

# Policy Plan Foundation

Adopted at Board Meeting on: 17-01-2022 | Version 1, 17-01-2022



The objectives of our Foundation Cardiomyopathy Research, the Netherlands are:

1. Raising funds to finance and support scientific Research on cardiomyopathy, so that gene carriers with cardiac disorders can be detected and treated at earlier stage;
2. Facilitating a patient group (peers) for patients, their loved ones and carriers of congenital and/or genetic heart disease (cardiomyopathy);
3. Organizing meetings and events for people with a congenital and/or genetic heart disease (cardiomyopathy) with the purpose of providing them information and/or expanding knowledge about scientific Research on this field;
4. Performing all further actions related to above mentioned activities in the broadest sense or which may be conducive to it.

## Realisation of part 1

For the realisation of 1, we maintain contact with companies active in the field of cardiomyopathy drugs and devices and with other Institutions, both public and private, that support our objectives. It goes without saying that donations do not lead to any compensation from the Foundation or its affiliates other than a mention of the donation on the website and in the annual report. It has happened, however, that Scientists give a presentation on (the physiology of) cardiomyopathy or Cardiogenetics at the request of the donating organization and that they then have their speakers' fee donated to the Foundation afterwards. This is also mentioned in our annual report.

## Realisation of part 2

Social Media are used for the realisation of 2. In the meantime, co-operation has started with the HCMA, the "Hypertrophic Cardiomyopathy Association", which has given permission to use their logo on our [website](#) as well.

Members of the Foundation's Board keep in frequent contact with the HCMA. Eventually they will provide us with their website material and films for translation, so that Dutch-speaking information also can be related to their American website and can then be linked to our Foundation's own website.



## Realisation of part 3

For the realisation of 3, it will be worked out in what frequency and where we can hold meetings. The Corona situation has stood in the way so far, but anything online is possible.

In addition, we consider it important to be able to hold meetings in person, initially at one of the locations of the Scientists involved but possibly also at other hospitals.

## Realisation of part 4

The Foundation already has a [website](#) (English) with information about cardiac disorders and also videos available on our website and via [YouTube](#) with explanations.

In addition, we want to explain concepts properly with new animations and information at various levels. We start very simply, about the way the heart works and we explain basic concepts. We want to do this in a differentiated way, so that people can better understand to get more in-depth information, but always in an accessible way, so that the information seeker does not give up before any understanding has been gained. The ultimate perseverance can then end up in texts of guidelines or scientific articles, but not after all kind of explanations have been able to take place in an interactive manner.

We also want to use Social Awareness campaigns, benefit meetings and Crowdfunding campaigns, newsletters, lectures at schools, colleges, universities and hospitals, and any merchandising... all aimed to increase knowledge for patients, family members and the public, and to promote understanding/interest in, and participation in, scientific Research on cardiomyopathies.

## Building bridges between researchers and patients

Unknown makes unloved... there may be prejudice and fear of medication, interventions and scientific Research among a number of patients, relatives and part of the public.

We want to build bridges between researchers and patients/the public in order to propagate and promote scientific Research, and to support Clinicians on the field of patients treatment by enabling those patients/families to have meaningful exchanges about their condition, treatment plans and the state of scientific Research.

[Dutch Website](#)

[English Website](#)