LIVErNEWS

Liver Patient Support Newsletter
Summer 2022



Glossary of abbreviations

Here are some frequently used abbreviations you might come across in this magazine and elsewhere in healthcare.

A&E AIH ALD ALF	Accident and Emergency Auto Immune Hepatitis Alcoholic Liver Disease Acute Liver Failure	LFT LFT LSM	Liver Function Test Lateral Flow Test Liver Stiffness Measurement
APEX ARDS ARI ARLD	Advising on the Patient Experience Acute Respiratory Distress Syndrome Acute Respiratory Infection Alcohol Related Liver Disease	MRC MRHA	Medical Research Council Medicines & Healthcare products Regulatory Agency
ВР	Blood Pressure	MRI NAFLD NASH	Magnetic Resonance Imaging Non-Alcoholic Fatty Liver Disease Non-Alcoholic Steatohepatitis
CCG CHB CRESTA	Clinical Commissioning Group Chronic Hepatitis B Clinics for Research and	NFIB NICE	National Fraud Intelligence Bureau National Institute for Health and Care Excellence
CQ CQC	Service in Themed Assessments Chloroquine phosphate Care Quality Commission	NHS NHSBT NIHR	National Health Service NHS Blood & Transplant National Institute for Health
CT	Computed Tomography Fatty Liver Index	Research NSAID drug	Non-steroidal anti-inflammatory
FLI	rally Liver index	urug	
GIT GP	Gastrointestinal Tract General Practitioner (doctor)	PALS Services	Patient Advice and Liaison
HAV HCC	Hepatitis A Virus Hepatocellular carcinoma	PBC PHE PPE	Primary Biliary Cholangitis Public Health England Personal Protective Equipment
HCQ HCRG	Hydroxychloroquine Hepatobiliary Clinical Reference	PPI/E	Patient and Public Involvement/Engagement
Group HCV	Hepatitis C Virus	PSC	Primary Sclerosing Cholangitis
HDU HE	High Dependency Unit Hepatic Encephalopathy	RAT	Rapid Antigen Test
HEV HIV	Hepatitis E Virus Human immunodeficiency virus	TED TX	technology, entertainment, design Transplant
HPB HRCT	Hepato-Pancreato-Biliary High-Resolution CT	T2DM	Type 2 Diabetes
ICP	Integrated Care Plan	UIOLI URSO	Us It Or Lose It Ursodeoxycholic acid
ICS ICU ITU	Integrated Care Scheme Intensive Care Unit Intensive Therapy Unit	(we will up	date this glossary every issue)

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- 2 Glossary of Terms Used
- 4 Chairman's Report
- 5 LIVErNORTH Talks on YouTube
- 6 The Geordie Hospital Talk
- 7 My Experience With Covid Debs Lovell
- 8 Mark Hudson Debs Lovell
- 9 A Silent Angel Stands Jean Ramsay
- 10 Waiting for the List Jayne Pilkington
- 11 Easy Gooey Brownies Jayne Pilkington
- 12 Finding Family travelling to find my ancestors Liz Bennett
- 14 Obituary June Ormiston
- 15 The PRINCIPLE Trial & PANORAMIC Study update Sian O'Dea
- 16 More On Captain William Smith Of Blyth Alf Bennett
- 18 New research to help organ donation & transplantation patients
- 20 Great Expectations
- 22 Letters
- 24 LOTTERY Winners
- 25 LOTTERY Application Form
- 26 Have You Seen This Plant? Alf Bennett
- 28 Essential Numbers Page Keep For Reference
- 29 Helen's Howlers
- 33 What would you take if marooned on a dessert island? Alf Bennett
- 36 UIOLI SUDOKU Summer 2022 & SUDOKU Spring 2022 solution
- 37 Insurance Matters
- 38 LIVErNORTH Information Leaflets Available

Contact Numbers - inside back cover Helpline Numbers - on back cover

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Chairman - John Bedlington

It's around twelve weeks ago that the last LIVErNEWS was published and it seems that the poor people of Ukraine are still enduring extreme hardship during the invasion of their country by the Russian Army. If there is anything positive to take from this awful situation it is that we have all seen wonderful support from the most unlikely places for the Ukranians. I'm not talking about sending weapons, I'm talking about ordinary people going to extreme lengths to house refugees, take ambulances and fire engines to Ukraine, take medicine, blankets, food and countless other essentials to support the people and the infrastructure. It's very hard to put any positive slant on this horrible war but the people of Ukraine surely deserve a big hug from the rest of the free world - if we can't help in any other way, it might help them to know that we are thinking about them and wishing them well.

The latest on Covid as that it is still here and mask wearing is still recommended in enclosed public spaces and healthcare environments so please continue to wear a mask that protects you. We're now in the early stages of Monkey pox and can only wait and see how that develops. So far, spread seems fairly slow and the Smallpox vaccine offers some protection but who knows where it's going? We must all continue to be vigilant and look out for each other.

I mentioned the Geordie Hospital TV programme in the last issue and the talk given about making the show by Mr Colin Wilson. This excellent talk is now available to watch on our You Tube channel as well as the latest talk from Prof David Jones from 25th May: PBC - 'Is the Fog about to Clear?' where some of the new, exciting and

interesting therapies are discussed as well as some that are available over the counter without a prescription.

I now need to tell you something quite amazing. Both my wife Joan (our Hon Treasurer) and myself each received a letter a month ago from the Cabinet Office.

Apparently we will both be awarded an MBE in the Queen's Jubilee Awards on the Jubilee Anniversary (3rd June 2022). The citation is 'For service to liver patients' and needless to say, we are both extremely humbled and basically, blown away.

The LIVErNEWS is a little late because there is a strict embargo on telling anyone so we have delayed publication until now. We have no idea who nominated us but what we do know is that it isn't just about us.

LIVERNORTH is now, and always has been, about the founder members, past members, governors, clinicians, friends and current members who have made it what it is. An MBE is a brilliant accolade and you should all take pride in being part of the journey that got us here today. Thank you from us both - we are very humbled.

As usual. I'm not going to list every LIVErNEWS article but I would especially like to thank again my fellow governors and our friends for their contributions to this issue - some really good and interesting reads. In closing - we still have a few Great North Run places (September) if you want to

fundraise for us by doing the half marathon -

Best wishes everyone and TAKE CARE.

apply now by email!

LIVErNORTH on





You can access lots of our talks and videos on YouTube. Go to YouTube in your browser (https://www.youtube.com/) and type livernorth into the search bar. When it loads, click on 'videos', and you will see the 30+talks and videos that are currently available.



