



## Patient Experiences

Patient Survey  
Dutch Patient Association HAE/QE  
Charles Picavet

## Participants

- 43 HAE & 31 QE
- Response: overall 63% / QE 86%!!
- Mean age: HAE 40 & QE 59
- 71% women



## The disease

- Average age start of complaints: 12
- Average diagnosis time: 10+ years
- 45% still have swellings at least every 3 months
- Mostly in the abdominal area or in arms/hands/knees/feet
- 31% of QE patients say they have relatives with the same disease!!



## Medicine use

- 16% don't use any medicine
- 47% use Cetor
- 56% use Danazol
- 30% use Cyklokapron
- 1/3 has at some time suspended medication for a period of time
- 1/3 forget medicines once in a while



## Cetor use

- **Used mainly for emergencies**
- **41% inject themselves or are injected by a relative**
- **For only 41% of users, swellings disappear quickly after injection**
- **For most users, swelling stops, but doesn't disappear**



## (Side) effects

- **More bodily hair-growth (24%)**
- **More muscles (16%)**
- **Lower voice (13%)**
- **Diarrhea (13%)**
- **Less energy (29%)**
- **Less sexual desire (22%)**
- **Skin problems (24%)**
- **Cholesterol (13%)**



## Social consequences

- About half of the respondents say HAE has no consequences for everyday life
- Small effect on the decision to have children
- About a quarter report consequences for work or study
- 17% pay more for health insurance



## Conclusions

- For most people, HAE is a disease they can pretty well live with
- For many patients, complaints do not disappear with medication
- Danazol has significant side-effects
- A new and cheap C1 inhibitor concentrate would be a welcome addition to medical treatment

