

WHY IS WORLD AMYLOIDOSIS DAY IMPORTANT?



« Amyloidosis is a rare disease that most general practitioners 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. »

Jean-Christophe Fidalgo, President of the Amyloidosis Alliance

« In my opinion, our objective for World Amyloidosis Day is to defend the interests of patients and to help them get the care they deserve. I am 45 years old, I live in São Paulo, Brazil. I was diagnosed with hATTR Amyloidosis 8 years ago, I had lost many relatives due to the illness including my father and grandfather. In my country there was no medicine available to treat the disease and I decided to start fighting for the interests of patients, to ensure that they have the best care. For 8 years I led the Brazilian Association of ATTR Amyloidosis (ABPAR) and today my focus is to take care of my health and make sure I have a good quality of life. I work as a volunteer at the Amyloidosis Alliance to continue helping patients throughout their journey. »

Fabio Almeda, Member of the Board of the Amyloidosis Alliance



« Because it fosters international solidarity and exchange of experiences between all parties which is so important for being effective in the combat against a rare disease. »

Koenraad Verhagen, Secretary of the Amyloidosis Alliance

« As member of the board of FAMY Onlus, the Italian Association, since the beginning I was involved in establishing relationship with other Patient's Associations and had realized how this disease is spread all over the world. One of the main tasks of the Amyloidosis Alliance- The Voice of Patients, we established in June 2018 with the friends of France and the Netherlands, is awareness. Well, we have organized the first Amyloidosis Day thus, in each country involved, patient's representative may talk about this disease with all Players are involved in the Healthcare. »

Giovanni d'Alessio, Treasurer of the Amyloidosis Alliance

