

# Scottish HepatoPancreatoBiliary Network (SHPBN)

Volume 1 Issue 5

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# Special point of interest:

# SHPBN Education Event Friday 27<sup>th</sup> January 2023

The Chancellor's Building, Edinburgh BioQuarter, 49 Little France Crescent, Edinburgh EH16 4SB

Details to follow

# Headlines



## Welcome to the SHPBN Winter Newsletter 2022/23.

I would like to start by thanking Lyndsay Campbell our Network Manager for over 14 years who is retiring this month. He has supported the Network and each of the clinical leads with so much enthusiasm and care. All your work is very much appreciated, and we wish you a very happy retirement.

I would also like to take this opportunity to warmly welcome Marie Gallagher our new Network Manager who has come into the job flying. We are all looking forward to working with you over the coming years.

It has been another busy year for the Scottish HPB community, thank you to those who have contributed to this newsletter keeping us up to date with some of these initiatives. In 2022 we held our annual educational event and National M&M meetings virtually, next year we hope to go back to some in person meetings and I look forward to seeing you all face to face over the coming months.

Wishing everyone a happy Christmas and best wishes for the New Year.

Ms Anya Adair SHPBN Clinical Lead Consultant HPB/Transplant Surgeon Edinburgh Royal Infirmary

# National Pilot for Liver Transplantation in Neuroendocrine Tumour Patients with Unresectable Liver Metastases

The National Pilot for Liver Transplantation in Neuroendocrine Tumour Patients with unresectable Liver Metastases is open as of August 2021.

**Tahir Shah** – Consultant Hepatologist and Chair of the National MDT for patient selection for liver transplantation for Neuroendocrine Tumour liver metastases.

**Stacey Smith** – Clinical Nurse Specialist and Operating Officer for the National MDT for patient selection for liver transplantation for Neuroendocrine Tumour liver metastases.

In 2018 NHSBT and the liver advisory group (LAG), the regulators for liver transplantation in UK and Ireland, asked for guidance on the usefulness of liver transplantation in patients with unresectable neuroendocrine tumour liver metastases. A panel of experts provided their opinion in 2019, recommending a pilot programme to determine feasibility and utility of liver transplantation for this group of patients.

The selection of patients began in August 2021, overseen by the National MDT. So far national MDT has assessed 20 patients referred by: Birmingham, King's, Leeds, Newcastle, Oxford, and Royal Free. 5 patients were deemed immediately suitable in principle for liver transplant assessment as all extrahepatic disease had been previously cleared; 11 patients were deemed likely suitable once the primary and associated LN disease has been removed. 4 patients were not suitable due to inability to clear all extrahepatic disease.

The first patient was placed on the national waiting list in October 2022 and we hope to list between 10 - 20 patients a year. The pilot will be complete on transplantation of 50 patients in total. If the pilot programme is deemed successful, we shall be able to continue offering liver transplantation for neuroendocrine tumour patients.

Guidance on selection of potential patients and referral to the national MDT is available on the UK and Ireland Neuroendocrine Tumour Society (UKINETS) website (links provided below).

There is a 'bitesize' summary of the programme and how to refer to the National MDT. Detailed information about the programme and the referral proforma are available on the UKINETS website also with a link from the bottom of the bitesize guidance document.

#### **USEFUL LINKS:**

Bitesize guidance: <a href="https://www.ukinets.org/wp-content/uploads/Liver-Bitesize-Guidance-FINAL-1.pdf">https://www.ukinets.org/wp-content/uploads/Liver-Bitesize-Guidance-FINAL-1.pdf</a>
Programme documents: <a href="https://www.ukinets.org/net-liver-transplantation-pilot-programme-supporting-documents/">https://www.ukinets.org/net-liver-transplantation-pilot-programme-supporting-documents/</a>
Referral proforma: <a href="https://www.ukinets.org/wp-content/uploads/NET-Liver-Transplant-mdt-tertiary-referral.pdf">https://www.ukinets.org/wp-content/uploads/NET-Liver-Transplant-mdt-tertiary-referral.pdf</a>

Further information and any enquiries should be directed to Miss Stacey Smith at Stacey.Smith@uhb.nhs.uk

# **Molecular Pathology**

## Working towards genomic profiling for biliary cancer patients in Scotland

Biliary Tract cancers are tumours arising from the lining of the bile duct. Recent advancements have led to the approval of novel drugs that fall within the precision oncology approach. To implement this therapeutic strategy, it is necessary to identify the genomic make-up of a given tumour, on the bases of which the most effective drug can be chosen. Through the study of small elements that hold genetic information (DNA and RNA), it is possible to identify the driving engine behind the tumour, that, if blocked, could lead to a long-term disease control.

