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Registry of Members of the Association Of Patients with Hereditary Angioedema Of Perú

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Rationale: Hereditary Angioedema (HAE) is a rare disease characterized by episodes of swelling, HAE crisis could cause death by suffocation, also affect the quality of life in these patients, In Perú there are 30 million inhabitants, according to the worlwide prevalence (1:50,000) it is estimated that there could be approximately 700 patients with HAE.

Our main objective is to report the current status and registry of the HAE peruvian patients association.

Methods: We used the questionnaire of the Latin American HAE committee, crisis information in patients belonging to the association (AEH PERU). Consent was requested from the patients association to report the data.

Results: We report data of 55 patients, 9 Male, 46 Female, range age between 5 to 73 years. Eight under 18 years old, 5/8 between 5 to 12 years.

Thirty-seven HAE C1-INH type I, 12 HAE-FXII, 5 HAE UNK, 1 AAE. Symptoms onset average age in 48/54 HAE patients was 15.8. In the remaining 6, symptoms began before the age of 5 years. In 46 adult patients the average diagnostic delay approximately was 18.3 years.

Laboratory tests: C4 complement is performed in most centers. Since 3 years ago we have access to C1-inhibitor antigenic and functional tests, in order to provide a better diagnosis for HAE patients.

Treatments: The patients have access to tranexamic acid and attenuated androgens for prophylaxis treatment. We do not have registered specific long-term prophylaxis treatments. Ecallantide is the unique specific treatment registered in Perú, medication for acute crisis.

Conclusions: We present the first registry of Patients with Hereditary Angioedema of Perú. Fifty five members registered in the Association of patients, also we calculate almost 10 patients (HAE symptoms), direct relatives of diagnosed patients, pending of laboratory tests. Approximately 15 patients with HAE diagnosed, non members of the Association, being a possible total of 80 patients.

We have improved laboratory diagnosis in the last years. Ecallantide is the unique specific treatment registered in Perú, our objective is the other medications for HAE, be availables in our country. Access to HAE medications for acute crisis and prophylaxis should be guarenteed for all the patients.