

IMP Annual Meeting, Angers France

29-31 May 2026

Summary from the Chair: Building a Stronger Global Voice for Mitochondrial Disease

At the 2026 International Mito Patients (IMP) Annual General Assembly, Chair Paula Morandi reflected on a year of growth, collaboration, and progress for the global mitochondrial disease community.

Despite the ongoing challenges faced by people living with mitochondrial disease, 2025 was a year that demonstrated the strength and resilience of our international network. Following the successful resolution of administrative challenges that had limited IMP's ability to grow, the organisation now brings together 25 member organisations across five continents, creating an even stronger global voice for patients and families.

Throughout the year, IMP continued to strengthen collaboration among members through regular international meetings, shared awareness campaigns, educational initiatives, and partnerships with researchers, clinicians, and industry. This unique combination of local expertise and international cooperation remains one of IMP's greatest strengths.

A major highlight of the year was World Mitochondrial Disease Week 2025, held under the theme "Decode the Mito Puzzle – Bridging Science and Symptoms." The campaign showcased the complexity of mitochondrial diseases while highlighting the lived experiences of patients and families. Awareness activities took place around the world, landmarks joined the "Light Up for Mito" initiative, and social media outreach reached more than 1.5 million people globally.

IMP also continued to ensure that the patient voice remains central to research, healthcare policy, and drug development. Through its active participation in international projects, including the GENOMIT initiative, IMP has contributed to the development of the Global Mitochondrial Disease Patient Registry, a project that has been in the making for a while and the time has now come to turn it into a concrete reality, an important step towards strengthening research, improving data collection, and preparing for future clinical trials.

Research and innovation remain key priorities. During 2025, IMP supported clinical trials, natural history studies, international consensus projects, and collaborative research efforts. The organisation continued advocating for patient involvement in trial design, regulatory discussions, treatment access, and quality-of-life outcomes. Progress in areas such as TK2 deficiency, Leigh syndrome, LHON, and drug repurposing initiatives has provided renewed hope for many patients and families.

IMP's growing influence was also reflected through participation in scientific advisory boards and consultations with the European Medicines Agency, ensuring that patient perspectives are represented at the highest levels of decision-making.

Behind these achievements lies the dedication of IMP's Board, volunteers, member organisations, and partners. Significant work throughout the year focused on governance, communications, fundraising, member engagement, and strategic planning. The establishment of a highly professional Scientific and Medical Advisory Committee further strengthens IMP's ability to support the community and advance its mission.

Looking ahead, IMP remains committed to strengthening the global mitochondrial disease community, improving awareness and education, advocating for earlier diagnosis, supporting access to care and treatments, amplifying patient voices, and accelerating research. The expanding Ambassadors Programme is helping connect member organisations more closely than ever before, ensuring that together we can speak with one strong and united voice.

"The challenges remain significant, but so does our determination," said Chair Paula Morandi . "The progress we are seeing today would not have been possible without international collaboration, shared commitment, and the extraordinary resilience of our community."

IMP extends its heartfelt thanks to all member organisations, partners, clinicians, researchers, patients, and families whose dedication continues to drive progress. Together, we are building hope and working towards a future where mitochondrial diseases are better understood, diagnosed earlier, treated effectively, and ultimately cured.