Due to the demonstrated relationships between mitochondria and common diseases scientists believe that research on mitochondria may have only an impact for mitochondrial diseases but could also advance research in genetics and other pathologies.

It is now discovered that mitochondria are involved in many pathologies neurodegenerative, certain cancers; processes in which they are considered and deserve to be scientifically, medically, pharmacologically studied ...

So many reasons to feel concerned and to join us

### **STRONGER TOGETHER!**

If you are affected by mitochondrial disease, becoming member will give more strength and legitimacy to ammi at a government level. You will help children and adults affected and will give research ways to

It is through your membership and donations that the association will be able to achieve its objectives...

## **Mitochondrial Diseases:**

#### (NON-EXHAUSTIVE LIST)

- Diabetes (3% of cases)
- Kearns-Sayre syndrome (external ophthalmoplegia with retinitis pigmentosa)
- **Leigh syndrome** (subacute necrotizing encephalommyopathy)
- MELAS syndrome (encephalomyopathy, lactic acidosis and strokes)
- Mitochondrial myopathy (child, adult)
- MERRF syndrome (myoclonic epilepsy with ragged red fibers)
- MNGIE syndrome (Myo-Neuro-Gastrointestinal encephalopathy)
- NARP syndrome (Neuropathy, Ataxia and Retinitis pigmentosa)
- Pearson syndrome (exocrine pancreatic insufficiencies and anemia)
- Chronic Progressive External Ophthalmoplegia (PEO)
- LEBER Hereditary Optical Neuropathy (LHON)
  - Ataxie de Friedreich
    - Alpers disease (progressive sclerosing poliodystrophy)
      - Nuclear mutations: daugk, tk2, twinkle, pola, mpv, SUCLG1, RRM2B, COX10, SCO1...
      - KJER or Dominant Optical Atrophy (AOD)

Mitochondria has a very important place within all cells of the body and in their functioning, the research sector extends considerably to the level of neuroevolutionary diseases, cancer, aging and become new targets for therapeutics.

# The Scientific and medical board

#### Clinicians and researchers:

- Pr Arnold Munnich.

Geneticist, clinical and molecular genetics, CHU Necker-IMAGINE

- Pr. Véronique Paquis,

Clinical and molecular aenetics. CHU Nice

- Prof. Agnès Rötig,

Laboratory for Genetic Diagnosis of Mitochondrial Diseases, Necker-IMAGINE

- Prof. Manuel Schiff,

Pediatrician Rare Diseases. CHU Necker-IMAGINE

- Pr. Nathalie Boddaert,

Radiologist, CHU Necker-IMAGINE

- Pr. Hélène Dollfus,

Ophthalmologist, medical genetics, CHU Strasbourg

- Pr. Julie Steffann,

Clinical Genetics Medical Biology, CHU Necker-IMAGINE

- Pr. Benoît Funalot,

Neurogeneticist. APHP Henri Mondor & Necker-IMAGINE

- Pr. Vincent Procaccio.

Genetics, molecular biology, CHU Angers

- Pr. Brigitte Chabrol,

Neuropediatrician, APM La Timone-Marseille

- Dr. Guy Lengers,

Cell Biology, CHU Angers

- Dr. Aurélien Trimouille,

Geneticist CHU Bordeaux-Pellearia

- Dr. Annabelle Chaussenot. Neurologist, CHU Nice Archet 2

- Pr. Emmanuel Gonzales.

Pediatric hepatoaastroenterologist, APHP Kremlin-Bicêtre

# Reference center:





CARAMMEL: Necker coordinator center: Henri Mondor (Créteil). Angers, Bordeaux, the Kremlin Bicêtre constituent centres; Tours, Dijon, Rouen and Caen competence centres.



CALISSON: Nice coordinator center: Marseille centre constitutif: Montpellier. Lyon, Toulouse competence center,

# A health network Rare Diseases



FILNEMUS (neuromuscular SMR pathway), Coordinator Pr. Shahram Attarian, APM Marseille. Due to the multiple disorders and handicaps of mitochondrial diseases. the A.M.Mi participates in workshops within sectors related to these diseases.



