FIRST WORLD AMYLOIDOSIS DAY 26TH OCTOBER 2021

Amyloidosis Alliance is participating in the first ever global amyloidosis awareness day, called **World Amyloidosis Day, which will take place on 26th October of this year**. In all, **18 countries from Europe, North and South America and Oceania are participating** along with them, and will be working to raise awareness about this rare disease **by letting patients from all over the world tell their story and by talking about the inequality of patient care and between countries** due to diagnosis, treatment or reference centre differences. As with all rare diseases, the number of diagnoses is vastly lower than the number of people who are actually ill. **An average of 1 new case is diagnosed per year for every 100,000 people** in the world.

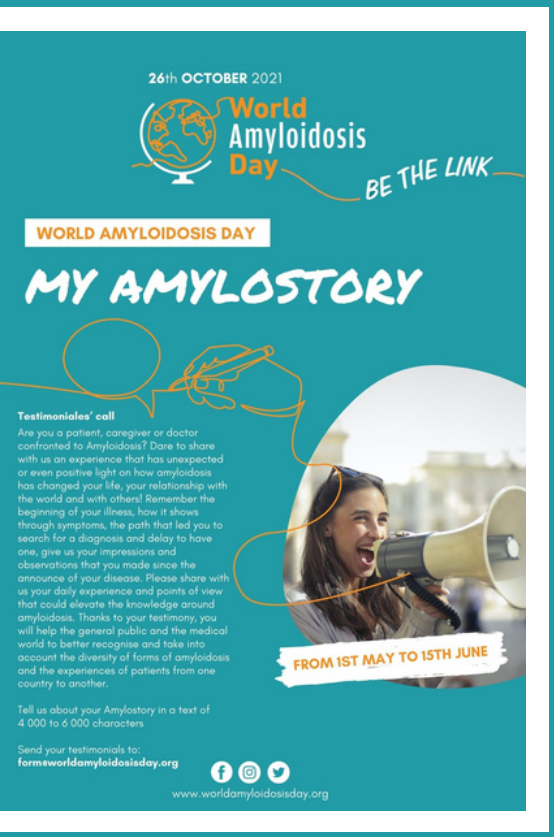
ÉRIC-EMMANUEL SCHMITT, INTERNATIONAL AMBASSADOR OF THIS WORLD DAY

The famous writer, playwright and thespian is the international ambassador of the first World Amyloidosis Day. He will be **participating in the My Amylostory project and will be reading one of the selected patient stories during the Facebook Live on 26th October**. He will act out some of the stories alongside amateur actors for the 2021 edition of World Amyloidosis Day, organised by and for patients, medical professionals and amyloidosis patient organisations from the 18 participating countries.

« The rarer the disease, the greater the need to stand united. If we work together, we can alter fate. Amyloidosis attacks insidiously, damaging organs, but causing no external symptoms, thus remaining undetected while slowly gnawing away at the patient's body. Currently, four years is the average time it takes to be diagnosed. Four years of suffering for the patient, from both pain and isolation. Four years that are wasted, causing distress to the patient and delaying life-saving treatment. Four years that are dangerous not only to the patient, but also to their family: amyloidosis is a potentially hereditary disease. Woe befalls the victims of this disease, so let us not allow that woe to propagate any further. We can stop it! Let us sprint our way to the finish line, even if we have to run a marathon to get there! I am honoured to be the ambassador for this first World Amyloidosis Day.»

The ambassador shall be participating in the My Amylostory miniseries on 26th October, but he will also later **visit an amyloidosis treatment centre in Paris to meet the personnel and patients**, to better understand the implications of this illness. He will be the media voice of patients to raise awareness for the disease and to promote medical research. He will also be **present for the Facebook Live event on 26th October**, which will bring together patients and doctors from all 18 participating countries.

WORLD AMYLOIDOSIS DAY ACTIVITIES



MY AMYLOSTORY

We sent **a call for testimonials to patients, their caregivers and medical professionals all over the world** to ask them to tell us about their day-to-day lives with amyloidosis and their fight against the disease. All the stories will be released online on the WAD website, and then a few will be selected by our committee as a basis for an acted miniseries (around 20 stories will be selected for this purpose).

