What is HCHWA-D?
Hereditary cerebral hemorrhage with amyloidosis-Dutch type is an autosomal dominant disease. The amyloid beta-protein (Abeta) E22Q mutation of this rare disorder causes severe cerebral amyloid angiopathy (CAA). In the Netherlands, HCHWA-D is mostly found with families in or near Katwijk and therefore HCHWA-D is also called ‘Katwijkse ziekte’ (Katwijk disease) or Family CAA dutchtype. HCHWA-D is also sporadically found in the United States and Australia due to emigration.

Scientific research of the LUMC (Leiden University Medical Center in the Netherlands) shows that CAA severity tends to increase with age, but may vary greatly among patients of comparable ages. The first hemorrhagic stroke of patients with HCHWA-d occurs between the age of 45 and 60 in the majority of the patients. While on average the first stroke is at the age of 50 years, the course of the disease is different for every case. Approximately a third of the patients dies of the consequences of the first stroke. Patients that survive the first stroke, often suffer several strokes during the course of the disease. These strokes can lead to serious brain damage. Particularly, microaneurysms may contribute to the development of (small) hemorrhages/infarcts and the latter to cognitive decline in affected subjects.

Can HCHWA-D be treated?
At the moment there is no treatment for HCHWA-D nor is there prospect of a possible treatment in the near future. The HCHWA-D patient association intends to stimulate continuous research focused on clinical trials of candidate disease-modifying treatments. Therefore a fundraising foundation will be imbedded in the HCHWA-D patient association. A cure for this disease will not only be life changing for HCHWA-D patients, it will probably also affect thousands of other CAA patients.

What can the patient association do for families concerned?
HCHWA-D association provides information on HCHWA-D. This association is not only for patients, people with hereditary risk and other persons concerned are more than welcome in the association.

The purpose of the association is:
‘Promoting both the individual and collective interests of persons with HCHWA-D, partners and other people involved’.

The association attempts to promote these interests through:
- gaining more knowledge on HCHWA-D;
- promoting of and participating in scientific research;
- transferring information through special meetings and through the website;
- raising awareness among the scientific/medical community;
- giving advice when referred to specialists;
- contact with fellow patients.

CHA polyclinic in LUMC
HCHWA-D is due to a point mutation at codon 693 of the amyloid precursor protein (beta PP) gene at chromosome 21. Since this point mutation is diagnostic for HCHWA-D, presymptomatic testing
is feasible and offered, together with genetic counseling and psychological support, to subjects at risk. To meet the need for information, genetic counselling and care the CHA polyclinic has been established in the LUMC. Purpose of this multidisciplinary polyclinic is: faster and better care and gaining more knowledge. For contact: LUMC, secretariat CHA-polyclinic. The HCHWA-D patient association collaborates with the CHA polyclinic.

Contact:
For more information about HCHWA-D you can contact us online on this site. Suggestions for further improvement of the organisation or ideas for the research agenda are welcome.