Shared Care Agreement: aHUS patients under the care of the National Renal Complement Therapeutics Centre

1. Background	Eculizumab and Ravulizumab are treatments available for patients with aHUS in England, and treatment is co-ordinated through NHS England. Our centre is based at the National Renal Complement Therapeutics Centre (NRCTC), and we are part of The Newcastle upon Tyne Hospitals NHS Foundation Trust. The model of care for these patients is one of shared care. In practice, this means that patients who are referred to our service remain under the care of the local nephrology team as well as the NRCTC. Sharing of information between the NRCTC and the local team is essential for the delivery of safe and effective care.
2. NRCTC Responsibilities	1. Authorise the initiation of treatment with Eculizumab for patients with a likely diagnosis of aHUS who may benefit from treatment and who meet the eligibility criteria. 2. Perform and review genetic and complement testing for causes of aHUS and report the results to the referring consultant. 3. Offer patients and carers the opportunity for appointments with an NRCTC Consultant and Specialist Nurse, then ongoing follow-up appointments with an NRCTC Specialist Nurse. 4. Provide patients and families with information about aHUS and treatment options in the short and longer term, including: drug therapies; giving time-limited treatment in most cases, then ongoing monitoring for disease relapse. 5. Offer appointments to family members for genetic counselling and provide information to family members. Offer testing to family members where appropriate. 6. When patients have completed time-limited treatment, work with local kidney team to make a robust plan for both routine monitoring, and developing a pathway for patients to follow in the event of suspected relapse. Ensure this plan is captured in an “Emergency Healthcare Plan” which is given to patient/parent, and copies to local kidney consultant and GP. 7. Ensure patients stopping treatment are counselled about the risk of relapse, know signs and symptoms to observe for, and know how to access urgent assessment is they are worried about relapse. 8. Provide ongoing advice and support to the local managing team for aHUS patients where needed. 9. Co-ordinate the measurement of meningococcal titres and recommend boosters where indicated. Share all results and recommended actions with the local managing team and GP. 10. Co-ordinate and facilitate any specialist aHUS monitoring required e.g. complement blockade assessment; factor H autoantibody titres etc, and ensure all results are fed back to the local managing team.

	11. Ensure summary letter is sent to the referrer, and subsequent clinic letters and other relevant clinical correspondence are copied to the local managing team; GP and patient/carer.
3. Local Team Responsibilities	1. Contact the NRCTC team if there are clinical concerns about an aHUS patient where it is suspected that aHUS or the treatment for aHUS is a contributing factor. 2. Provide information about the patient to allow clinical decision-making 3. Prescribe and administer Eculizumab or Ravulizumab according to the manufacturer's instructions (the NRCTC will advise whether any dose adjustments are indicated based on clinical picture and complement blockade results). 4. Mitigate risk of meningococcal infection by following guidance on NRCTC website https://www.atypicalhus.co.uk/following-approval-of-eculizumab/ This includes: • Prescribing prophylactic antibiotics for the duration of treatment with Eculizumab or Ravulizumab and for 4 weeks (eculizumab) and 4 months (Ravulizumab) following any discontinuation of treatment. • Vaccinating with a tetravalent (ACWY) vaccine and Men B vaccine (against serotype B). • Make patient/parent/carer aware of the increased risk of meningococcal infection and possible symptoms of meningococcal infection and advise what to do if concerned 5. When prompted by the NRCTC, send specialist aHUS samples to where directed. 6. For aHUS patients *on treatment*, monitor renal function, platelets, LDH, haptoglobin, urinalysis and urine protein / creatinine ratio – frequency will depend on clinical picture. **7.** For aHUS patients who have *withdrawn from treatment*, perform and review blood tests and share results according to the schedule agreed with the NRCTC. 8. Report any adverse events (including any cases of suspected / confirmed meningococcal infection) to the NRCTC as well as through the MHRA Yellow Card scheme. 9. Notify the NRCTC of any variations in treatment, including: patient deterioration; non-compliance with treatment or monitoring; deviations in dosing/frequency; and pregnancy 10. If an aHUS diagnosis is confirmed, explain the principles of shared care to the patient to ensure they understand the benefits of shared care including access to clinical information and appointments with the NRCTC. They should be enabled to understand the need for ongoing information sharing e.g. past and current medical information, and other relevant details that can affect care. Ensure

	the patient is made aware about the involvement of the NRCTC in their care, and that the NRCTC will contact them to have ongoing appointments. 11. *Register aHUS patient with RaDaR where available and request that the data feed is switched on to allow NRCTC to see blood results 12. *Discuss with the patient about "Patients Know Best" where available and make them aware of how to sign up to this. Request that the data feed is switched on so that if the patient shares their record with us (at the NRCTC) we will be able to see blood results. *Registration with RaDaR and PKB allows for the collection of outcome data and help us to have oversight of blood results where bloods are done at a renal centre where there is a feed into the Renal Registry / PKB.
4. NRCTC Specialist contact information	Daytime telephone number: 0191 282 0385 Out of hours contact details: Hospital switchboard 0191 233 6161 (ask for aHUS consultant on-call) Email address: nuth.atypical.hus@nhs.net
5. Additional information	Where patient care is transferred from one specialist service to another, a new shared care agreement must be completed.
6. Further information	aHUS and C3G NHS specialists Newcastle - Atypical Hus

Please sign and return your agreement to share care.within 10 days of receiving the request.
By completing this form, you agree to the local team responsibilities set out in the shared care agreement for this patient:

Patient Name:	NHS No:
DOB:	Local hospital number:

☐ I accept sharing care as per the shared care agreement and above instructions

Local Consultant Name:	Signature:
Hospital:	
Telephone Number:	Date:
Email:	

NRCTC consultants:

Professor David Kavanagh, Professor Neil Sheerin, Dr Edwin Wong, Dr Emma Montgomery, Dr Vicky Brocklebank, Dr Sally Johnson, Dr Michal Malina