

The First World Amyloidosis Day

The Amyloidosis Alliance and worldwide patients organisation have created an international day of awareness dedicated to this rare disease, with 18 participating countries throughout the world.

18 COUNTRIES TAKING PART

EUROPE

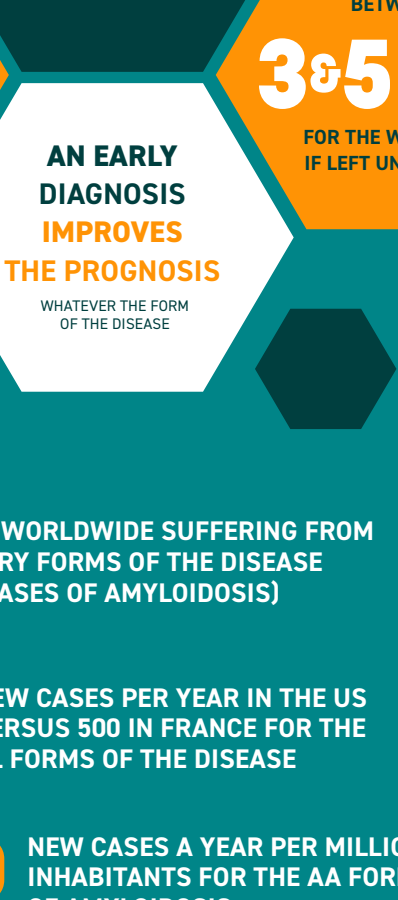
- FRANCE
- SPAIN
- UNITED KINGDOM
- IRELAND
- THE NETHERLANDS
- ITALY
- GERMANY
- SWEDEN
- AUSTRIA



REST OF THE WORLD

- USA
- AUSTRALIA
- CANADA
- BRAZIL
- MEXICO
- COLUMBIA
- ARGENTINA
- NEW ZEALAND
- VENEZUELA

DIFFERENT TYPES OF AMYLOIDOSIS



AL AMYLOIDOSIS
a non-transmissible form of amyloidosis

HEREDITARY AMYLOIDOSIS

WILD FORMS OF AMYLOIDOSIS

4 SORTS OF AMYLOIDOSIS
We ATTR hATTR

AN AVERAGE OF 4 YEARS BEFORE DIAGNOSIS¹

3 & 5 years
LIFE EXPECTANCY BETWEEN FOR THE WILD TYPE IF LEFT UNTREATED

AN AVERAGE OF 4 SPECIALISTS CONSULTED BEFORE DIAGNOSIS²

AN EARLY DIAGNOSIS IMPROVES THE PROGNOSIS
WHATEVER THE FORM OF THE DISEASE

10,000 PATIENTS WORLDWIDE SUFFERING FROM HEREDITARY FORMS OF THE DISEASE (20% OF CASES OF AMYLOIDOSIS)

4,000 NEW CASES PER YEAR IN THE US VERSUS 500 IN FRANCE FOR THE AL FORMS OF THE DISEASE

10 NEW CASES A YEAR PER MILLION INHABITANTS FOR THE AA FORMS OF AMYLOIDOSIS

1 NEW CASE PER 100,000 INHABITANTS EVERY YEAR

WORLDWIDE AMYLOIDOSIS FIGURES*
* regardless of type

WILD FORMS OF THE DISEASE, LINKED TO AGING, ARE DIFFICULT TO QUANTIFY DUE TO THE HIGH RATE OF UNDERDIAGNOSIS.



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WHAT IS AMYLOIDOSIS?

AMYLOIDOSIS CAN AFFECT SEVERAL ORGANS

- THE HEART
- THE KIDNEYS
- THE DIGESTIVE SYSTEM
- THE LIVER
- THE PERIPHERAL NERVOUS SYSTEM



A GROUP OF VERY DIFFERENT DISEASES

VARIOUS CAUSES AND SYMPTOMS, AMYLOIDOSIS CAN BE VERY LOCALISED, IN A SINGLE ORGAN, OR AFFECT SEVERAL AT ONCE.