As a cooperative team within NHS Scotland, we are working towards the identification of pathways that could support genomic profiling of biliary cancer patients, so that Scottish patients are given the chance to access additional therapies for their own benefit.

Dr Chiara Braconi (Medical Oncologist, The Beatson West of Scotland Cancer Centre)



# **Lindsay Campbell's Retirement**

As some of you may already know Lindsay will be retiring from his post as the SHPBN manager on 12th December 2022. Lindsay was instrumental in setting up the national HPB Network with clinical colleagues over 14 years ago. Since then, the Network has continued to go from strength to strength and Lindsay, together with various Clinical Leads, has played an important role engaging and working hard with Network members across the various specialties and organisations to drive improvements in care for all patients with HPB cancers in Scotland. Lindsay's friendly and can-do attitude, and ability to get things done by knowing who to go to for what has enabled us to achieve a great deal over the years. We have held many successful education events that have included patients and carers; we have

strengthened our partnership working with the charities and more recently we have just launched our pathway improvement project with Lindsay's support, guidance and perseverance. No matter what, Lindsay has always kept patients and their families at the centre of everything he and our Network strives to do.

We will miss Lindsay but wish him a happy and healthy retirement pursuing his many interests which range from travel, curling, spending time with his family and walking Florrie the dog.

Lindsay's last job was to get Marie, up to speed to ensure a smooth handover and continuity of support for the Network. Marie is the new Programme Manager at the Scottish Cancer Network who will be taking over responsibility for the National Networks. Both have been out and about over the past few weeks and hopefully have managed to catch up with some of you, allowing Lindsay to say farewell and Marie to say hello!

Lindsay a fond farewell and our sincere thanks for all your hard work over the years ©

For future reference Marie can be contacted at: marie.gallagher4@nhs.scot

# Pancreato-Hepatocellular Cancer Pathway Improvement Project (PHCC PIP)

The Pancreato-Hepatocellular Cancer Pathway Improvement Project (PHCC PIP) has recently launched in several regions of NHS Scotland to help patients with suspected hepatocellular carcinoma (HCC) or pancreatic cancer (PC) receive the diagnostic tests they require more quickly. A prior audit identified delays in investigation and inconsistent communication to be major contributors to adverse patient experience.

This pilot project is an initiative spearheaded by the SHPBN and funded by the Scottish Government. It aims to ensure that patients who have a scan suspicious of PC or HCC are referred through an accelerated pathway via a National Virtual Cancer Care Team within National Services Scotland, who will triage the patient following a referral. The Team will work with the patient's local health care teams to ensure earlier diagnostic and staging investigations take place, improving the efficiency of the referral to regional multidisciplinary teams (MDTs) process and therefore more rapid initiation of appropriate treatment. A retrospective audit has taken place to establish a baseline data from which to assess the success of the project.

A phased rollout recently commenced on a regional basis, initially across the North and subsequently the West and then East of Scotland, with National rollout due to be completed in January. Radiology teams in these regions have been advised that if they have a suspicion of a new pancreatic or hepatocellular carcinoma on a scan, they should notify the patient's CHI to <a href="mailto:nss.hpb@nhs.scot">nss.hpb@nhs.scot</a> as per their agreed local protocol. FAQs and a poster that should be displayed in reporting rooms have also been circulated to radiology throughout these regions.

If you have any queries or would like any further information on the project, please contact nss.hpb@nhs.scot

# **Education and Events**

Annual Mortality and Morbidity Review: 18th November 2022 (virtual) - Compared 2021 with the previous 3 years. Thanks to Mr Nigel Jamieson, Mr Andrew J Heally and Mr Euan Dickson for chairing the sessions.

SHPBN Education Event 2023: 27th January 2023, The Chancellor's Building, Edinburgh Royal Infirmary This will be our first face to face event since the pandemic. Programme to be announced soon.

