



Patients' Needs and Expectations responses, Access to Health Services.

The EurordisCare 3 study



Patients'
Survey

Speakers name

Logo or
association's
name

Purpose of the study

- **To describe and compare experiences and expectations of patients or patients relatives regarding access to health services in Europe**
- **To make the patient voice heard at the time when several European countries are involved in the reorganisation of health services for RD**
- **At the end of the survey, to produce comparisons**
 - between diseases
 - between countries

EurordisCare 3 Methodology

- **One common questionnaire was developed in collaboration with patient organisation representatives, methodologists ...**
- **Adapted to:**
 - 16 RD (the 8 main medical services for each disease)
 - 22 countries (family income values)
- **Translated into 15 languages**
- **20 022 copies were**
 - provided to 126 committed patient organisations,
 - sent to members resulting in disease-specificity in surveyed patients
- **5 995 (30%) questionnaires were returned to Eurordis:**
 - anonymously completed by patients
 - communicated data remained confidential

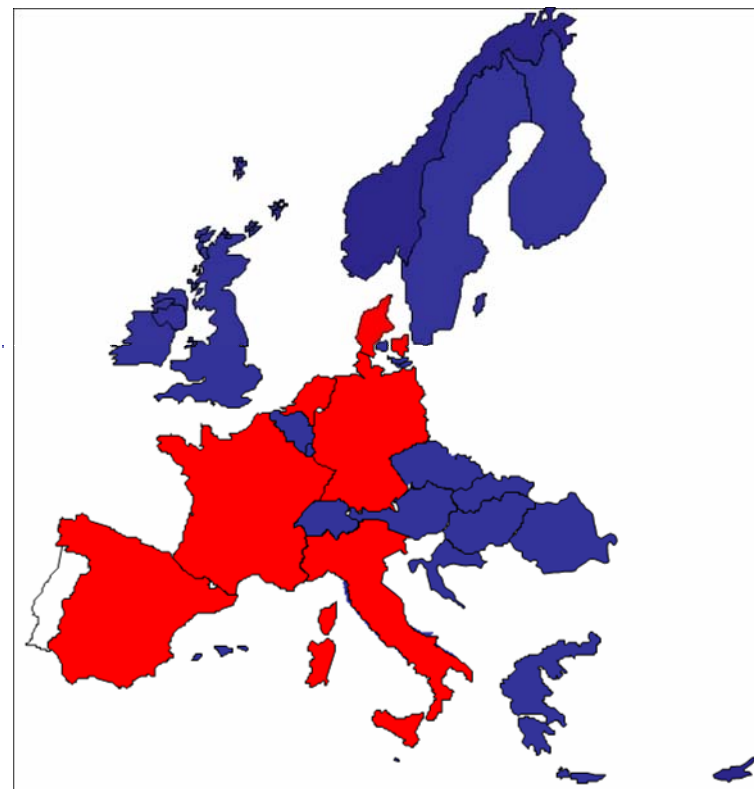
Participation of POs from 23 countries

- Austria, 31 responses, 3 RD
- Belgium, 255 responses, 8 RD
- Croatia, 38 responses, 2 RD
- Cyprus, 9 responses, 4 RD
- Czech Republic, 31 responses, 3 RD
- Denmark, 277 responses, 8 RD
- Finland, 146 responses, 5 RD
- France, 1574 responses, 16 RD
- Germany, 451 responses, 6 RD
- Greece, 77 responses, 2 RD
- Hungary, 408 responses, 6 RD
- Ireland, 93 responses, 2 RD
- Italy, 691 responses, 15 RD
- Luxembourg, 8 responses, 5 RD
- Netherlands, 396 responses, 6 RD
- Norway, 45 responses, 3 RD
- Romania, 60 responses, 4 RD
- Slovakia, 25 responses, 1 RD
- Spain, 499 responses, 13 RD
- Sweden, 497 responses, 9 RD
- Switzerland, 60 responses, 6 RD
- United Kingdom, 340 responses, 5 RD



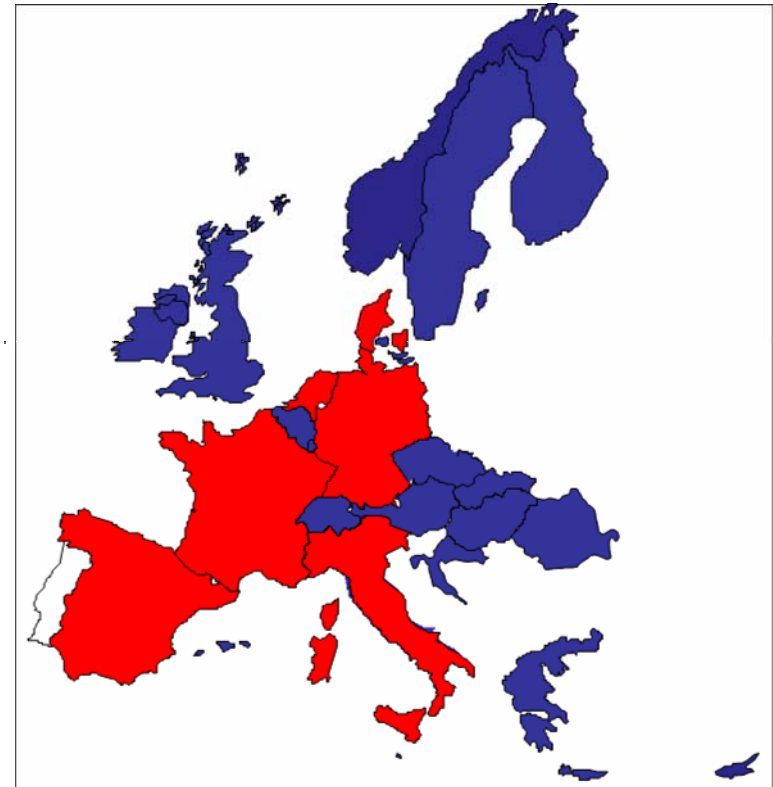
Participation of POs for 16 rare diseases

- **Alternating hemiplegia (79 from 6 countries)**
- Aniridia (145 from 6 countries)
- Ataxias (570 from 7 countries)
- Chromosome 11q disorders (40 from 9 countries)
- Cystic fibrosis (539 from 7 countries)
- Ehlers-Danlos syndrome (822 from 13 countries)
- Epidermolysis bullosa (249 from 11 countries)
- Fragile X syndrome (257 from 9 countries)
- Huntington disease (207 from 8 countries)
- Marfan syndrome (419 from 9 countries)
- Myasthenia (647 from 8 countries)
- Osteogenesis imperfecta (421 from 8 countries)
- Prader-Willi syndrome (371 from 10 countries)
- Pulmonary arterial hypertension (456 from 7 countries)
- Tuberous sclerosis (383 from 10 countries)
- Williams syndrome (390 from 9 countries)



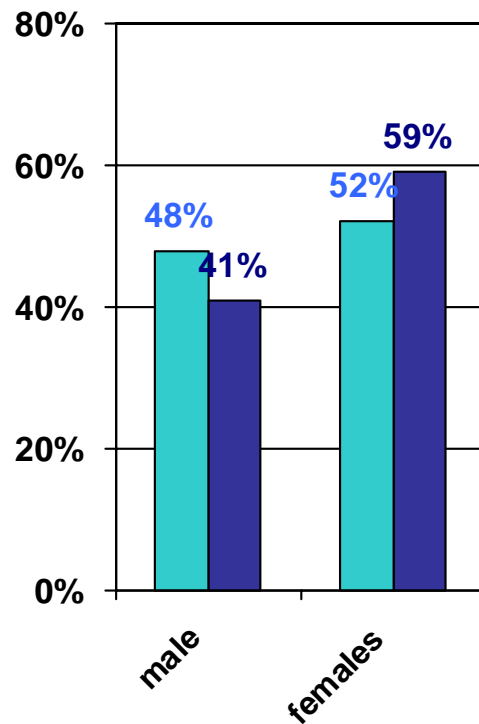
Alternating hemiplegia: 79 responses from 6 countries

- Denmark, 3 responses
- France, 30 responses
- Germany, 21 responses
- Italy, 16 responses
- Netherlands, 3 responses
- Spain, 6 responses

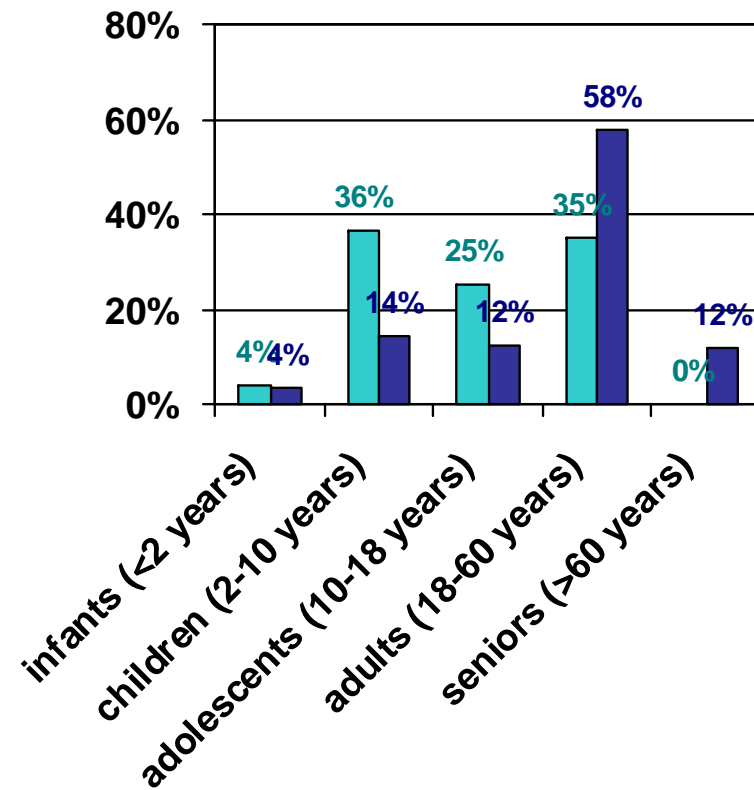


Survey participants PATIENT profiles: Patients with Alternating hemiplegia vs Overall

Patient gender distribution:



Age distribution:



■ Alternating hemiplegia: 79 responses
■ All: 5995 responses

Survey participants FAMILY profiles

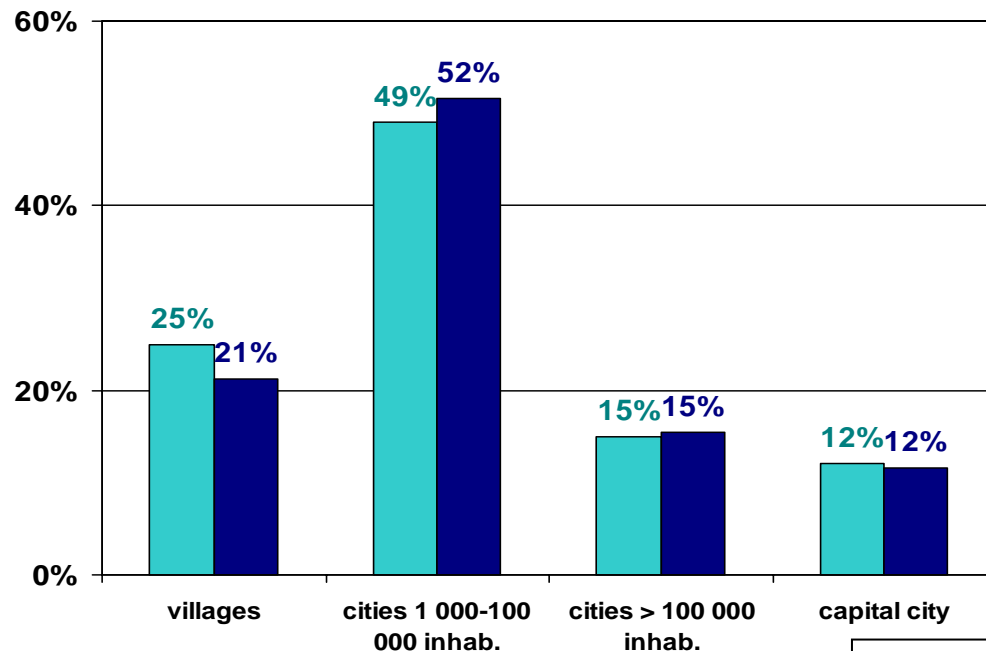
Patients with Alternating hemiplegia vs Overall

The patients' families included on average

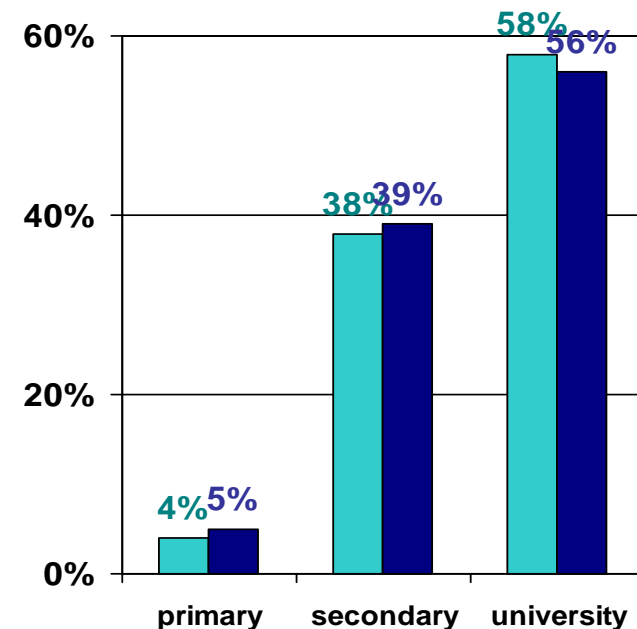
2.2 adults, 2.1 children and 1.0 patients with Alternating hemiplegia

2.2 adults, 1.8 children and 1.2 patients for all responders

They were located in:



The highest level of education was:



Legend:
■ Alternating hemiplegia: 79 responses
■ All: 5995 responses

Results: the experience of patients

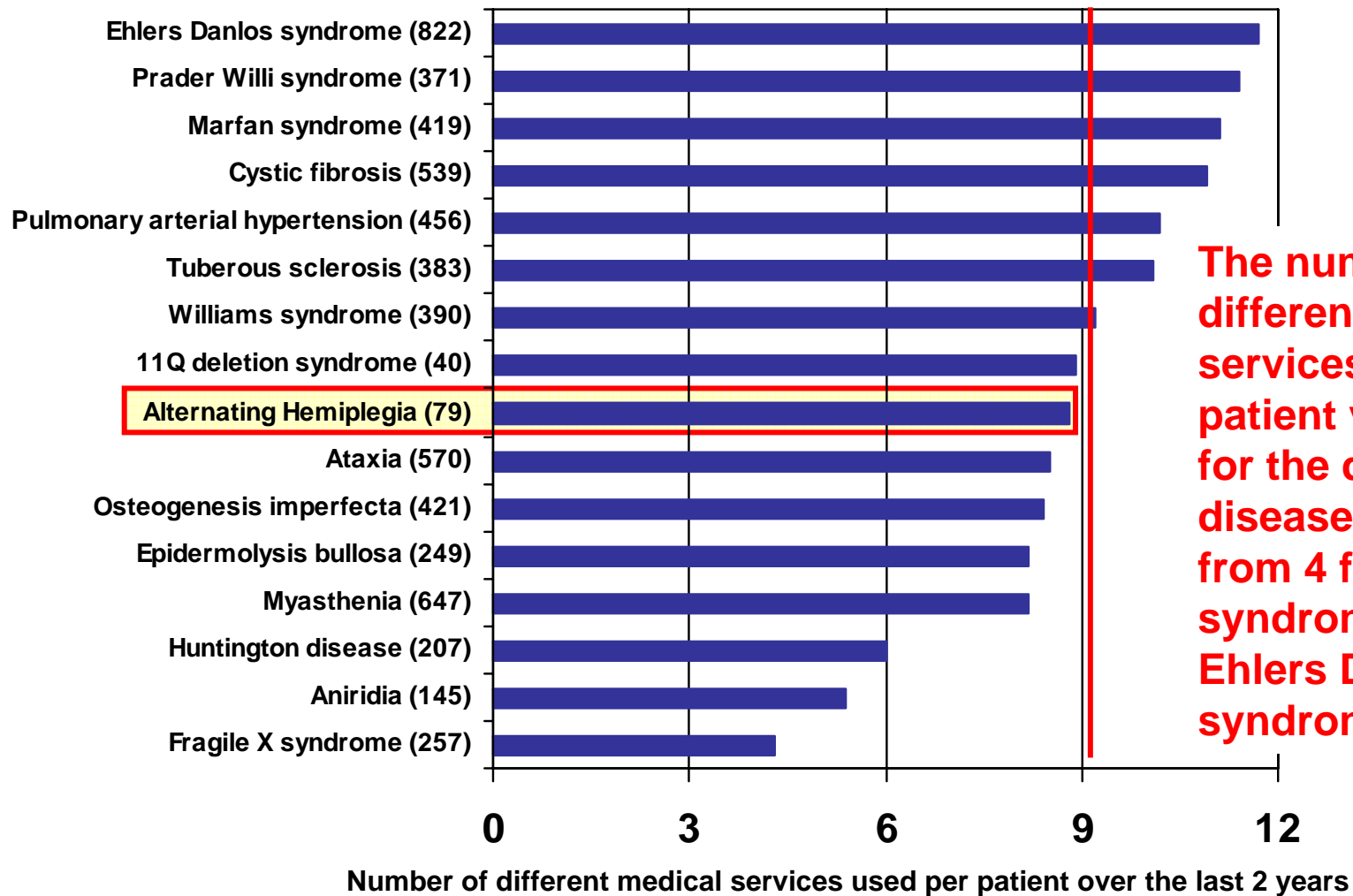
- **Medical service requirements for patients with rare diseases**
- **Access to medical services**
- **Rejection by health professionals**
- **Social assistance**
- **The day to day consequences for patients and families**

Medical service requirements for patients with rare diseases

- **Diversity in medical services needed by each patient**
- **Types of medical services needed (consultations, tests, care)**
- **Frequency of hospitalisation**
- **Duration of hospitalisation**

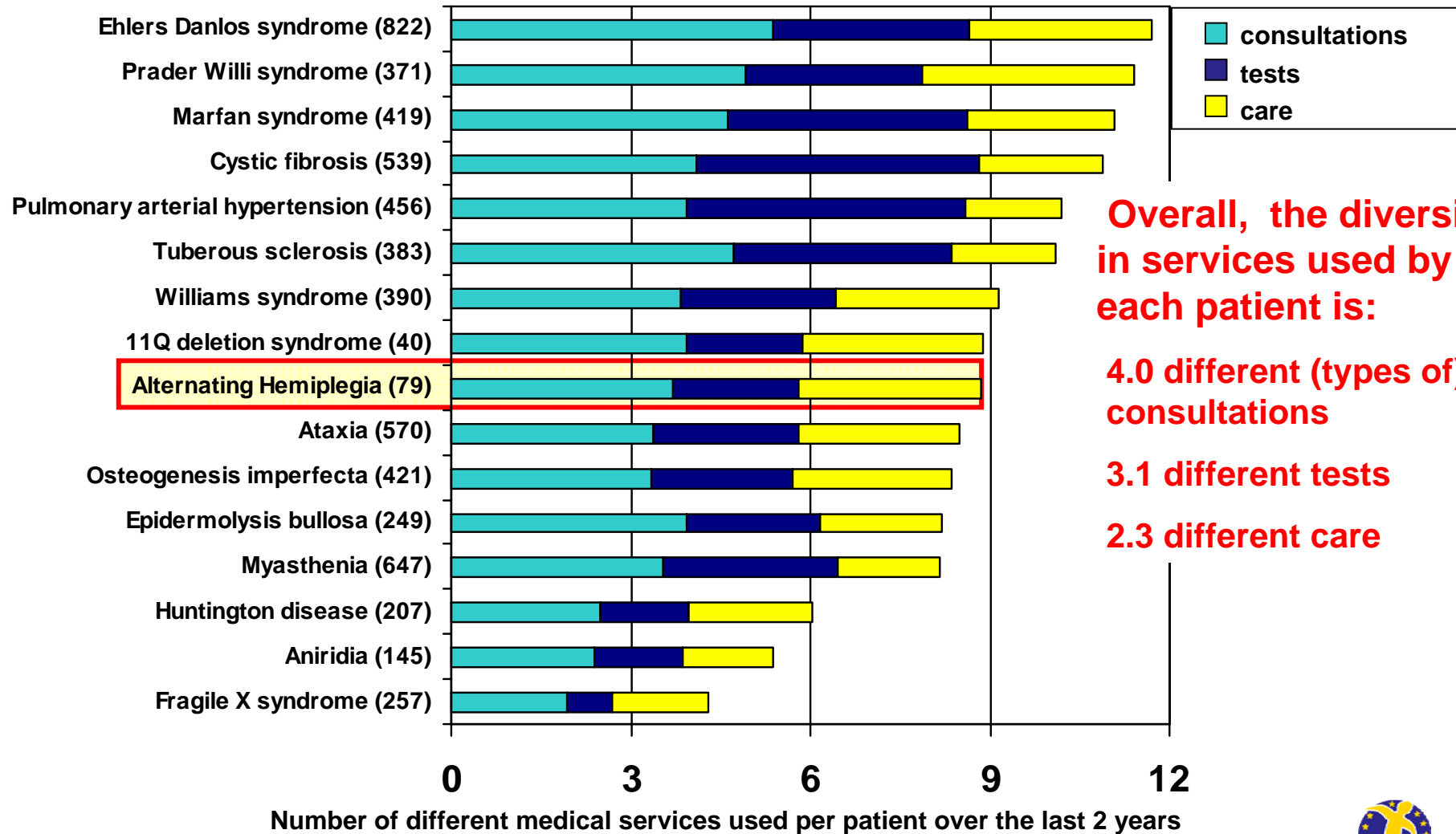
Medical needs per patient

Overall: 9.4 different medical services



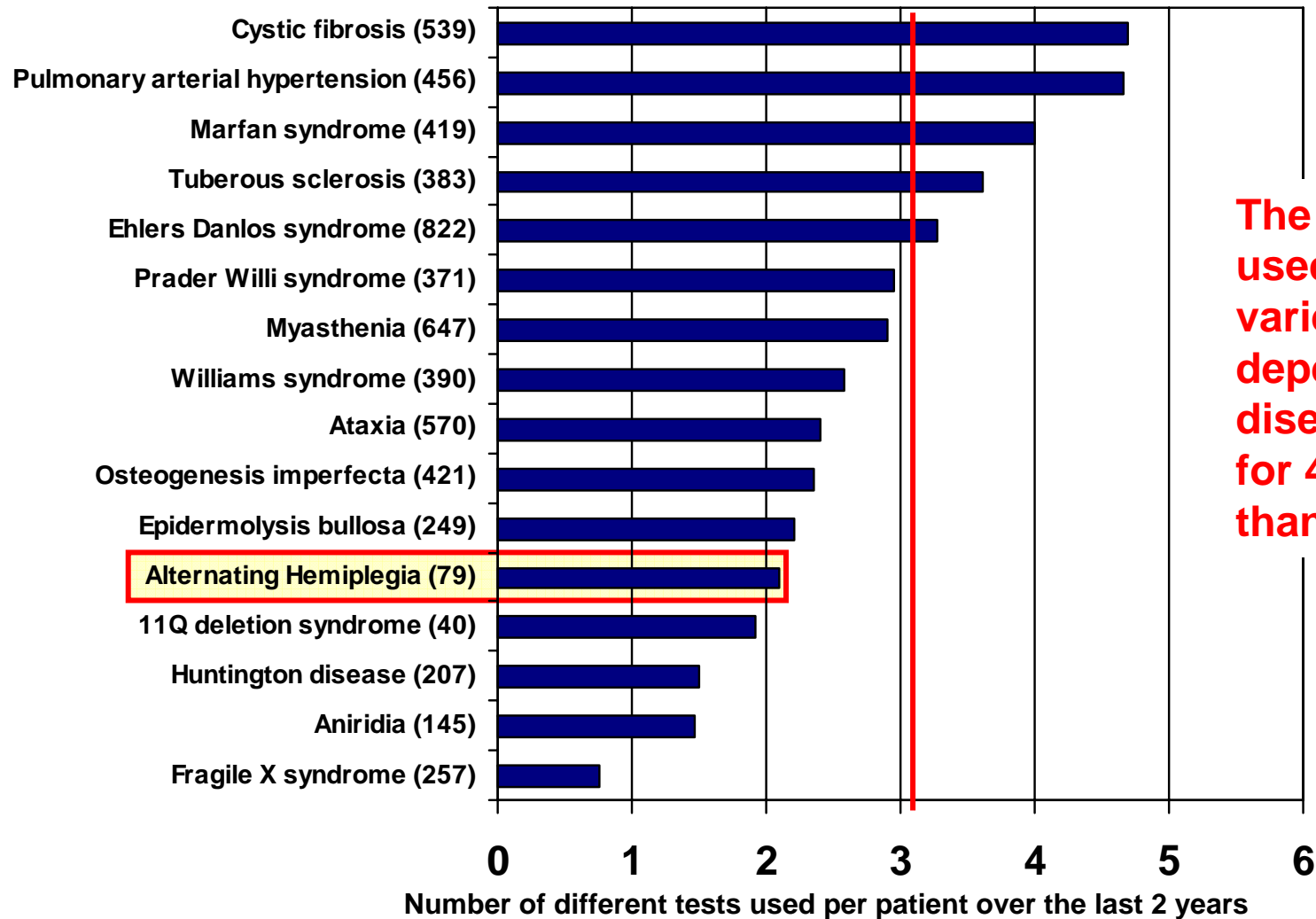
The number of different medical services used per patient varied widely for the different diseases surveyed, from 4 for Fragile X syndrome to 11 for Ehlers Danlos syndrome

