

INFORMATION LETTER N°2

The Ligue contre la Cardiomyopathie (Cardiomyopathy Foundation) was created on 12th July 2007 and registered as a non profitable and charitable society (registration number 409) in Chateaudun (28). It is today, the first French association dedicated to promoting research in cardiomyopathy and supporting patients and their families.

What is cardiomyopathy?

“Cardiomyopathy” covers affections of the cardiac muscle in general and includes the different types of affections such as

- Dilated cardiomyopathy
- Hypertrophic cardiomyopathy
- Arrhythmic right ventricular dysplasia

While little is known about the disease, it appears to often have a genetic origin and is frequently complicated by heart failure and/or ventricular arrhythmia.

Treatments, today include drugs, invasive procedures (defibrillator, stimulator) and even heart transplants where possible.

The Foundation's Mission

The primary mission of the Foundation is to promote research and raise awareness on cardiomyopathy and provide a support network for patients and their families.

The Association's main objectives are

- To promote and implement fundamental and applied research on the different forms of the disease
- To generate awareness on cardiomyopathy through the different medias
- To liaise between the medical profession and international/national associations
- To mainstream patients and their families at all levels of society – educational, professional, social, etc.

And generally to undertake all measures to achieve the above objectives, as well as to similar or related objectives that would help in realising the Association's mission.

The Association's Main Achievements

Since its creation the Foundation has achieved the following:

- Collaborated with the Reference Centre for Hereditary Heart Diseases which is coordinated by Professor Philippe CHARRON (PARIS Hopital La Pitie Salpetriere),
- Joined the EURORDIS, The Federation des Maladies Orphelines (the Orphan Disease Federation), the French Alliance for Rare Diseases and ORPHANET,
- Created the Foundation's online site - www.ligue-cardiomyopathie.com,
- Constituted a scientific committee composed of : **Professor Jean Noel Trochu**, NANTES University Hospital, **Doctor Robert Frank** PARIS Pitié-Salpêtrière University Hospital, **Professor Christophe Leclerq** RENNES University Hospital, **Professor Michel Komajda**, PARIS Pitié-Salpêtrière University Hospital, **Professor Gilbert Habib**, MARSEILLE University Hospital, **Professor Michel Desnos**, PARIS Georges Pompidou University Hospital, **Professor Olivier Dubourg**, BOULOGNE Ambroise Paré University Hospital. This committee will select the best research project that will be financed by the foundation at the end of the year.

Disease is still one of life's main "injustices". Each one of us could be touched one day, with out being prepared. This struggle against the disease is a daily challenge for the patients and their families. The aim of an association, such as The Cardiomyopathy Foundation, is to help each person to take part in this challenge by giving a little of their time and money