

diagnosis



COLLECTIVE VOICES PROJECT

Demographics

183 complete responses

31 countries

United States 44%

28 states

UK
8%

Italy
6%

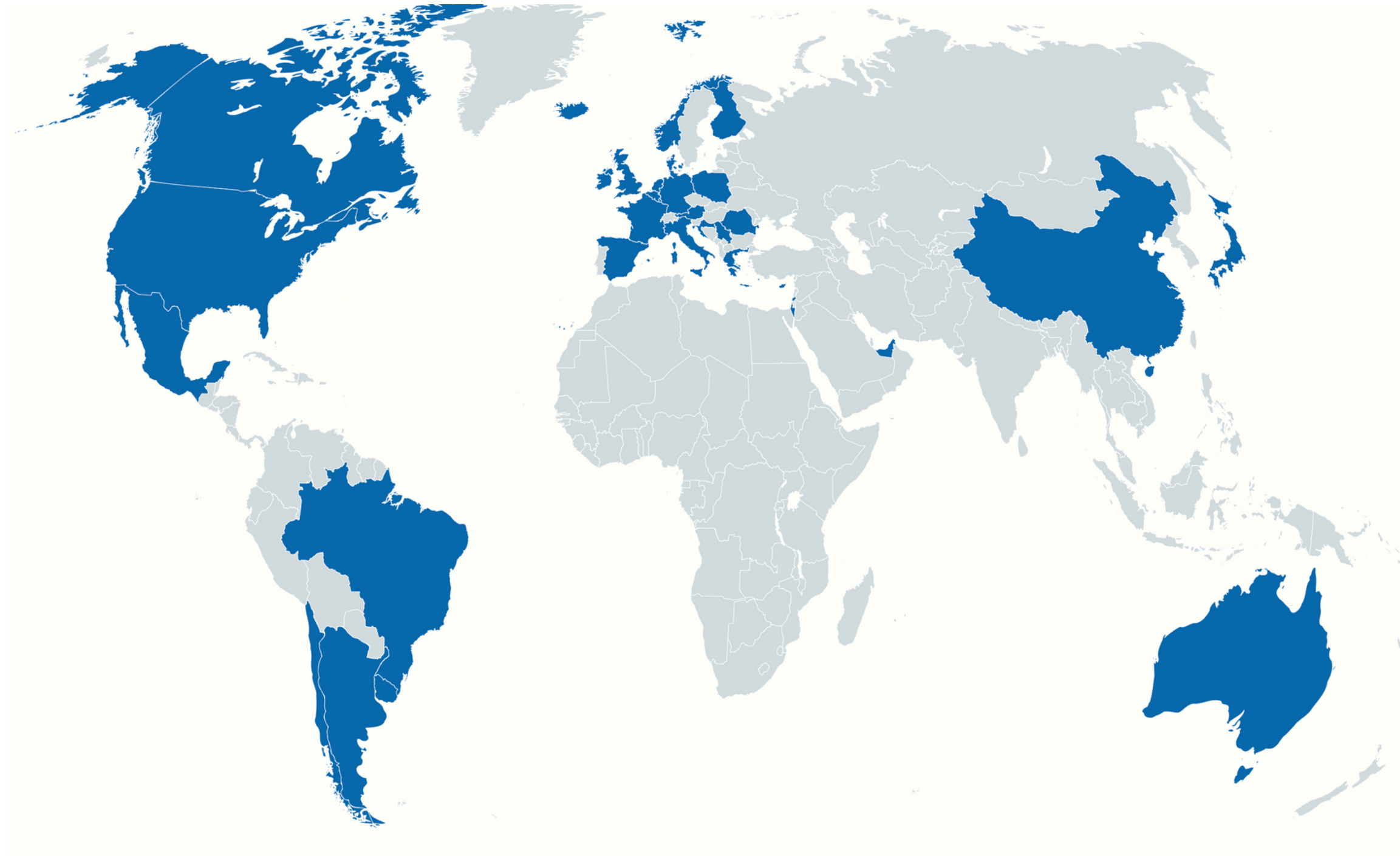
GER
5%

CAN
4%

ARG
3.3%

NL,ES,
RO,PL
3%