Diversity in medical needs



Tests: Patients' needs

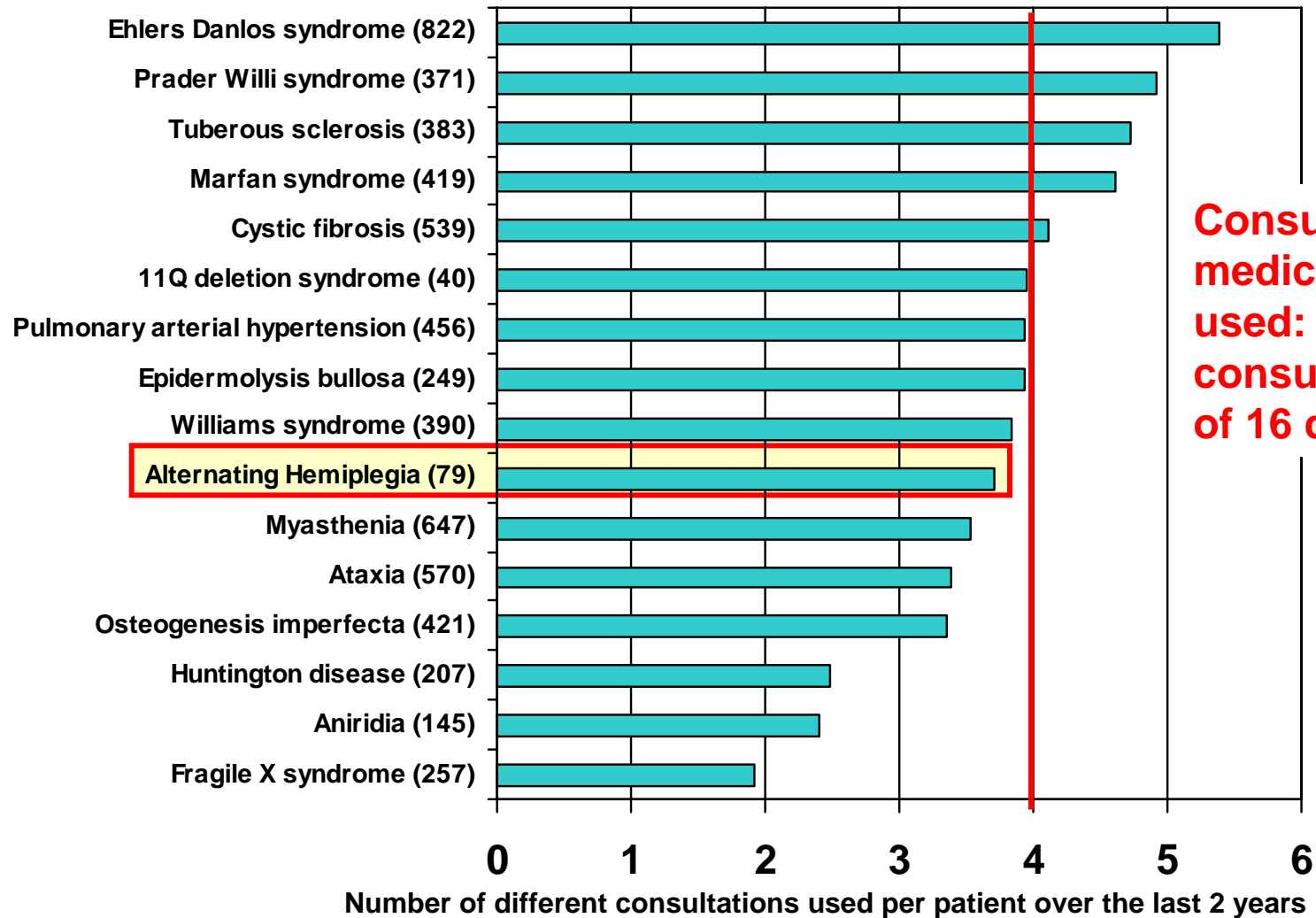
Overall: 3.1%



The number of tests used by patients varied widely depending on the disease: less than 2 for 4 diseases, more than 4 for 3 diseases

Consultations: Patients' needs

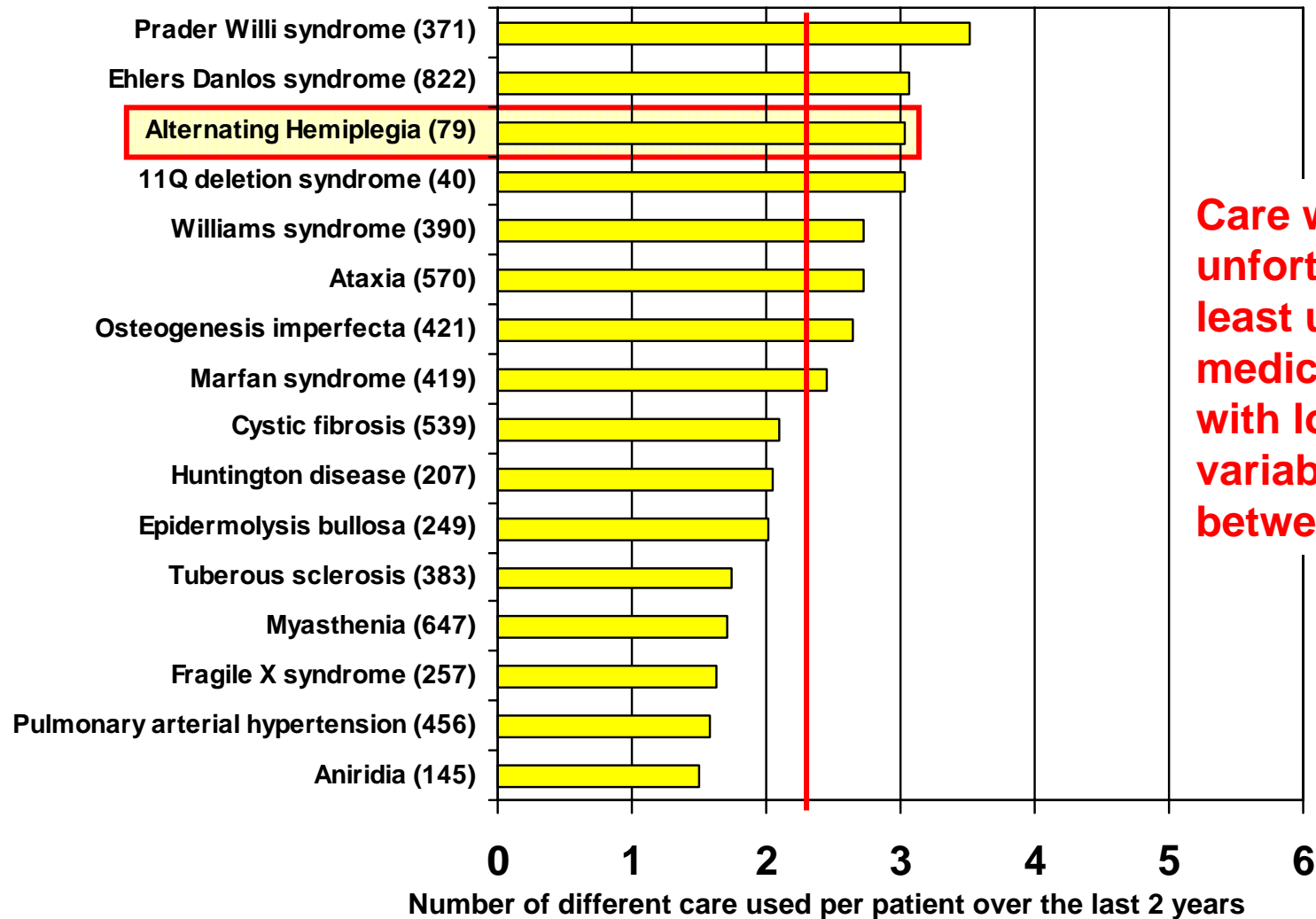
Overall: 4.0%



Consultations are the medical services most used: with 3-5 different consultations in 12 out of 16 diseases

Care: Patient's needs

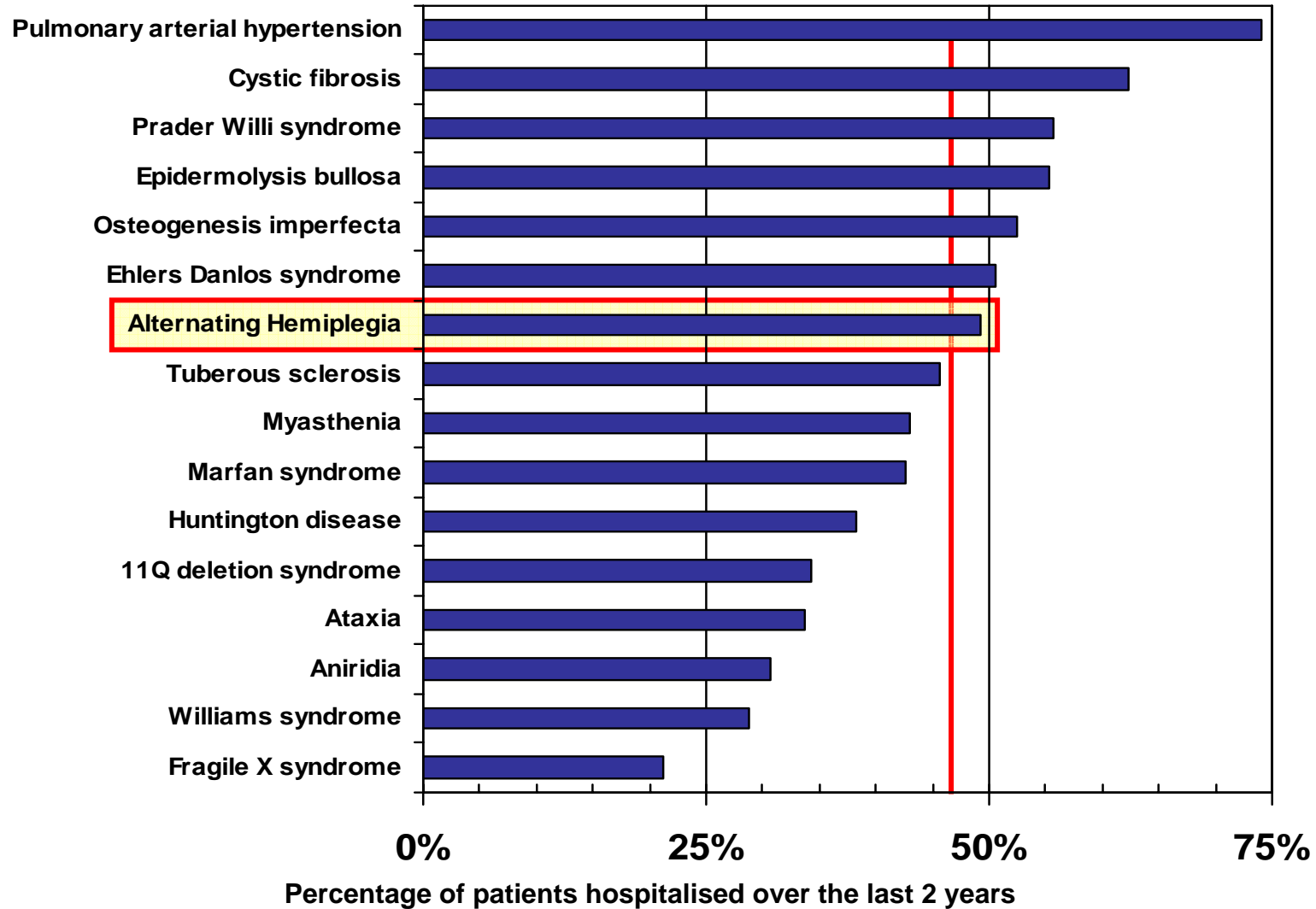
Overall: 2.3%



Care was unfortunately the least used medical service with low variability between diseases

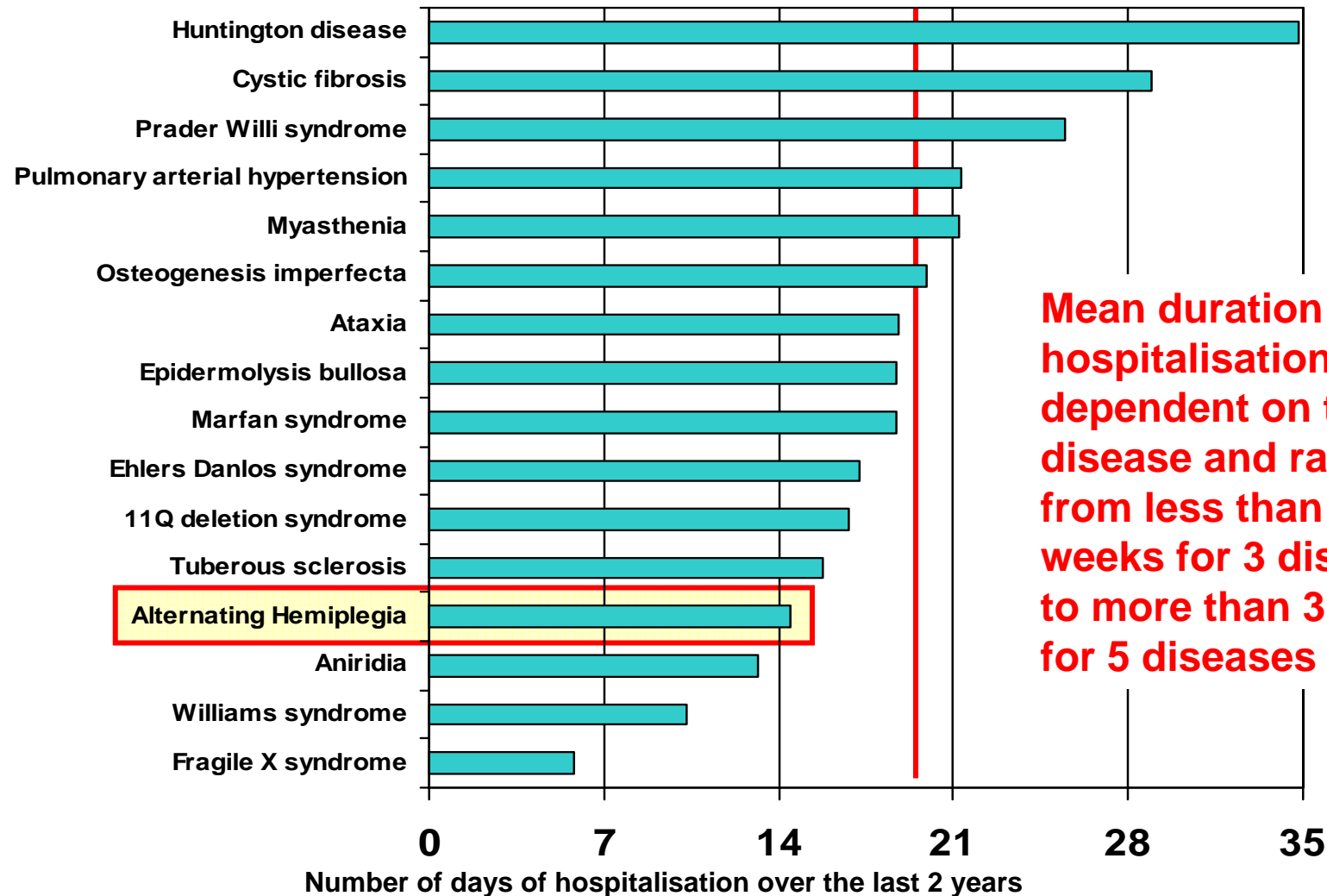
Hospitalisation

Overall: 47%



Duration of hospitalisation

Overall: 20 days



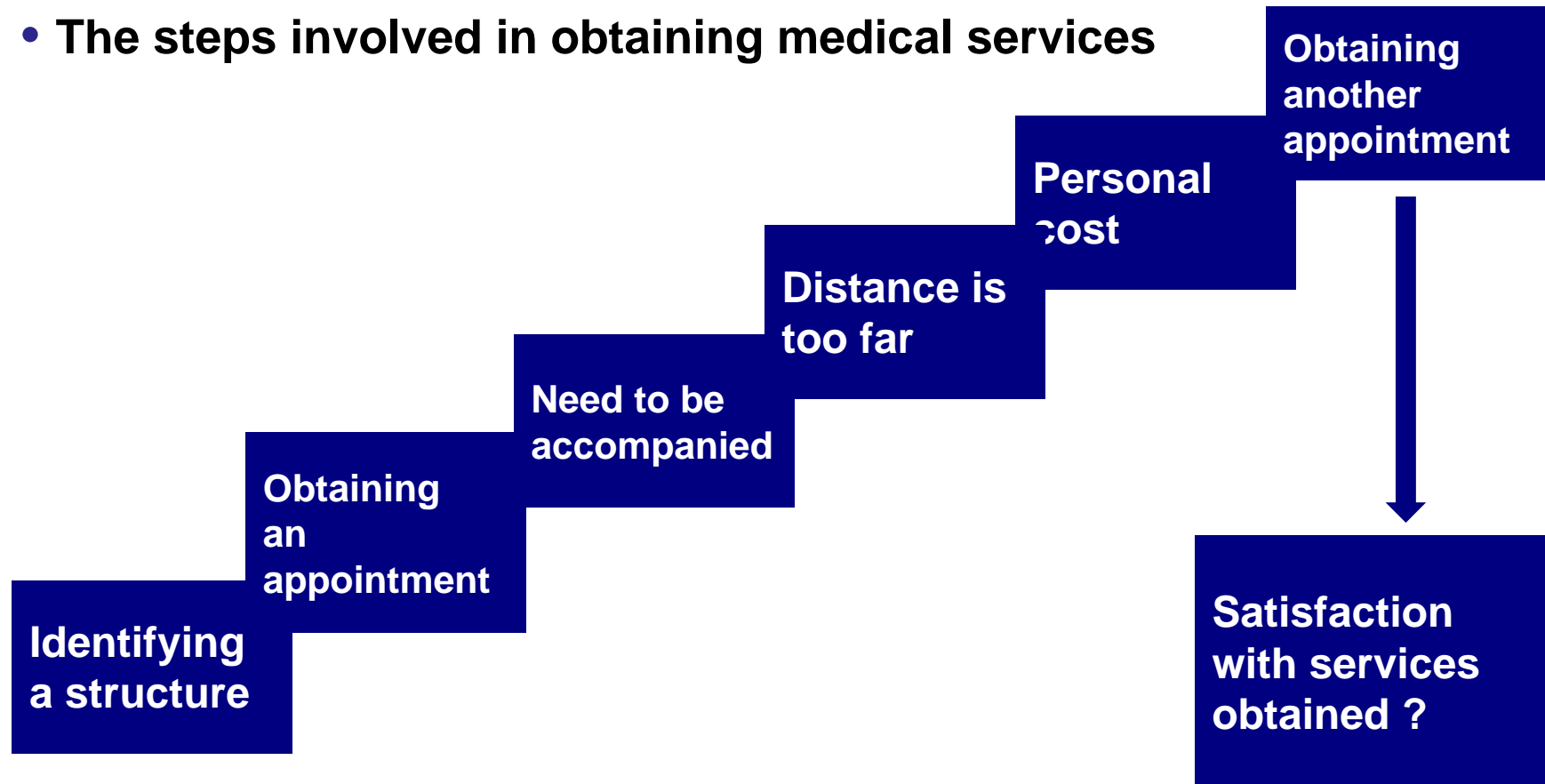
Mean duration of hospitalisations is dependent on the disease and ranges from less than 2 weeks for 3 diseases to more than 3 weeks for 5 diseases

Access to Medical services

- **Ease**
- **Causes of impossibility of access**
- **Quantitative**
- **Personal cost**
- **Location of the structures**
- **The journey to the medical structure**
- **Time for obtaining appointment**
- **Satisfaction with medical services**

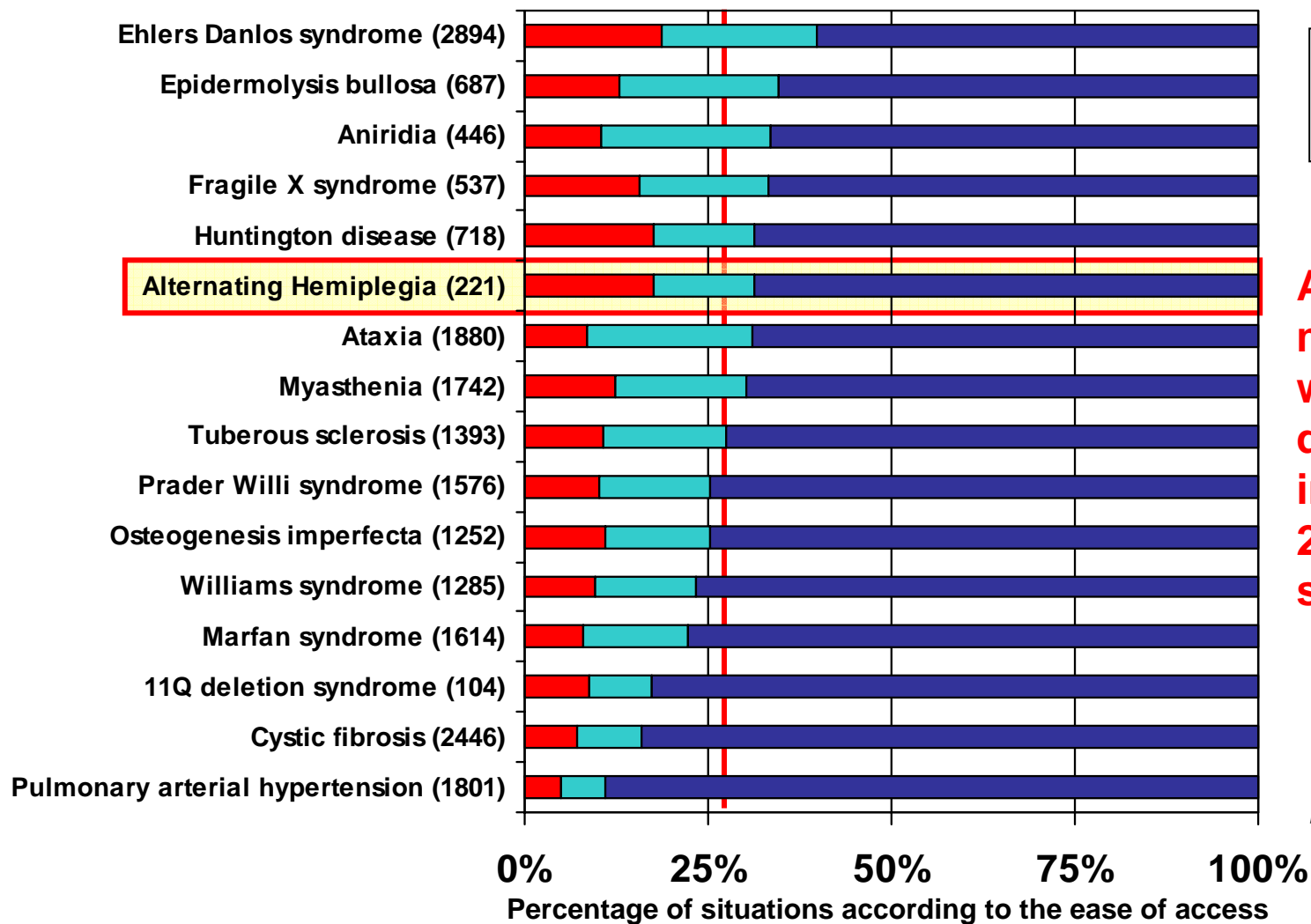
Access to medical services: is this a right?