« BE THE LINK » T-SHIRT

A special amyloidosis t-shirt will be available on the WAD website. Patients, their loved ones, medical professionals, but also the general public are invited to wear the t-shirt on their Facebook and Instagram pictures to show their support for World Amyloidosis Day.

FACEBOOK LIVE

Finally, on 26th October, during the World Amyloidosis Day event, **an international Facebook Live** shall bring together all the WAD players with its official ambassador: Éric-Emmanuel Schmitt!

THE 18 COUNTRIES TAKING PART IN THE FIRST WORLD AMYLOIDOSIS DAY TO IMPROVE DIAGNOSIS OF THE DISEASE

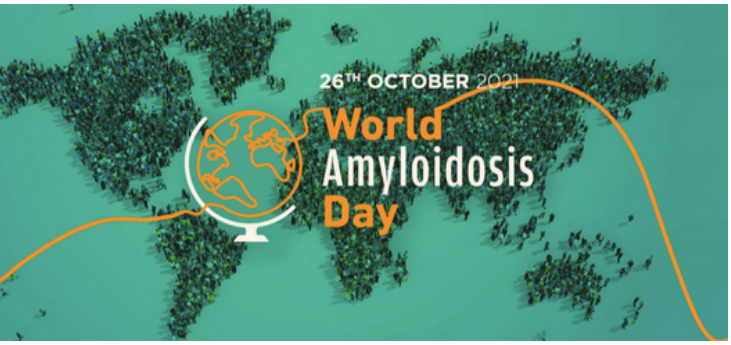
Early treatment and diagnosis, as soon as the first symptoms appear, improves the quality of life and life expectancy of patients. Like many rare diseases, amyloidosis requires innovative treatments, the technology for which could potentially be adapted to the treatment of other diseases, such as Alzheimer's. Better recognition and treatment of amyloidosis is advantageous even for those who are not directly affected by it.

« Amyloidosis is a rare disease that most general practicioners have never encountered, and which takes a little over three years on average to diagnose. The "World" part of World Amyloidosis Day is important as it brings patients from all over the world together and shows them that they are not alone. Our World Amyloidosis Day will raise awareness for the disease while also providing insight into how other countries deal with the disease » states **Jean-Christophe Fidalgo**, President of the Amyloidosis Alliance.

ONE THE MAIN GOAL OF THIS WORLD DAY IS TO ACCELERATE DIAGNOSIS OF THE DISEASE

The first symptoms of amyloidosis are often vague or unspecific. Because of the variety of initial symptoms and the rarity of the disease, which is often unknown to GPs, diagnosis is frequently delayed. The goal of this first World Amyloidosis Day is to decrease delays in diagnosis, and thus to increase life expectancy of patients (if left untreated, life expectancy is around 10 years for hereditary forms, 3 to 5 years for wild-types and 1 to 2 years for AL amyloidosis)

AMYLOIDOSIS: A RARE, COMPLEX AND DEADLY DISEASE, THAT PROGRESSES UNDETECTED



Amyloidosis is currently a barely-understood and complex disease. It is linked to the misfolding of proteins on our bodies called "amyloid proteins". They accumulate in organs under the form of plates that disturb their function. The organs most frequently affected by amyloidosis are the heart, the kidneys and the peripheral nervous system.

Wild-type amyloidosis is heavily underdiagnosed, and will very certainly be recognised as one of the most common forms once diagnosis is facilitated. Wild-type amyloidosis patients suffer through **4 years of diagnostic delay on average, and are only correctly diagnosed after seeing 4 specialists on average**. This delay in treatment causes wild-type amyloidosis patients to have a very short life expectancy (3-5 years for untreated wild-type cardiac amyloidosis).

MORE INFO ABOUT WORLD AMYLOIDOSIS DAY ON : WWW.WORLDAMYLOIDOSISDAY.ORG

THE PARTNERS OF THIS FIRST WORLD AMYLOIDOSIS DAY

Pfizer · Alnylam · IONIS · eidos · sobi · janssen

If you wish to conduct **an interview with the official ambassadeur of the WAD**, contact the press service of the Day.

(Miss)
(Mail / tel)