BRIEFINGS & TALKS

Sept	2015	Dr Quentin Anstee	NAFLD for link.
Oct	2015	Prof Derek Manas	Liver Transplantation
March	2016	Dr Peter Littler	Interventional Radiology
Oct	2016	Mr Jeremy French	A Case to Remember
March	2017	Dr Robert Samuel	ITCH in PBC and other liver diseases
July	2017	Dr Kate Hallsworth	NAFLD Lifestyle Interventions
Sept	2017	Mr Colin Wilson	Liver Perfusion
Oct	2017	Dr Kofi Oppong	Endoscopy in Liver Disease
March	2018	Dr Lin Lee Wong	UK-AIH Study
May	2018	Prof David Jones	The Revolution Moves On (PBC)
June	2018	Prof Dave Talbot	The Effect of the Media on Transplantation
Sept	2018	Mr Jeremy French	Human Factors in Surgical Crisis
March	2019	Rahul Bhugra	The Yellow Card Scheme
March	2019	Prof David Jones	PBC
March	2019	Dr Anand Reddy	QE Hospital Liver Services
May	2019	Prof Derek Manas	Transplant Matters
June	2019	Mr Colin Wilson	Liver Perfusion Update
July	2019	Dr Steve Masson	Research Update
Sept	2019	Dr Jess Dyson	AIH/PBC/PSC clusters & findings
Oct	2019	Mr Jeremy French	Training Transplant Surgeons
April	2020	Prof Matt Wright	Environmental chemicals and PBC
Nov	2020	Prof Quentin Anstee	NAFLD
Dec	2020	Prof David Jones	PBC - Where We Are In 2020.
March	2021	Dr Jess Dyson	What's New in AIH?
April	2021	Mr Colin Wilson	What's New in Transplantation?
June	2021	Organ Donor Team	The Organ Donation Journey
July	2021	Prof David Jones	PBC, The Vaccine and the Immunosuppressed
Sept	2021	Mr Aimen Amer	A King's Fellow Returns
March	2022	Mr Colin Wilson	The Geordie Hospital TV series.
May	2022	Prof David Jones	PBC - Is The Fog About to Clear?

TEDx TALK A patient's perspective | Tilly Hale | TEDxNewcastle **DVD** (not interactive) A Patient's Guide to PBC

GEORDIE HOSPITAL TALK - Alf Bennett

For those of you who missed it, here are some brief notes on the talk given by Mr Colin Wilson, Consultant Transplant Surgeon on his appearance in "Geordie Hospital" at the LIVErNORTH meeting on the 9th March 2022.

What an incredibly fascinating presentation. The episode that Colin was involved in focussed on transformational surgery. It showed how a patient's life could be changed over the course of a day. The camera team followed him for a full day, starting from home travelling to the hospital (including getting him to park the car six times until the director was happy with the outcome) and finally finishing back at home on the evening. The key part was the kidney transplant during the day which went very well.

There was obvious anxiety as to how the programme would be received, as participants did not see the episode before it was screened. The outcomes were very positive, across all social media and TV reviews with comments like,

"Geordie hospital is the NHS reaching out and giving you a warm hug"

"It showed the very best of the NHS"

Following the series success, there surely must be more episodes.

Don't forget you can access many of the past talks through LIVErNORTH on YouTube and you can join our future meetings with guest speakers via ZOOM. Details are always provided in our quarterly newsletters, email us for an invite: info@livernorth.org.uk

Organ Donation - have the conversation.

Register your wishes by signing the NHS Organ Register online at www.organdonation.nhs.uk or by calling 0300 123 23 23

Most Importantly
Speak to your family to
LET THEM KNOW YOUR WISHES.

My Experience with Covid

At the end of the first week in March I suddenly developed a heavy cold. It was literally overnight. Looking back on it now, I had been experiencing head pain (not a headache) for the week prior. However, I did not for one minute think it was COVID 19, just a heavy cold. A week later my condition was beginning to improve. However (and when it first crossed my mind) the following morning I woke and the cold was a lot worse. After speaking with my sister Erica, she enquired as to whether I had taken a lateral flow test. I said no. I had just had a cup of tea so I waited a while before taking it. Straight away it turned positive. I waited another 2 hours and took another one, which was again positive. The first thing I did was report the test result to the NHS COVID 19 App entering the QR number. I then turned my attention to the PCR test which had previously been delivered on Boxing Day by hand. The leaflet that comes with the kit explains precisely what and when you are required to do it. BEFORE the test it is important to find out where a PRIORITY post box is and the collection times. This is because the PCR must be done 'at the most' 1 hour BEFORE the collection time. Also, the kit must be registered, just before the test itself is done (online or by text). So, some ordination is the key here! After the PCR is posted results takes up to 2 days, and you will be informed by email or text (by which ever method you will have chosen). The leaflet does say that the NHS will contact you if you have a positive result. However, in my experience I was contacted by an NHS COVID doctor the same day as I reported the positive lateral flow test. It was the following day when the PCR was posted off. The doctor asked a number of questions including when my symptoms developed. I explained what I have written at the beginning of this article. Because I had been unwell for at least 10 days the doctor explained I would no longer be infectious. If I had reported a positive test within the first 5 days then it would have been possible to have anti-viral treatment. The doctor explained there were 4 different anti-virals, one of which is given intravenously over 3 days. The only problem being that the side effects of this would make me feel even worse. The doctor then suggested taking part in the Covid Oximetry at Home Monitoring Service run by the Fylde Coast Virtual Ward. Participants are required to download the DOCOBO App. Patients are given a small device called a 'pulse oximeter' which takes your oxygen levels and pulse rate. (The device and paperwork were hand delivered to my home within one and a half hours from talking to the COVID doctor). The device is pressed on, then opened and pressed onto your middle finger. Wait 30 seconds. Then record the 2 readings on the sheet which is provided. The App is then accessed which is where the 2 readings are entered. The App is linked to the virtual ward so your results can be seen. This was done 3 times a day. As well as this a COVID doctor would ring me daily to check on my condition. Over the next 6 days my recordings were within the normal range, therefore the condition was not getting worse so the Oximeter was returned to one

of 3 local Health/Care centres. Over the following 3 days I took daily lateral flow tests which were all negative so I returned to 'normal' life. Although the cold itself took a few more days to recover completely.

DEBBIE LOVELL

Dr Mark Hudson - Retirement

As a patient, I first met Dr Hudson back in 1995 or earlier. He has been 'part of my life' for a considerable length of time. But no longer. As many of you will know he has recently retired. Dr Hudson had for many years shown utmost dedication to his patients and career as a liver transplant physician. He was, as I say, a 'human' doctor. He always made time to have a chat when medical things were not going as expected. You



could talk to him and he always responded in a caring and understanding manner. Having been a patient of his for at least 27 years I will miss seeing him in clinic and in the hospital.

Dr Hudson please be aware that I (and my family) appreciated your kind, personal and understanding manner. You are held in the highest regard possible as far as I am concerned. Thank you from the bottom of my heart because I will never forget how you were over these passed years.

Enjoy a long and 'healthy' retirement. You deserve it!

Take Care

DEBBIE LOVELL

Took the words right out of my mouth Debbie. He was loved and respected by so many of his patients being their 'physician of choice'. We have been in touch with Mark and hope to meet up with him some time soon. (ed)



On a windswept hill not far away a silent angel stands, wings open in welcome, protecting, guarding our northern lands.

A symbol of pride, strength and power, where past and present meet, she stands on a site of memories, coal-dusty ghosts beneath her feet...

Marking the end of an era, on the land of the old Teams mine, where proud men toiled in the darkness, she embodies a lasting shrine.

The scars of industry vanished now, lands reclaimed are green and fruitful, yet, northerners know they're home again.... when they catch the sight of an angel.

© Jean Ramsay 2019

Waiting for the List by Jayne Pilkington

We've done everything we can; we must now consider the 'list', But first comes a raft of tests, to make sure nothing is missed

A chance for a new start, much removed from the life I now live, An unbelievable opportunity, something that seems so hard to achieve

My life at the moment, less ups, more downs, Appointments and letters, waiting around, full of frowns

Imagine no itching, normal sleep and more choice, Living a life more spontaneous would make me rejoice

The tests are now all done; it's time to wait, The results and medical professionals now decide my fate

> So time for me to wait and be calm, No room for panic or alarm

As anticipated, the phone did ring with a decision, They said 'Yes', agreeing it would put me in a better position

A new liver is required; I need to join the transplant list, But first to meet the surgeon, so no details are missed

We discuss the operation, the benefits and risks, How long I'm likely to wait, it's not going to be brisk

Now it's time to sign the consent, A big step on my journey this does represent

Central to all of this is a selfless donor family, Amazing human beings, shining examples of humanity

Not sure how I feel, a strange notion of relief, But conscious when my call comes, it will mean another families grief

Organ Donation - have the conversation.

