

AFM-TELETHON'S *galaxy*

A PATIENTS AND FAMILIES ORGANIZATION



A board of trustees

consisting of voluntary patients and relatives of patients

Voluntary advisers

- The finance committee
- The scientific council

Operational departments

- Scientific
 - Medical action
 - Actions for families
 - General secretariat
- Marketing and development of resources
 - Public affairs
 - Communication
- Fundraising and mobilisation
 - Human resources

Génocentre

A conference centre to contribute to the influence of Genopole® Évry

Our support networks for families

16 teams of professionals in different regions of France (regional departments)

68 delegations in the French départements made up of volunteers affected by disease

9 interest groups, volunteers who are experts in their specific diseases

Patients' location to live in France

The Yolaine de Kepper centre (A residential care home for highly-dependent patients; Gâte-Argent: an innovative concept of accommodation and services; Respite home: "Le Village Répît Familles®" La Salamandre), the houses of Étioilles and La Hamonais, an apartment in Paris

Our Telethon network

148 local teams of volunteers which coordinate the development of fundraising events during the Telethon in each French department

THE RARE DISEASES PLATFORM

A unique resource centre for rare diseases

- Rare diseases alliance
- Eurordis
- Rare diseases info service
- Orphanet
- Rare diseases foundation

Ever since it was created AFM-Telethon has created or initiated many entities to serve the fight against disease.

Our partners

In therapeutic innovations

- **ACADEMIC**
Bpifrance, Inserm, CNRS, AP-HP, CEA, Universities, Pasteur Institute, ANR, CHU (University Hospitals), EFS, Imagine Institute...
- **PATIENTS' ORGANISATIONS**
IFCAH, Vaincre la Mucoviscidose, Retina France, DEBRA France...
- **INDUSTRY**
Biotechs, international and national pharmaceutical groups
- **INTERNATIONAL NETWORKS**
SMA Europe, Alliance collagène VI, EuroNMD, IRDiRC, COST Exon-skip

In social, medical and technological innovation

- **INDUSTRY**
- **NON-PROFIT ORGANISATIONS**, including in French overseas departments and territories
- **MULTI-DISCIPLINARY CONSULTATION NETWORKS**

For Telethon

- **FRANCE TÉLÉVISIONS GROUP**, producer of the TV broadcast
- **CLOSE TO 100 NATIONAL PARTNERS:** companies, professional and sport federations and non-profit organisations

BIOETHERAPIES INSTITUTE FOR RARE DISEASES

INSTITUT DE MYOLOGIE

European reference centre for muscles (care – research – training) and its clinical trial platforms for children and adults (I-Motion Institutes)

I-STEM

First French stem cell research centre for genetic diseases

GENETHON

Centre of expertise in the design, development and production of gene therapy drugs for rare diseases

GENOSAFE

Service provider control and safety of biotherapeutic products

ATAMO THERAPEUTICS

A mission-led biotechnology company, created by Genethon, focused on the development of gene therapies for Limb-Girdle Muscular Dystrophies

YPOKESI

An industrial pharmaceutical facility dedicated to the development and production of gene therapies created with Bpifrance, the French public investment bank

SEED FUND

"Innovative biotherapies for rare diseases" seed fund, created in partnership with Bpifrance, the French public investment bank

GENOPOLE® EVRY

research campus, centre of excellence, in genome and post-genomic studies

AFM PRODUCTIONS

Movies to spread knowledge and public awareness

VILLAGE REPIT FAMILLES
Les Cizes
respite home
in Jura, France

- Entity created and predominantly controlled by AFM-Telethon
- ⊖ Entity created and/or financed by AFM-Telethon