

Luisa BOTELLA

Asociación HHT España, Spain

Our Association was formally constituted on April 2005, as "Asociación HHT España". It is constituted by, Hereditary Haemorrhagic Telangiectasia patients, their families, friends, and some physicians and researchers involved directly in the disease. When inscribed in the register of associations at this time, the group was small. The board was formed by the president, the vice president and the treasurer, and around 20 associates. It is a national association, representing all the communities of Spain, and associates from Latino American countries.

It was declared of Public Utility, or Non-Profit Organization, in 2011. We belong to Eurordis, and also to HHT-Europe transnational group. We are linked to doctors and researchers, forming one unit: the Spanish HHT Unit, with three main parts: Clinical part: physicians and specialists on HHT from the main Hospital, Sierrallana/Valdecilla, Cantabria (North Spain), but also from other more recently HP, in Madrid, Catalunya and Canary Islands. Research: mainly conducted in the Centro de Investigaciones Biológicas in Madrid, belonging to the National Research Council of Spain, CSIC Association, whose executive committee is now formed by the president, Mr Bienvenido Muñoz, the vicepresident, Mr Eder Castro, the secretary Mrs Ana-M. Carrera, the treasurer, Mr Manuel Machado and as additional member, Mrs, Rosa del Río. We have also a board of experts, or advisory board, formed by former president, vice president, and secretaries, by doctors coordinating the units of the Hospitals specialized in HHT, and by researchers of CSIC.

We celebrate national assemblies once a year, with associates, doctors and researchers. Last was held in Madrid, October 2015.

Information at: info@asociacionhht.org