Register your wishes by signing the NHS Organ Register online at www.organdonation.nhs.uk or by calling 0300 123 23 23

Most Importantly
Speak to your family to
LET THEM KNOW YOUR WISHES.

Easy Gooey Brownies by Jayne Pilkington

Prep 20 mins

Cook 30 mins plus cooling

Makes 16 (or 8 if you like big bits of cake!)

The secret to gooey brownies is not to overcook them and to dot through caramel or chocolates filled with liquid caramel or ganache to help add moisture.

Ingredients

150g butter
75g light soft brown sugar
150g plain chocolate, broken into
pieces
1 tbsp golden syrup
3 eggs
125g golden caster sugar
1 tsp vanilla extract
150g plain flour
½ tsp baking powder
3 tbsp cocoa powder, plus more to dust
4-6 tbsp dulce de leche, caramel or
chocolate hazelnut spread

Method:

STEP 1

Heat the oven to 180C/160C fan/gas 4. Line a 20cm square cake tin with baking parchment. Melt together the butter, brown sugar, chocolate and golden syrup gently on a low heat until it is smooth. Remove the pan from the heat.

STEP 2

Whisk together the eggs and caster sugar in a large bowl until light and

fluffy – this will take a few minutes and is worth doing properly. Add the vanilla extract, then sift over the flour, baking powder and cocoa powder and add the chocolate mixture. Fold everything together quickly and scoop half of the mixture into the tin. Dot over scoops of caramel or chocolate hazelnut spread and then scoop the rest of the brownie mixture over the top. Add more scoops of caramel or chocolate spread, if you like, and bake for 30 mins. The top of the mixture should now be set and slightly cracked looking, but the mixture underneath will still have a slight wobble.

STEP 3

Remove from the oven and allow to cool completely before cutting into squares. Dust the tops with cocoa or icing sugar, if you like, or if serving as a dessert drizzle with more caramel. Will keep for 3 days in an airtight container.



Finding family - travelling to find my ancestors by Liz Bennett

Continuing with the building of my family tree, my latest finds are from my paternal side. After the first struggle and search I found that my father Samuel McVeigh was born in Scotland, however his father George, my grandfather was born in Co. Down, Northern Ireland, even though the family were living in Glasgow at the time. It appears that his mum Margaret (nee Moffat) had gone home twice to have her babies while the others were born in Glasgow.

I found the searches for the wife of George, Hannah so much easier and have been able to go back to my 11th great grandparents John Cowan born 1625 in Argyle.

Still continuing with my search I was able to identify that George's parents were Samuel McVeigh and Margaret Moffat both born about 1850. This was confirmed in other family trees. Then suddenly I was able to find their marriage, using an Irish archive site, along with the actual licence. They were married in 1872 in Raffrey, Presbyterian church, in Co. Down. On the licence it stated that they were of full age, but not how old and that they lived in Tullyveery, this was another small hamlet near to Raffrey. Samuel's father's name was also Samuel and his occupation was a labourer. Margaret's father was listed as a soldier named Thomas

So I now had the names of my 2nd great grandfathers. Continuing searches I found some possible hints at the soldier

link but nothing definite. Where I found Samuel and Margaret in other family trees I messaged and asked if they had more information. Some I got replies from but saying they also got no further. Others no replies, this can be because they don't want to or that they are no longer on Ancestry. So you just have to wait.

Initially, we did a bit of background search on County Down and thought a visit would be nice to see where the family roots started. I made contact with the Presbyterian church in Raffrey asking if they had information on these two families and could we visit. They replied saying the records they had didn't go that far back, however, that was last year and Covid restrictions put that on hold.

Finally, a reply to a message I'd sent months earlier, saying they had just come back onto Ancestry after a break: He gave me the names of the wives of Samuel (Sarah May) and Thomas (Catherine Kimmons) saying he'd been given this by family. But to date I've not been able to confirm with births or marriages. Then another similar long awaited reply with links to the Moffat family saying her grandmother went to the family farm for holidays.

Then I got a message saying hello I'm your relative can we communicate. This turned out to be my distant cousin Peter, we share our 3rd great grandfather, Robert, born 1784 Barnamaghery, Co. Down.

Now staying with the Moffatts – Margaret - great Gran, Thomas - great great grandad, Robert- 3x great grandad, who married Margaret Nixon. This cousin Peter has provided so much and we are now confirmed family. I have a list of the Moffat family register from Killinchy, listing all the baptism dates of the 11 children of Robert and Margaret. Then it goes on to provide marriages of them and some of the grandchildren. Some of these emigrated to New Zealand and America... he has also provided, a copy of Robert's Will, a copy of military papers relevant to Thomas's discharge papers, land maps with the farms, and some personal family history, which I won't share. From then, we decided to meet up and visit Northern Ireland. But we watched the Covid numbers and waited until it was safe to travel. So we booked up for a week took the ferry to include meeting new family.



Robert had farms, these were ..small and extremely rural. The copy of his Will is dated 1859, he died 1860.

The opening isIn the name of God amen I Robert Moffet being of weak body but of sound judgement and memory and knowing that all men have to die...

It is detailed in who got what. He had 3 possibly 4 farms 2 already occupied by 2 sons, and his own was to be left to his namesake Robert. They grew crops as the Will stated that John & James make use of the threshing machine. It also made allowance for my great great grandfather Thomas to be given an allowance by the others should he return home.

We have pictures of the farm he lived in, now modernised but still the same footprint. They will not have changed much since Roberts time, other than tarmac on the same narrow roads. Farms still the same size, roofs now tiled, not thatch. But still so very remote. Laurence lives in one of the original farms, but he had to buy it and he farms cows (not dairy) or as he calls them sucklers.

So onwards with the searches on both sides, and the anticipation of who will be my next find.

Liz Bennett

This is me outside the church in Raffrey with my new cousins Laurence and Peter.

Obituary June Ormston

8th June 1934 - 30th March 2022

It was with great sadness that we received this letter from June's husband Keith. For those of you, who like us, were fortunate enough to have known June, she will be remembered as someone who fully appreciated her 'Gift of Life' and who paid tribute to her donors and their families by living life to full. It is poignant that Keith would like her legacy to be an inspiration for all transplant patients.

Dear John,

I write with some sad news of the passing of my wife June on 30th March.

As you will know she was among the first to be transplanted at the Freeman on 1996, 26 years ago.

Her first transplant failed and a second liver was transplanted 8 weeks later. Thanks to the skill and dedication of Prof Derek Manas and surgeon Darius Mirza who performed the operations, June completely recovered and went on to enjoy her golf, her holidays and to lead a very full life.

Ably looked after for many years afterwards by Dr Mark Hudson and the wonderful staff at the Freeman.

I think it must be comforting for any transplant patient or potential transplant patient to know that quality of life can go on and be enjoyed.



As you know she was a staunch supporter of LIVErNORTH particularly in the early days, as we all were, she used to love the Christmas dinners in the restaurant.

June died aged 87 years from natural causes, not liver disease.

Best wishes to you both and LIVErNORTH in the future, you are doing a great job.

