

Basic data of Patient Association: *The Netherlands*



Name

Stichting Amyloïdose Nederland

Date of establishment

April 2013

Juridical status (Association or Foundation)

Foundation. Registered by fiscal authorities as ANBI (Institution which serves general interest)

Official address

Beekhoven 12 , 3863 PZ Nijkerk

Type(s) of Amyloidose covered

In principle all types (AA; AL; ATTR hereditary, mutation hereditary and wild type)

Estimated numbers of persons affected

For all types together 800.

Number of patients treated at the major expertise centre (Groningen) 200.

- ◆ AL 80
- ◆ Hereditary ATTR 50
- ◆ Carriers mutation hereditary ATTR 35
- ◆ Wild type ATTR 15
- ◆ AA 30

Goal and Objectives of the organisation

The major goal of the organisation is to support and empower patients to enhance their quality of life and life expectancy by pursuing the following objectives:

1. Giving patients and caretakers access to accurate and up-to-date information on the nature of the disease, new developments in diagnose and treatment, and ongoing or planned clinical studies through the Foundation's website (www.amyloidose.nl).

2. Promote patient education and their participation in clinical studies .
3. Promote Amyloidosis disease awareness in medical circles, especially general practitioners and specialists, for earlier diagnose and appropriate treatment.
4. Organize patient contacts through meetings, symposia and an Internet forum.
5. Maintain contacts, internationally, with other patient organizations and pharmaceutical companies, if and when this can serve the interest of patients.
6. Fund raising to achieve these objectives.

Administration (Board/Secretariat, Advisory Councils)

The Board has 6 members. Chairmanship rotates. It has an Advisory Council of 4 specialists.

(Statutory) meeting and frequency

Board and Advisory Council meet every 3 to 4 months together.

Activities accomplished, undertaken or planned (in relation to each of the objectives)

- ◆ maintenance and updating of a website, and editing of a Newsletter
- ◆ organise a yearly patients day for patients and caretakers with presentations by experienced doctors and specialists in mental support
- ◆ maintenance of an Internet forum
- ◆ the organisation has participated in the definition of standards and benchmarks for the treatment of AL Amyloidose and socio-psychological accompaniment of patients ('zorgstandaard'). A similar standard is in preparation for ATTR patients. A series of interviews have already taken place.
- ◆ a brochure for general practitioners (first line) has been produced with guidelines on how to deal with carriers of the disease (accessible by Internet)
- ◆ a program is in preparation to make medical doctors of different disciplines, working in hospitals (second line), more aware of the existence of Amyloidosis and its symptoms for more timely diagnose (search for funding is still going on)
- ◆ an information brochure for patients and their medical and non-media all care providers, earlier published in the USA, has, with their permission been translated into Dutch. Subsequently it has been adapted and partly re-written with a view of adjusting it to the Dutch situation. First print 2015, second print 2016.
- ◆ the organization participates in international medical congresses and meetings on Amyloidosis, as and when appropriate, e.g. First European Congress on ATTR Amyloidosis (Paris, September 2015) ; International Congress on Amyloidosis (Uppsala, July 2016)
- ◆ the organization has actively promoted the recognition of the University Medical Centre Groningen as an Center of Expertise for Amyloidosis which should guarantee the permanency of the services actually provided and its further development. It has also facilitated its chief medical advisor to be awarded the national 'Award for rare diseases'.

Main centers of expertise in the country

Universitair Medisch Centrum Groningen (University Medical Centre Groningen); official status as 'Center of Expertise'.

Other centre, part of the network: University Medical Centre, Utrecht.

Financing (main sources of income)

Subsidies; donations from private persons, (small) donations from pharmaceutical companies for specific patient-oriented activities.

Cooperation with other organizations or membership of federal bodies (national or international)

Member of the VSOP (the Dutch umbrella association for all rare disease organizations. It provides several support services)

Contact

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