2014: an Atypical HUS Global Poll Collaboration

SURVEY QUESTIONS

2014 aHUS Global Poll: Survey Questions

In 2014, the aHUS Alliance collaborated with the EURORDIS sponsored RareConnect team to conduct a survey of adult atypical HUS patients and family caregivers of pediatric aHUS patients. (N= 217 participants from 17 nations)

While the RareConnect platform of rare disease communities was retired in 2023, some poll assets were previously archived and remain available. Unfortunately, the actual 20214 tool is not available but here are the questions involved in that global poll.

An archived whitepaper written regarding the 2014 poll data and analysis is available here: https://bit.ly/2014aHUSpollWhitepaper

More 2014 poll assets, along with the 2016 aHUS Alliance global poll info and results, may be viewed here:
https://www.ahusallianceaction.org/patients-research-agenda-ahus-global-polls/

Based on the slides and reports resulting from the 2014 aHUS global poll, survey questions covered these areas:

1. Role of the person filling in the questionnaire
2. Gender of the aHUS patient
3. Age of the aHUS patient at the time of the poll
4. Patient’s country of residence
5. Age at which the patient became ill
6. Did the patient undergo genetic screening for aHUS?
7. If yes, what was identified as the predisposing/genetic cause of aHUS?
8. If genetic screening was done, how did it take to receive test results?
9. What do you think was the likely trigger of the first manifestation of aHUS?

10. Was the patient initially diagnosed with TTP or HUS?
11. Did the patient receive screening for ADAMTS13 levels or E.coli/ Shigatoxin?
12. Length of time it took for the patient to be correctly diagnosed with aHUS
13. How many doctor visits did it take before an accurate diagnosis was made?
14. At any time in the years before becoming ill with aHUS, were there any unexplained symptoms experienced? (detail)
15. Which specialists were involved in the patient's diagnosis?
16. Were there any consequences of misdiagnosis or delay or lack of diagnosis? (detail)
17. Do you have access to a national aHUS expert/specialist centre?
18. Current treatment for aHUS (detail)
19. Are you receiving renal replacement therapy?
20. Do you consider your current treatment to be your treatment of choice?
21. For patients with access to eculizumab, who/what pays for it?
22. Did the disease cause changes to housing or lifestyle? (detail)
23. Have you participated in aHUS research in the past?
24. If you had the opportunity, would you participate in future research about aHUS (to include full genome testing)?
25. Are you enrolled in an aHUS clinical registry for research?
26. From what sources do you receive information about aHUS? (detail)
27. Prior to taking this survey, which patient organisations were known to you? (detail)
28. Are you a member of a patient organisation?