

Winter 2013

LIVERNEWS No. 46

LIVErNEWS

Support Newsletter for Liver Patients, their carers and families

In this edition:
LIVErNORTH at the Great North Run 2013
Christmas Dinner booking form!!!!!
Autonomic dysfunction
Using MRI in liver disease
Living with Sjogren's



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Chair's letter

I have always wondered where the time went and lately, it seems to be going no-where. Two weeks ago we were enjoying a sunny Autumn and today, on the front cover of the Times is a lovely photograph of a village in upper Teesdale covered in 2" of snow. It seems as if the last half of this year has flown by and we are in 'Winter' without any warning. Hopefully I'm wrong and we have a few more days of sunshine before the turn of the year. On this subject, as I get older, I have actually worked out why time flies now so I'll share it with you. I have to say everything twice now for some reason, I'm still using a clear voice and the right words but for some reason, those around me don't hear me the first time so there's extra time taken up repeating everything. When people say things to me, they don't speak as clearly as they used to or are using unfamiliar words so I have to ask them to repeat everything - more time taken up. Lastly, whenever I put something down, it is lost immediately. My glasses, my phone, my TV remote, my wallet, my car keys, my car!, the dog - all disappear as soon as they are out of my sight. The time I spend looking for things is considerable and such a waste of time. So there you have it, a simple explanation of where my time goes. I wonder if this is familiar to any of you and has anyone else noticed how the minute hand races around the clock face now? It's almost a blur! On the liver front, we have joined forces with other liver patient support groups in the UK to form the Liver Patient's Transplant Consortium (LPTC) to give liver patients a stronger voice with NHS Blood and Transplant when they are deciding on the allocation of organs. As you probably know, organ allocation is supposed to be based on need but some regions have a much greater need than others, taking more organs per head of population than other regions, even though they don't have as many organ donors. Also, some organs previously considered unsuitable for transplant may be now becoming suitable due to huge advances in technology and intensive care techniques. These are the kind of issues we will be addressing on your behalf and if you would like to make any comment then please get in touch with me or any committee member.

On the health front, you may have seen adverts for flu jabs at pharmacies for under £10. This

might seem quite a bargain but if you think you need a flu jab, it's worth asking at your GP's surgery about it rather than going to a pharmacy. Don't get me wrong, I think pharmacies are great and are under utilised - we should use them all the time for minor aches and pains, cold or hay fever but the flu jab is a little different. Firstly, your GP makes a little profit on every flu jab so there is a small financial incentive to give you one. Secondly, your surgery has your medical records and know what other medication you are on - the pharmacy doesn't and won't be able to put their jab on your records. Thirdly, your GP may check you out before giving you the jab (worth having) and finally, it is illegal in the UK for an NHS GP to charge for a flu jab so it will be free.

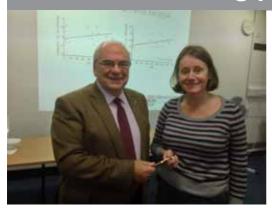
Our next events are the Carol Service and the Christmas Dinner - I look forward to seeing many of you there and enjoying your company. Please do try and come along. LIVErNORTH will be 20 years old next year and we are moving our meeting nights and times so that more of you can attend our talks and listen to our excellent speakers. We will still meet in the same place and still have free parking, just meeting a little earlier and booking different nights. We will of course, keep you posted and in the meantime, enjoy the forthcoming festive season and take care on the roads. This is the time of the year when road traffic accident rates are the highest - many people who passed their driving test this year will be driving on ice, snow or frost for the first time so please be extra careful yourself and watch out for others with less experience.

Best wishes, John Bedlington

Photo below shows John with Dr Pete Thelwall who spoke at the October meeting (see p. 27 for a summary of the talk).



Meeting photos



LIVERNORTH Chair John
Bedlington presenting Prof Julia
Newton with her LIVERNORTH
pen at the September meeting
(see the talk report in this issue of
LIVERNEWS).

Dr Pete Thelwall with John at the October meeting (Dr Thelwall's summary of his talk is in this issue of LIVErNEWS)





LIVERNORTH Governors Yvonne Gray and Peggy Oliver folding raffle tickets at the October meeting.



Above: Five Livers! The LIVERNORTH PBC meeting on November 5, 2013, presented the chance to photograph five PBC transplantees together. Left to right, Marjorie Batey (16 years since transplant), Hilda Heaton (15 years), Tilly Hale (14 years), Julie Pyburn (11 years) and Joan Reed (18 years).

