

Eastern Liver ODN/Network Meeting

Robinson College, Cambridge, 26th September 2019, 1700 – 1830

Apologies: Deb Ghosh, Chirag Oza, Andrew Douds, Debashish Das, Achuth Shenoy, Stuart Kendrick, Wendy Smeeton, Marianna Mela, Mike Allison, Paula Roberts

Present: Syed Alam, Bristi Basu, Rachel Bates, Tillie Bond, Philip Branch, Gary Bray, Jo Brown, Jamie Browne, Tanya Chapman, Lucy Dagher, Rachel Dix, Katie Eiloart, Sarah Fairclough, Abi Ford, Natasha Gaskin, Will Gelson, Bill Griffiths, Janeane Hails, Matt Hoare, Pooja Khanna, Jo Leithead, George Mells, Marie Moore, Gabriella Oliver-Wilkins, Martin Phillips, Liz Read, Georgina Rutherford, Sambit Sen, Vicky Snowdon, Tracy Woodall

Minutes:

Research:

Abi Ford discussed inclusion/exclusion criteria relating to commercial NASH trials running at CUH:

- GENFIT RESOLVE IT (Elafibranor)
- REGENERATE (obeticholic acid)
- Enyo study (EYP001a)
- MAESTRO-NASH (Resmetirom).

Luton, Basildon and Norwich are running commercial NASH trials in addition.

1 x commercial PBC trial running at CUH: ENANTA (EDP-305)

Norwich running commercial PSC trials

ODN (HCV): (Jo Brown/Will Gelson)

- Discussed use of hotspot data (courtesy of Gwilym Webb) to identify areas of unmet need and thus a targeted approach to HCV screening/treatment in the region
- SVR 12 data was shown 2016-2019 with excellent results across the region
- CUH has the largest increase in run rate of all the ODNs nationally (907 ie 227 per quarter) - currently an appeal is in progress
- Q1 treatment figure of 186 cf 177 comparable quarter 2018 – below target but reflects everyone's efforts in maintaining this level of treatment within the network, JB/WG grateful
- PTPPS (per treated patient payment scheme) now in place with £500 remuneration for blueteq + minimum 4 weeks treatment (excludes prisons). CUH received Q1 payments, from Q2 will be direct to treating centre
- Discussed use of money from PTPPS as needs to directly feed into methods that will help attain run rate – regional 'roaming' nurse,

associated treatment van, pharmacy technician, dry blood spot testing, swabs

- Discussed prison initiatives
- Requested that the HCV registry be updated for each patient
- Jo Brown announced that she is leaving her role – group thanked her for all her work to date, replacement to be sought

ODN (PBC): (Jo Brown/Janeane Hails)

- In search still of patients requiring 2nd line treatment
- Norwich approved as hub and will be starting shortly
- Basildon in process of setting up
- 80 patients referred to CUH to date: 44 OCA treated (9 stopped mainly due to itch), 26 fibrate treated
- Plan is now to discharge patients to the referring centre for face to face follow up supported by 3 monthly telephone clinics from CUH until 12 m for OCA (thereafter 6 monthly) and 6 m for fibrates (thereafter as required)
- Request to sign up all new patients to UK PBC

HCC: (Matt Hoare, Vicky Snowdon, Bristi Basu)

Discussed use of LiRADS system to provide consistency in lesion diagnosis and which lesions to biopsy/treat

Discussed transplant criteria including downstaging where patients outside initial criteria may be eligible subsequently

Discussed the BCLC staging system for categorizing potential treatment options

Discussed that palliative chemotherapy has expanded – sorafenib or lenvatinib first line with regorafenib 2nd line, new agents coming through with potential to double life expectancy

Explained that there are now trials at every phase – early detection (breath test), adjuvant therapy, TACE related, SBRT, chemotherapy

Videoconferencing to be rolled out within the current MDT structure (1-2.30 pm Thursday)

Clinical networking: (Bill Griffiths and group)

- NAFLD screening in primary care – discussed that CUH have a pathway that seems to be working using FIB4. Not much uptake across the region although N&N are soon to pilot FIB4/ELF – some barriers across the region include GP access to AST, disintegrating primary care services, concern will overwhelm secondary care, funding. Good evidence from the recently published Royal Free study that FIB4/ELF pathway is cost effective and hones the significant fibrosis population into secondary care.
- Decompensated cirrhosis identification – plan from the CRG is a new ‘liver centre’ specification and an expectation that the care bundle will be used for majority of patients admitted with decompensated cirrhosis. One issue is that ICD coding does not

readily identify these patients and the HES data that NHSE receive is not very accurate.

- ICU admission difficulties – there is a plan for a survey monkey via BSG to assess attitudes. The general feeling is that newer appointed ICU consultants are more amenable to admitting cirrhotics (esp alcohol).
- Barriers to transplant referral – eg patient perception/understanding of the severity of their liver disease, language barriers, recognition the first sign of decompensation should alert clinicians. Piece of work being done nationally (Jo Leithead involved).
- Patient support groups – Sarah Fairclough mentioned that Basildon have a nurse led group in conjunction with palliative care, Bristi Basu mentioned an HCC support group. We don't have a regional patient led group for liver disease and is something to think about.
- Newsletter – it was agreed that a Spring newsletter covering overarching issues would be informative. The ODN will continue with their specific monthly newsletter.

AOB: Dr Allison organizing a regional liver CRN research forum in Feb/March 2020

Date of next meeting: 24.9.2020, 5 pm, Murray Edwards College

WJHG 30.9.19