Yours,

Keith Ormston

The PRINCIPLE Trial & PANORAMIC Study update - Sian O'Dea

The PRINCIPLE trial is currently looking for participants with COVID-19.

What is the PRINCIPLE Trial?

The information below is taken from the study website and explains more about the research:

'PRINCIPLE is a UK-wide clinical study from the University of Oxford to find COVID-19 treatments for recovery at home.

We are looking for medicines that can help people with COVID-19 symptoms get better quickly and stop them needing to go to hospital. PRINCIPLE is recruiting participants through this website (www.principletrial.org) and also through GP practices across the UK.

PRINCIPLE is open to all with ongoing symptoms of COVID-19, regardless of vaccination status.'

Who can participate in the PRINCIPLE Trial?

Below are further details from the study website about who can participate in the research. You are eligible to join PRINCIPLE if:

You are currently experiencing COVID-19 symptoms for 14 days or less. AND: You have had a positive test for COVID-19 in the last 14 days

AND: You are aged 18 or over'

So far, over 10,000 people have volunteered to participate.

Where can you find out further information about the study?

The PRINCIPLE Trial has its own website: www.principletrial.org. This has additional information about the study, including a Participant Information Leaflet.

Contact details for the study are:

Email: principle@phc.ox.ac.uk Telephone: 0800 138 0880

There is a link on the website where you can click to join the PRINCIPLE Trial if you wish. Alternatively, you can ring the telephone number above. Your GP may also be able to help you to enrol for the study.

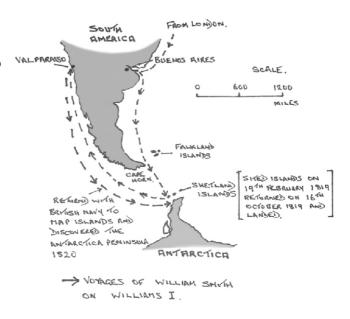
Update on the PANORAMIC Clinical Study:

Over 25,000 people have now participated in the PANORAMIC Clinical Study which was outlined in the last edition of LIVErNEWS. You can no longer join this trial online. There are however still some GP practices who can enrol people for the trial. The results of this study are awaited.

More On Captain William Smith Of Blyth The Man Who Discovered Antarctica By Alf Bennett

In the Spring Newsletter, I wrote about William Smith of Blyth who discovered the last continent on Earth, namely Antarctica. I have recently been asked about the distances he travelled around South America. Hopefully, the sketch map with a scale presented below will explain the extraordinary distances involved. He was the first person to discover the islands which he named the Shetlands on the 19th of February 1819 located over 500 miles from Cape Horn. This discovery occurred because he went further south than normal, rounding Cape Horn in search of good sailing winds. When he reported this discovery on arrival at Valparaiso in Chile, he was ridiculed as no one believed that any land lay south of the Cape. Determined to prove their existence, on the next voyage he landed on the islands on the 16th of October the same year. The Admiralty now took him seriously and chartered his boat Williams One and successfully surveyed the islands and discovered what we now know as the Antarctic Peninsula further south. Unfortunately, he died penniless in 1847. It was not until 1913 that the Royal Geographical Society recognised his achievement when they published details of, the "Voyages of Captain William Smith", describing the actual route taken and the dates of each discovery.

I have since been back to Blyth (no, I am not sponsored by the Tourist Board 1 to see Williams II, a similar boat to the one used by Smith. This was purchased by the Blyth Tall Ship Project and is moored at Blyth Ouavside. The notice shown on the next page is provided at the mooring to provide more information on the



project.

When you see the actual ship (below) which is only 24 metres long (about 8 average cars put end to end). You really appreciate how remarkable it was to sail such a boat over such distances through some of the potentially roughest seas in the World. What a remarkable man?

Alf Bennet



The Port of Blyth is the operating division of Blyth Harbour Commission, a modern Trust Port operated for the benefit of all stakeholders. Port of Blyth, South Harbour, Blyth Northumberland, NE24 3PB

Williams II

+44 (0)1670 357 004 enquiries@portofblyth.co.uk

New research to help organ donation & transplantation patients

NHS Blood and Transplant (NHSBT) has launched a £20m set of research units in the UK across blood, organs, plasma, and stem cells.

The five Blood and Transplant Units (BTRUs) - co-funded by the National Institute for Health and Care Research (NIHR) and NHSBT - are aimed at providing new technologies, techniques or insights that will benefit donation, transfusion, and transplantation.

Experts at Newcastle University are working with scientists at the University of Cambridge for the NIHR BTRU in Organ Donation and Transplantation research unit - which is receiving a total of £4 million. Their aim is to increase the number of organs available, improve long-term outcomes and enhance quality of life after transplant.

Research at the Unit

The research unit will involve a variety of work, including:

- Trial the use of enzymes to remove blood group A and B antigens from donated organs during machine perfusion, to create universal donor O type organs. This could transform clinical practice and especially benefit ethnic minority groups who currently have reduced access to transplantation due to high prevalence of blood group B.
- Increasing the use of donated organs through image analysis. The unit will further develop an app which can rate the likely performance of an organ based on its appearance for example, how much fat there is on a donated liver giving a prediction of the transplant outcome.
- Develop new patient reported measures that assess the impact that an organ transplant has had on a recipient's wellbeing and assesses the quality of their experience of going through an organ transplant journey.

Andrew Fisher, Professor of Respiratory Transplant Medicine at Newcastle University and Deputy Director of the new NIHR BTRU in Organ Donation and Transplantation, said: "We are delighted to be co-hosting this new BTRU, dedicated to increasing the quantity and quality of organ transplants performed and addressing inequalities in access to organ transplantation.

"Our team of researchers from Newcastle University and Newcastle upon Tyne Hospitals NHS Foundation Trust, covering a wide range of disciplines, will continue to work closely with colleagues at the University of Cambridge and NHS Blood and Transplant to deliver on the unit's aims.

"Input from patients and the public will play a pivotal role in our work and forms an important partnership for achieving maximum impact from the research performed."

Many of the work strands in the BTRUs could result in new technologies and practices that can then be delivered, helping to save and improve even more lives.

They are multi-disciplinary centres of excellence which will pursue cutting-edge research in donor health and behaviour, improve transfusion practice in hospitals, increase the number of organs available and improve long-term outcomes after solid organ transplant, develop new kinds of cell therapies for blood disorders and blood cancer and, finally, reduce the risks of transmitting infections through the work that we do.

Developing innovative treatments

Health and Social Care Secretary, Sajid Javid, said: "These new research units will allow NHS Blood and Transplant to lead the way in developing innovative treatments for blood disorders and blood cancer - allowing the NHS to save even more lives.

"It will also mean more people will have access to life-saving donations, blood transfusions, and cell therapy, helping us tackle disparities that exist among those waiting for organ transplants and stem cells.

"I urge more people to consider becoming an organ, blood or stem cell donor, especially those from Black, Asian and other ethnic minority backgrounds."

Dr Gail Miflin, Chief Medical Officer for NHSBT, added: "By collaborating with universities, these five new Blood and Transplant Research Units will help us to deliver on our mission to 'save and improve even more lives' and drive innovation to inform future clinical practice and improve patient outcomes."

https://www.ncl.ac.uk/press/articles/latest/2022/05/bloodandtransplantresearchunit/ 16th May 2022

Great Expectations: The Role of the Lay Co-Applicant in Research Project Moves Forward

A further five years of funding ensures that the BTRU in ODT can continue not only its research but also its public and patient involvement and engagement (PPIE) activities. One of the main PPIE projects within the Unit has been Great Expectations.