Below: A group photograph from the Elucidate Meeting at St James Hospital Leeds, which Joan and Tilly attended. Among other people, the photo shows Prof William Rosenberg (who invited us to be part of the group) second from the right, Michael Messenger (with whom we are working as Patient and Public Involvement representatives) to the right of Tilly wearing a blue shirt, and Prof Peter Selby behind Joan. More on the Elucidate project in the next LIVErNEWS.



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Letters

Dear Tilly,

I hope you are well? We received your summer newsletter earlier this month, it is fab as always! Unfortunately, due to financial reasons we no longer run a helpline, please could you remove this number from the back of your newsletter?

I look forward to hearing from you and receiving the next newsletter.

Kind regards

Sandy Forsyth

Patient Support and Information Manager, British Liver Trust

Dear Tilly/John,

Please find enclosed my sponsor forms and cheque for the Great North Run. I enjoyed every minute of the run and felt very proud to wear my LIVErNORTH t-shirt. Thank you for letting me have one of your places.

It was lovely to meet Tilly a few weeks ago at the meeting in Bishop Auckland and I look forward to meeting again at sometime in the future.

Take care

Alison Wilkinson

(Alison raised a magnificent £533.50 in sponsorship - sincere thanks from everyone at LIVErNORTH)

Dear Joan & John,

Once again we want to say how much we enjoy receiving and reading LIVErNEWS; the information from the speakers has been very interesting and the 'howlers' provide us with a laugh which is a good tonic, we also gain information about the on-going role of LIVERNORTH and other interesting articles.

Kind regards to everyone and best wishes for the September Fair.

J&SR

Cumbria

Dear Sir.

Please find enclosed a cheque for £1200.00. This money was raised through a sponsored football match in aid of LIVErNORTH, as my mam was waiting for her transplant. Now my mam has had her transplant, my dad, myself and my sister would like to thank everyone involved in her recovery, they are a fantastic team and she has received the best care possible. Without the wonderful gift from the donor this would not have been possible and this will give my mam quantity and quality of life.

Yours faithfully.

Gary Scott

Sunderland (The match took place on 19th May 2013 at The Stadium of Light, Sunderland)

Dear Tilly.

Thank you so much for sending the DVD on PBC. My disease is closely related to this and I have the same symptoms. Seeing the information has given me a clearer understanding of the problems and how I can help ameliorate them.

Yours faithfully,

CT

Doncaster



Dear John.

Thank you for my Cheque for £250.00 which I won in your Annual General Meeting draw it was a lovely surprise! Will you please accept my Cheque for £50.00 as a donation to help you to continue your good work.

Yours sincerely

JN, Tyne & Wear

Dear Tilly,

Thank you most sincerely for your response and I have found the DVD most enlightening and helpful. It was very useful in that there are questions raised and answered which are not thought of when one goes to see a gastroenterologist (especially on first diagnosis). I was only diagnosed with PBC last year. It took over ten months from the initial view that something was wrong with blood and cholesterol tests to diagnosis of PBC and unfortunately one's mind is in no fit state to know what questions to ask initially. I have only seen the consultant once since then and GPs seem to not know much about it. The DVD is very helpful in that you can sit down and listen to it again and again if you wish. I am enclosing a cheque to cover your costs.

Yours sincerely

JM, Somerset

Dear Tilly,

Thank you for sending the DVD, it has helped me so much in understanding this disease. I live in Calgary, Alberta and it seems no-one knows about PBC. When first diagnosed nearly 2 years ago I was told I had between 10 and 20 years left and at my age, 52 at the time, was a good life span, if you can imagine how I felt when I got out of the doctor's office.

I am enclosing a cheque and hoping you could send me another DVD so I can give it to my liver specialist so he can spread the wonderful information you're providing.

Thank you for the clarity and all your hard work.

With Gratitude

ΚB

To LIVErNORTH.

Please find enclosed my sponsorship forms for the Great North Run. Thank you for letting me run for you - I had a wonderful day (despite the weather) and have a great sense of achievement.

Best wishes

Alison Pitts

(Alison raised a magnificent £222.00 in sponsorship - sincere thanks from everyone at LIVErNORTH)

Dear Sir,

Please find enclosed a cheque for £1000.00 for LIVErNORTH, following a bequest from the estate of Mrs Isabel Clark of Carlisle.

