aHUS ACTION

National Institute for Health Care and Excellence
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AHUS Action response to ECD 2 HST - evaluation of Eculizumab for the treatment of aHUS

aHUS Action welcomes the advice of the NICE Highly Specialised Technologies Committee in recommending Eculizumab for the treatment of aHUS. The Committee has rightly recognised that Eculizumab marks a step change for the treatment of aHUS and this initial recommendation provides much needed hope for patients after many years of uncertainty.

aHUS Action is committed to supporting the development of a national treatment protocol, as requested by NICE, to ensure the cost effective use of Eculizumab in the NHS, and that all patients who are proven to clinically benefit from Eculizumab receive it.

Further to the recommendations, aHUS Action seeks clarification from NHS England on whether an NHS Highly-Specialised National Service is required to implement the recommendations or an Expert Centre is sufficient.

Many thanks in advance.

Yours sincerely,

[redacted]