented the Mito Stories Project, designed to capture patient experiences and strengthen understanding of mitochondrial disease. AMMi highlighted its national advocacy and awareness work in France. Mitocon Brazil described new awareness initiatives and engagement with public authorities. LHON Deutschland showcased its support services and patient engagement model, while Cure Mito Foundation shared updates on accelerating research into Leigh syndrome.

Additional presentations from ASANOL, BOKS, DGM, UMDF, POL-G Foundation, CORD/Hope for Rare and others demonstrated the breadth of activity taking place across the international mito community. Each presentation was based on a poster created by the organisation. View posters here.

Industry Engagement

Representatives from UCB, Chiesi and Pharming participated in the meeting and provided updates on their engagement with the mitochondrial disease community.

Discussion focused on patient-centred approaches to research and development, collaboration with patient organisations and opportunities to strengthen communication between industry and the community. UCB also introduced plans for the 2026 UCB Mito Art Show, encouraging participation from people living with mitochondrial disease and their families. More information can be found here.

Annual General Meeting – Closed Session (Members only)
The AGM reviewed organisational performance, governance matters and financial sustainability.

Members approved the minutes of the previous AGM and received the Chair's and Treasurer's reports. Pedro Mendes presented the financial position of the organisation, outlining income, expenditure and reserves. Members agreed on the importance of maintaining financial sustainability while continuing to expand IMP activities.

Input has been sought from the Members with regards to the updating of the Constitution. Feedback and proposed changes were discussed, and it was agreed that Jo de Bry would seek member's feedback/consensus on the additional changes via email. It was recognised that legal amendments may still be required as part of the formalisation process, as directed by a Dutch Notary. An Extraordinary General Meeting (EGM) will be organised to vote on the final Constitution.

Board succession planning was mentioned, with Members being invited to consider becoming an IMP Board meeting in the future. They were advised to ask questions and discuss the position with existing Board Members or Jo de Bry.

IMP Priorities Discussion
Paula led a session on IMP's strategic priorities for the coming years. The importance of expanding awareness activities, improving diagnosis, increasing treatment access, strengthening policy engagement and supporting research participation were all highlighted as potential priorities.

There was broad agreement that patient organisations must continue to work collectively to ensure that patient perspectives influence research, healthcare policy and regulatory decision-making.

Workshops
Day One workshops focused on understanding medicine regulatory bodies and exploring developments in mitochondrial donation across different countries and regions. Participants in the mitochondrial donation workshop requested a follow up meeting be organised to allow the continuation of information sharing about this important topic.

Day Two workshops addressed media and policy engagement as well as understanding clinical trials. Delegates shared experiences and practical approaches for supporting patients, engaging policymakers and preparing communities for emerging therapeutic opportunities.

Research Updates

Professor Guy Lenaers provided an overview of current developments in mitochondrial disease research, highlighting advances in understanding disease mechanisms and potential therapeutic approaches.

Professor Michelangelo Mancuso discussed the importance of international consensus-building and clinical trial readiness in primary mitochondrial diseases. Particular emphasis was placed on natural history studies, patient registries and harmonised outcome measures.

Professor Alessandro Prigione reviewed research investigating the potential of sildenafil as a possible treatment for Leigh Syndrome and related approaches in mitochondrial disease. His presentation demonstrated the importance of continued translational research and international collaboration.

Key Outcomes and Strategic Priorities

The meeting reaffirmed the importance of international collaboration and patient-led advocacy. Key priorities identified for 2026–2027 include:

- Expansion of World Mitochondrial Disease Week.
- Advancement of the Global Patient Registry.
- Increased engagement with regulatory authorities and policymakers.
- Increased patient participation in the development of clinical trials.
- Strengthening of research collaborations.
- Expansion of awareness and educational activities.
- Continued development of the Scientific and Medical Advisory Committee.
- Increased member engagement through the IMP Ambassadors Programme.

Acknowledgements and Conclusion

Sincere appreciation was expressed to AMMi and Emma Del-Rey, and her colleague Karine Millasseau, as well as to Paula Morandi and Jo de Bry for organising the meeting. Gratitude was also expressed to all participants, member organisations, researchers, clinicians, partners, and volunteers for their attendance and input into the meeting.

Special thanks were extended to meeting sponsors UCB, Chiesi and Pharming and supporter Tisento Therapeutics.

The Annual Meeting demonstrated the strength of the international mitochondrial disease community. As IMP enters its next chapter, the organisation remains committed to building a stronger global voice, accelerating research, supporting patients and families, and working towards a future where mitochondrial diseases are better understood, diagnosed earlier and treated more effectively.