Yours sincerely

JC Executor

Everyone at LIVErNORTH offers condolences to the family on their loss and are indebted to the late Mrs Clark for her kindness in remembering the group in her will.

LIVErNorth Meetings 2013

Meetings are open to all liver patients and those who support them. They are friendly, relaxed and non-judgmental. We may not all have the same liver disease, but many of us have similar symptoms and challenges. As well as a talk about a particular aspect of liver disease, for those who want there is always time for tea or coffee and a chat. Many of us find it helpful to be in the company of others with similar issues, and it is always interesting to hear the speakers (even when they are not talking about our own liver disease!).

All meetings are held on Wednesday evenings, opening at 7pm with the talk at around 7.30. They are held in the Functions Rooms (137/138) on Level 1 at the Freeman Hospital unless stated.

If you are coming from the Main Entrance which is on Level 2 you should take the lift (or the stairs) down to Level 1. Coming out of the lift you turn left (right from the stairs) and go through the double doors into the corridor of the Education Department. You walk to the far end of this corridor, passing various classrooms, offices and female toilets. You then turn right through double doors and the Functions Room is on the left hand side. Unfortunately the doors to the corridor are often locked by 7pm, and if that is the case you need to go out of the exit double doors on Level 1 and turn right and walk to the double doors just past the portakabin. If you are coming by car, you drive to the roundabout inside the grounds and take the first exit past the various staff car parks. There are tokens in this newsletter which allow you to park for FREE in the Multi-storey car park, Levels 1 and 2 (at the back of the hospital on the way to the Cancer Care Unit). Walk back out of the car park and follow the road round to a set of double doors (you have driven past them, they are near a portakabin) and go through these doors and another two sets of double doors and the Functions Room is ahead on the left hand side.

8 December 2.30pm LIVErNORTH Carol Service. Freeman Chapel LIVErNORTH Christmas Dinner will be at 6.30 for 7pm, Freeman Dining Room.

If you have any ideas for talks in 2014 please contact me and I will do my best to organise. I really would like to get speakers who will speak on subjects which are of particular interest to you so I look forward to hearing from you.

Tilly Hale, 01670 714901, tilly.liveliver@gmail.com

PBC Meetings 2013-2014

We had an excellent meeting on 5 November 2013. Dr Laura Griffiths stood in for Prof Julia Newton and she gave us a very interesting talk on clinical trials and how they progress through to having new medications. Laura works in the PBC Clinic with Prof David Jones and also runs the Rituximab Trial.

I have been trying to sort out dates for 2014 and I have managed to book two dates at Freeman Hospital. We had a meeting at Sunderland and at Bishop Auckland earlier this year but both were difficult to organise and the parking at Sunderland is proving to be a real problem for everyone. At the Bishop Auckland meeting, where Dr Laura Griffiths also spoke, Dr Dhar who is a gastroenterologist at Bishop Auckland stayed for the meeting and we really appreciated his input.

However, he did say that future meetings at Bishop would not be easy to organise and that really he felt we should think about moving the meeting to Durham. At the moment this is still all in the air but Durham would be a good compromise for both Sunderland and Bishop Auckland. I do regret leaving both hospitals, especially Bishop Auckland which has always had very good support from the members but unfortunately I do not think we have any option.

The two Freeman dates are as follows:

Tuesday 29 April 12.00 – 2.00 Freeman Hospital, Functions Room 137. Tuesday 11 November 12.00 – 2.00 Freeman Hospital, Functions Room 137.

The meetings are open to everyone. Tea, coffee, orange juice and biscuits are served, and we have a small raffle – the proceeds of this are given to Professor David Jones' PBC Research Fund. Please feel free to bring your own sandwich.

PLEASE NOTE: We are able to park without paying at Newcastle Freeman Hospital, but due to changes in the parking plans it is now essential that I give car registrations to Freeman Security and then you are asked to park in the Multi-storey Car Park, at the back of the Hospital. Obviously, if you have a disabled badge and are able to obtain a space in the front car park you may prefer to do this, but to make sure you do not have to pay it would be wise to contact me at least three weeks prior to the Newcastle meetings so that I can pass your details on to Security. PLEASE DO NOT PAY AT THE PARKING METER AS I CANNOT REFUND THIS – JUST PARK THE CAR AND AS LONG AS I HAVE HAD YOUR CAR REGISTRATION FREEMAN SECURITY WILL KNOW ABOUT YOU AND YOU WILL NOT BE CHARGED FOR PARKING WITHOUT A TICKET. (TO BE ON THE SAFE SIDE IT IS WISE TO PUT A SLIP IN YOUR WINDOW SAYING YOU ARE ATTENDING THE LN PBC MEETING IN THE FUNCTIONS ROOM.)