Funding bodies are placing greater emphasis on the inclusion of lay co-applicants within health and social care research projects. Co-applicants work alongside professional researchers as part of a research team to develop an application and, if funded, have some responsibility for the management or delivery of a study.

There is guidance available which outlines how effective integration of a coapplicant into a project can be achieved but researchers and co-applicants alike agree the advice can be difficult to navigate and implement successfully.

With this in mind researchers, key stakeholders and guest speakers came together in May 2021 in Newcastle to explore the challenges, attitudes to, and experiences of working with lay co-applicants to develop research proposals, especially within pre-clinical and clinical research. There was a recognition from all parties of the complexities of developing an effective research team with lay co-applicants integrated into a project from its early stages.

During the workshop attendees were given the opportunity to discuss all facets of the process, both positive and negative, to uncover learning opportunities for both co-applicants and researchers. It is clear that some unique challenges arise when co-applicants and professional researchers work together but five key learnings, seen as crucial for effective collaboration have been garnered and form the basis of a new animation.

These key principles include:

- Flexibility There's no 'one size fits all' approach. Every project, every coapplicant and every research project is different. Co-applicants should be offered a diverse range of ways to get involved in research.
- Roles Everyone involved should have a clear understanding of their role and responsibilities within the research project. Respecting and valuing the knowledge and experience of all those working together ensures that all those involved are of equal importance.
- Support & Training Training should be available for everyone involved in the research project, and individuals should be made aware of who to approach for

assistance or support.

- Communication is Key Everyone involved must be kept 'in the loop' through each stage of the project, even if nothing is happening.
- Diversity Researchers should make sure their processes allow everyone to have the opportunity to contribute, no matter their identity or background.

The project working group has collaborated with Newcastle-based multidisciplinary design company Roots and Wings to create an animation which outlines the key learnings of the workshop, and we are pleased to announce that the finished product will be shared with all stakeholders very soon. The project working group is very proud of what has been produced and the animation marks the beginning of a journey which will lead to further activities, for example a workshop, later in 2022.

The BTRU-ODT would like to thank everyone who has been involved in this project. We would particularly like to thank everyone who attended the workshop in May 2021 and the members of our project working group: Dr Sarah Fahle (BTRU in Donor Health and Genomics at University of Cambridge), Lucy Kershaw (NHSBT), Dr Joanne Lally (NIHR Research Design Service North East and North Cumbria), Dr Bill Scott (PI of the Project, Blood and Transplant Research Unit in Organ Donation and Transplantation at Cambridge and Newcastle Universities), Roxanne Stirling (NHSBT PPAG), Joan Bedlington (LiverNorth/BTRU-ODT PPRP), and Siân O'Dea (BTRU-ODT PPRP).

We would also like to thank Engage FMS and The Tilly Hale Fund for their support, Roots and Wings for their amazing work and Jenny Hasenfuss (former BTRU in OD&T PPIE Lead) for her dedication and tireless efforts in ensuring the success of the project.

Hannah Murray Patient and Public Involvement and Engagement (PPIE) Manager NIHR/NHSBT Blood and Transplant Research Unit in Organ Donation and Transplantation

acronyms used:

BTRU ODT Blood and Transplant Research Unit - Organ Donation and Transplantation

FMS Faculty of Medical Sciences PI Principal Investigator

PPAG Patient and Public Advisory Group PPRP Patient and Public Research Panel

Letters

Dear John,

I was on annual leave last week but thank you so much for the liver leaflets. They're going to be really helpful.

Best Wishes,

Rebecca

North Tees & Hartlepool NHS FT

Please accept the enclosed cheque which is from a collection box at my late wife's funeral. I saw your charity mentioned on some literature provided by the Freeman Hospital, so rather than give it to the usual big charities, I thought it would be better to help one of the lesser known ones.

Thanks

MI

Newcastle

Dear Sir/Madam,

Please find enclosed several cheques for donation to your charity. My partner passed away recently at the Freeman Hospital with liver disease. I cannot commend the staff highly enough for the care he received up to and including his last days.

Ideally, I would like the donations to be split between general use and research so that one day people will not have to have their lives cut short.

Every good wish for the success of the charity.

Yours faithfully

LS

N. Yorkshire.

Editor's note: The kindness and thoughtfulness shown by people at such a sad and difficult time is amazing...thank you so much.

Many thanks for sharing the self-care liver bundle, which will be useful for my patients in Northern Ireland. You guys do great work.

RF

NI

Great DVD, very informative and now have a very good understanding of PBC.

CS

Tyne & Wear

Dear Sir,

I enclose a cheque towards your charity 'LIVErNORTH' that I know was such a help and comfort to my dear Goddaughter.

Yours sincerely

AM Wells

Hi,

We have been receiving hard copies of your excellent LIVErNEWS for many years, which we enjoy reading each quarter. It's certainly packed with information and news.

We were wondering if it would be possible for you to include our Group contact details as a reference alongside the other organisations you promote? We have been providing non-medical support for liver patients across Northern Ireland since 1998, and work hand-in-hand with the medical staff in the Regional Liver Unit based in the Royal Victoria Hospital in Belfast to provide mentoring, emotional, practical and in certain circumstances financial support to patients, their families and friends.

Our details are -

Royal Victoria Hospital Liver Support Group, Belfast

Contact: Kay Duffy (Founder)

07737 718493

www.rvhliversupportgroup.org

rvhlsg@gmail.com

John,

Thank you for sending me the 14a booklet. It will be a great help. My liver assessment had excellent results but I still need to exercise (which I love) and eat correctly. Took some lovely choices from the sample menus.

DW

Northumberland

Dear John,

I just wanted to let you know that we have started the approvals process for the next phase of UK-AIH and hope to be able to reopen to recruitment within the next few months LIVERNORTH have kindly supported the project for the last few years and we very much hope you will feel able to support the next phase.

if this is something you would be happy to consider, we would be very happy to complete a formal application for funding please would you be able to send me a copy of an application form if this is something that might be possible?

On a linked note, I am also pleased to let you know that the work LIVErNORTH supported us with undertaking a patient survey to assess experiences of autoimmune hepatitis and its treatments has now been accepted for publication in Digestive Diseases and Sciences.

We are very grateful for your support, thanks very much

best wishes Jess (Dyson)

JOIN OUR LOTTERY AND SUPPORT OUR WORK

Every penny raised goes to liver patient support - we have NO paid employees ${\bf P}$

To join the 2022 lottery please complete the form on page 25.

If you use online banking and would prefer to set up your own standing order please email: info@livernorth.org.uk or phone 0191 3702961

£1.2 million so far given to liver disease research and funding trials of drugs, equipment and techniques. The lottery income is used solely for prize money and for liver patient support & research.



£250 prize winners this year:

*BD of Bourton on the Water
with number 55

*RM of Ash, Surrey
with number 22
both drawn on 25/5/22

Registered under the GAMBLING ACT 2005 with the city of Newcastle upon Tyne

LIVErNORTH Lottery application form

Your contact details	
Name	
Address	
	Postcode
Daytime telephone	
E-mail	
Preferred payment method	I confirm that I am over 16
Standing order (please comp	lete the form below)
Cheque (please enclose a mi	inimum of 1 quarterly payment of £13)
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Amount to be paid until further n £52 annually	otice £13 quarterly on 1st Jan, 1st Apr, 1st Jul & 1st Oct
Preferred first payment date (or AS	SAP)
Signature	Date
Please return the comp	pleted form to freepost LIVERNORTH

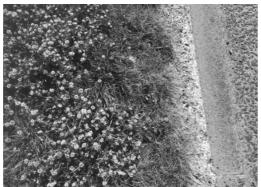
HAVE YOU SEEN THIS PLANT?