all others 2% or less



Demographics

female 57% **male 43%**

caregiver or parent 95% **patient 5%**

age and distribution



**youngest
infant**

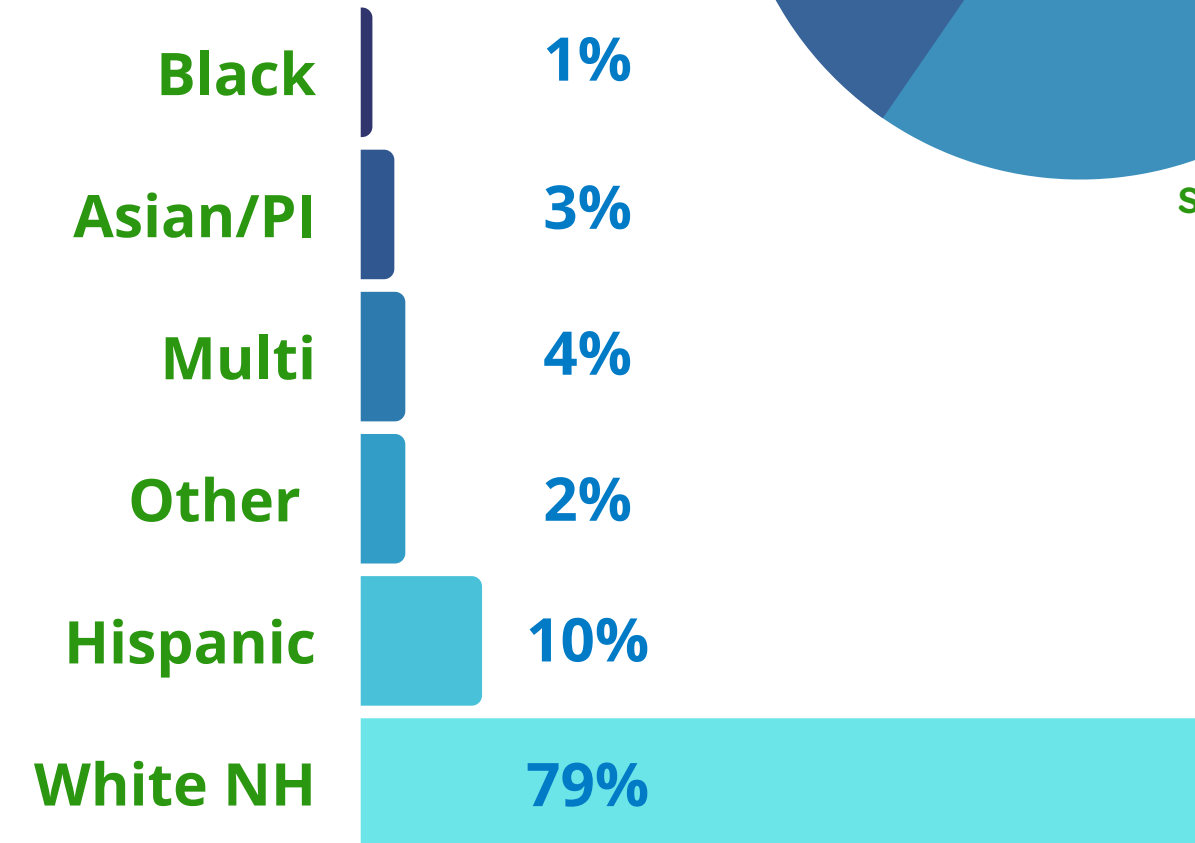
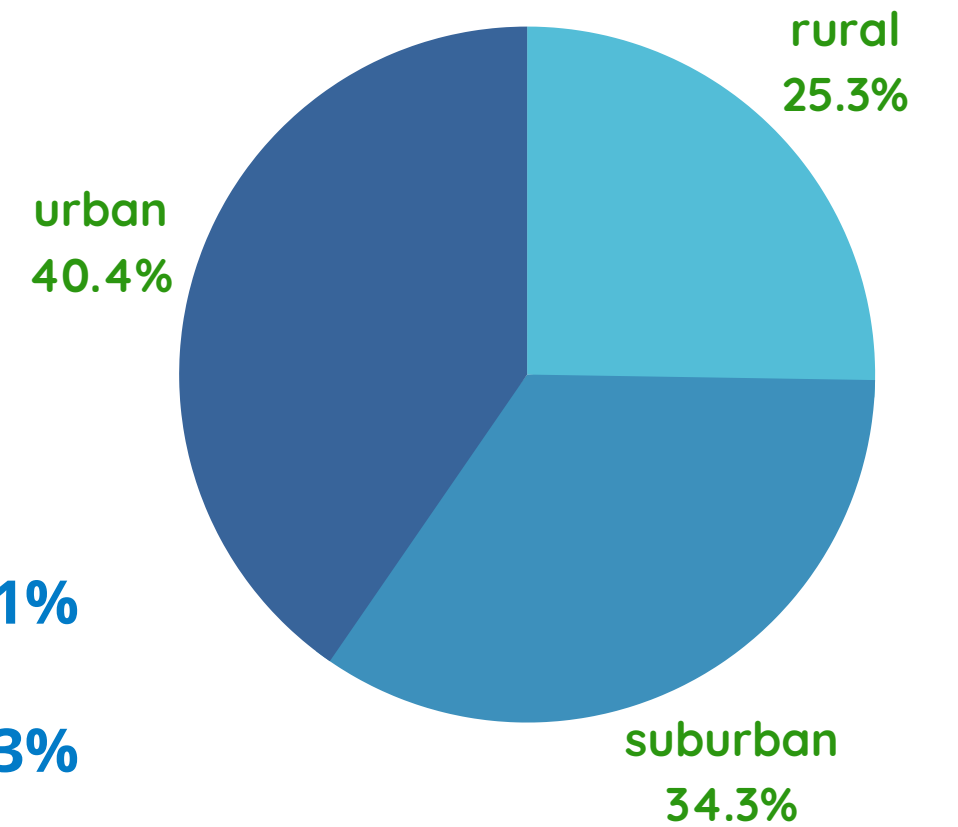