- The steps involved in obtaining medical services



Difficult access to medical services

Overall: 27% difficult or impossible

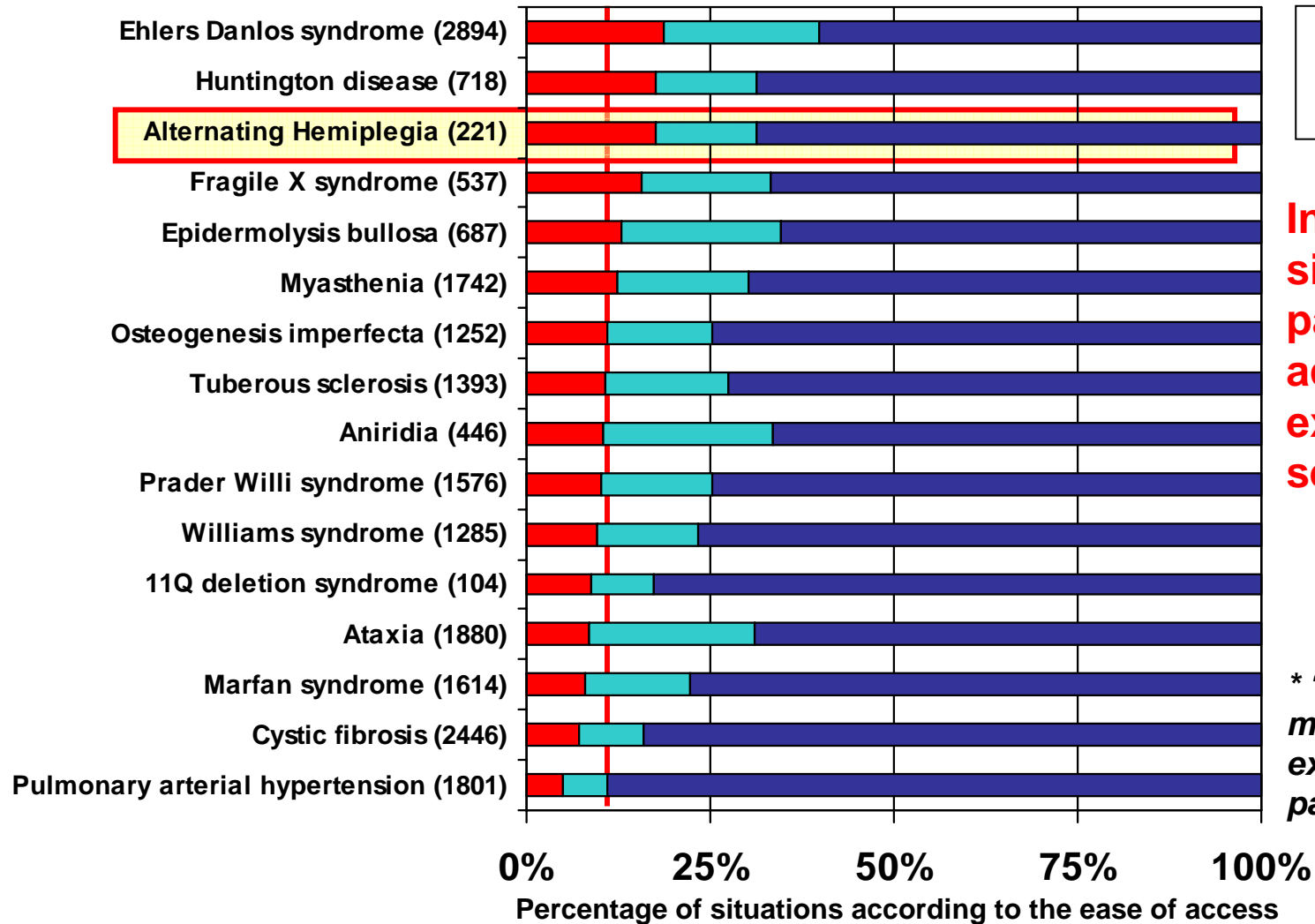


Access to medical services was considered difficult to impossible in 27% of situations*

* "situation": one medical service expected by one patient

Lack of access to medical services

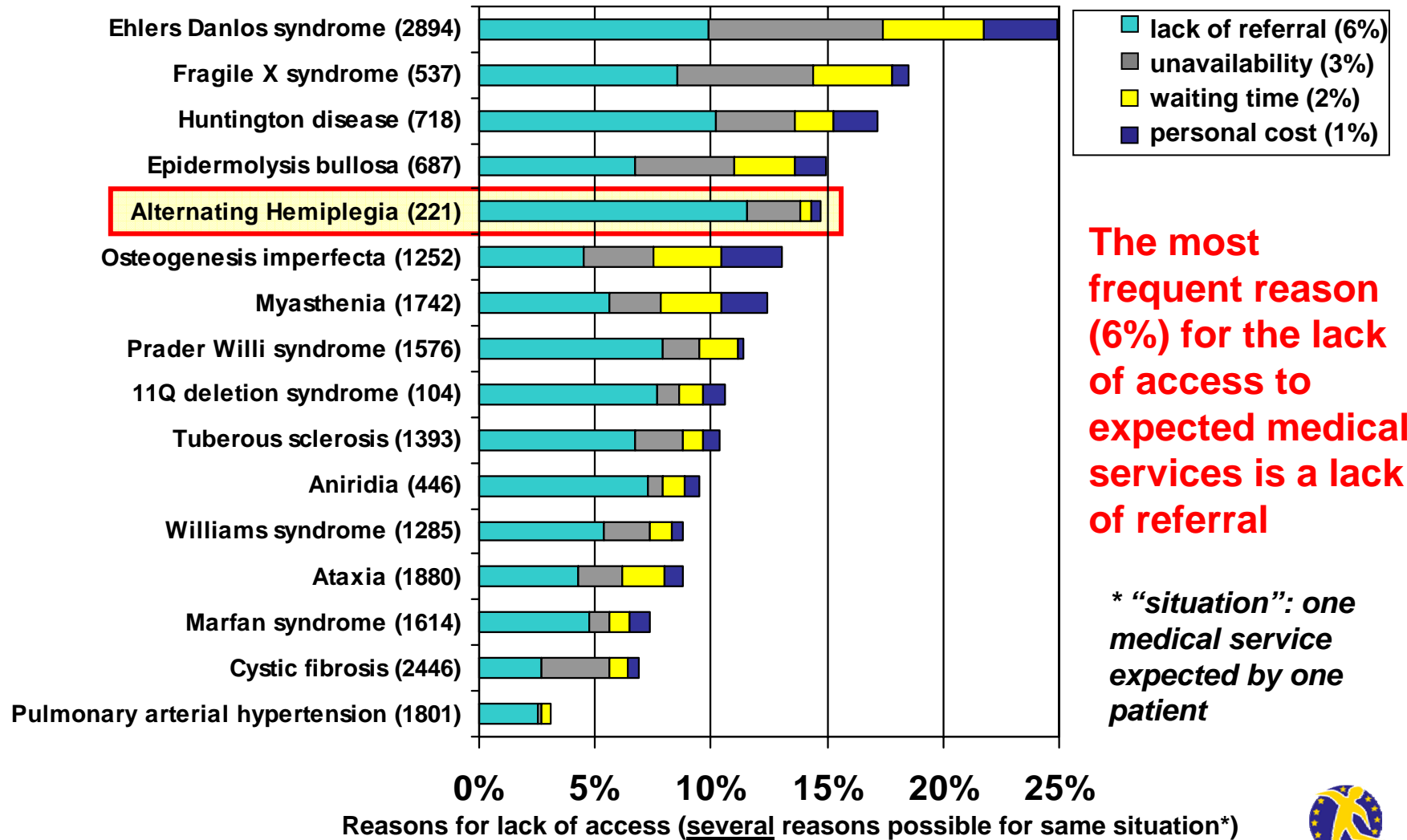
Overall: 11% impossible



In 11% of situations*, patients have no access to the expected medical service

* "situation": one medical service expected by one patient

Reasons for lack of access to medical services, excluding travel

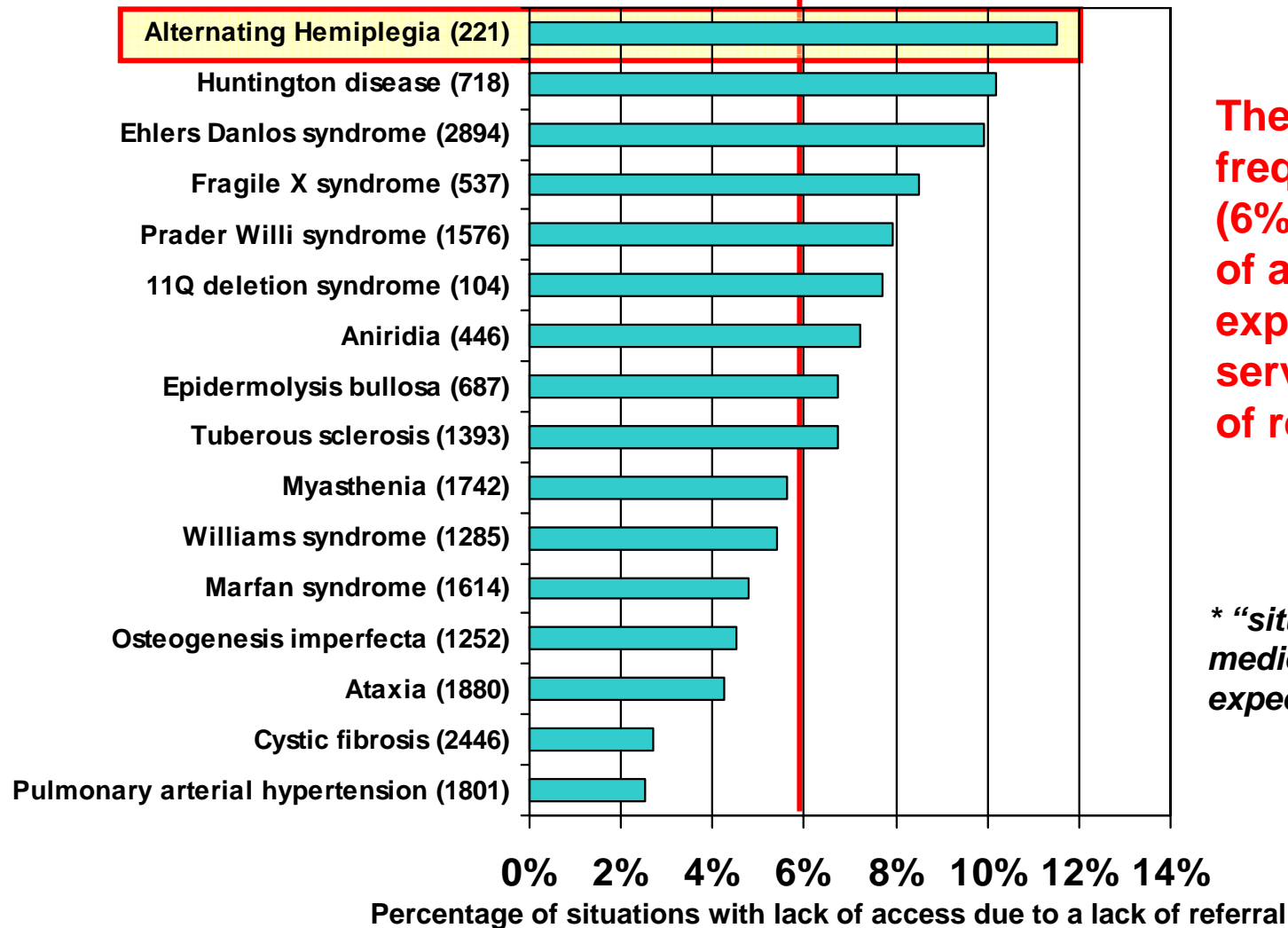


The most frequent reason (6%) for the lack of access to expected medical services is a lack of referral

* *“situation”*: one medical service expected by one patient

Lack of access to medical services due to a lack of referral

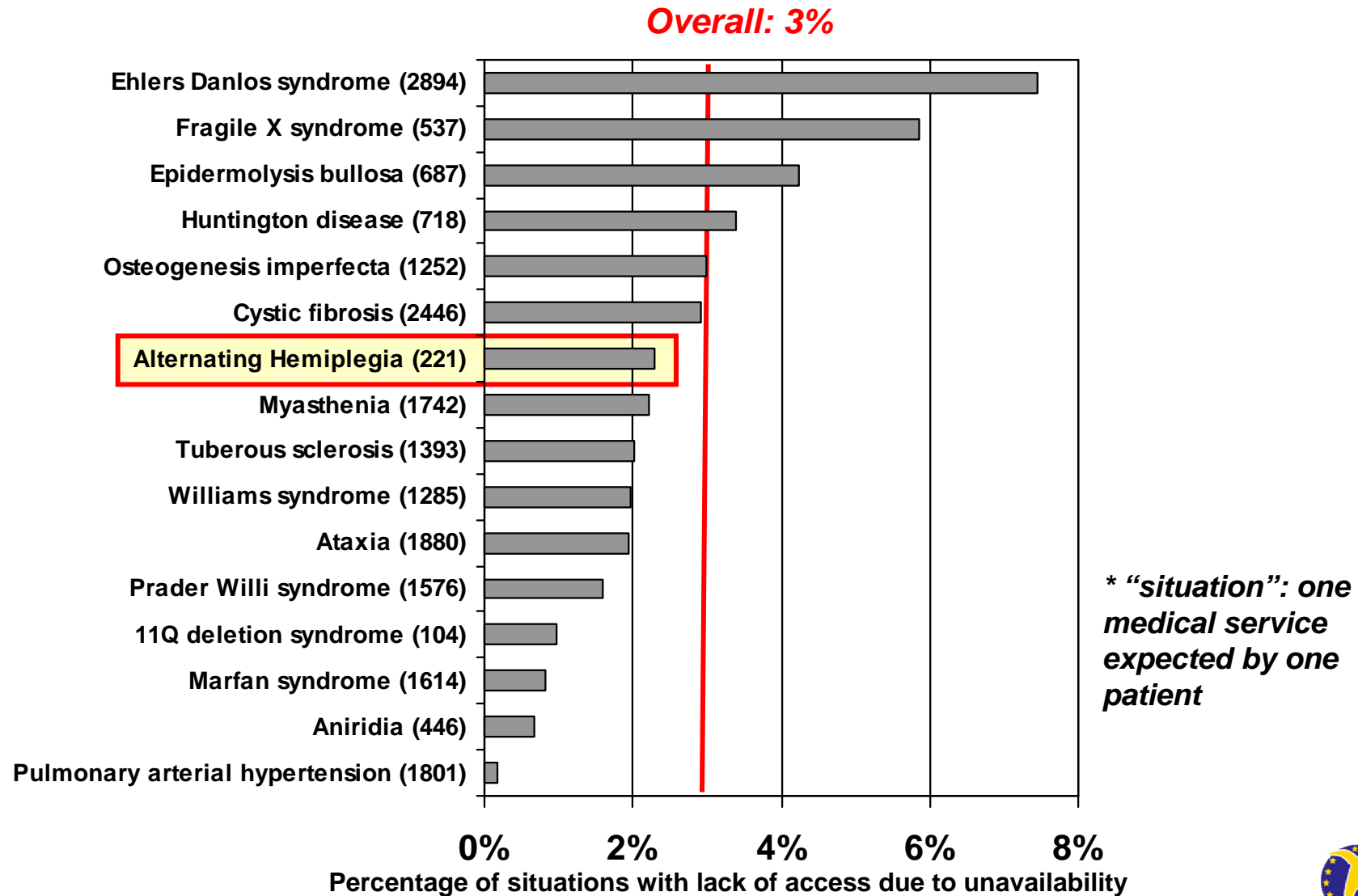
Overall: 6%



The most frequent reason (6%) for the lack of access to expected medical services is a lack of referral

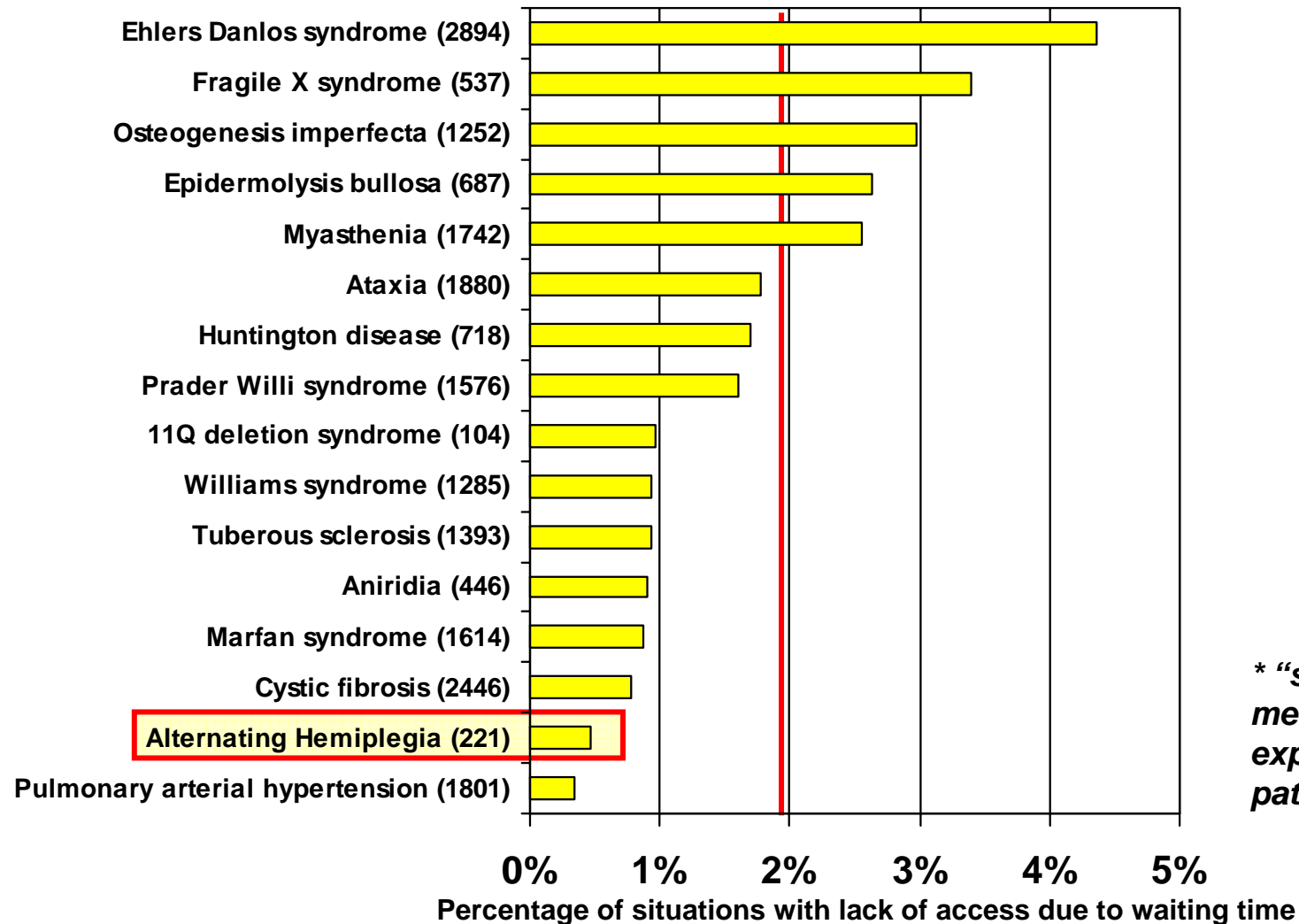
* *“situation”*: one medical service expected by one patient

Lack of access to medical services due to its unavailability



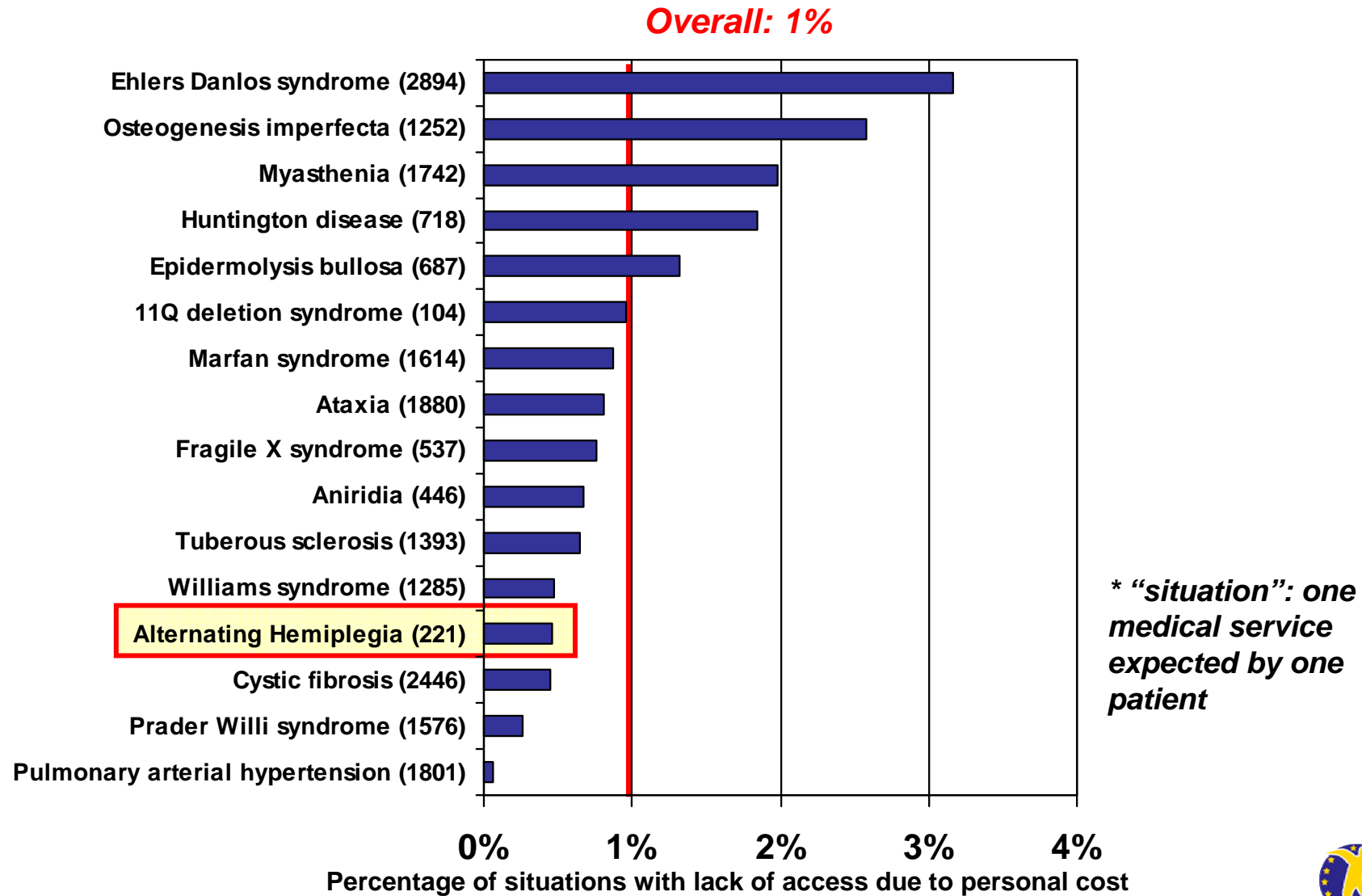
Lack of access to medical services due to waiting time

Overall: 2%

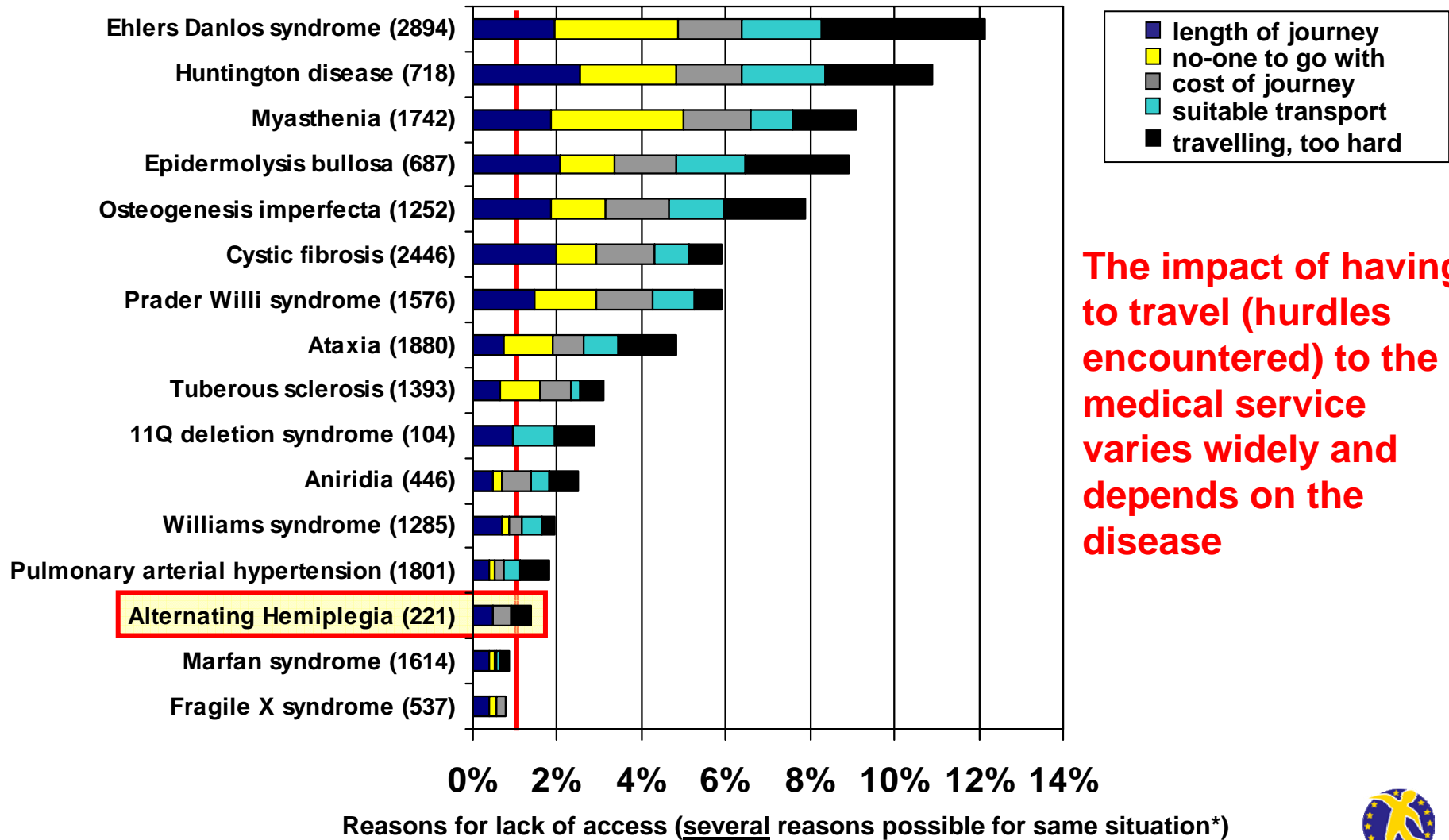


* "situation": one medical service expected by one patient

Lack of access to medical services due to personal cost

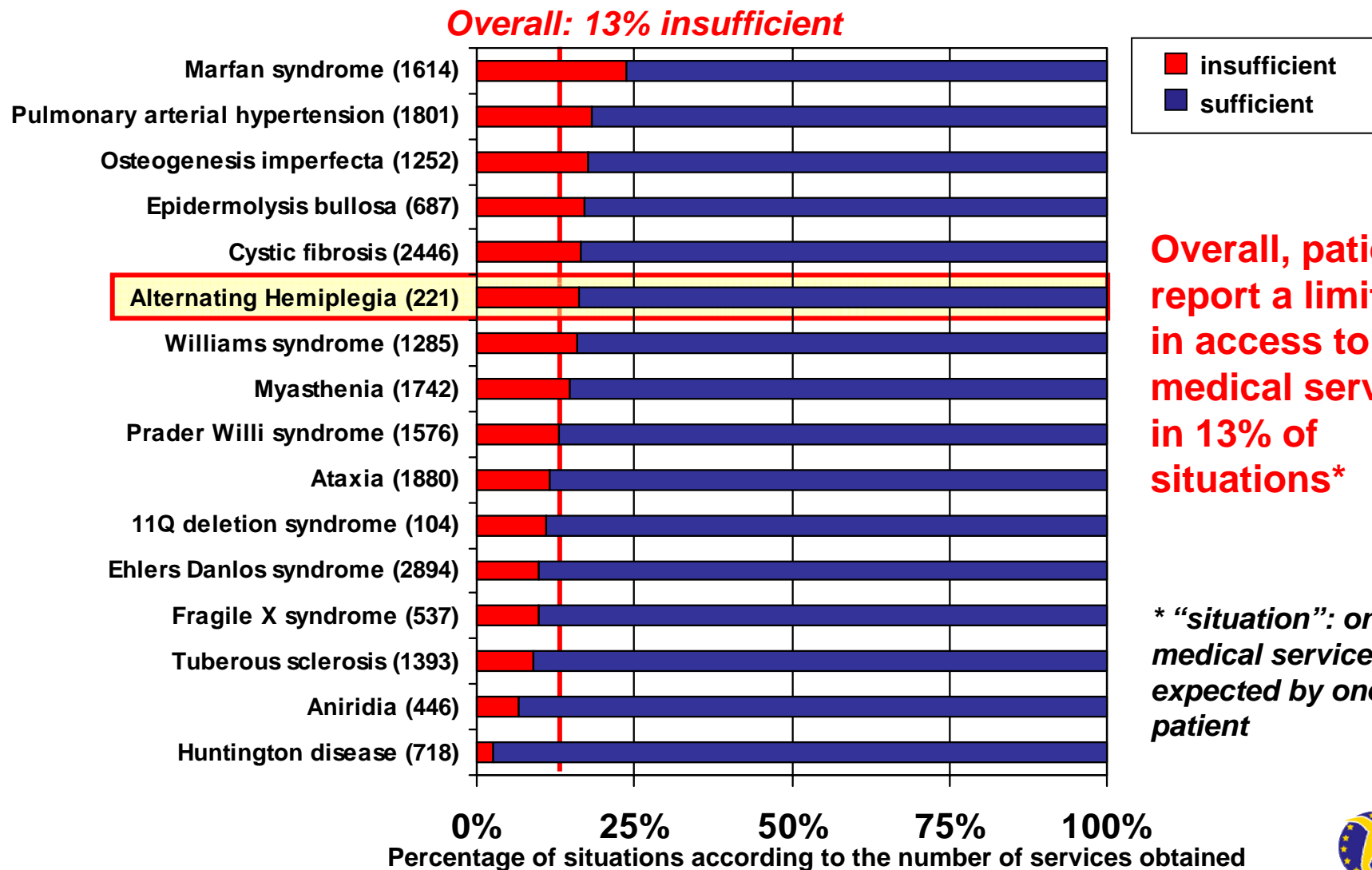


Reasons for lack of access to medical services, related to travel



The impact of having to travel (hurdles encountered) to the medical service varies widely and depends on the disease