You must have seen this white flowered plant which is now so common across many areas of the country, especially along roadside verges. It can be seen flowering either as individual plants or as blanket coverings during April and May.

Twenty years ago this plant would have only been found along the coastal areas of the country on cliffs and salt marshes as unlike most plants it is able to withstand high levels of salt in the atmosphere and soil. Today, it is common across the country and can be seen flowering in April and May. I have even seen it along the verges of the M6 around Birmingham and that is a significant distance from the coast.

Scurvy Grass – notice the spoon shaped leaves.





Scurvy Grass – on the central reservation of a dual carriageway, note how it has carpeted the area and outgrown other plants because it can tolerate salt.

The photographs were taken within 100 yards of each other several miles from the coast in April. They show two species of a

plant known as Scurvy Grass or Spoonwort. It must be stressed this is not a grass, but a flowering plant with white flowers, each with four petals and spoon shaped fleshy leaves (hence its common name). It is more commonly called Scurvy Grass, because it is the plant that was eaten by sailors from the 1600's onwards to recover from Scurvy. Such was its importance that a number of books were written on its beneficial effects in the 17th century, the most popular one was "Curiosities of Scurvy Grass". It was later found to contain high levels of vitamin C which is essential to prevent scurvy. Historically, there is evidence that the plant was used to prevent a condition with symptoms like scurvy in Roman times as far back as the first century. It is certainly not recommended to eat this plant today due to other pollutants.

The larger plant is Common Scurvy Grass and the smaller, low growing plant is Dutch Scurvy Grass. So why are they growing in places miles from their normal habitat? Well the answer lies in our use of salt to keep the roads ice free in winter especially when substances were added to the salt to make it stick to the road better. The seeds have been dispersed by becoming attached to vehicle tyres in coastal areas then washed onto roadside verges where, because of the saline conditions, they have ideal conditions for germination.

So thanks to our use of salt and motor car tyres which disperse the seeds we have coastal plants which flourish miles inland. Rather like the old maxim, "if you build it they will come". For plants if you provide the right conditions, nature will respond.

Alf Bennett

Thank you Alf for this insight - It's brilliant having a retired science teacher on the committee! (ed).



Take time to talk about organ donation

Many people don't realise that their family's support is needed for organ donation to go ahead.

KEEP THIS PAGE FOR REFERENCE



999 Is the phone number for an EMERGENCY

999 is the official emergency number for the United Kingdom, but calls are also accepted on the European Union emergency number, 112, All calls are answered by 999 operators, and are always free.

In the United Kingdom there are four emergency services which maintain full-time emergency control centres (ECC), to which 999 emergency calls may be directly routed by emergency operators in telephone company operator assistance centres (OAC). These services, listed in the order of percentage of calls received, are as follows:

Police Ambulance Fire **HM Coastquard**

Other emergency services may also be reached through the 999 system, but do not maintain permanent emergency control centres. All of these emergency services are summoned through the ECC of one of the four principal services listed above:

Lifeboat Mountain rescue Cave rescue Mine rescue Bomb disposal

Calling 999 from a landline automatically gives the police information about your location.



If you smell gas, think you have a gas leak, or are worried that fumes containing carbon monoxide are escaping from a gas appliance, please call the free Gas Emergency Services emergency line immediately.



A The Electrical Emergency phone number is 105

In the event of an electrical emergency or power outage please call 105 from your mobile or landline and the telephone service will automatically direct you to the network distributor's emergency number for your area.105 is a free service, available from most landlines and mobile phones in England, Scotland and Wales.

You should call NHS 111 if:

You need medical help fast but it's not a life-threatening emergency

You don't know who to call for medical help or you don't have a GP to call

You think you need to go to A&E or another NHS urgent care service but are not sure which one is most appropriate or closest

You require health advice or reassurance about what to do next

You have medication enquiries

Helens Howlers

Most of the funnies you see in these pages are sent from friends and colleagues (like Billy Venus) or are freely circulating via the internet. I am constantly on the look out for more material so please send in anything you have or have

heard whilst out and about. It doesn't have to be 'professional' – your witty observations on life a e always welcome.

If you're feeling a bit low - read on... As they say, laughter is the best medicine! Thanks for this issue go to my many facebook friends, LIVErNORTH colleagues and 'the internet'

. (13)

My mate reckons he can throw a stick a mile and his dog will bring it back to him. I think that's a bit far fetched.

Two flies in an airing cupboard which one is in the army? The one on the tank.

Before I met my current wife in 1975 I split up with a girl 'cos she wouldn't stop counting. I often wonder what she's up to now.

My current wife said she doesn't understand anything about cloning. "That makes two of us" I replied.

Been thinking about breeding dogs! but not sure how to get started, can anyone give me some Pointers?

I hope they weren't expecting a tip!
I went out for a meal in a London
restaurant once and I arrived a bit early.
The guy behind the bar said "Do you
mind waiting a bit?"
I said "No" so be said "Great, take these

I said "No" so he said "Great, take these drinks to Table 7"

When my grandad died he left 50 clocks and a hundred watches. Took me ages

to wind up his estate!

My partner asked me to pass her the lip balm. I gave her super glue by mistake. She's still not talking to me.

My friend decided to become an archeologist...now his life is in ruins.

Stopped by a roadside stand that said lobster tails £2. I paid my £2 and he said "Once upon a time there was this lobster..."

'What time is it?' - 'I don't know, pass me the trombone' (blows trombone loudly). Neighbour shouts 'who the hell is blowing a trombone at 2 in the morning!'

A young monk arrives at the monastery. He is assigned to helping the other monks in copying the old canons and laws of the church by hand. He notices, however, that all of the monks are copying from copies, not from the original manuscript.

So, the new monk goes to the head abbot to question this, pointing out that if someone made even a small error in

the first copy, it would never be picked up. In fact, that error would be continued in all of the subsequent copies.

The head monk says, "We have been copying from the copies for centuries, but you make a good point, my son." So, he goes down into the dark caves underneath the monastery where the original manuscripts are held as archives in a locked vault that hasn't been opened for hundreds of years. Hours go by and nobody sees the old abbot. So, the young monk gets worried and goes down to look for him. He sees him banging his head against the wall and wailing, "We missed the "R", we missed the "R". His forehead is all bloody and bruised and he is crying uncontrollably.

The young monk asks the old abbot, "What's wrong, father?" With a choking voice, the old abbot replies, "The word was CELEBRATE!"

There's been quite a few ladders stolen around our way, police said if the culprits are not caught, further steps will be taken.

Once upon a time there was a King who was only 12 inches tall. He was a terrible King but he made a great ruler.

What did the drummer call his twin daughters? Anna One, Anna Two

I enjoyed my Christmas dinner today. Very nice but I'm not very impressed with slow cookers! Happy New Year everyone! My New Year's resolution is to get faster internet.

I just heard on the news that someone is stealing the wheels off police cars. The police are working tirelessly to catch him.

Got home from work today to find my kids have been on ebay all day. If they are still there tomorrow I will lower the price.

I grilled a chicken for two hours...It still wouldn't tell me why it crossed the road.

I lost the fingers on my right hand in a freak accident and I asked the doctor if I would still be able to write with it. He said 'probably, but I wouldn't count on it'.