# **ASSOCIATION AGAINST** MITOCHONDRIAL DISEASES

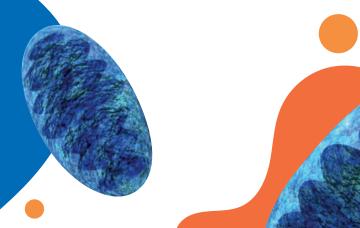
cell: +33 6 30 84 58 27 assoammi@gmail.com

www.association-ammi.org









# **Our Goals**

- Create a network of families of patients with mitochondrial diseases,
- To support these families
- To promote, inform fundamental biological, genetic and therapeutic research on mitochondrial diseases
- Promote information for medical teams that may be in contact with families,
- Provide material assistance to researchers, their networks, reference centres, congresses, etc.
- To be a representative association of patients and their needs.
- Promote early diagnosis for parental projects, access to care, move towards therapies...

# **Our Actions**

A.M.MI receives the Gold Medal of the National Academy of Medicine under the Awards Service for all its dissemination activities and information.

Since 1998, we have enriched our means and information:

- By setting up Regional Delegates, who can give information and contact the members, organizing events... according to their geographical area,
- Annual meeting with national and regional experts of Mitochondrial Diseases
- Creating various communications
- I.M.P (International Mitochondrial Patients) European and International Association of Mito Diseases patients, A.M.Mi is the co-founder of it and is part of the board
- ERN (European Rare Disease Reference Networks) in which A .M.Mi participates in various neuromuscular working groups
- An annual family weekend
- A God Father, Guy Lecluyse (French actor) represents us in our actions and promotes the association
- Organizing events to raise awareness for mitochondrial diseases,
- MeetochOndrie is a network, linked to MitoDiag network, supported by us and was created in 2006 with the objective of bringing together all the French actors of research concerned by mitochondria. The success of this network constantly developing and leading vocations.





# Mito.... Mito what?

Mitochondria are present in a large number of cells in the body, they produce about 90% of the cellular energy including the tissues, the organs and the whole organism need to function.

#### — WHO CAN BE AFFECTED ?

Anyone can be affected at all ages of life, with a predilection for very young children, young adults, and a growing number of adults.

#### - HOW MANY PATIENTS ?

The estimated prevalence is 1/5000 and 1/10000 in the general population, about 200 new cases per year in France. In the absence of accurate epidemiological data

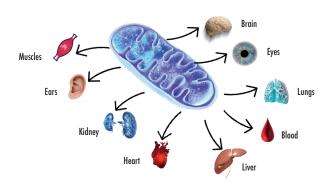
#### — WHAT IS THE ORIGIN OF THESE DISEASES?

These diseases are genetic: the damage may be on the cell nucleus DNA, on the mitochondria DNA or the transmission of the disease can be done in different ways.

#### — WHAT ARE THE TREATMENTS?

They are no treatments for the moment Clinical trials are underway, these new phases are open doors to hope.

#### **MITOCHONDRIA: ENERGY PRODUCTION**



#### MITOCHONDRIA DEFICIENCY = MITOCHONDRIAL DISEASES

Diabetes, Nephropathy, Ataxia, Epilepsy, Chronic acidosis, Hypotonia, Cardiomyopathy, Blindness, Liver damage, Rhythm disorders, Dystonia, Deafness, Autism, Dysphasia, Stroke, Encephalopathy, Myopathy ...

MITOCHONDRIAL DISEASES AFFECT ALL TISSUES THAT NEEDS ENERGY. MITOCHONDRIA ARE ESSENTIAL METABOLIC PATHWAYS.

# **DONATION FORM** AND MEMBERSHIP

Membership : 25,00€ Full payments

HelloAsso³ Bank transfer⁴

Check<sup>2</sup>

paying

Donation

and/or

# PLEASE COMPLETE THIS FORM

Relashionship with the person..... Who do you support NAME

? NAME:

**ADRESS** 

COUNTRY

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