For a given obtained service, number of consultations, testing, care... obtained

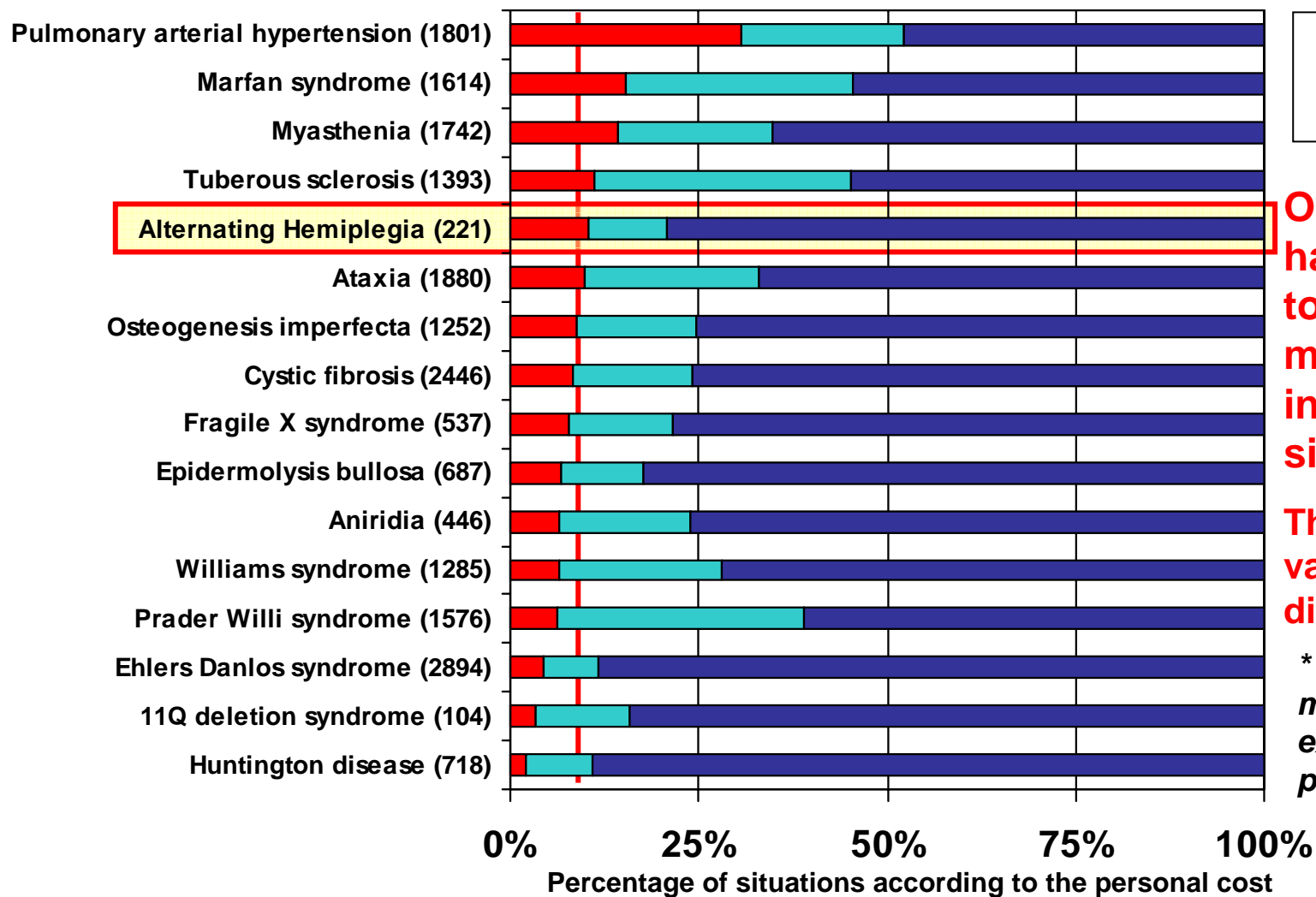


Overall, patients report a limitation in access to medical services in 13% of situations*

* *“situation”*: one medical service expected by one patient

Personal cost for medical services

Overall, total: 9%



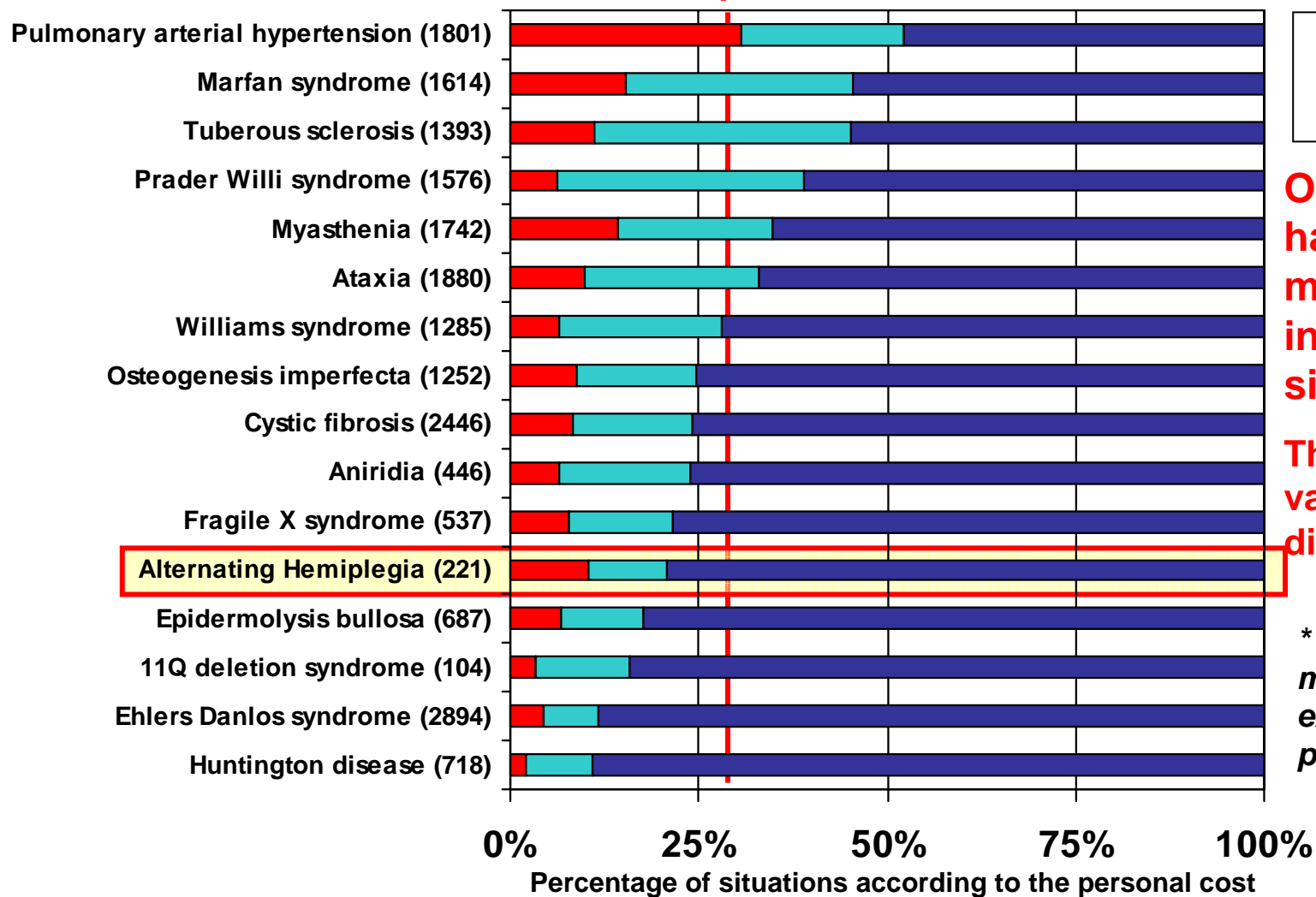
Overall, patients have to pay the total cost for medical services in 9% of situations*.

There exists great variability between diseases

* "situation": one medical service expected by one patient

Personal cost for medical services

Overall, total or partial: 28%

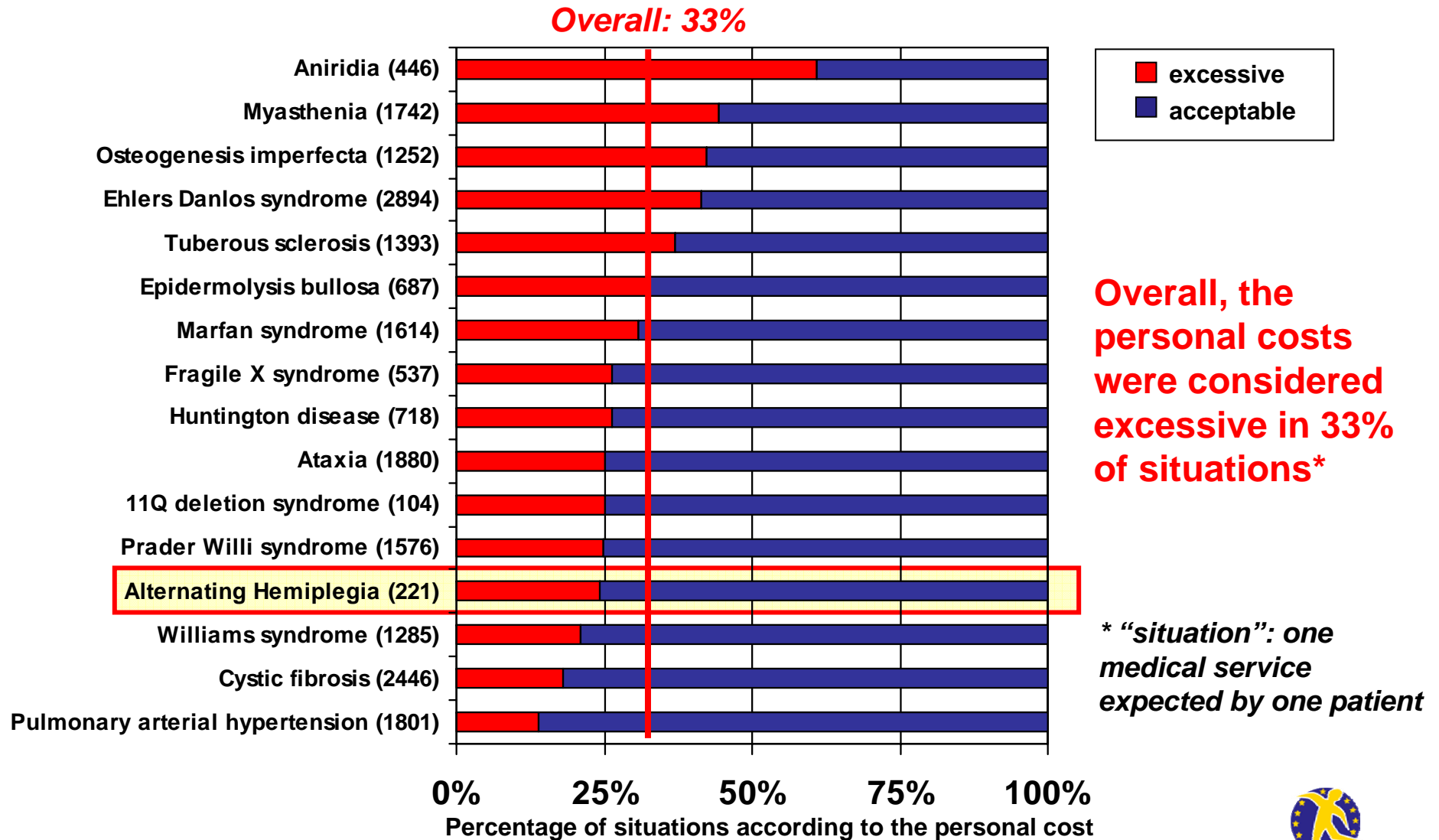


Overall, patients have to pay for medical services in 28% of situations*.

There exists great variability between diseases

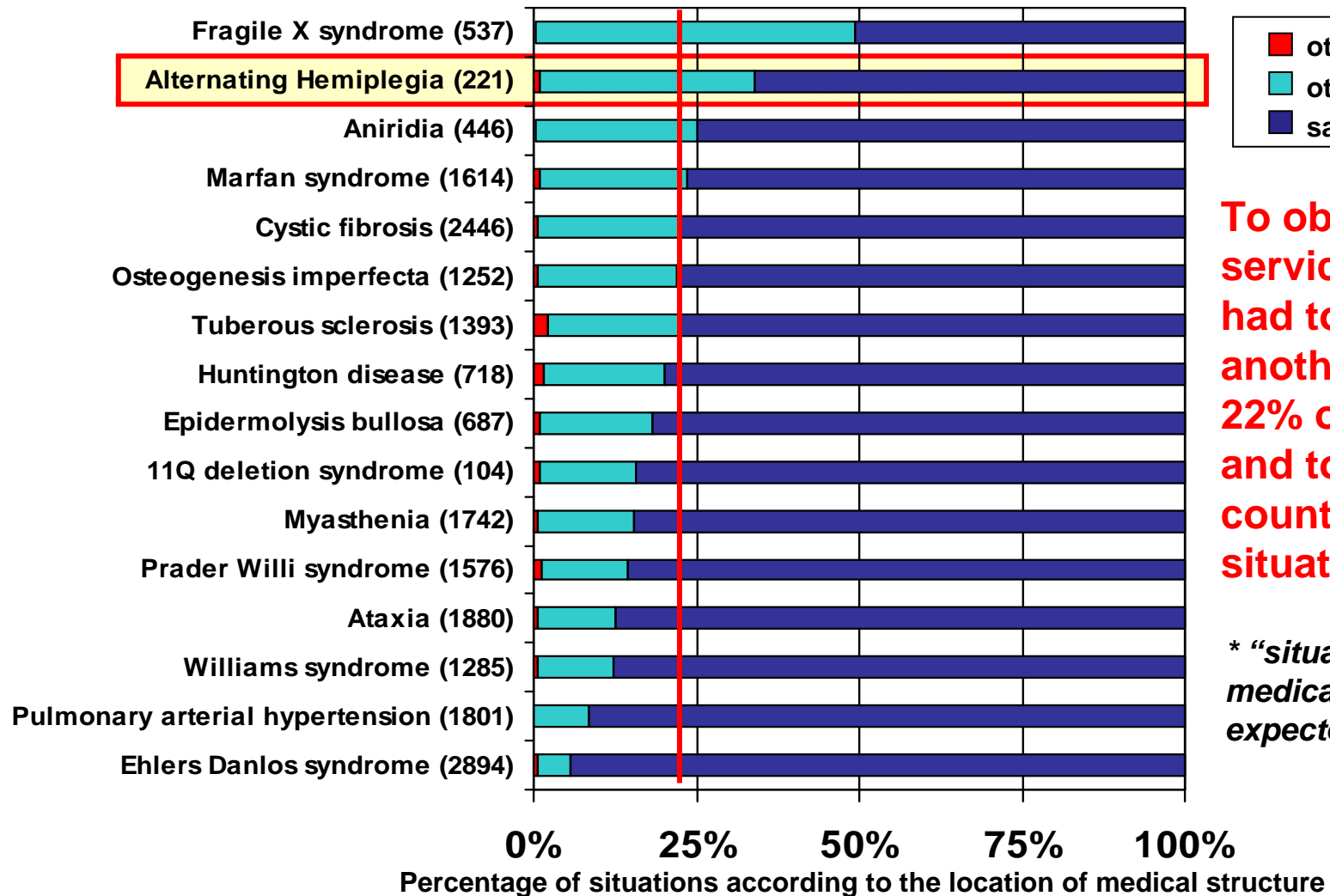
*** "situation": one medical service expected by one patient**

Patients' opinion on personal cost for medical services



Location of structures providing the medical services

Other region or other country: 22 %

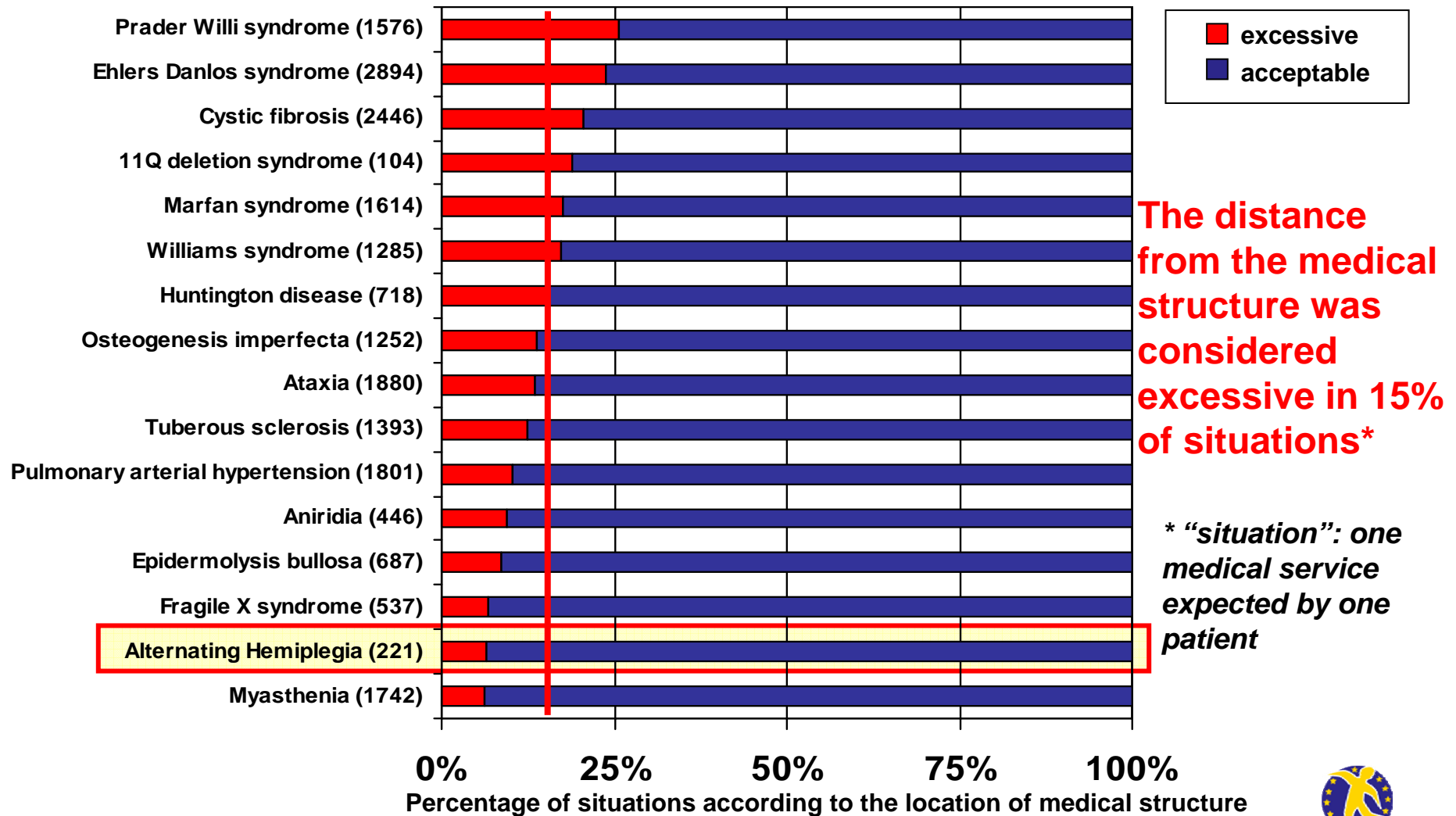


To obtain medical services, patients had to go to another region in 22% of situations, and to another country in 1% of situations*

** "situation": one medical service expected by one patient*

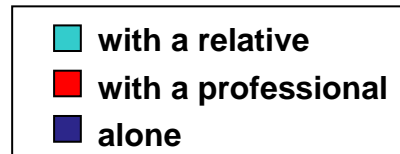
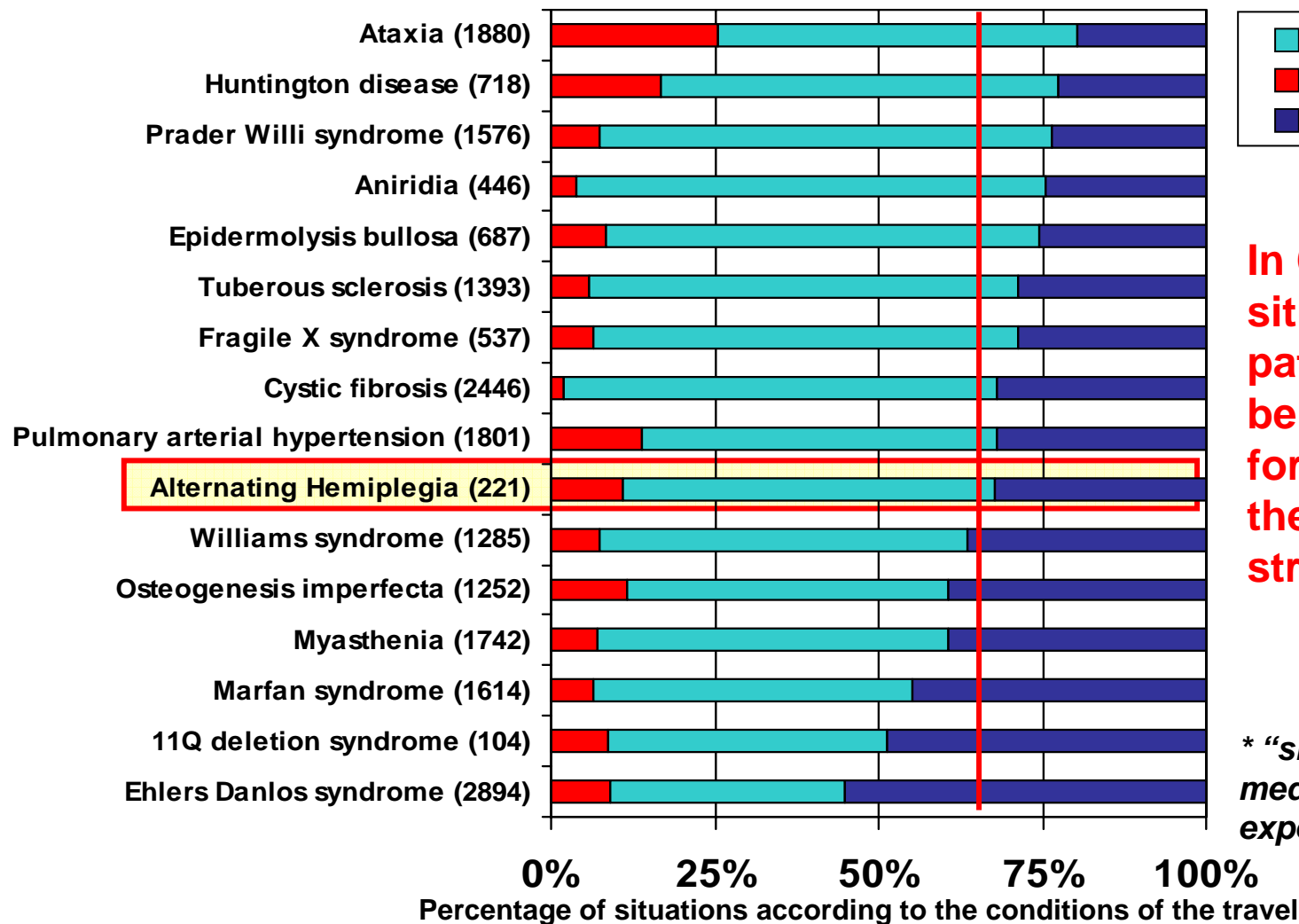
Patients' opinion on distance from structure providing medical services

