



# **AMYLOIDOSIS ALLIANCE**

**THE VOICE OF PATIENTS**

First Meeting – Paris September 15, 2018

# The Alliance is involving a great number of countries



Brazil – ABPAR  
France – AFCA  
Germany – FAP-eV  
Israel – Amyloidosis Israel.org  
Italy – fAMY  
The Netherlands – SAN  
Sweden – FaMY Norbotten  
USA – Amyloidosis Support Groups

Spain (Balearic Islands) – ABEA  
Venezuela – FAP Venezuela

Canada - Canadian Amyloidosis Support Network  
Canada – Hereditary Amyloidosis Canada  
Mexico – FFAM  
New Zealand - New Zealand ATTR Amyloidosis Patients Association  
UK – ATTR Amyloidosis Patient Organisations

Australia  
South Korea,  
Spain (national) - Amilo

# Alliance Objectives and priorities

Awareness -  
Diagnosis

Treatment and  
Care

Research

Communication  
and mutual  
support  
between POs

Advocacy at  
International  
level

Support other  
countries in  
initiating  
patients group



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# Strategic Plan 2020 ongoing

## Awareness & Diagnosis

Development and spread of supportive educational material targeting patients and families  
Developing channels of communication with different categories of specialists, especially neurologists and cardiologists

## Treatment and Care

Support member POs to ensure that patients get treatment in their respective countries  
Establish and update a register of Expert's center in Europe and in the World,  
Set up a map of the medicines available and accessible in each country  
Develop universal standards of quality for cure and care facilitate its spread in member and non-member countries.  
Promote an Holistic Approach ( including genetic counseling)

## Research

Be involve in the definition of research  
Promote research and clinical trials by regular contacts with all the stakeholders  
Strengthen the patients voice in the design and implementation of clinical trials  
Inform members about ongoing trials, open label studies, and early access programs, trials outcomes

## Communication and Support between POs

Establish a digital platform ( website) for members to share information, expertise, knowledge  
Maintain and update a Register of POs with basic data  
Maintain and update a Register of Centers of Expertise  
Organize conference calls or webinars around common themes  
Organize a two yearly international meeting of Patients and Doctors

## Advocacy at international Level

Build up a working relationship with international institutions contributing to access of the most appropriated treatments and care institutions such as:  
EURORDIS (Alliance of rare disease patients organizations in Europe)  
ARC (Amyloidosis Research Consortium)  
EMA (European Medicines Agency)  
ISA (International Society of Amyloidosis)

## Support initiating group in other countries