ÉRIC-EMMANUEL SCHMITT, OFFICIAL AMBASSADOR OF THE FIRST WORLD AMYLOIDOSIS DAY 26TH OCTOBER 2021

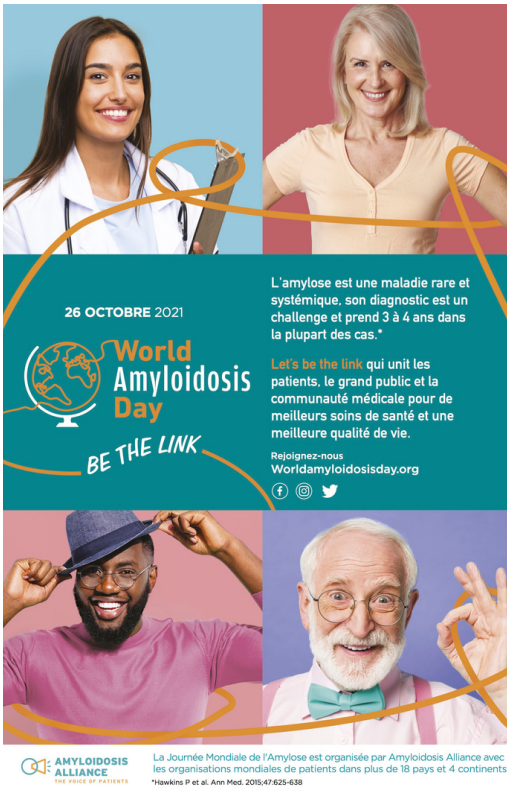
The **first global amyloidosis awareness day, called World Amyloidosis Day, which will take place on 26th October of this year**, welcomes Éric-Emmanuel Schmitt as its official ambassador. He shall **be representing the 18 European, North American, South American and Oceanian countries** that are participating in the event, whose goal is to raise awareness about this rare disease and to talk about the inequalities in treatment throughout the world, caused by diagnostic, treatment and reference centre difference

ÉRIC-EMMANUEL SCHMITT, INTERNATIONAL AMBASSADOR OF THIS WORLD DAY

The famous writer, playwright and thespian will be acting as international ambassador of World Amyloidosis Day. He shall **be participating in the My Amylostory event, and will be reading out one of the patient testimonials** during the Facebook Live event on 26th October, dedicated to the patients, doctors and patient organisations from all 18 of the 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. We can stop it!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.



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.

WORLD AMYLOIDOSIS DAY ACTIVITIES

MY AMYLOSTORY

A **call for testimonials has been sent to patients, carers and medical professionals all over the world**, asking 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.

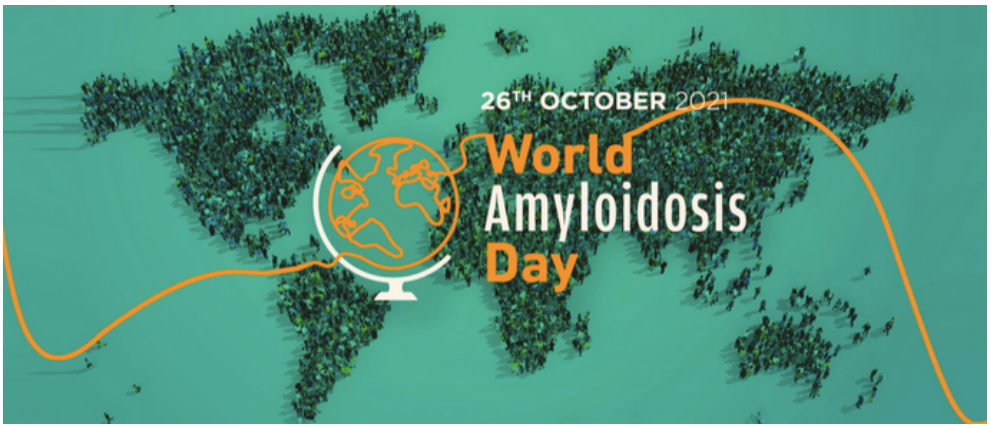
« BE THE LINK » T-SHIRT

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!

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



If you wish to conduct **an interview with the president or a representative of the AFCA, a health professional or the ambassador of the WAD**, contact the press service of the Day.

(Miss)
(Mail / tel)

THE PARTNERS OF THIS FIRST WORLD AMYLOIDOSIS DAY

Regarding Amyloidosis

Amyloidosis mainly affects the elderly. Depending on the form, it can appear between 30 and 90 years of age, with diagnosis peaking between 50 and 75. 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. Patients that suffer from Amyloidosis 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).