

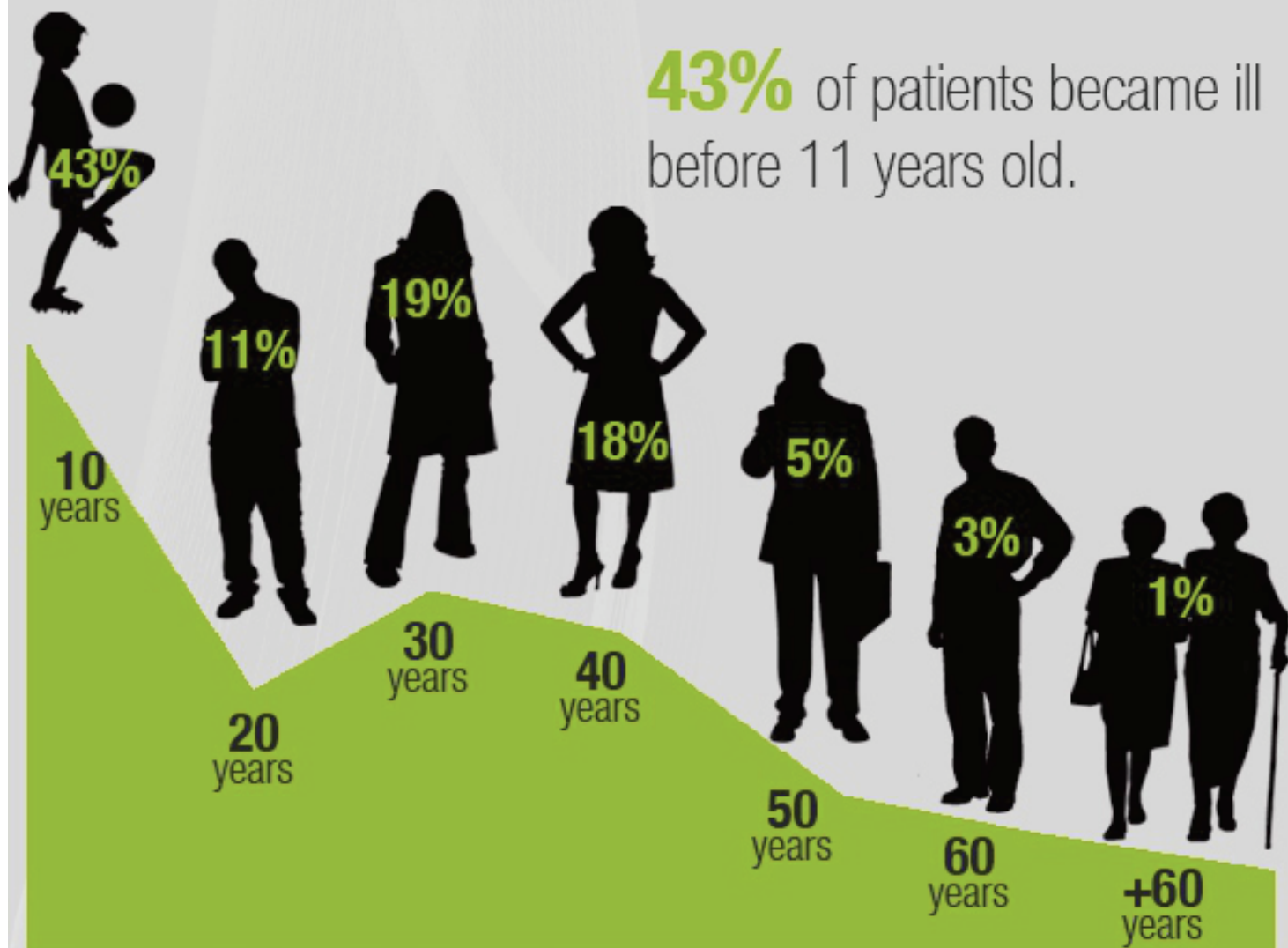
LIVING WITH aHUS

*Atypical Hemolytic-uremic syndrome (aHUS) is a ultra rare autoimmune disorder which can lead to sudden blood clotting, kidney failure, other severe complications and premature death.

RESULTS FROM THE RARECONNECT ATYPICAL HUS COMMUNITY POLL

214 PARTICIPANTS

17 COUNTRIES



23% saw 4 or more doctors before diagnosis



DOCTORS

... including
Nephrologists
Hematologists
Pediatricians
Oncologists
Immunologists



GENETIC SCREENING

81% have undergone genetic screening

CURRENT TREATMENT



48%
Eculizumab



13%
Transplant + Eculizumab



7%
Plasma therapy



2%
Liver + Kidney transplant

REGISTRIES

“Less than half of patients said they definitely were in an aHUS Registry. About 50 said they were not and an amazing **65** patients said they did not know.”



EXPERT CENTRE FOR aHUS



54% of the respondents have access to a centre of expertise.

“Undertaking the survey itself has created more awareness and understanding, and survey results have provided fresh insights into the rare disease issues faced by aHUS patients and families.”

The full poll results are available on RareConnect.org - <http://bit.ly/aHUSPoll>


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