Press release
Evry (France), 16th September 2025

Launch of www.mitogether.com, the reference website for professionals and families affected by genetic mitochondrial diseases

To celebrate the World Mitochondrial Disease Week (September 15th to 21st), the MitoGether consortium, comprising 12 patient associations and their families, is launching a reference website providing expert information on research, diagnosis, medical care, and treatments for these diseases, which are associated with significant clinical and genetic heterogeneity. Aimed at patients and their families, healthcare professionals, researchers, and those involved in the pharmaceutical industry, Mitogether.com aims to be the reference website for genetic mitochondrial diseases.

There are more than 400 forms of genetic—or primary—mitochondrial diseases linked to mutations in genes directly involved in the functioning or maintenance of mitochondria. Mitochondria are unique in that they have their own genome and are therefore influenced by two genomes: the nuclear genome, with its 23 pairs of chromosomes contained in our cell nuclei, and the mitochondrial DNA within the mitochondria themselves, which explains the high degree of heterogeneity of these diseases. These diseases affect approximately 1 in 4,300 people in Europe, and at least 16,000 people in France.
These genetic mutations cause dysfunction in the mitochondria, the power house of the cell present in almost all of our cells, and are the cause of diseases affecting vision, brain, muscles, metabolism, and more. Mitochondrial research has made major progress in recent years, and as our understanding of these diseases and their management advances, the first innovative therapies are emerging for some of them.

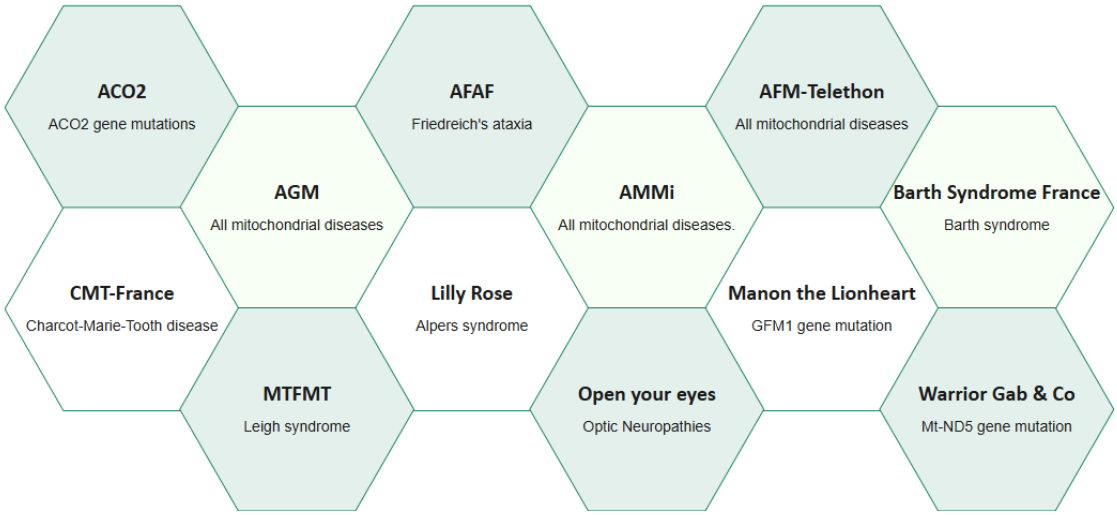
In order to centralize knowledge and facilitate information searches (monitoring, care, research, clinical trials, etc.), 12 French associations of people affected by primary mitochondrial diseases, with the help of the AFM-Telethon, have created MitoGether, a consortium whose objectives are to:

- → **Better inform those affected:** understand mitochondrial disease, find a local center of expertise to receive care from specialists, identify the relevant patient advocacy group, follow and understand ongoing research, be notified of trials in preparation or recruiting participants... all this information helps people find their way and receive better care.

- → **Better inform and support doctors and researchers**: keep up with the latest knowledge and medical-scientific publications, learn about optimal care, be alerted to current and upcoming studies and clinical trials, and available research support, identify relevant scientific events and conferences for disseminating information... All of these are valuable resources for professionals.

→ **<u>Better inform pharmaceutical companies about the specific characteristics and strengths of France and its centers of expertise in order to accelerate the development of tomorrow's treatments</u>**: gain a thorough understanding of the population affected by mitochondrial disease in France, understand how patient care and research are organized, identify key patient advocacy groups ,mitochondrial experts and clinicians, and get in touch with them... An asset for accelerating the availability of mitochondrial treatments.

The 12 pilot associations of MitoGether



<u>Press contacts</u> :
Stéphanie Bardon, Marion Delbouis – presse@afm-telethon.fr – 01.69.47.29.01 - 06 45 15 95 87