**average
22 years**



**oldest
53 years**

birth to 6 yr	23%
7-12 years	37%
13-17 years	17%
18-53 years	23%



identity groups

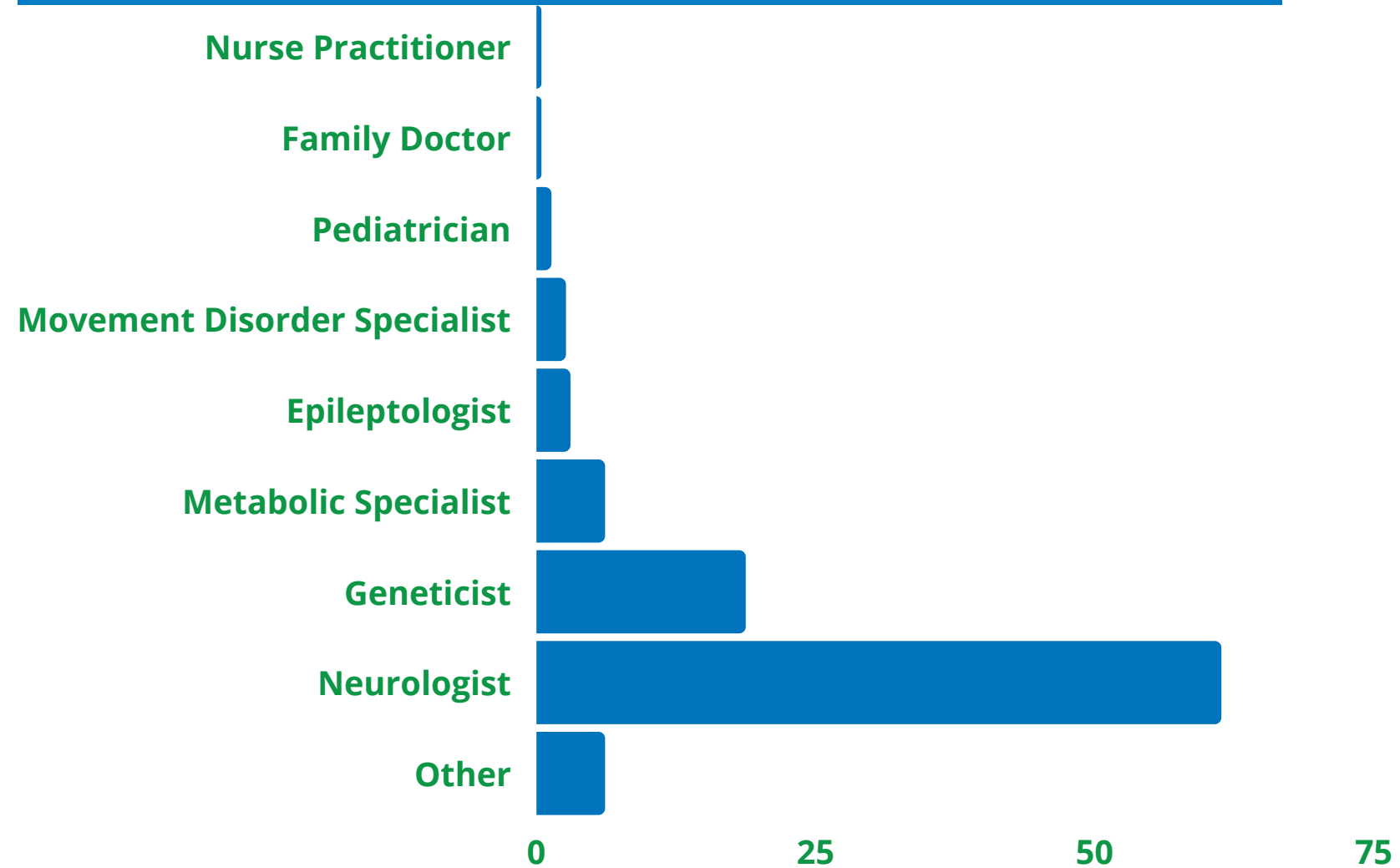


Diagnosis

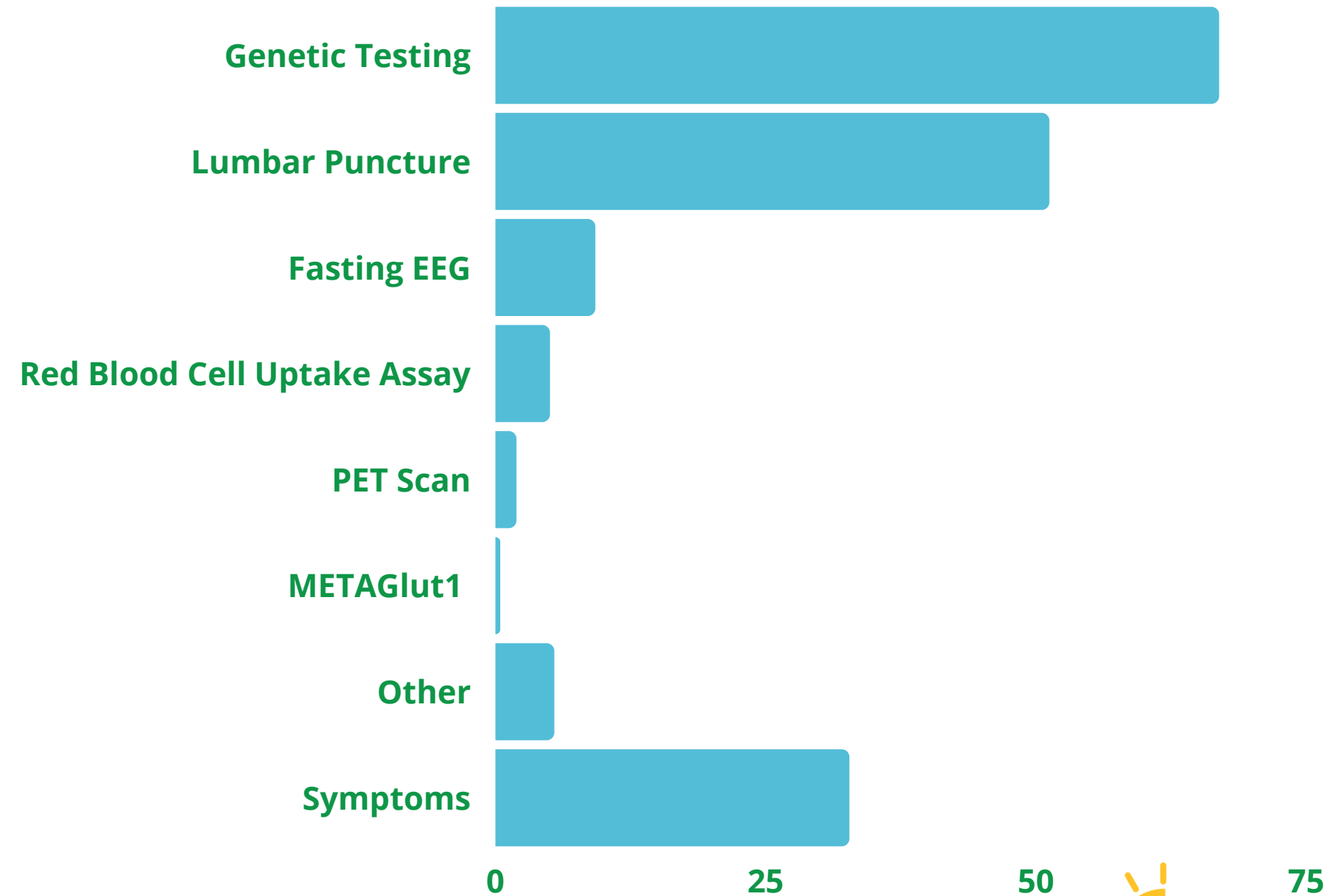
average # of physicians
seen to get diagnosis