Overall: 15 %



Travel to structures providing the medical services: need to be accompanied

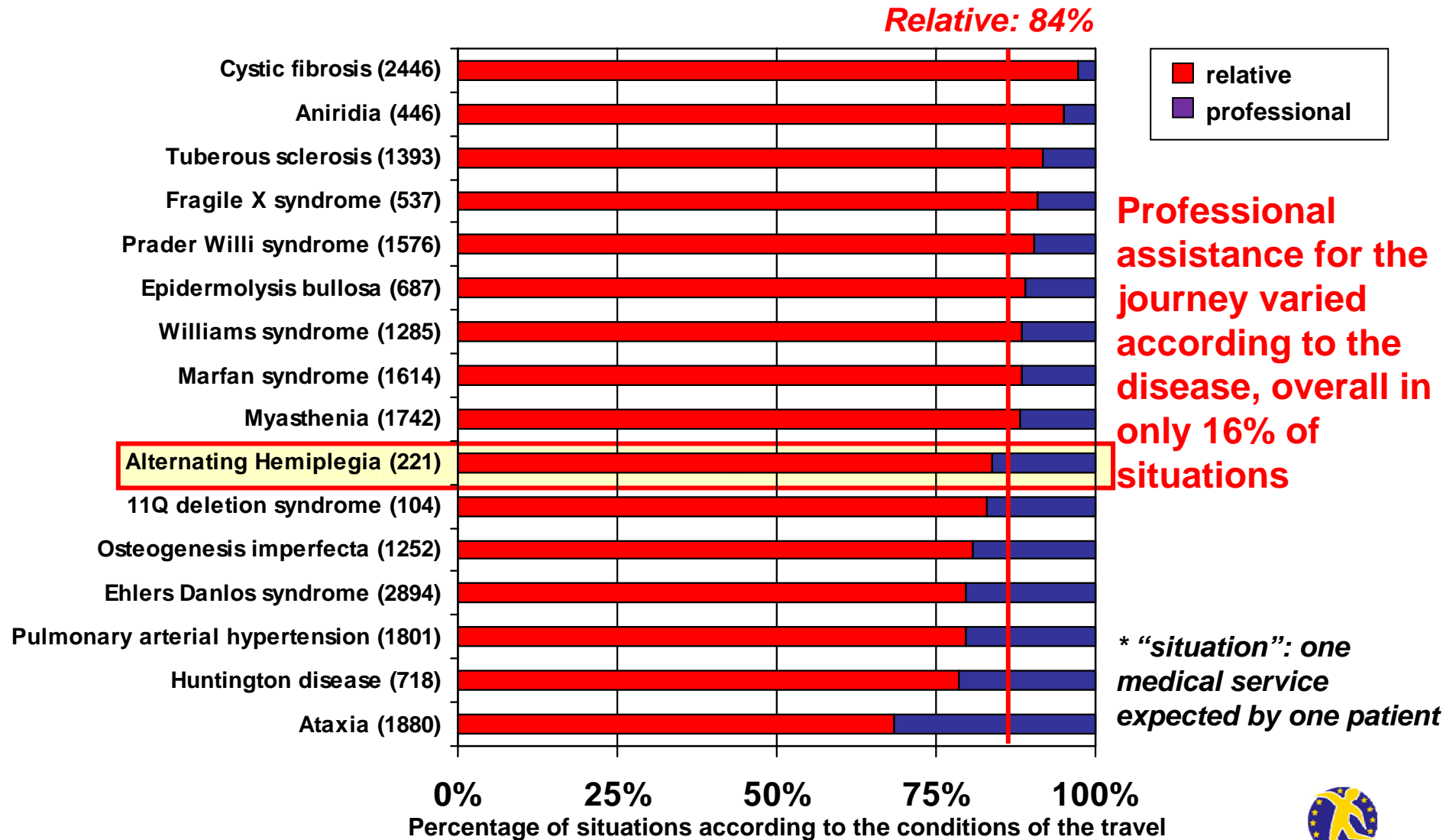
Need to be accompanied, overall: 65%



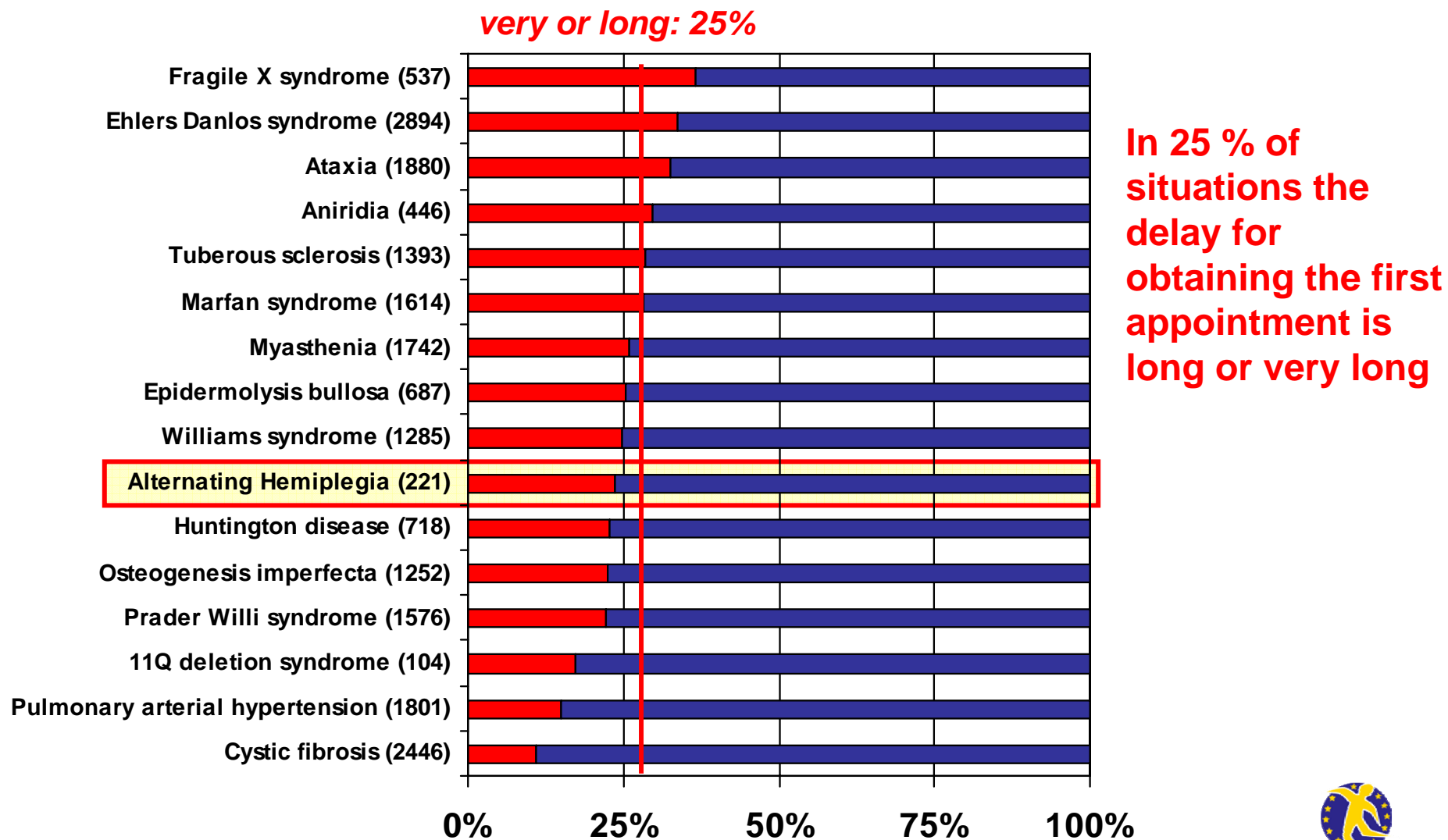
In 65% of situations*, the patient needed to be accompanied for the journey to the medical structure

* "situation": one medical service expected by one patient

Travel to structures providing the medical services: need to be accompanied

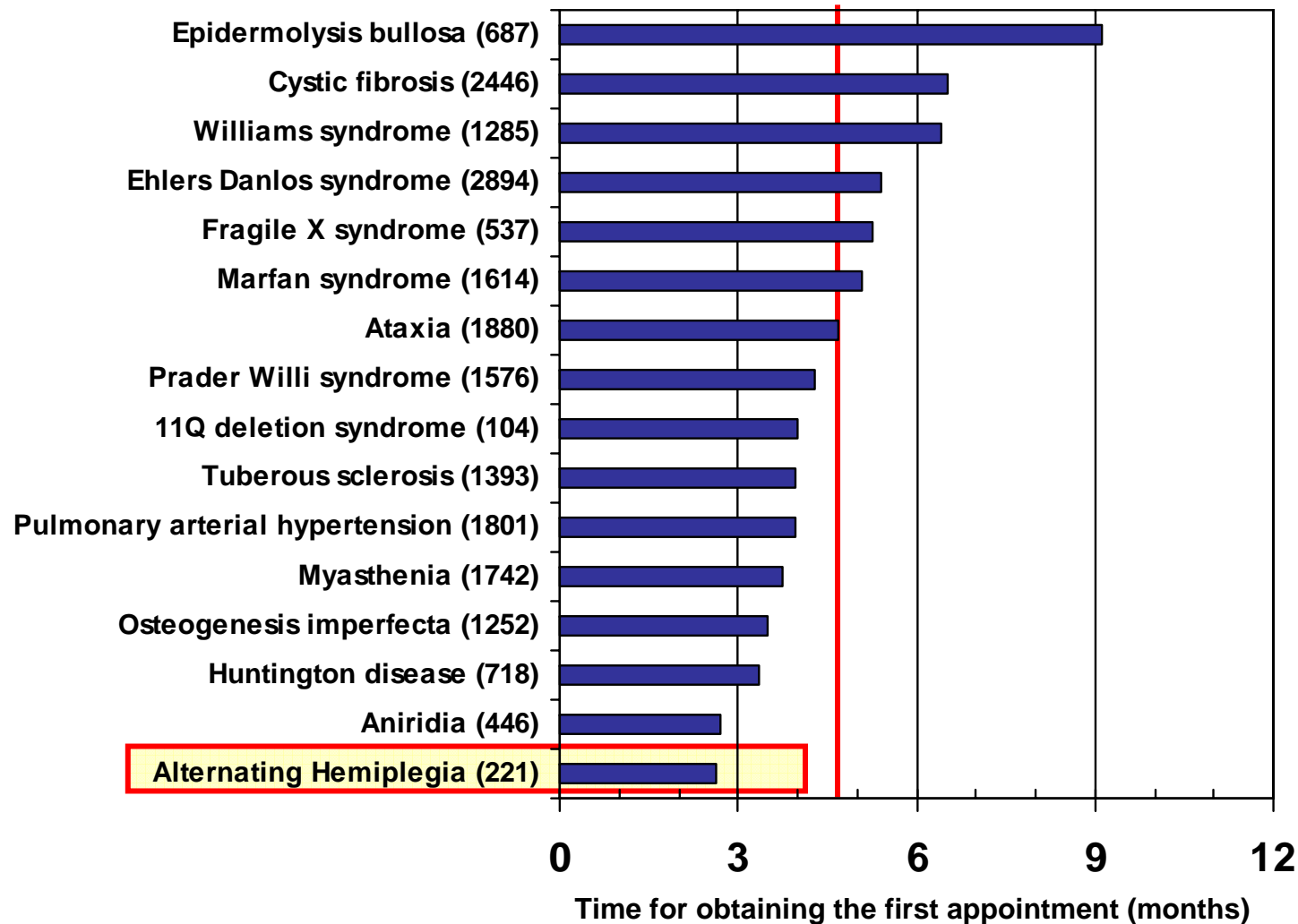


Delay in obtaining the first appointment



Time taken to obtain first appointment

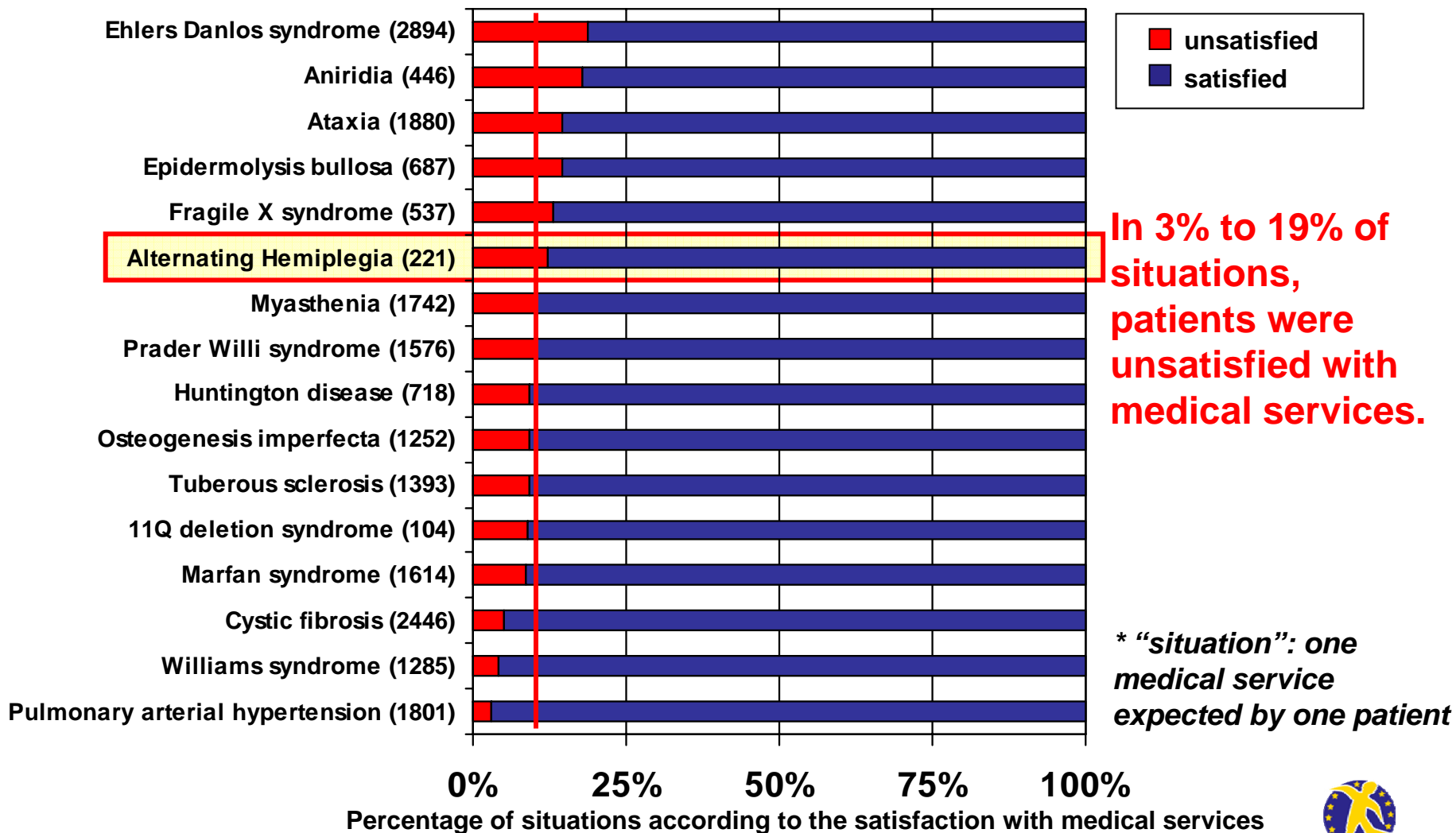
Overall: 4.9 months



Patients report long delays in obtaining a first appointment for any given medical service. A high variability exists between the different diseases

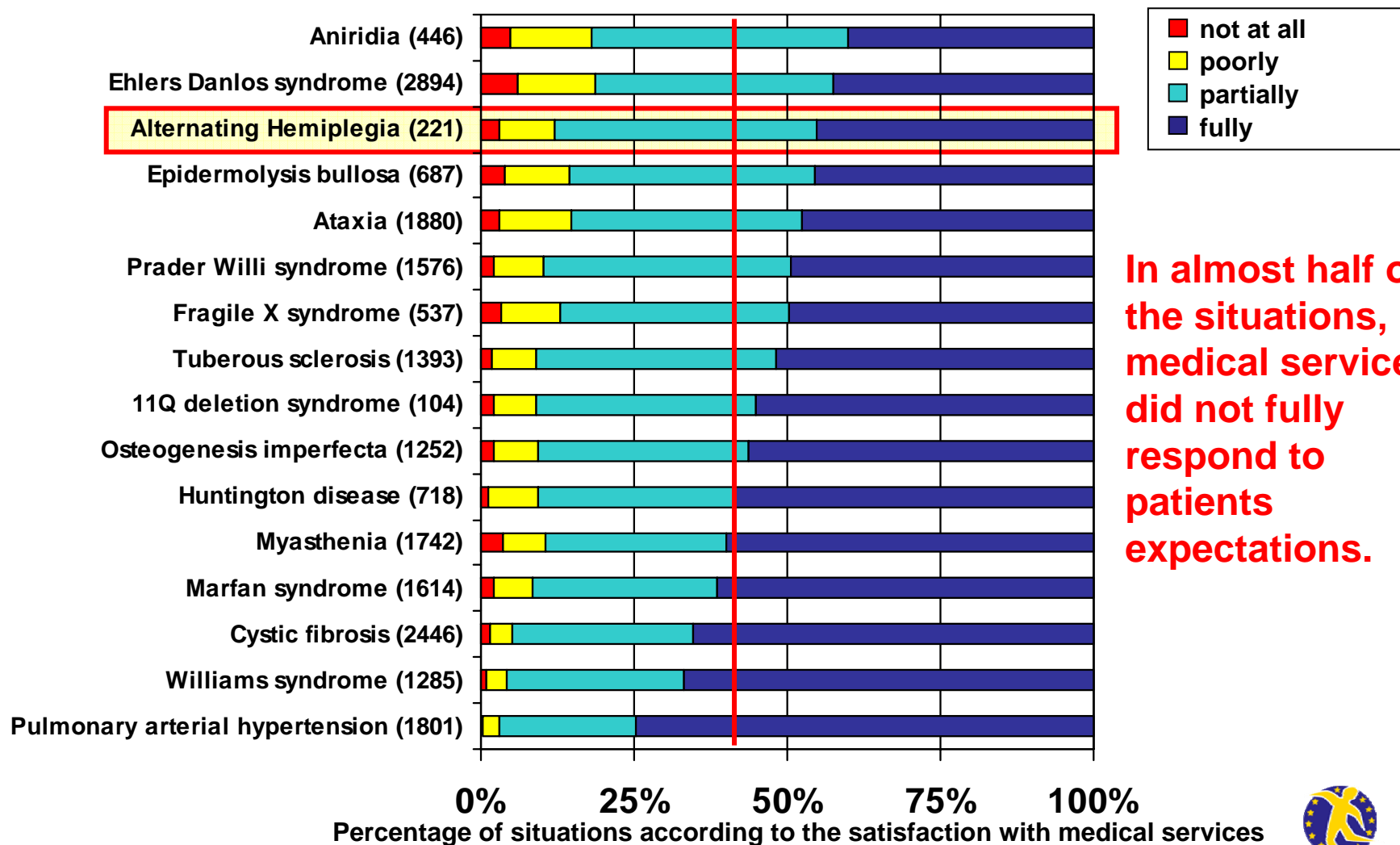
Satisfaction with medical services

Unsatisfied: 10%



Satisfaction with medical services

Partially, poorly or not satisfied: 44%



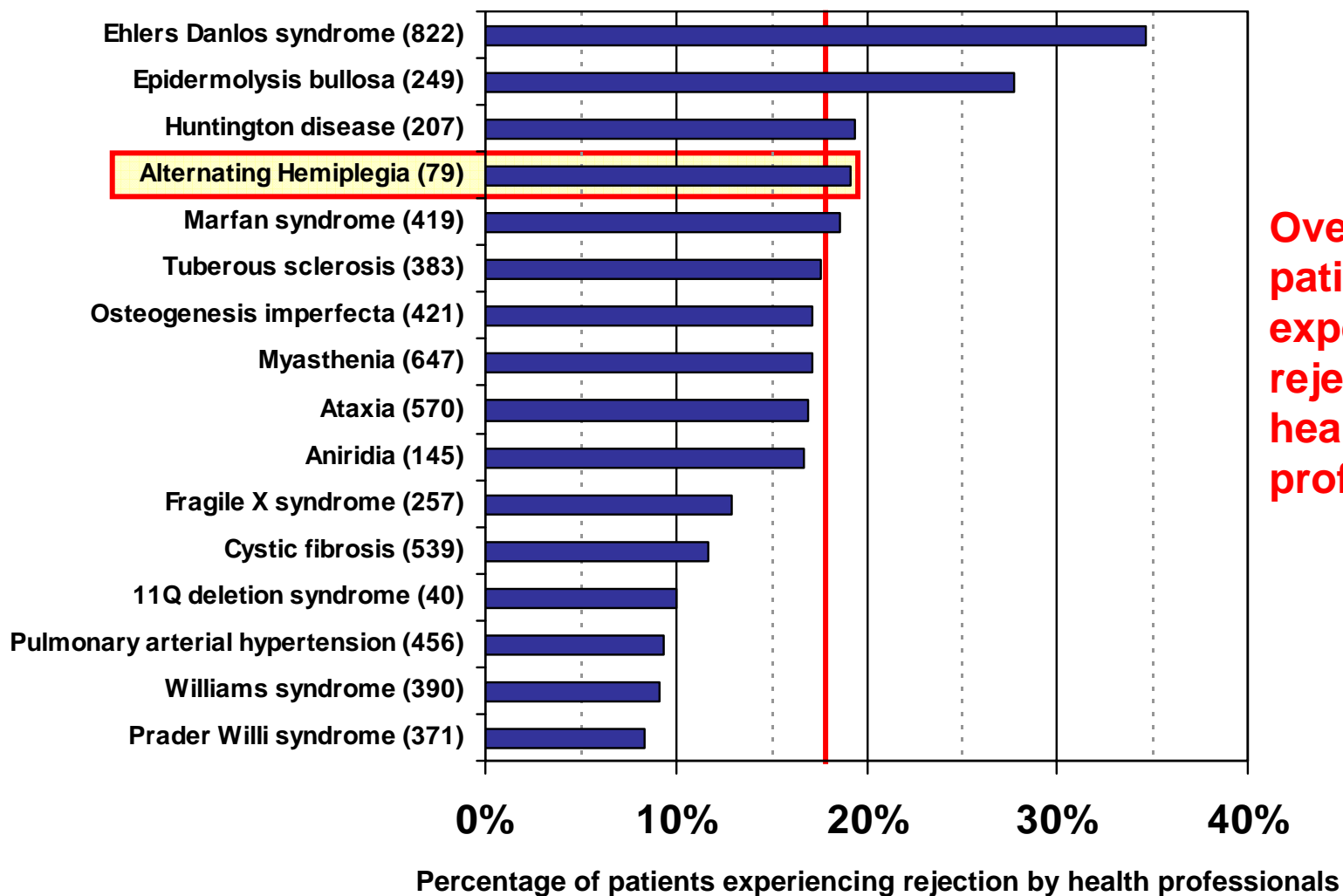
In almost half of the situations, medical services did not fully respond to patients expectations.

Rejection by health professional

- **Extent**
- **Reluctance of professional because of the complexity of the disease**
- **Rejection linked to the patient**

Rejection by health professionals

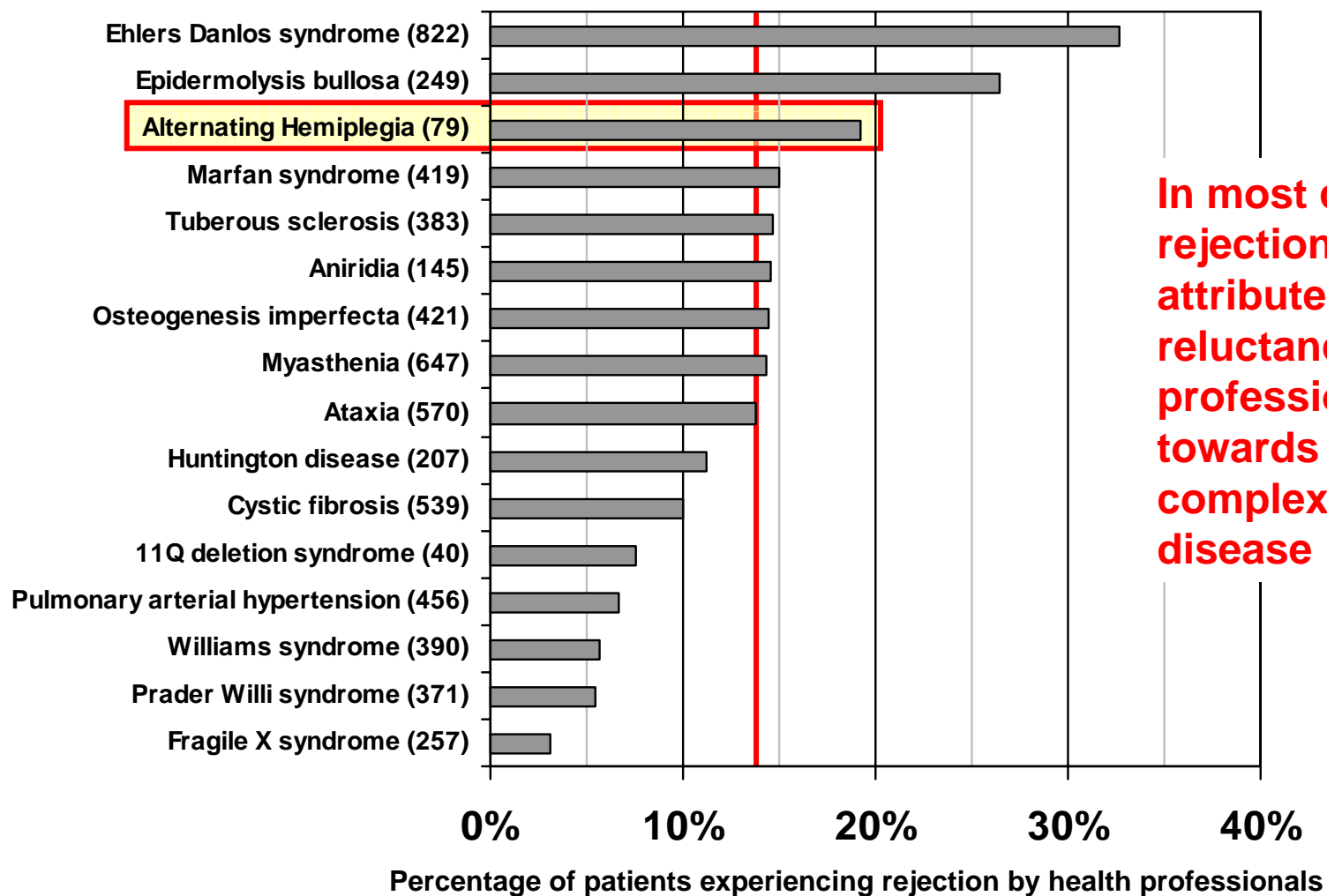
Overall: 18%



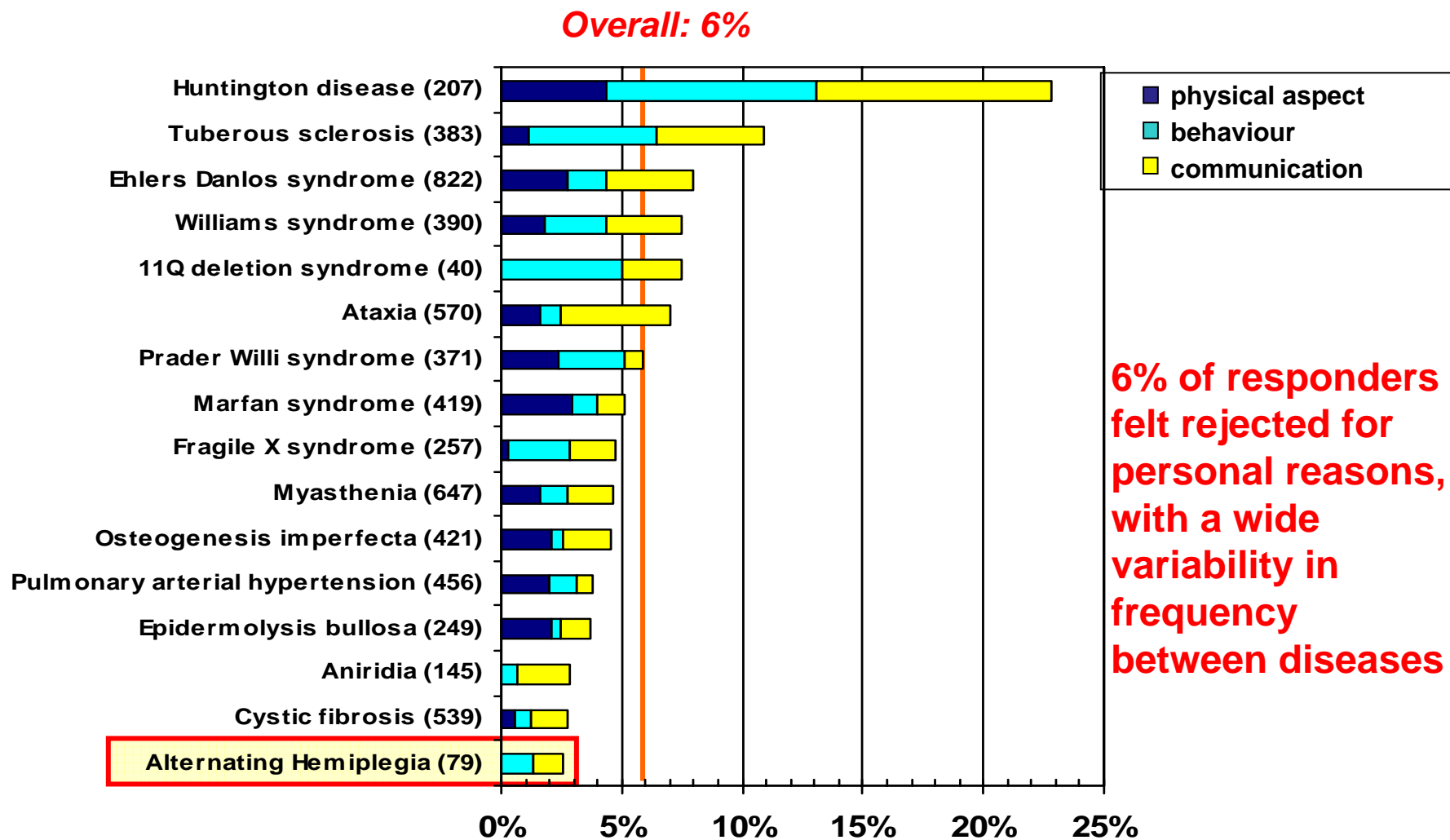
Overall, 18% of patients experienced rejection by health professionals