A DISEASE THAT CONCERNS ADULTS AT ANY AGE

between **30-90** years old
FIRST SYMPTOMS (VARIES BETWEEN FORMS)

between **50-75** years old
PEAK OF DIAGNOSIS

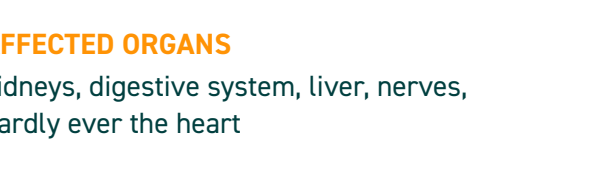
2 POSSIBLE ORIGINS OF THE DISEASE

01 | EITHER CONTRACTED

NON-COMMUNICABLE

AL AMYLOIDOSIS

AGE SPAN
Between 50 and 65 years old



CAUSE
Dysfunction of the bone marrow

AFFECTED ORGANS
Heart, liver, kidneys, peripheral nervous system



KEY FIGURES

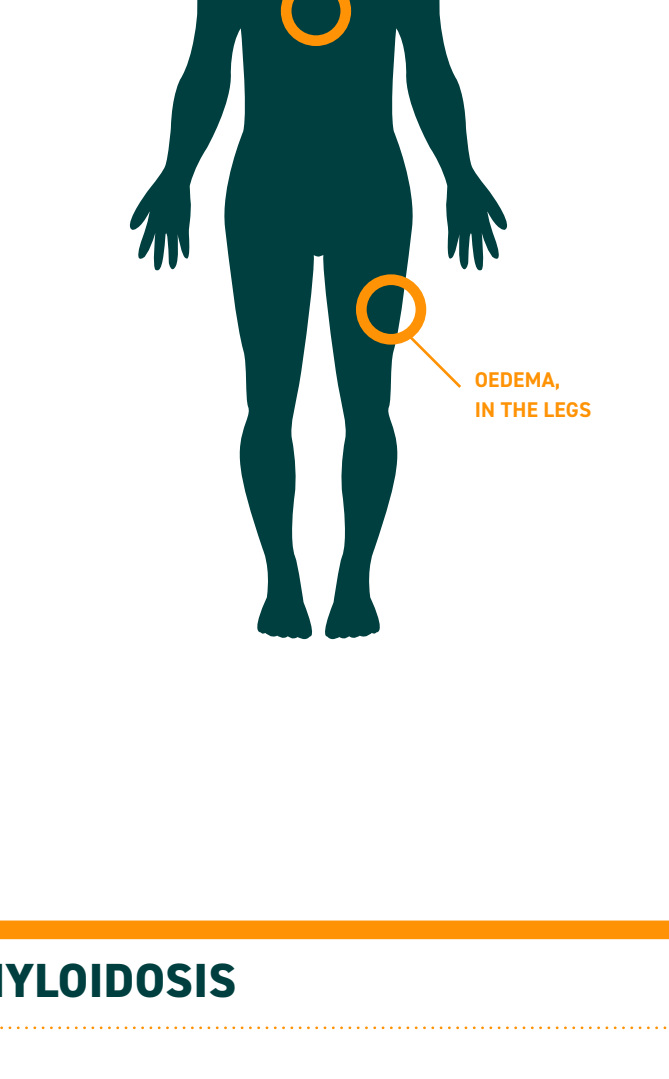
US **4,000⁴** NEW CASES PER YEAR

FR **500** NEW CASES PER YEAR

WESTERN COUNTRIES

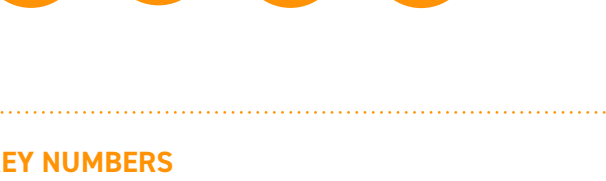
6-10 CASES PER YEAR PER MILLION INHABITANTS

MOST FREQUENT SYMPTOMS³
They depend on which organs are affected



AA AMYLOIDOSIS

AGE SPAN
The average age is 50⁵

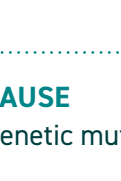


CAUSE
Secondary to chronic inflammation⁶

AFFECTED ORGANS
Kidneys, digestive system, liver, nerves, hardly ever the heart



INCIDENCE



<10 NEW CASES PER YEAR PER MILLION INHABITANTS

MOST FREQUENT SYMPTOMS
AA Amyloidosis symptoms are not specific



Wt ATTR AMYLOIDOSIS

AGE SPAN
Over 60



CAUSE
Consequence of aging

AFFECTED ORGANS
Heart, auditory system, digestive system, peripheral nervous system⁸



