Primary **B**iliary **C**holangitis (PBC)

Pathway for **O**beti**C**holic **A**cid (OCA)

NHS
Cambridge University Hospitals
NHS Foundation Trust

2nd line treatment Referral Letter

- Referral letter to be completed by clinician and sent to Dr Mells (patient should be in PBC genetics study). Review if potentially suitable for Acid study. When F2F booked then will also see research study staff. re research study.
- Patient is added to PBC management spreadsheet by co-ordinator for monitoring purposes.
- Dr Mells reviews patient face to face— recruit to research studies if appropriate. Patient given Ultrasound scan / bloods and Fibroscan (if possible)
- Clinical decision made if suitable for second line treatment—Refer into MDT
- Patient referred to MDT (reviewed by clinician CNS and Pharmacist) - PBC management spreadsheet

MDT

- Patient is listed on the agenda and discussed at CUH MDT. (once per month). Coordinator to let referral centre know MDT date so they can dial in. Research nurses on MDT call re pharmaceutical clinical trial

Outcome of MDT is communicated back to referrer from CNS.

Not approved

1. Any required actions are implemented by referrer and then re-referred when appropriate.

Approved

1. Confirmation to start prescription (Basildon, Addenbrookes, Norfolk & Norwich)
2. Confirmation that treatment will be started under Basildon, Addenbrooke's or NNUH

Clinical Trial

1. If patient is considered potentially suitable for a trial, a member of the research team will contact the patient to asses suitability.
2. If suitable then research team to initiate treatment as per trial requirements.
3. If not suitable or willing then treatment returns to standard Home Care pathway.

Treatment

- Blueteq application completed by CNS. Prescription is populated. Patient consent obtained to share details with alcura inline with GDPR. Prescription signed by Lead Consultant.
- Co-ordinator sends prescription to Homecare Pharmacy for review and processing—Pharmacy to send to Alcura
- Alcura will arrange the first delivery with patient and inform prescribing hospital of first delivery date.

Monitoring for first 12 months

Patients are requested to have LFT's U&E's & FBC every 3 months and possibly every month for 3 months if they have severe Liver damage. Prescriptions from the Hub hospital will not be processed if up to date bloods not received.

- All patients MDT review at 6 months.
- If any changes to dose prescribing hospital notifies patient and referring hospital
- Patient's queries regarding OCA i.e side effects to come through to central MDT. All other PBC/ non OCA queries to go through patient's referring clinician.

After 12 Months

- MDT at Month 12—Patient will be discharged or require a change in treatment
- Patient to continue on medication and have 6 monthly bloods (CC CUH into GP Letters)