I phoned my local radio station today. When the guy answered the phone he said 'Congratulations on being our 1st caller, all you have to do is answer the next question correctly to win our grand prize.' 'Whooohoo' I shouted with joy. 'It's a maths question' he said 'Feeling confident?'. 'I've got a degree in maths and I teach it at our local school' I proudly said. 'Okey then, to win the 2 VIP tickets to see Justin Bieber and to meet him back stage afterwards, what is 2+2?' '7' I replied.

I gave all of my dead batteries away today, free of charge.

I was hopping mad last night. The

Odeon cinema refused to accept a £50 for my pick-n-mix. In the end I had to pay with two twenties and a tenner.

I waved at a woman, I thought I knew her because she looked over to me, in fact she was looking at another man! Anyway to avoid an awkward situation I kept my hand up and a taxi pulled over and took me to the Airport. If your looking for me I am currently in Barcelona.

If you're a vet and have to be close to a bear, always tranquilise it. That way it's not so dangerous. There's safety in numb bears.

Olaf the Norseman is shopping at a supermarket when he comes across an old lady in a wheelchair, almost in tears. "What's the matter?" asks Olaf. "Oh," sobs the old lady. "I want to have a look at the frozen puddings but, as you can see, there are three steps down into the chiller cabinets."

"No problem," says Olaf, lifting her onto his back. "I'll take you."

Olaf strolls through the chiller cabinets with the old lady on his back. She selects several puddings and puts them in the basket he is carrying for her. At the other end the old lady's husband is waiting with her wheelchair.

"I'd really like to thank you," says the old lady as Olaf sets her back down in the chair, "but I don't even know who you are!"

Olaf just waves and walks off.
"I was really worried about you," says

the old lady's husband. "What have you been doing?"

She replies, "Well, I've been through the desserts on a Norse with no name."

Me: "I wish I'd listened to my mum when I was younger." Mate: "What'd she say?" Me: "I don't know. I wasn't listening."...

Fuel prices are so high that taxi drivers have started taking the shortest route...

My mate got arrested today for shop lifting in Boots which is bit out of character for him as he always wears trainers.

I bought a book online 3 months ago for £40 'How to be a Successful Scammer'... still waiting to have it delivered.

Did you hear about the cheese factory that exploded in France? De Brie was everywhere.

Has anyone tried blindfolded archery yet? Try it, folks, you don't know what you are missing.

Apparently it's good to talk to your plants. I tried to teach my carrots mathematics but they ended up with square roots.

My partner told me to get off the computer and stop posting jokes or she'll slam my head into the keyboard. I'm not too worried becaufrjjbdkk hhevdogkPg

I went for my medical today and the doctor said that I should get an earring made. I thought, that's a strange thing to say...When I parked in the surgery car park a traffic warden approached me and said, this space is for badge shoulders only" I said, 'That's why I'm here mate, I've got a bad shoulder.

If anyone's got any tips on how to reverse cheap plastic surgery, I'm all ears.

Someone threw some fabric conditioner at me in a shop today missing my head by an inch. It must have been Lenor, it was too close for Comfort...
That was followed by a bottle of mayonnaise. I thought what the Hellman !!

English Lesson:

going to work?"

I told my wife I saw a deer this morning on the way to work. She said, "How do you know it was

I'm getting annoyed with people moaning about the cost of things. £2.50 for a coffee, £1.75 for a tea, £2.25 for a cupcake. If I hear any more complaints I'll stop inviting people

around.

Today, I learned that if you're in a canoe and it tips over in water, you can safely wear it on your head. Because it's capsized.

So sad to hear today that the man who invented the Raffle Draw has died.... R.I.P. Tom Bowler.

Thought for the day. With higher energy prices we should consider generating all of our power from solar energy

... its not going to happen overnight!

My wife just said, "Will you stop doing those stupid Flamingo impressions, I'm sick of it!"

I thought "I'm going to have to put my foot down here..."

What a terrible dream.

I dreamt that something was biting my neck.

It was so vivid, I got up to check. And now the mirror has stopped working!

I woke up to drink some water in the middle of the night and I accidentally ate a whole pizza and a cheesecake.

That's it for this issue folks - keep them coming, we love to hear people groaning...

What would you take if marooned on a desert island?

I am sure that many of you will recognise this as the key theme of "Desert Island Discs", the programme which is broadcast on Radio 4. It is one of the longest running radio programmes first broadcast in January 1942. During Lockdown, I spent many a happy hour listening to past episodes and trying to decide what I would take. A task I found very hard, changing my mind several times. In fact, I am still undecided now.

Just to recap, for each episode, a guest called a "castaway" is asked to choose eight recordings, not necessarily music, from which they must select their favourite. In addition, they also select a book and a luxury item, which must be inanimate and of be of no use in escaping from the island. Apart from these selections they are also given the Complete Works of Shakespeare and either the Bible or another religious or philosophical work.

Over 3000 episodes have been recorded and they include the "great and the good" over nine decades. In some cases, people have been castaways twice. It really is a snapshot of genuinely interesting people across the generations. The first castaway was Vic Oliver who was a British actor and radio comedian. Others include, David Attenborough, Harold Wilson, Ken Dodd, John Mills, Vera Lynn, Hattie Jacques, Bob Hope, Margaret Thatcher, David Frost, Maggie Smith, Eddie Waring, Jilly Cooper, Sophia Loren, Mary Berry, Tom Hanks and the last one so far was Bradley Walsh in May this year.

Not only do the castaways have to select the specific items, but they need to give reasons for their choice as well as discussing their lives. Many of the items are practical and show careful thought to the decisions made, while other are either really personal or reflect their true interest or love in their life. Some of the more interesting choices made are:-

Piers Morgan – favourite song – Always look on the bright side of life.

Simon Cowell – luxury item – a mirror. I wonder why?

Theresa May – favourite song – yes, you guessed it, Dancing Queen by ABBA.

Nick Clegg – luxury item – a stash of cigarettes.

Harvey Smith – favourite book – none, because he does not read books. When pressed that he had to select one, it was decided he would get "a selection to sample".

Celia Johnson – luxury item – a Rolls Royce, not exactly practical.

Kylie Minogue – book – The Outdoor Survival Guide by Ray Mears. Good choice under the circumstances.

Yoko Ono – luxury item – Her life for the next 30 years.

Miranda Hart – Wimbledon Centre Court including racquets, balls and a ball

machine. Now that would be a logistical challenge.

Celia Imrie – A cut glass chandelier with candles. That's what you call maintaining standards under difficult circumstances.

However, I think the best one must be the choice of luxury item by John Cleese. He decided this must be Michael Palin. Unfortunately, according to the rules the object has to be an inanimate one. It was therefore decided that Michael would be stuffed. Anyone know a good taxidermist? This has the makings of a great Python sketch.

Let's see if you can work out the which of the following castaways fits their selected items. The castaways are: David Jason. Spike Milligan. Michael Caine. Boris Johnson. Frankie Dettori. Judi Dench. Cilla Black. Jack Charlton. Pavarotti and Esther Rantzen.

CASTAWAY	FAVOURITE DISC/SONG	LUXURY ITEM
1	My Way – Frank Sinatra.	A large bed with 50% goose down and 50% feathers duvet.
2	Brahms, Variations on St Antoni Chorale.	A large pot of French mustard.
3	Help – The Beatles.	A complete carpenters tool box.
4	I've got you under my skin – Ella Fitzgerald.	Cut outs of all my friends and family.
5	September Song – Frank Sinatra.	A bath sometimes with hot water, sometimes with cold and sometimes with Champagne.
6	Yesterday – The Beatles.	A Barclaycard.
7	Amazing Grace – Royal Scots Dragoon Guards	A lifetime supply of Pinot Grigio.
8	Land of Hope and Glory	A Spyglass.
9	Anyone who had a Heart – Cilla Black	The Mona Lisa.
10	Mozart – Symphony No 40	A Bicycle.

