



Didier ERASME

Amro, France

AMRO-HHT-France is the 25 year's old French patient association devoted to HHT-Rendu-Osler disease with 500 individual members. A small team of administrators meets about 3 times a year. A general assembly takes place once a year.

Every year AMRO organized a one-day information meeting where patients and relatives may exchange with medical research staff, researchers, social workers,..., on the evolution of knowledge, care taking, laws and regulations concerning HHT.

AMRO financially supports research via a 2-years-period call for project.

An AMRO representative participates to the national HHT-network meetings that brings together medical staff and academics involved in HHT treatment and research issued from the national Reference and Competence Centres. Another representative is member of the FAVAMulti Rare disease "filière" that is the national equivalent to VASCERN.

AMRO is member of the alliance Maladies rares and of HHT-Europe.

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