BTS NHSBT Joint Congress 2023: 1st - 3rd March 2023, EICC Edinburgh

**HCC-UK Annual Conference 2023**: 16<sup>th</sup> – 17<sup>th</sup> March 2023, The Royal College of Physicians, Edinburgh

AMMF European Cholangiocarcinoma Conference 2023: 10th - 12th May 2023, Hybrid & Stansted

# **National Clinical Trials**

Dr Alan Christie, Consultant Medical Oncologist, leads on National Clinical Trials available in Scotland. The list can be found on the SHPBN website's Clinical Trials page: https://www.shpbn.scot.nhs.uk/clinical-trials/

# **Charity Corner**



Pancreatic Cancer UK is here so people don't have to face pancreatic cancer alone. A diagnosis can be a terrible shock, but we are here to help them make sense of it and guide and support them and their family at every step that follows. For Health Professionals, we have a range of free events, training and resources so you can learn, develop and collaborate with the pancreatic cancer community. You can also access our expert information and **services** to support your patients at every stage of their journey.

# **Health professional training and events**

We've held a range of events so far this year, with a highlight being our pain management event which explored the pain your patients can experience, how it can impact them and how to assess and manage it. View the recordings and slides

The event was very informative, easy to listen to and engage with. This was very relevant to practice and kept you engaged throughout the event. Thank you all for the informative content and the way this was delivered

Palliative care specialist

#### **Online courses**

We have a three-part course providing an introduction to pancreatic cancer as well as a guide to pancreatic cancer and pancreatic enzyme replacement therapy. These are aimed at health professionals, free and can be taken any time. Find out more here

## Stay up to date

We send out a monthly bulletin which highlights all the support and information we have available to you as well as your patients. Sign up to our health professional support and information bulletin to hear about our upcoming events, courses, and resources.

## Partnership opportunities

We love partnering with teams across the UK to deliver useful and relevant events for the health professional community. In November we held a two-part event with Belfast and Southern Health and Social Care Trusts on nutritional management for dietitians and CNSs based in Northern Ireland. 100% said they'd recommend another event to their peers and rated them good or excellent.

Excellent morning - very well organised. relevant informative. Great to have NI speakers that know the local pathways and services - makes it more relevant

If you're interested in teaming up with us to deliver an event, please get in touch with our events manager: abi.lester@pancreaticcancer.org.uk

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# Support for your patients

# Support line

Our specialist nurses are experts in pancreatic cancer and are only a phone call away. Our confidential support line is open Mon, Tue, Thu and Fri, 9am – 4pm, and Wed 10am – 6pm. Please tell your patients to call 0808 801 0707 or contact a nurse via email.

# **Online Support Sessions**

Our specialist nurses run regular sessions over Zoom to help support your patients with managing nutrition, coping with symptoms, managing chemotherapy and more. We also run monthly sessions for family and friends.

<u>Check out our upcoming support sessions and share with your patients.</u>

It's easy to feel very alone with our problems. It was so nice to be able to hear from others at different stages of the journey

Attendee at an online support session

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## **Publications**

We've recently published our dealing with the <u>emotional impact of pancreatic cancer</u> information. We have <u>more free information</u> covering all aspects of pancreatic cancer which is easy to understand and reviewed by clinical experts so you can share it with your patients with full confidence.

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<u>Our end of life care booklet</u> is one of our most popular information resources providing key information for people at this difficult time, explaining the symptoms people may get and how to manage these, and how to access the care and support they need.

We also launched patient information on type 3c diabetes on our website and a free diabetes fact sheet for patients to download.





# Liver Cancer UK launched to improve the lives and outcomes of those affected by liver cancer

Liver Cancer UK, part of the British Liver Trust, has been launched so that everyone living with liver cancer has better access to high-quality information and we can better advocate on their behalf. With a new dedicated website and set of resources, it will make it much easier for people with liver cancer to find and access support.

While the British Liver Trust is recognised as the UK's leading charity for people affected by liver disease, the charity felt the need to do more to help people understand and feel connected to their work to support those affected by liver cancer. In collaboration with clinical experts and people affected by liver cancer, the Trust developed Liver Cancer UK. Through this programme of activity, they will build on their existing work within the liver cancer community and maximize the impact of their campaigning to improve early diagnosis and drive up standards of care.

Find out more www.livercanceruk.org