Rejection linked to the disease

Overall: 14 %

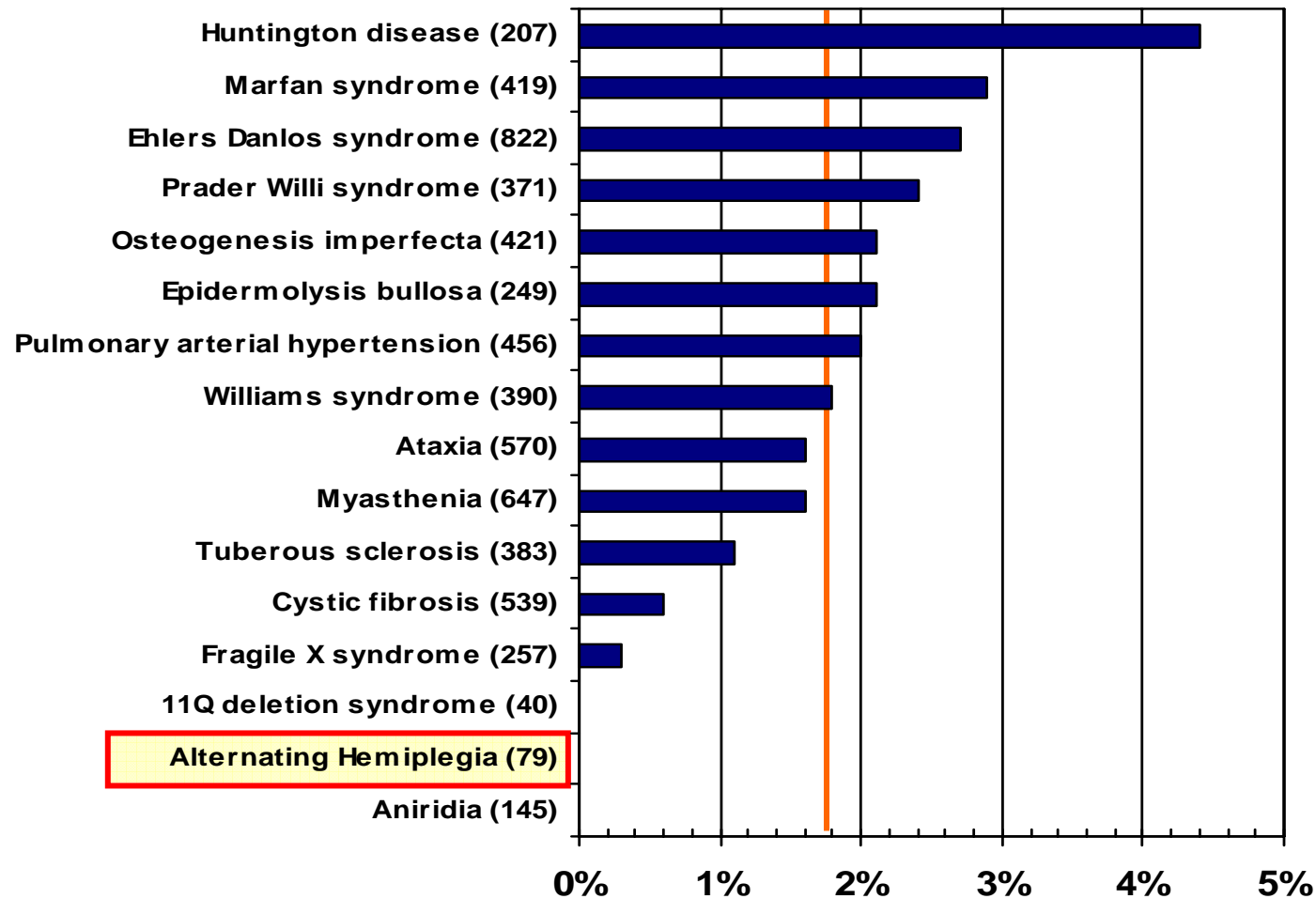


Causes of rejection linked to the patients



Rejection due to physical aspect

Overall: 1.8%

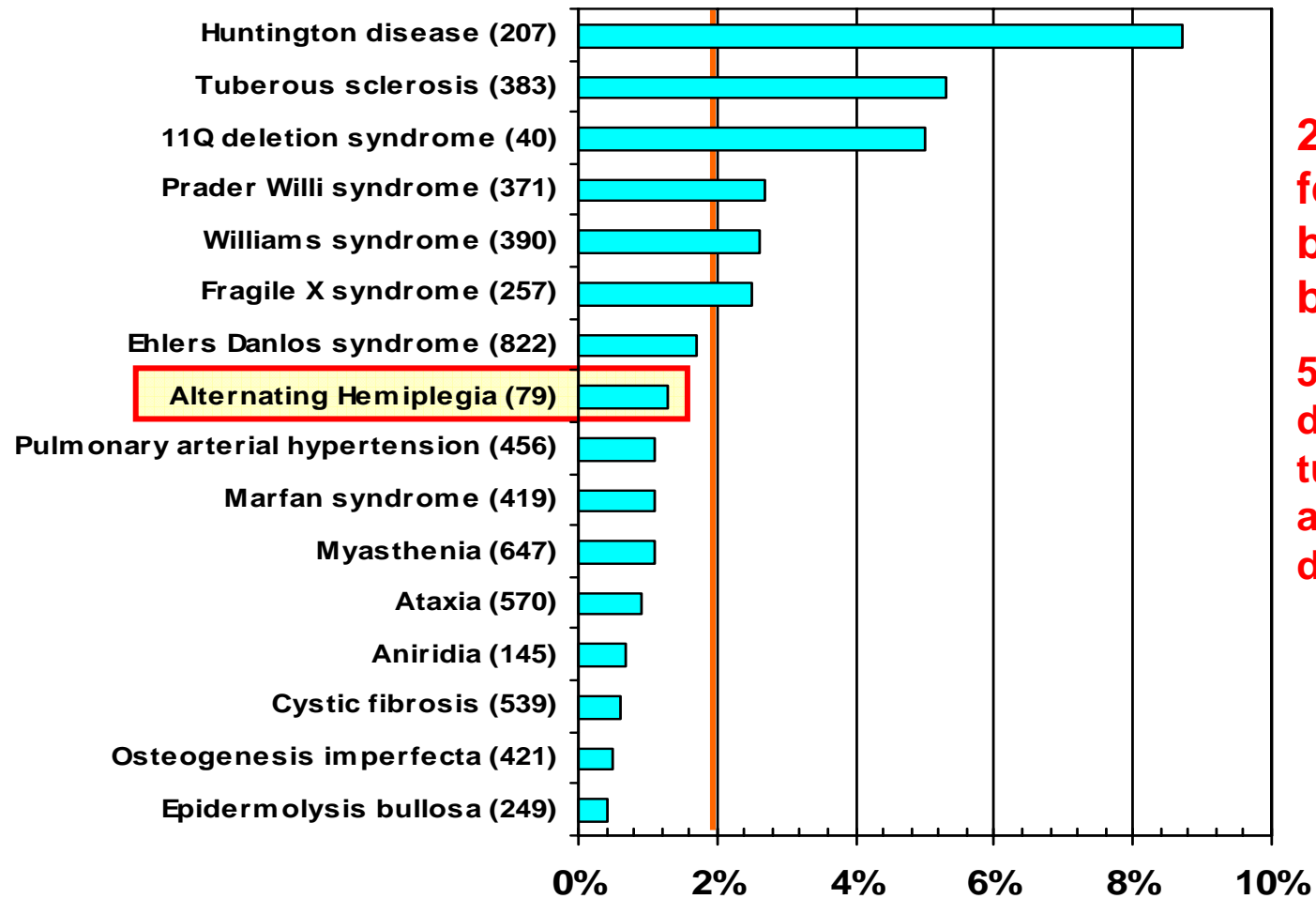


1.8% of responders felt rejected because of their physical aspect, with a wide variability in frequency between diseases

Percentage of patients experiencing a rejection due to physical aspect

Rejection due to behaviour

Overall: 1.9%

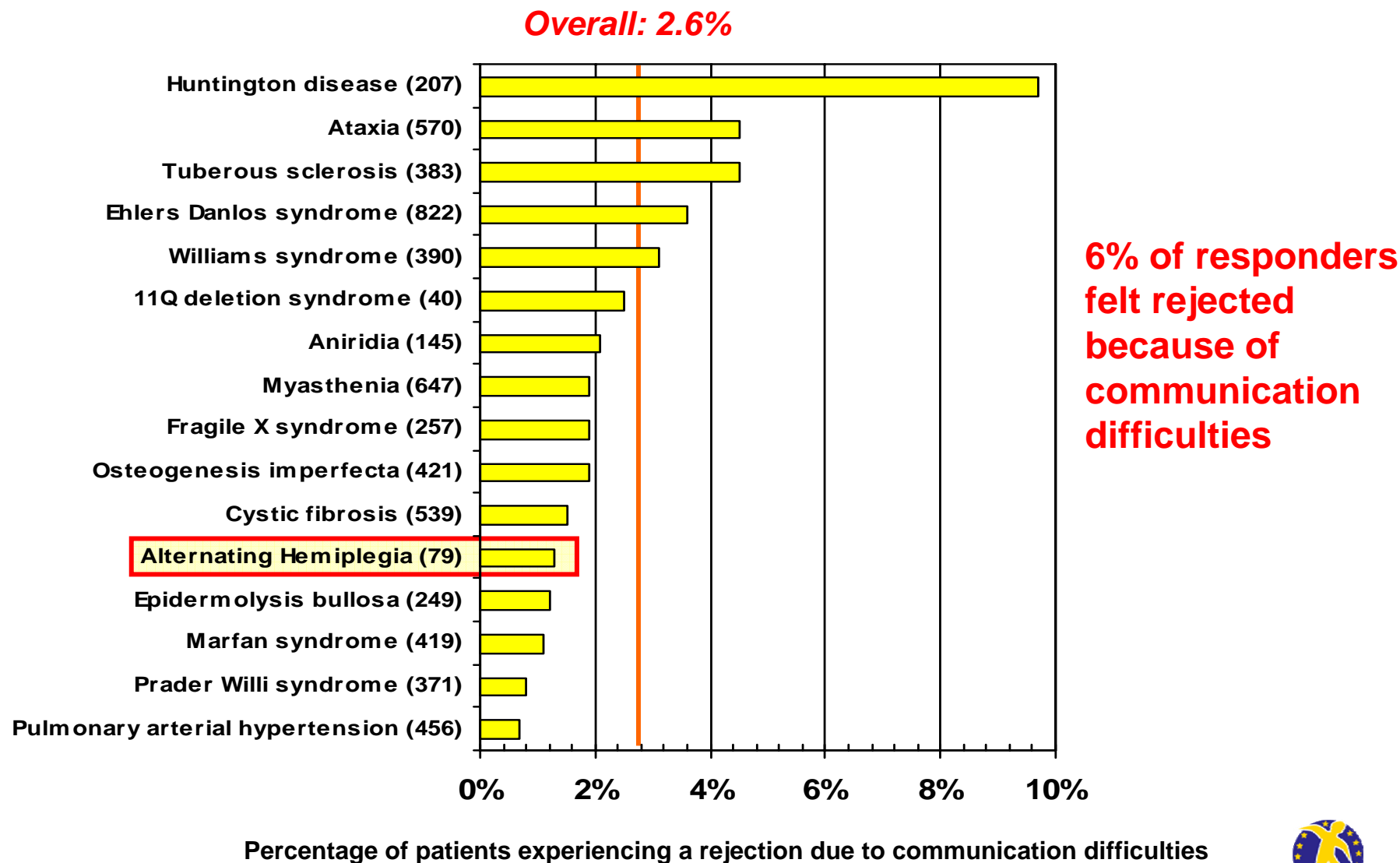


2% of responders, felt rejected because of their behaviour.

5% or more for 11q deletion disorders, tuberous sclerosis and Huntington disease

Percentage of patients experiencing a rejection due to behaviour

Rejection due to communication difficulties

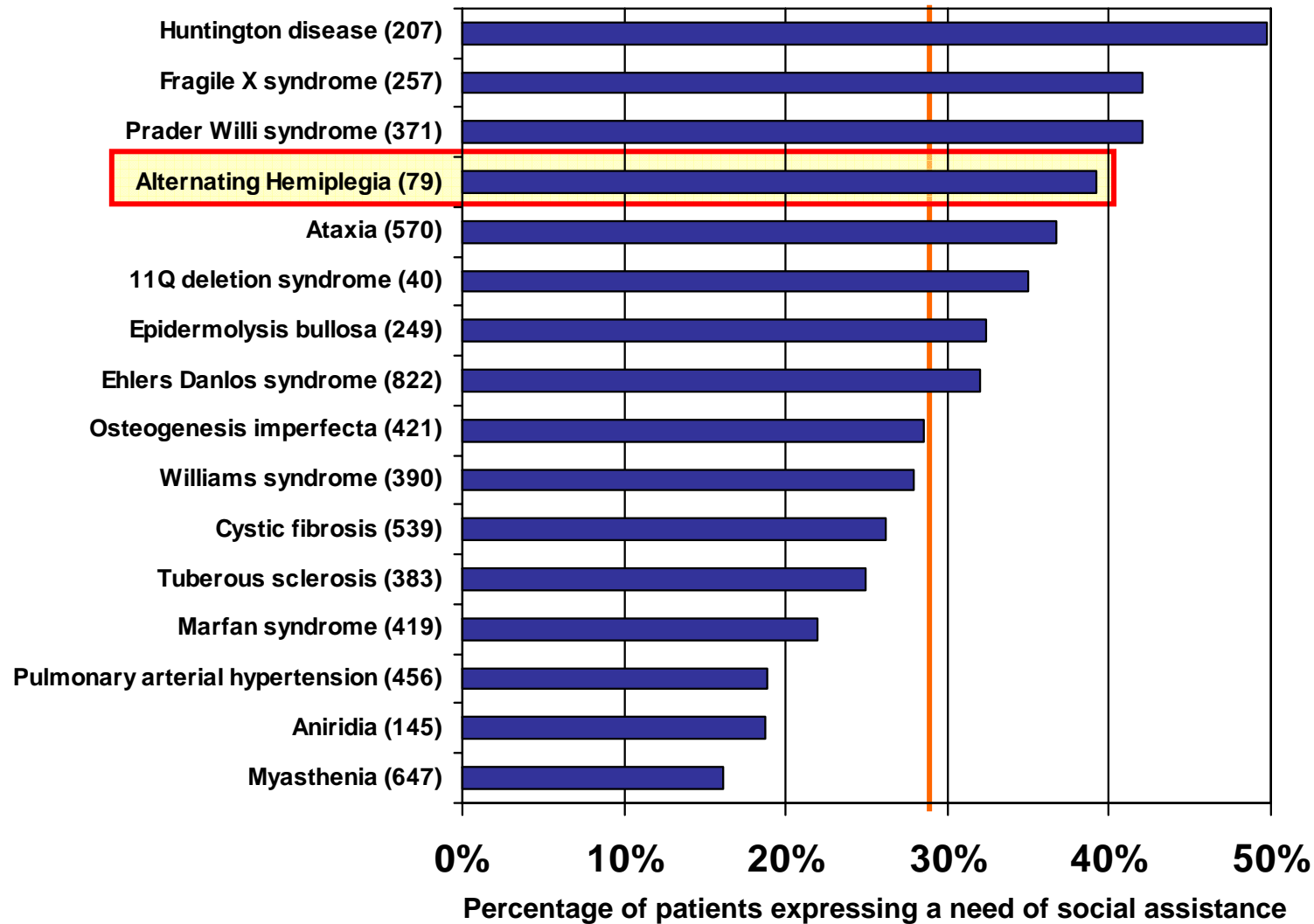


Social assistance

- **The need**
- **Easiness in obtaining**
- **Impossibility in obtaining**
- **Satisfaction with social assistance**
- **Satisfaction depending the specialisation of assistance**
 - Information on social, legal and financial rights (92% concerned)
 - Information on specialised technical supports (65% concerned)
 - Frequency vs satisfaction of the need

