



SPAIN AEDAF

(Asociación Española de Angioedema Familiar)

Maria Arraiza

AEDAF Regional Representative for Navarra, La Rioja and Aragón

Spain

- My name is Maria and I am from Pamplona (as in the “running of the bulls”), Navarra, in northern Spain
- The population of Spain is around 46 million
- Based on a prevalence of 1 in every 50,000 people, there are some 1,000 HAE patients in Spain
- AEDAF has 385 members, 312 of whom have HAE

Spain



SPAIN – 50 PROVINCES IN 17 AUTONOMOUS COMMUNITIES

Management of HAE: Diagnosis and doctors

- HAE Diagnosis and Management:
 - The knowledge of general physicians about HAE in Spain is improving but is still quite deficient, especially in emergency room situations.
 - HAE patients are usually seen by allergists.
 - There is no “official” national reference center for HAE yet in Spain. Hospital Universitario La Paz in Madrid is our leading Care Center.
 - Hospital Universitario Virgen Rocío is a reference center for Andalucía.

Management of HAE: Diagnosis and doctors

- Spain has an excellent group of 19 allergists who focus on HAE: the Spanish Study Group on Bradykinin-Induced Angioedema (SGBA, or GEAB in Spanish). It is coordinated by Dr. Teresa Caballero.
- The level of care varies widely in Spain, from poor to excellent and mostly depending on geographical location, but with the SGBA and an increasing emphasis on education and dissemination, HAE patients, generally speaking, receive good care compared to other rare diseases.

Management of HAE: Medication and treating attacks

- Treatment:
 - Androgens (Danazol and Stanozolol) and to a lesser extent Tranexamic Acid are used for treatment.
 - The modern HAE medications licensed in Spain are Berinert®, Cinryze® and Firazyr®.
 - All medications are reimbursed under Spain's national healthcare system.
 - Again, depending on geographical location and attending physician, the criteria differ, but the consensus is to allow patients to keep the modern HAE medications at home and learn to self-administer.
 - The same is true of restrictions. In most cases there are none. Patients who are allowed to keep medications at home are required to report to their physicians all attacks and the number of vials used for each attack.



Management of HAE: An emergency situation

- Emergency rooms are the weak link of the chain
 - More often than not HAE is not recognized by ER doctors.
 - Medication is available in only some hospitals around Spain. In some cases ER staff refuse to administer medication, even if the patient brings it himself/herself.
 - We have a telephone number and a Twitter account to receive urgent messages from anyone needing help in an emergency room situation.

- First specific questionnaire to assess Health Related Quality of Life in adult patients with HAE due to C1-inhibitor deficiency
- Developed & validated by an international group led by Dr. T Caballero & Dr. N Prior
- 25 items, 7 dimensions
- Self-administered
- 5-10 minutes to complete
- Available in more than 18 languages
- Free of charge for independent clinicians



- **Asociación Española de Angioedema Familiar por Deficiencia del Inhibidor C1**
 - 385 members from all around Spain
 - Regional representatives for all of Spain's 17 autonomous communities
 - Emergency card
 - Patient Diary (financed by CSL Behring)
 - Patient Guidance booklet, written by the GEAB and endorsed by AEDAF and the SEAIC (Spanish Society of Allergology and Clinical Immunology) (financed by Shire)
 - Annual Meeting and General Assembly, usually in the spring in Hospital Univ. La Paz, Madrid
 - “School for Patients”: regional workshops for patients and their families. 8 held in 2014-15. The next one scheduled for June 2016.



- Member of HAEi, FEDER (Federación Española de Enfermedades Raras) and EURORDIS (European Organisation for Rare Diseases)
- Website: www.angioedema-aedaf.org
- A new website launched in 2016. Spain has been the first national HAE organization to introduce a website under the HAEi umbrella www.haei.org
- Social media:
 - ✓ Twitter: @haeday_ES
 - ✓ Facebook: https://m.facebook.com/pages/Angioedema-Familiar-AEDAF/935511563173011?hc_location=ufi
- For AEDAF it has been very important to work together with the doctors and have their unwavering support in order to carry out our activities and raise awareness and educate the medical community and the general public about HAE.



- For hae day :-) AEDAF has been pleased to sponsor and organize with HAEi the HAE Camino Walk.



HAE/AEDAF CAMINO WALK 2016





- AEDAF
- Contact person: Sarah L. Smith Foltz
- AEDAF contact details
 - Telephone: +34 629 47 75 66
 - Website: www.angioedema-aedaf.org
 - Facebook page: https://m.facebook.com/pages/Angioedema-Familiar-AEDAF/935511563173011?hc_location=ufi
 - Twitter: [@haeday_ES](https://twitter.com/haeday_ES)

“Common misfortune brings people together to cement friendship”. Miguel de Cervantes





día
aeh:-)

MUCHAS CARAS
UNA FAMILIA

hae
day:-)

MANY FACES
ONE FAMILY

**THANK
YOU
VERY
MUCH**



HAEI/AEDAF CAMINO WALK 2016

