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

AN AVERAGE OF **4 YEARS BEFORE** DIAGNOSIS[1]

AN AVERAGE OF **4 SPECIALISTS CONSULTED** BEFORE DIAGNOSIS[2]

AL, AA, Wt ATTR, hATTR: **4 SORTS OF AMYLOIDOSIS**

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

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.

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-CUMMUNICABLE

AL AMYLOIDOSIS

AGE SPAN
Between 50 and 65 years old

0 10 20 30 40 50 60 60 80 & +

CAUSE
Dysfunction of the bone marrow

AFFECTED ORGANS
Heart, liver, kidneys, peripheral nervous system

KEY FIGURES
US: **4,000**[4] NEW CASES PER YEAR
FR: **500** NEW CASES PER YEAR
WESTERN COUNTRIES: **6-10** CASES PER YEAR PER MILLION INHABITANTS

MOST FREQUENT SYMPTOMS[3]
They depend on which organs are affected
- DIZZINESS WHEN CHANGING POSITION
- BREATHLESSNESS
- HEART FAILURE
- DIGESTIVE PROBLEMS
- KIDNEY FAILURE
- FATIGUE
- OEDEMA, IN THE LEGS

AA AMYLOIDOSIS

AGE SPAN
The average age is 50[5]

0 10 20 30 40 50 60 60 80 & +

CAUSE
Secondary to chronic inflammation[6]

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
- FATIGUE
- LOSS OF APPETITE
- OEDEMA, IN THE LEGS

Wt ATTR AMYLOIDOSIS

AGE SPAN
Over 60

0 10 20 30 40 50 60 60 80 & +

CAUSE
Consequence of aging

AFFECTED ORGANS
Heart, auditory system, digestive system, peripheral nervous system[8]

KEY NUMBERS
PREVALENCE OF WILD CARDIAC AMYLOIDOSIS IS LARGELY UNDERESTIMATED[7]

MOST FREQUENT SYMPTOMS
- FATIGUE
- BREATHLESSNESS
- HEART FAILURE
- LUMBAR SPINAL STENOSIS
- CARPAL TUNNEL SYNDROME

02 | HEREDITARY

hATTR AMYLOIDOSIS

AGE SPAN
30 for early forms

0 10 20 30 40 50 60 60 80 & +

CAUSE
Genetic mutation

AFFECTED ORGANS
Heart, digestive system, peripheral nervous system

KEY NUMBERS
10,186[9] PEOPLE
ESTIMATION OF GLOBAL PREVALENCE

MOST FREQUENT SYMPTOMS[10]
- DIZZINESS WHEN CHANGING POSITION
- BREATHLESSNESS
- HEART FAILURE
- WEIGHT LOSS
- DIARRHOEA
- FATIGUE
- LOSS OF SENSATION IN THE FEET IN PARTICULAR FOR HEAT AND COLD

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 DESPOSITS
- **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 phygitally 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.

wad@amyloidosisday.org

AMYLOIDOSIS ALLIANCE
THE VOICE OF PATIENTS

www.worldamyloidosisday.org

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