8

who made the diagnosis?



diagnostic tools used



Diagnosis

additional family members 10%



first symptom to diagnosis

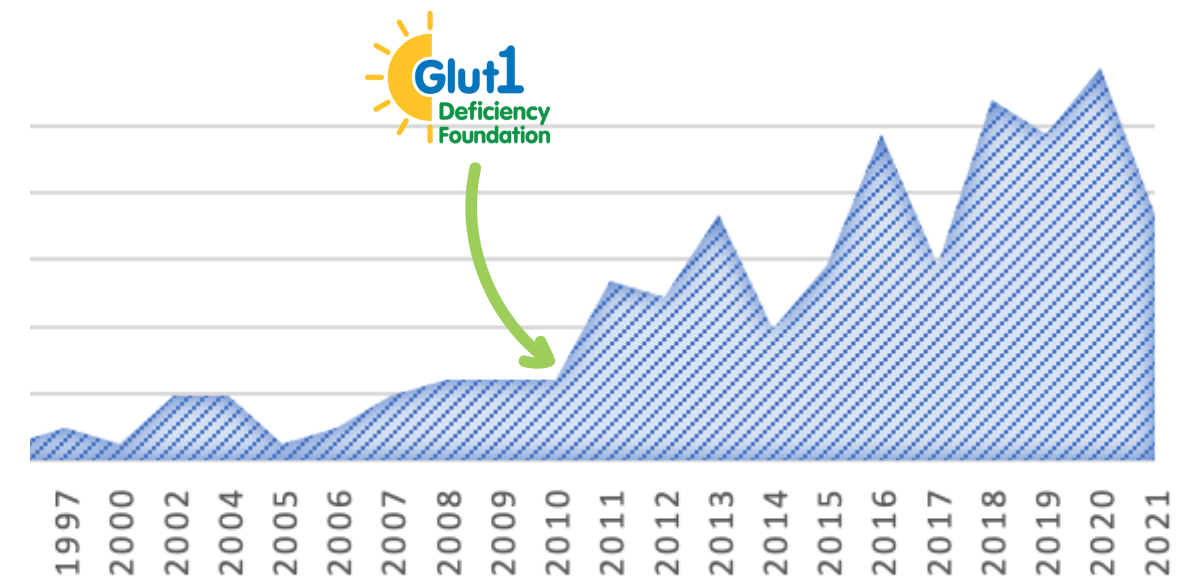
shortest 1.5 weeks
longest 34 years
average 2.8 years

0 to 11 months	18%
1-4 years	44%
5-9 years	22%
10-14 years	9%
15-35 years	7%

age at diagnosis

youngest 12 days
oldest 39 years
average 6 years

year of diagnosis



Diagnosis

biggest obstacles to diagnosis

