aHUS Causes and Precautions

1.1 Are the predisposing genetic and triggering factors of aHUS fully catalogued and understood and will it help to know how variable are the risks of these between individuals?

1.2 When it comes to genetic testing of aHUS family members what is best – to know or not to know -and what can be done with the knowledge?

aHUS Diagnosis

2.1 Is there a diagnosis sweet spot which can be found before a developing thrombotic microangiopathy turns into a catastrophic episode of aHUS?

aHUS Treatment

3.1 Is there an optimal way in which a complement inhibitor can be delivered to suit an individual's need?

3.2 Can a clinically effective therapy be developed that is affordable for all aHUS patients?

3.3 Is it more cost effective, as well as clinically effective, for the management of an aHUS patient's treatment to undertake genetic testing?

3.4 Can a complement inhibitor be stopped safely when not needed by some aHUS patients and what makes them different?

3.5 Is there a significant difference in outcome between having a complement inhibitor before or after a kidney transplant?

3.6 Will there be a cure eventually?

aHUS Impact: Clinical/Psychological

4.1 Are there long-term studies of outcomes of those in remission whether treated by a complement inhibitor or not?

4.2 Can the side effects of treatment using a complement inhibitor be distinguished from those temporary and permanent ongoing ailments which follow initial onset?

4.3 Does the anxiety and self-esteem of aHUS patients vary significantly between treatment types and what can be done to reduce and boost them respectively?

aHUS Impact: Socio-Economic

5.1 How does living with aHUS impact on education and work?

5.2 Do aHUS families have all the correct information to make informed family planning decisions?

5.3 How many aHUS patients are there in my local area, my country and the world and how do they differ?