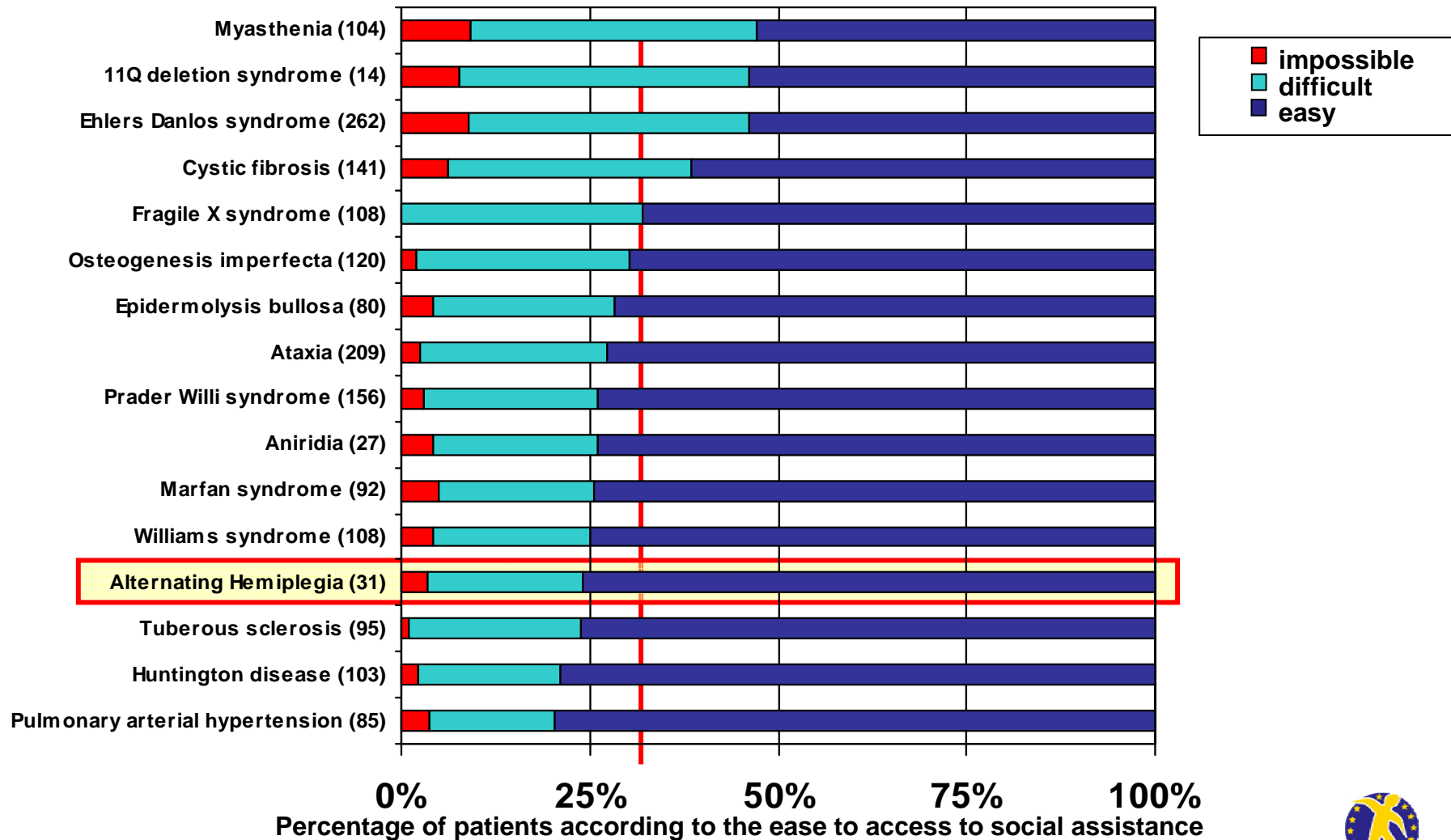
Need for social assistance

Overall: 29%



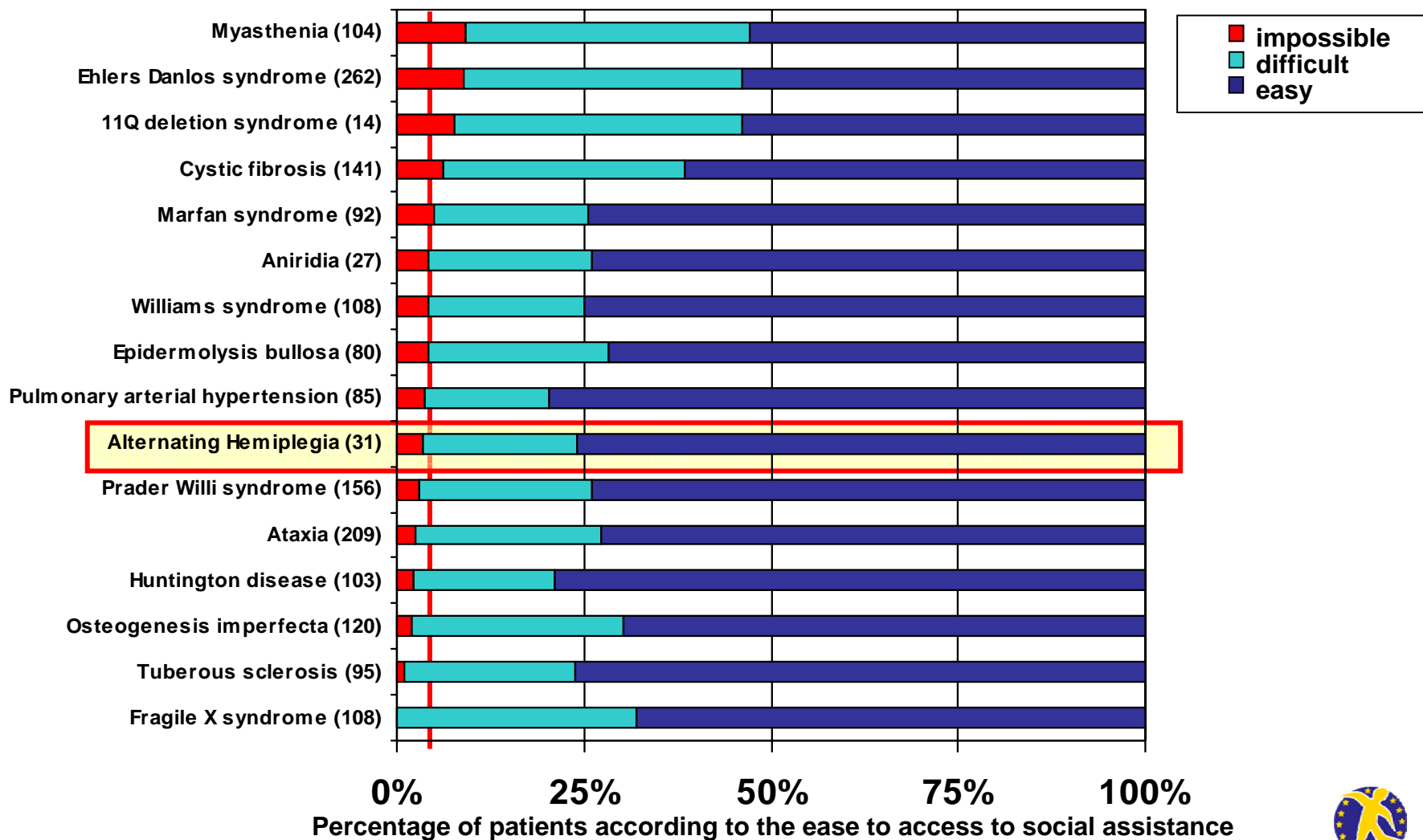
Access to social assistance

Overall: 32% difficult or impossible



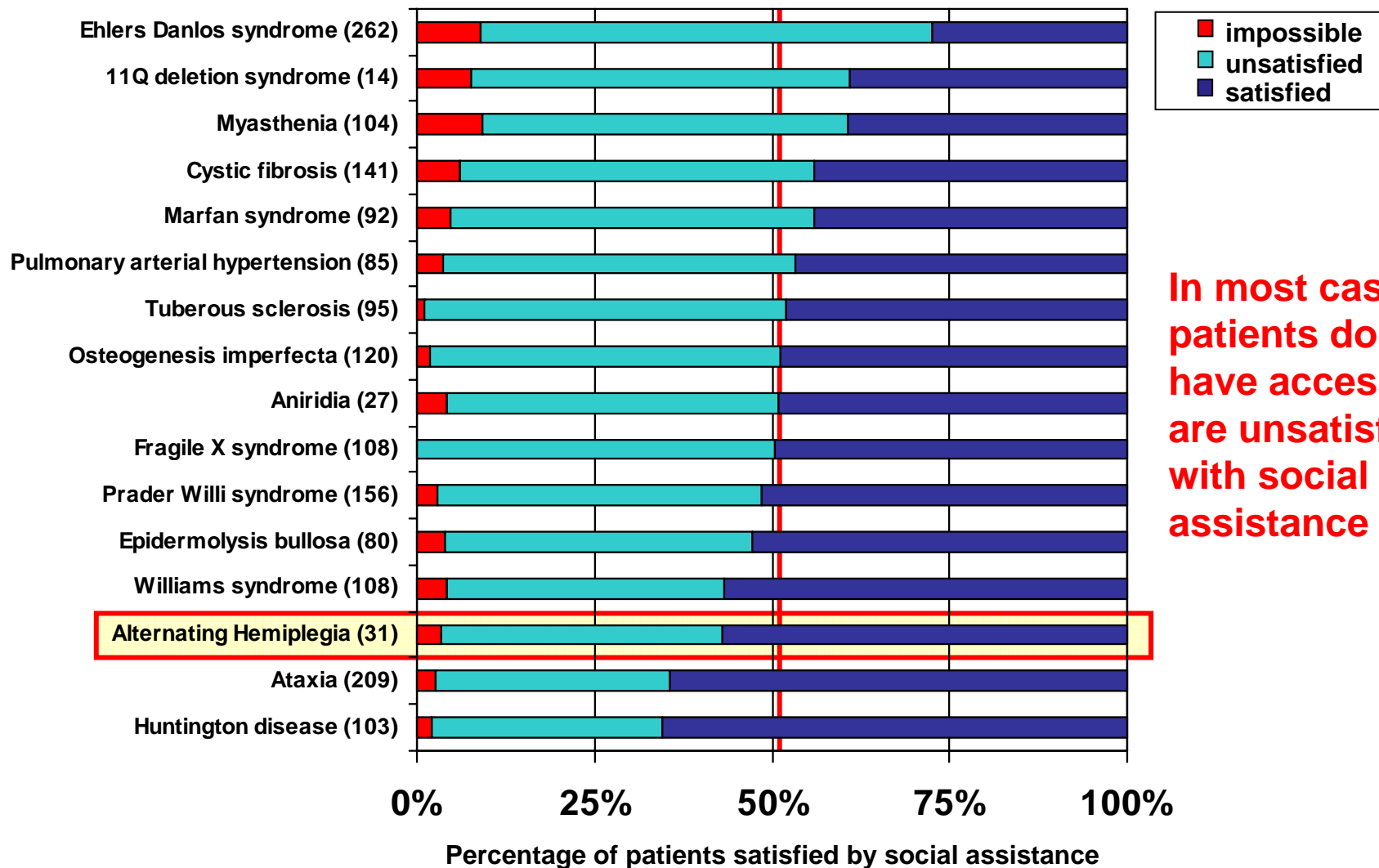
Lack of access to social assistance

Impossible, overall: 4.4%



Satisfaction with social assistance

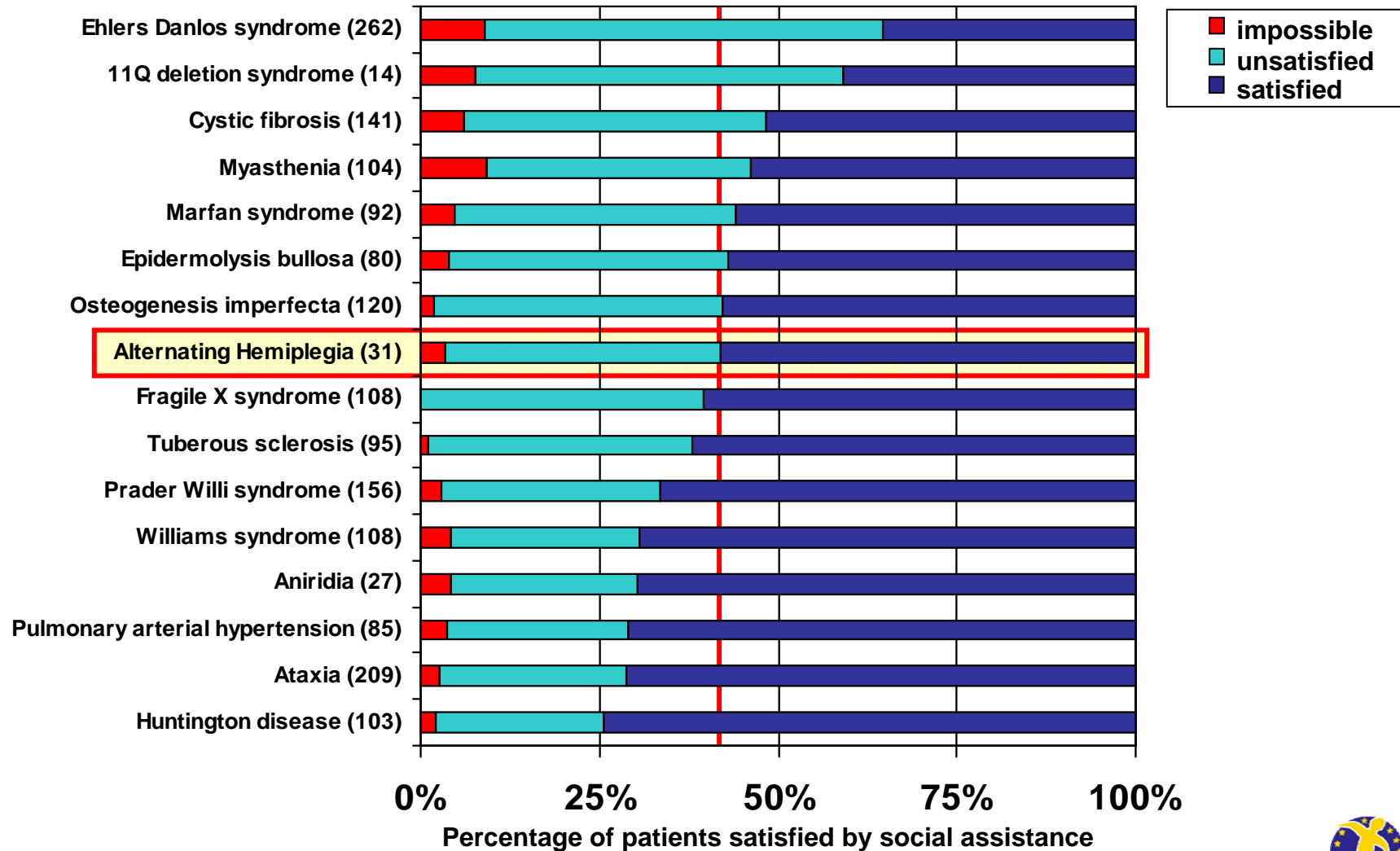
Lack of access or Unsatisfied, overall: 52%



In most cases, patients do not have access to or are unsatisfied with social assistance

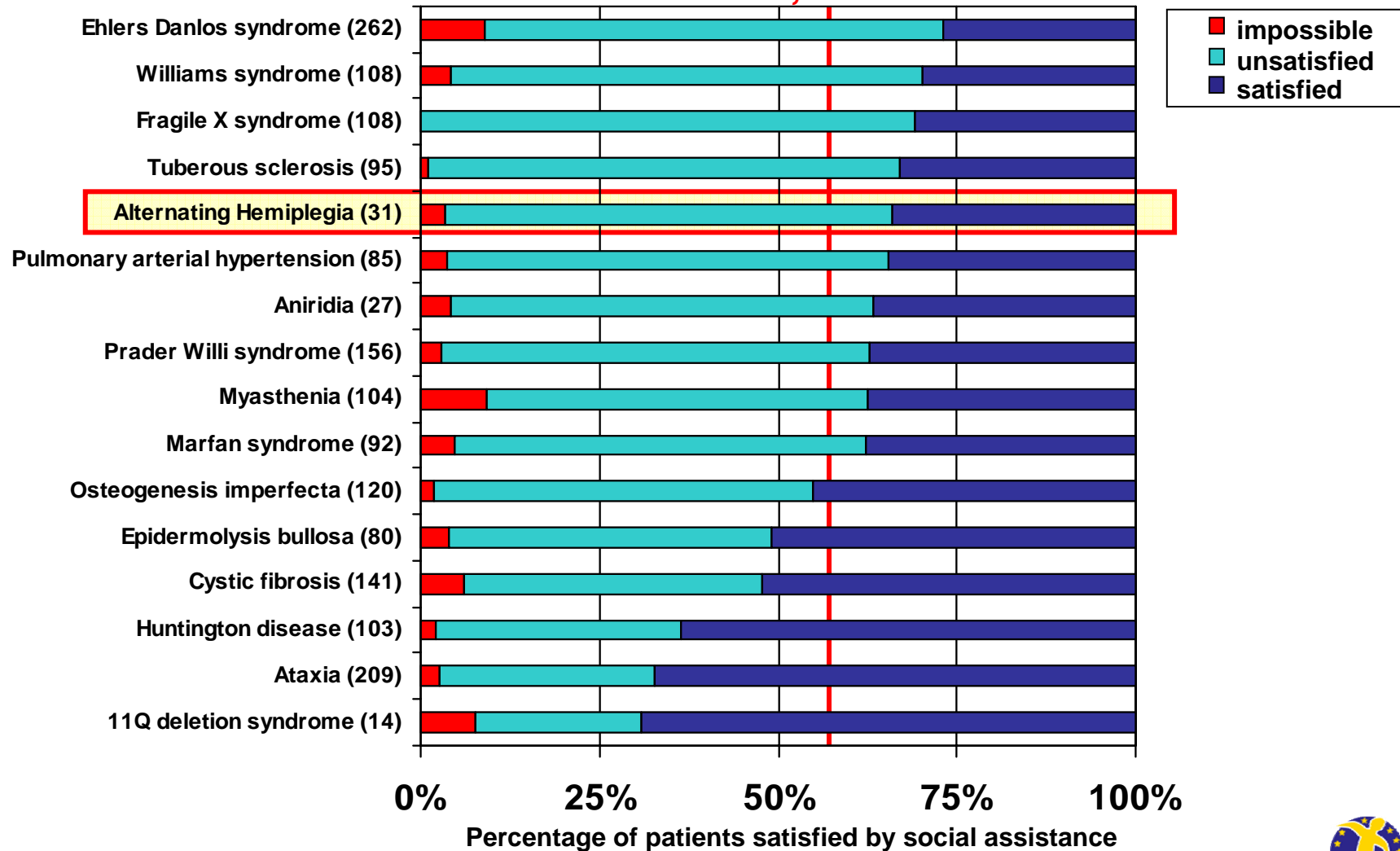
Satisfaction with information on social legal and financial rights (92% concerned)

Lack of access or Unsatisfied, overall: 42 %



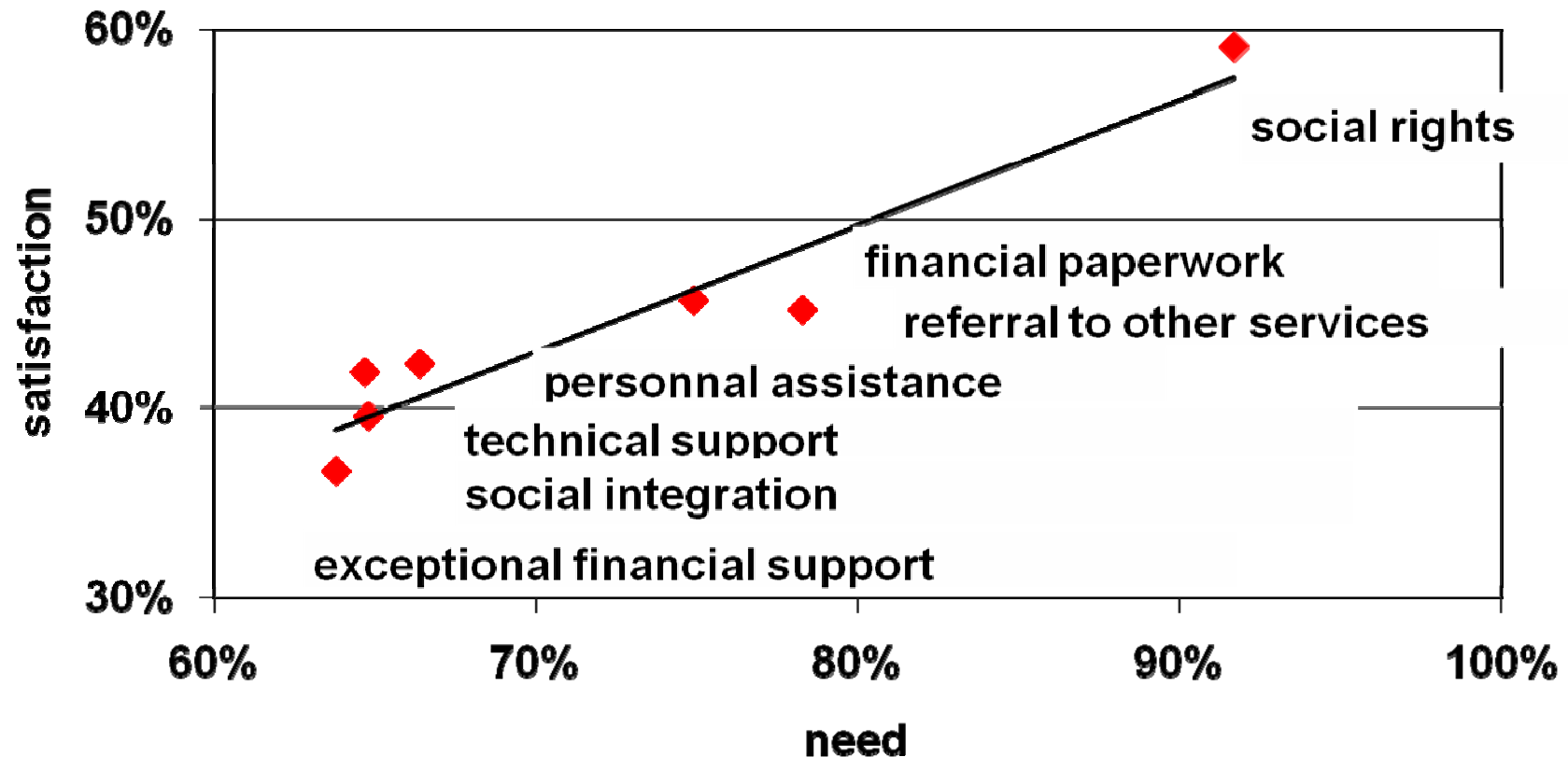
Satisfaction with information on specialised technical supports (65% concerned)

Lack of access or Unsatisfied, overall: 57%



Need versus Satisfaction

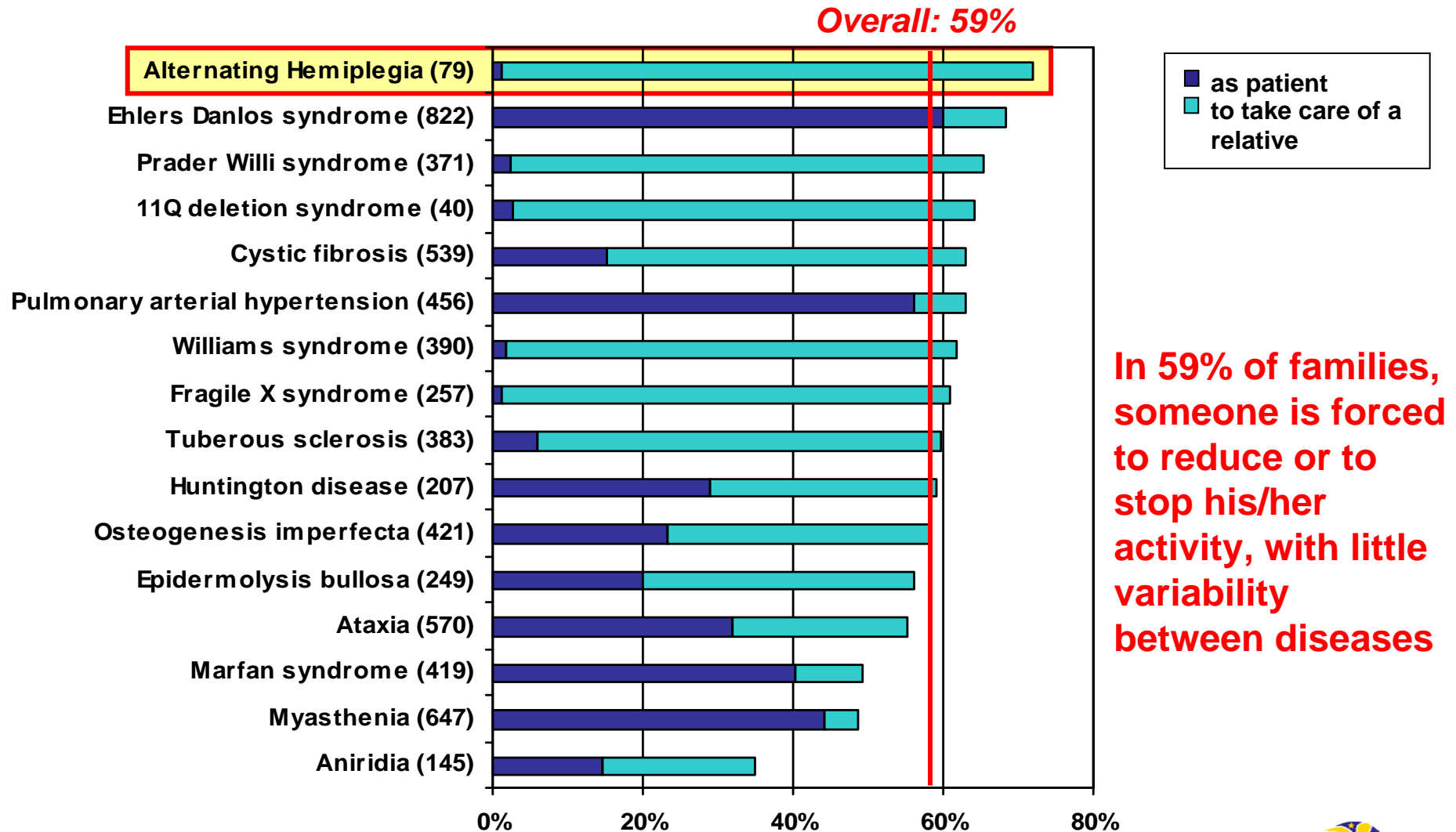
The more frequently a service is required, the more satisfied the responders are with the service



RD day to day: reduction in professional activity and moving

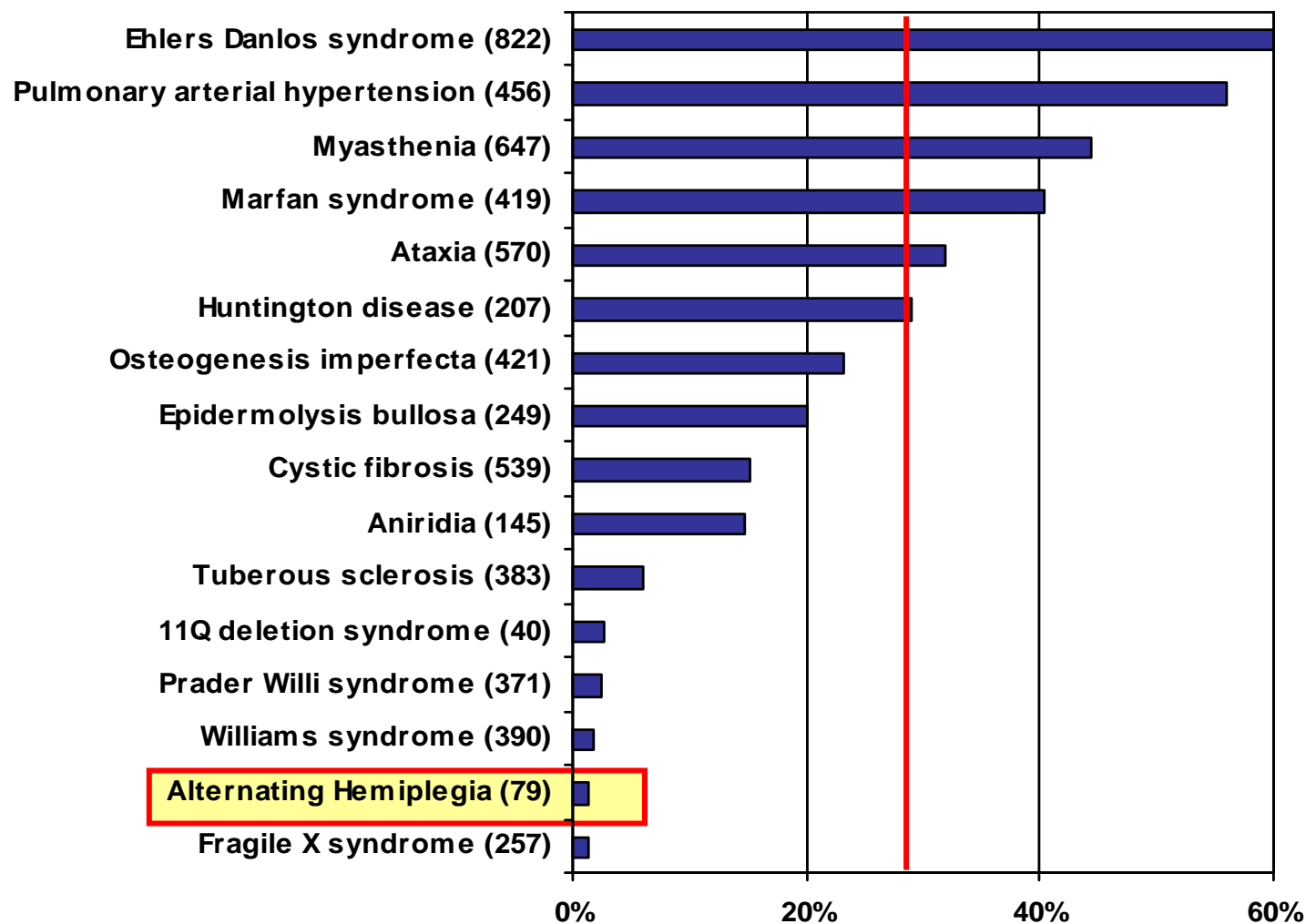
- **Reduction in professional activity**
 - Overall extent
 - Reduction in professional activity as patient
 - Reduction in professional activity to take care of a relative
 - Does reduction in professional activity reflect an unmet social need or a social assistance?
- **Moving in relation to the disease**
 - Extent
 - Reasons for moving

Reduction in professional activity



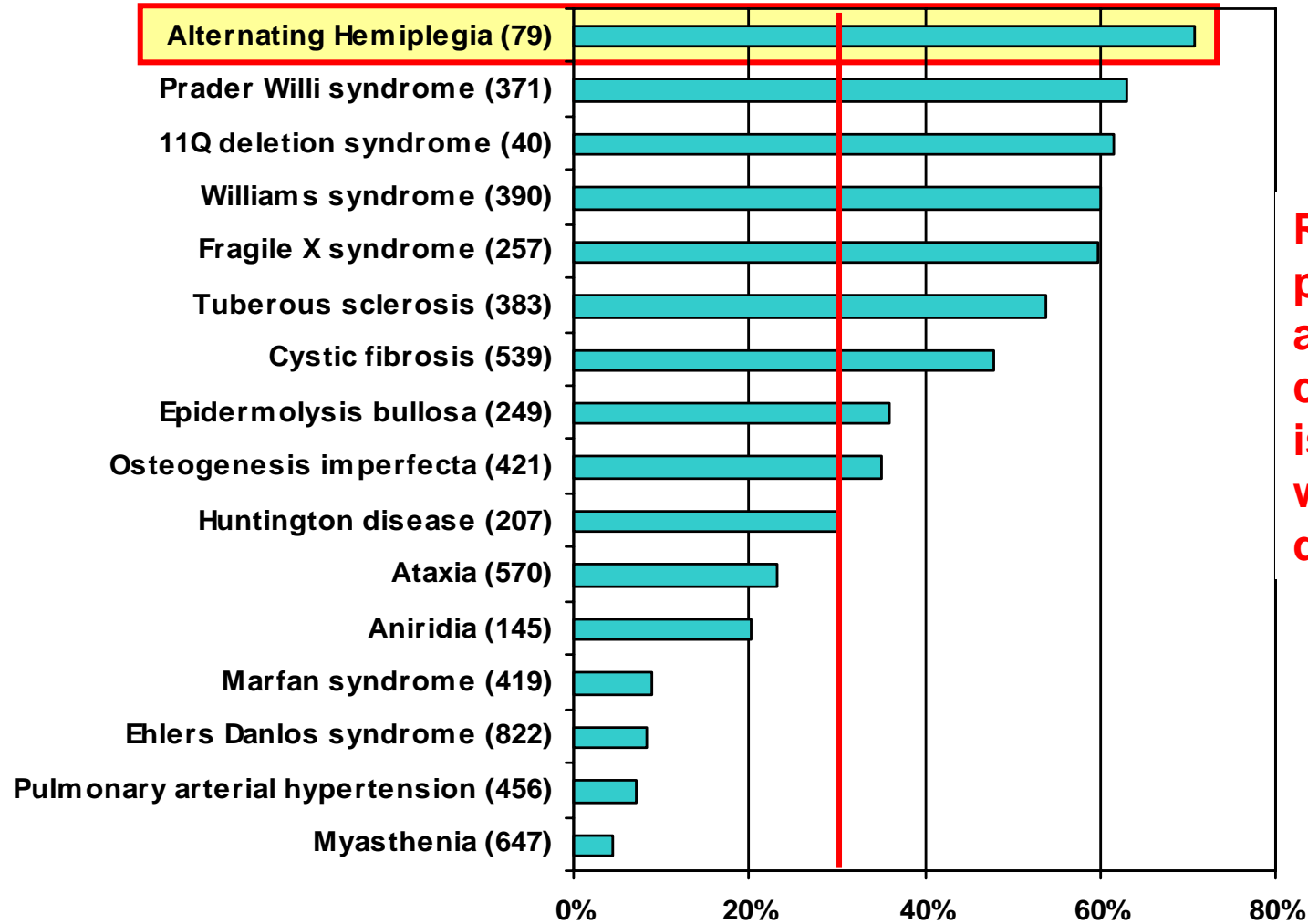
Reduction in professional activity as patient