So how did you do? And what would you take? Answer below (use a mirror to read them)

1.	Michael Caine.	2.	Boris Johnson.	3.	David Jason.
4.	Judi Denck	.2	Either Rantzen.	۵.	Spike Milligan.
٦.	Frankie Dettori.	8.	Jack Charlton	9.	Cilla Black.
10	Devent				

Organ Donation - have the conversation.

Register your wishes by signing the NHS Organ Register online at www.organdonation.nhs.uk or by calling 0300 123 23 23

Most Importantly
Speak to your family to
LET THEM KNOW YOUR WISHES.

NOTICE. Please be assured that we will NEVER share your details with any other organisation or person.

A Good Communicator:



Always listens to you.

Always answers - even if it's just to say 'I heard you'.

Answers emails - even if it's just to say 'I got it, thanks'.

Answers phone calls - even if it's just to say 'Can I ring you back?'

Leaves phone messages - even if it's just to say 'just me, don't worry'.

and is never too busy to say - 'sorry, busy at the moment, but I'll answer asap'.



Take time to talk about organ donation

Many people don't realise that their family's support is needed for organ donation to go ahead.

UIOLI Summer 2022

SUDOKU... With the kind permission of the creator (Wayne Gould of Pappocom). You don't need to do any arithmetic or be good at maths - all it takes is logic so please have a go - it will help to keep your brain active. Just fill in the missing numbers in every square, row & column using 1 to 9 without repeating any. There is strict copyright so they may not be redistributed in any way whatsoever although you can of course photocopy the page if you don't want to spoil your copy of LIVErNEWS. Good Luck!

HAVE A GO - YOU MIGHT LIKE IT

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Insurance Matters

members report having been able to get reasonably priced holiday cover here:

Able2travel	01483 806826
Age Co (formerly Age UK)	_0345 1238008
AVIVA	0345 0308715
Bib Insurance Brokers (www.bibinsurance.co.uk)	01325 353888
Boots Travel Insurance	_0333 9992683
Cigna (was FirstAssist)	_01475 492119
City Bond	0333 2070506
Churchill*	_0800 0326534
CNA (via Brunsdon brokers)	_01452 623631
Direct Travel*	0330 8803600
Freedom ^	_01223 446914
JLT Insurance	_02476 851000
Leisure Care Insurance	_01702 427166
Post Office	0330 1233690
RIAS*	0345 0451320
SAGA	0800 0158055
Sainsbury's	_0345 3052623
Sladdin & Co Ltd. (brokers)	_01422 262614
www.lnsurancewith.com	0333 9992679
www.miatravelinsurance.co.uk^	0800 9993333
www.Paying looMuch.com	01243 216007
www.staysure.co.uk (Staysure UK call centre) ^	_0808 1786151
https://www.world-first.co.uk/	0345 9080161
https://www.freespirittravelinsurance.com/medical-conditions/liver/	<u>02392 419080</u>

^{*} not TX patients - please check with the others also.

Please help to keep this page current and useful by letting us know of your own experiences both good and bad. You can email us at info@livernorth.org.uk or drop us a line at our Freepost address above, no stamp necessary..

The latest version of this page is always available as a PDF file. Email us and ask for a copy: info@livernorth.org.uk

All our leaflets including No.16 'Travel Insurance for Liver Patients' are available to read online by scanning the QR code on the right with your smartphone.



[^] specifically includes cover for declared pre-existing medical conditions.

LIVERNORTH Information Leaflets Available:

- 1. Liver Patient Support
- 2. Accommodation for patients & families
- 3. Autoimmune Hepatitis
- 4. Alcoholic Liver Disease
- Look After Your Liver
- 6. Primary Biliary Cholangitis (PBC)
- 7. Coping With Stress
- 8. Primary Liver Cancer
- 9. You and Your Consultant
- 10. Primary Sclerosing Cholangitis (PSC)
- 11. NAFLD Lifestyle Guide
- 11a. Non Alcoholic Steatohepatitis
- 12. Liver Disease
- 13. Skin Care for Liver Patients
- 14. Diet and Liver Disease
- 14a. Nutrition Support in Liver Disease
- 15. Hepatitis C
- 16. Travel Insurance for Liver Patients
- 17. Hepatitis E
- 18. Fatigue in Liver Patients/A Patient's Journey
- 19. Understanding Healthcare Tests
- 20. Liver Cirrhosis Self Management Toolkit*
- 21. Exercise & Osteoporosis in Liver Patients
- 22. Hepatic Encephalopathy
- * only from your healthcare professional email for more information

Scan the QR code below to read the leaflets online



How to get information leaflets:

1. ISSUU: https://issuu.com/search?q=livernorth

2. Website: http://www.livernorth.org.uk/pages/factsheet.htm

3. Email us: info@livernorth.org.uk

4. Phone/FAX: 0191 3702961

5. Facebook pm us: https://www.facebook.com/livernorth/

6. Write to us: Freepost LIVERNORTH

CONTACT NUMBERS

LIVERNORTH National Liver Patient Support

freepost LIVERNORTH www.livernorth.org.uk tel: 0191 3702916 info@livernorth.org.uk

Addenbrookes Liver Transplant Association (ALTA)

Gill Kitchener, secretary@alta.org.uk info@alta.org.uk tel: 07885 123528

British Liver Trust

tel: 01425 481320 helpline@britishlivertrust.org.uk ww.britishlivertrust.org.uk

Gift of Life Derby Liver Support Group

(for transplants and all liver disease) Contact: Sister Gerri Casey 0133 234 0131 bleep 1926

Haemochromatosis UK 03030 401102

helpline@huk.org.uk

IPC Support

07939 871929
helpline@ipcsupport.org
or www.icpsupport.org
Registered Charity No: 1146449

NHS

https://www.nhs.uk/

https://www.nhs.uk/conditions/coronavirus-covid-19/

Norfolk & Norwich Liver Support Group

marjorie.dingle@hotmail.com 0300 120 0796

PSC Support

Martine Walmsley help@psc.support.org.uk Helpline 01235 25 35 45 www.pscsupport.org.uk

Royal Victoria Hospital Liver Support Group, Belfast

Contact: Kay Duffy (Founder) 07737 718493 www.rvhliversupportgroup.org rvhlsg@gmail.com

South West Liver Buddies

https://southwestliverbudies.org.uk/

Wilson's Disease Support Group - UK

Val Wheater - 01223 364982 val@wilsonsdisease.org.uk www.wilsonsdisease.org.uk

We can always make space here for your support group details. If you are already listed, please let us know of any changes to your contact details. Please also reciprocate by advertising LIVErNORTH via your own media.

If you are worried about liver disease and would like to talk to someone, please telephone one of our helpline numbers below

JOAN	0191 3702961
ANN	0191 4131827
SUSAN	01207 271707
ALAN	0191 4821802
MARGARET	0191 2622550
SUE	01642 706302
KATHRYN	01207 505231

Get free Liver Patient and Carer Support Leaflets:

- Download from our website (www.livernorth.org.uk)
- Read online (https://issuu.com/livernorth/docs)
- Email us (info@livernorth.org.uk)
- Phone us (0191 3702961)
- Write to us at: freepost LIVERNORTH
- Message us (https://www.facebook.com/livernorth/)
- Scan our website QR code here with your mobile phone –



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