

Table SI. Information retrieved from questionnaires, interviews, patient diaries and medical records

Age
Sex
Other family members with HAE +/-
Number of acute hospitalisations caused by HAE attacks
Trigger factors
Prodromal symptoms
Onset and duration of attack
Location of attack (abdominal, throat, face, other to be specified)
Severity ^a (1=mild, 2=moderate, 3=severe)
Current and previous treatment of acute attacks
antihistamines
glucocorticoids
epinephrine
intubation
tracheotomy
fresh frozen plasma
pdC1INH concentrate (Berinert®)
pdC1INH concentrate (Cinryze®)
rhC1INH concentrate
icatibant
Prophylactic therapy
danazol
stanozolol
tranexamic acid
Side effects
Concerns about
– suffocation risk
– hereditary aspects
– potential side effects of treatment
Disease impact on physical issues
Disease impact on psychological issues

^amild attack: no limitation in activities; moderate attack: limitations in activities; severe attack: being unable to perform activities.