Overall: 29 %



Reduction in professional activity to take care of a relative

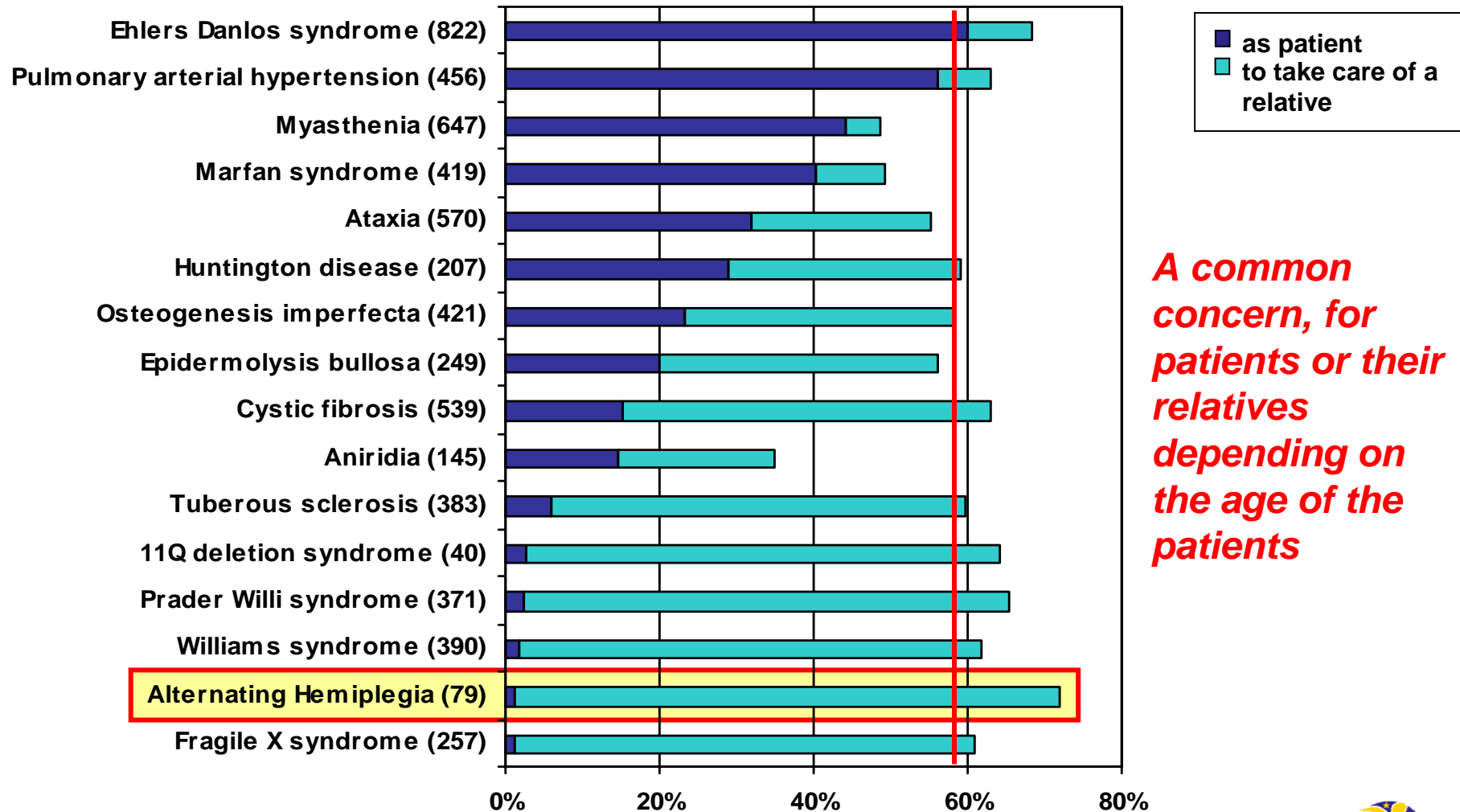
Overall: 30%



Reduction in professional activity to take care of a relative is more frequent with paediatric diseases

Reduction in professional activity

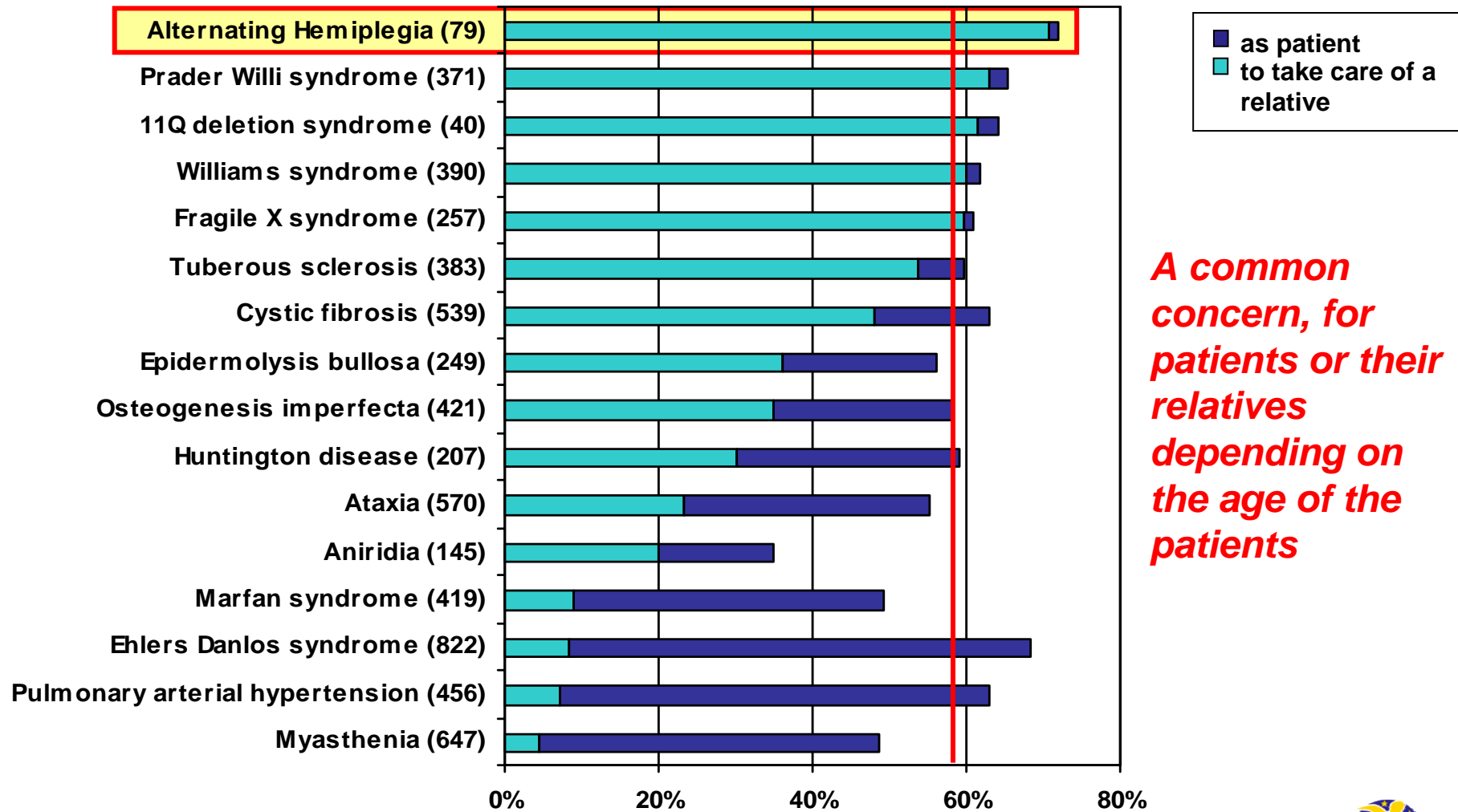
Overall: 59%



A common concern, for patients or their relatives depending on the age of the patients

Reduction in professional activity

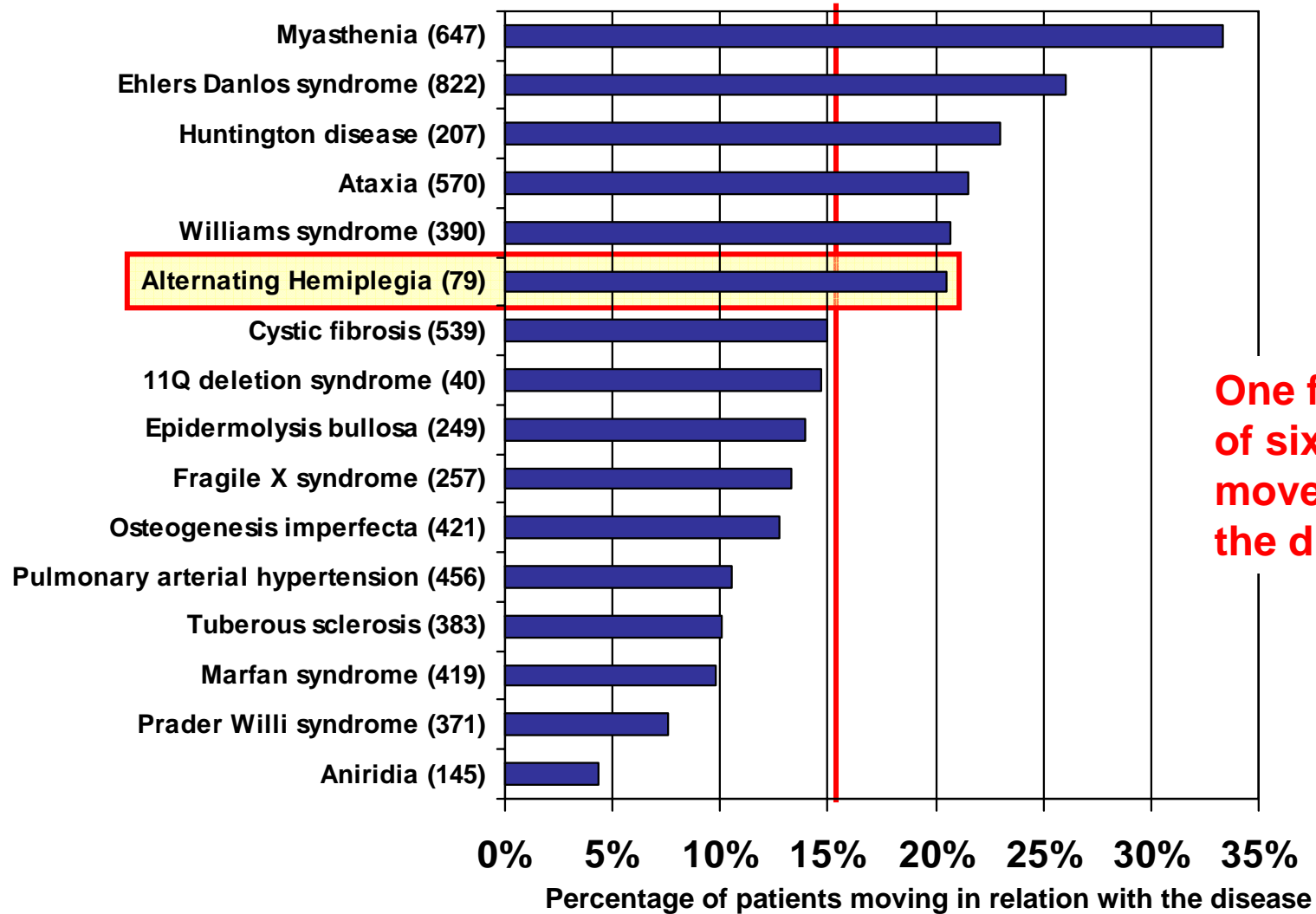
Overall: 59%



A common concern, for patients or their relatives depending on the age of the patients

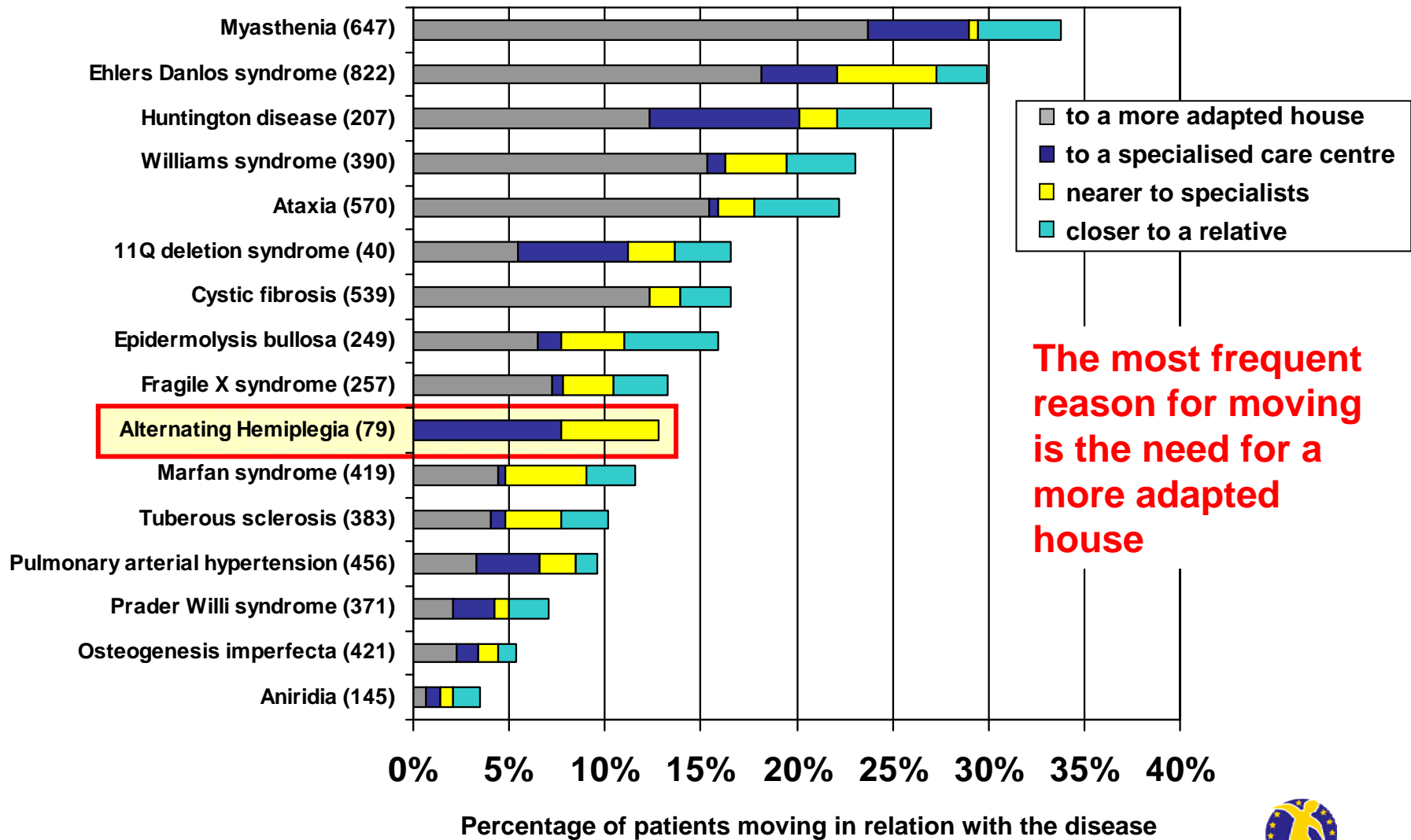
Need for moving

Overall: 16%

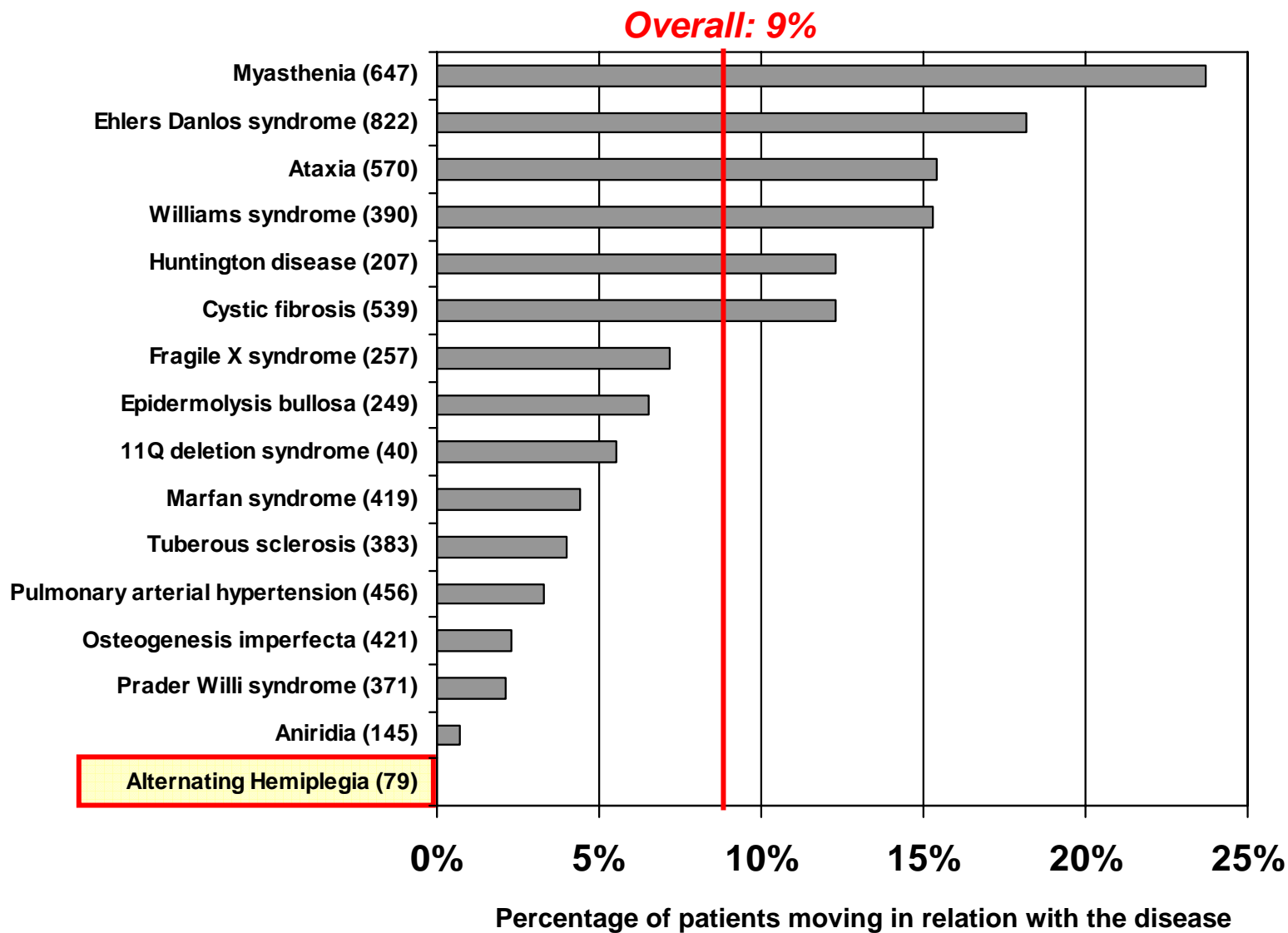


One family out of six has to move because of the disease

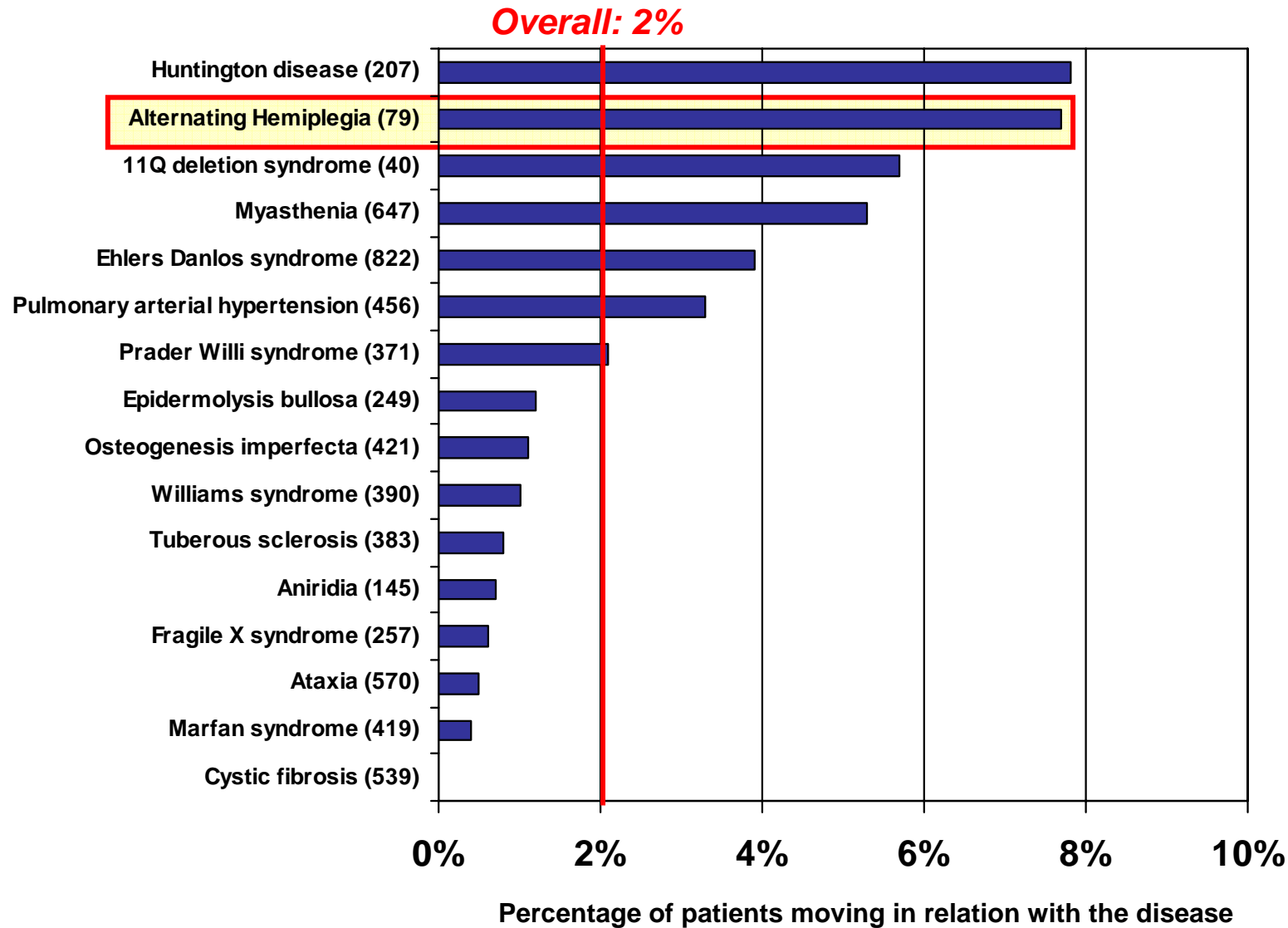
Reasons for moving



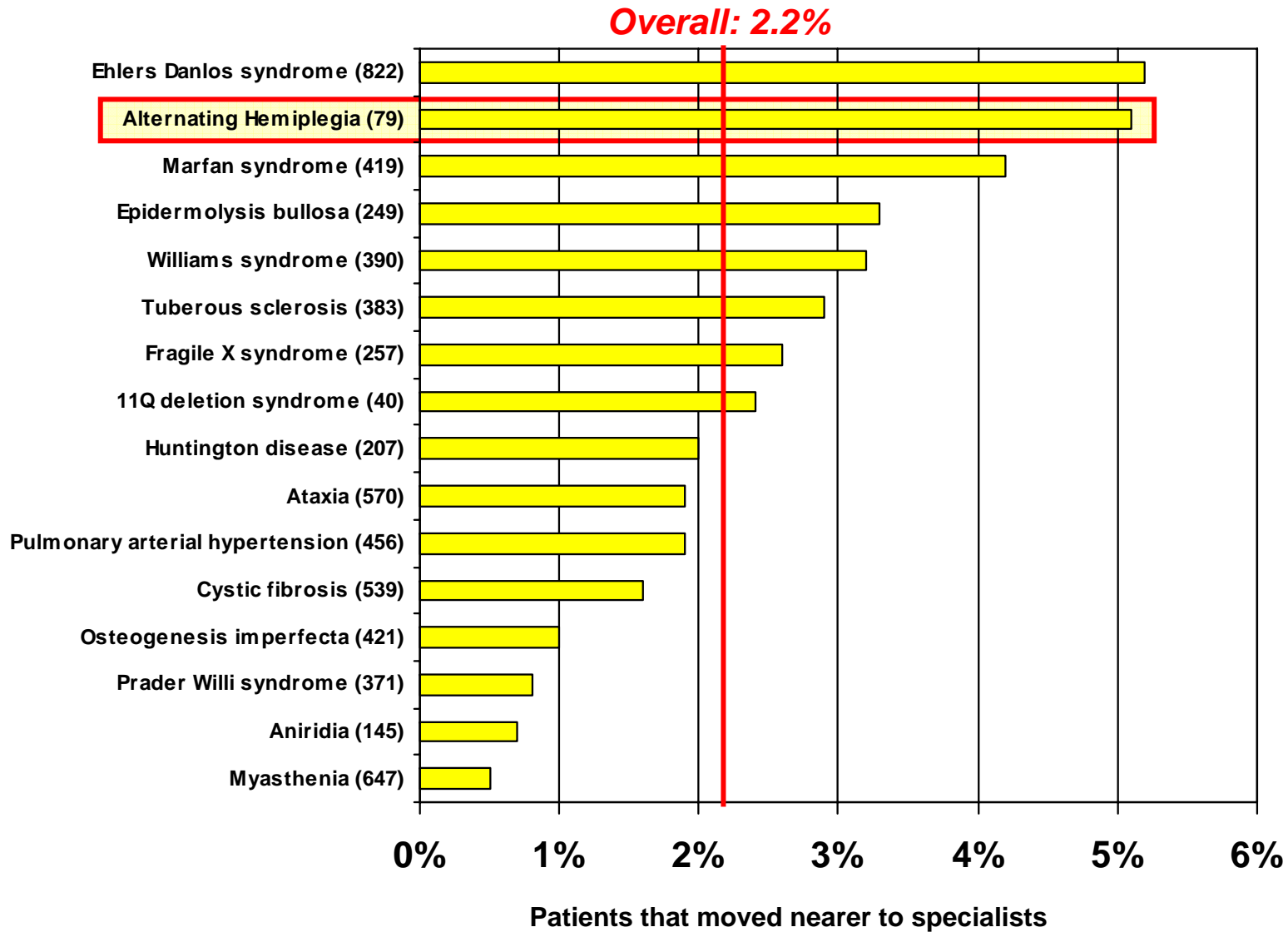
Moved to a more adapted house



Moved to a specialised care centre



Moved nearer to specialists



Moved closer to a relative