KEY NUMBERS



PREVALENCE OF WILD CARDIAC AMYLOIDOSIS IS LARGELY UNDERESTIMATED⁹

MOST FREQUENT SYMPTOMS



02 | HEREDITARY

hATTR AMYLOIDOSIS

AGE SPAN
30 for early forms

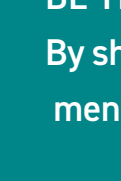


CAUSE
Genetic mutation

AFFECTED ORGANS
Heart, digestive system, peripheral nervous system

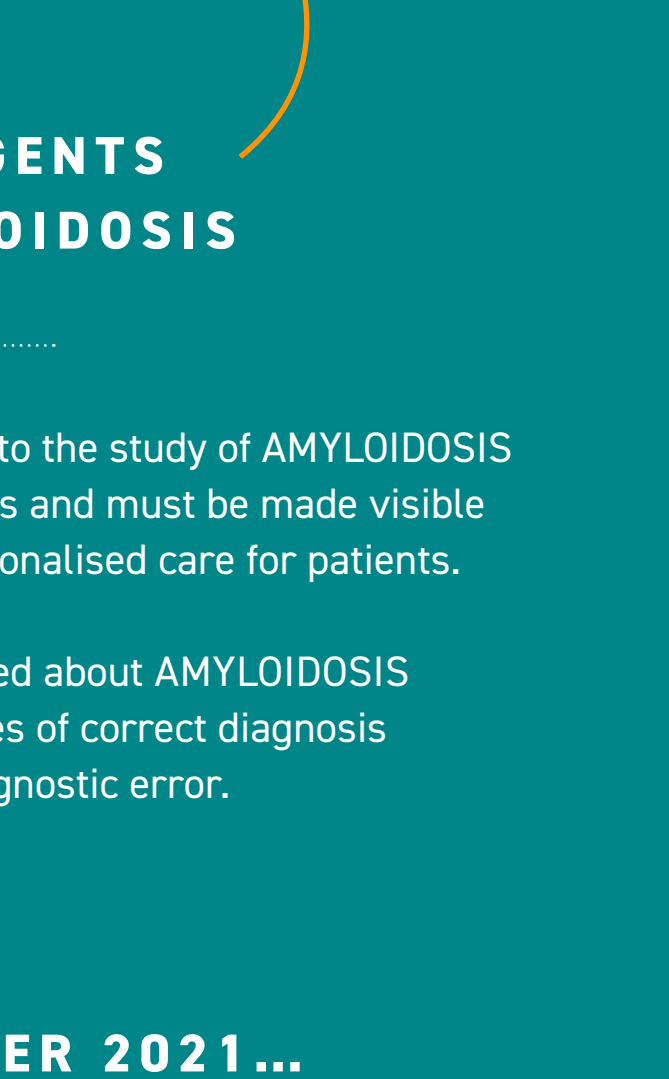


KEY NUMBERS



10,186⁷ PEOPLE ESTIMATION OF GLOBAL PREVALENCE

MOST FREQUENT SYMPTOMS¹⁰



NB: Depending on the mutation (over 100 identified), the symptoms may vary from polyneuropathy to cardiomyopathy. Some mutations manifest in mixed phenotypes.

THERAPEUTIC STRATEGIES

STOPPING AMYLOID DEPOSITS

REMOVING THE AMYLOID DEPOSITS

IMPROVING THE QUALITY OF LIFE

LIMITING THE SYMPTOMS & THE DAMAGE OF THE ORGANS

EACH FORM BENEFITS FROM SPECIFIC TREATMENTS & ACTIVE RESEARCH

THE AGENTS OF AMYLOIDOSIS

Centres of expertise dedicated to the study of AMYLOIDOSIS can be found in most countries and must be made visible so as to facilitate early, personalised care for patients.

GPs must be well-informed about AMYLOIDOSIS so as to increase chances of correct diagnosis and reduce diagnostic error.

26TH OCTOBER 2021...

The first ever World Amyloidosis Day will be held in 18 countries throughout the globe, so as raise public awareness and help health professionals to get to know this rare disease better, and support medical research. A digital awareness tool, BE THE LINK, will be launched on social media and phygittally on the same day. By sharing the orange link on social networks, we will all contribute to the improvement of global knowledge of amyloidosis, and help in reducing diagnostic error.

Interviews with doctors, amyloidosis patients and Amyloidosis Alliance spokespersons will be available on request to the press on World Amyloidosis Day.

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AMYLOIDOSIS ALLIANCE
THE VOICE OF PATIENTS

www.worldamyloidosisday.org

SOURCES

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OUR PARTNERS