Tilly Hale, 016670 714901, tilly.liveliver@gmail.com

Photo shows Dr Laura Griffiths (seated at the table, front right) at the PBC meeting on November 5 2103. Thanks Laura for a really interesting talk.



PBC DVD

We are now well into distributing the latest order of the DVD which takes us to over 400. Recently we have had requests from the USA, Canada, Australia, Norway, Denmark, and several places in the UK. As you can see from the letters page the feedback is always good and people find it very helpful.

When we send it out we enclose a short leaflet explaining how the DVD was funded in the first place and explaining the costs so that if people wish to make a donation they know what we spend on each DVD. Whilst we do appreciate the donations as this allows us to continue to fund production without having to use other LIVErNORTH funds we would not like to think that anyone did not ask to have the DVD because of financial problems, so please do remember this and feel able to ask for a copy.

If you would like a copy please do get in touch.

Tilly Hale, tilly.liveliver@gmail.com, 01670 714901

UPDATE ON GILL

In the last issue of the newsletter we had an item on "Liver disease in the news" and featured Gill McLachlan who had been waiting for a transplant for over two years.

The good news is that Gill had her transplant in August and is now at home and making a good recovery. Gill is very grateful to all the various doctors, nursing staff, and everyone on Ward 12 and to LIVErNORTH who have supported her throughout her long wait.

Tilly Hale

Photo shows Gill (left) and her mother and daughter. As you can see from the photo, Gill is looking really well since having her transplant. We wish you all the very best, Gill!



Tilly Tattle

Here we are with the final newsletter of 2013.

During July, August and September we were selling raffle tickets in the Charity Booth at the Freeman Hospital. I would like to thank those people who volunteered and helped to swell the amount raised for the Grand Draw. The first prize was £500 and there were many other good prizes including vouchers from some of the stores in Newcastle, a Day at the Races from Gosforth Park Race Course, and a jacket from Barbour. We are very fortunate in that many of these firms donate year in year out and these make the prize list very exciting. At the end of September we had the Annual Fair. This was opened by Denise Robertson, MBE, the Patron of LIVErNORTH. A full report on the Fair can be found elsewhere in the newsletter. We have had our last talk of the year which was a very interesting talk by Dr Pete Thelwall, who is a physicist, based at the General Hospital in the MRI Department. This was a fascinating insight into the work done in early stage research and was most enjoyable. Throughout the year we have been fortunate to have several excellent talks from our speakers and as always we are very grateful to them. Each speaker gave interesting talks on their specific area and provided us with a great deal of information. The talks are always pitched so that we can understand them and we are always encouraged to ask questions. The speakers are also willing to talk to individuals afterwards and this gives people a chance to ask questions with regard to their own disease and to get information out of the clinic setting. We would like

to thank Mr Jeremy French (February), Dr Stuart McPherson (March), Professor David Jones (May), Professor Derek Mann (June), Professor Oliver James (July), Professor Julia Newton (September) and Dr Pete Thelwall (October). Thanks also to Professor David Jones and Dr Laura Griffiths for their talks to the LN PBC Meetings during 2013. It was especially good to have Professor Oliver James speaking at our AGM – as well as being the President of LIVErNORTH Prof. James was instrumental in helping to set up LIVErNORTH back in February 1994. He is now supposed to be retired but to see and hear about the amount of work that he is doing you would not realise this. The last events in 2013 include the Thanksgiving Service on 10 November. This is for the donor families and transplant patients and their families. It is always a very lovely service, and very emotional. After this we have the LIVErNORTH Carol Service which will be on Sunday 8 December at 2.30pm in the Freeman Chapel and as always is followed by tea/ coffee and mince pies. Finally, on 11 December we hold our LIVErNORTH Christmas Dinner which begins at 6.30 with the meal on the table at 7pm. Dates for 2014 are now being organised, along with speakers. If you would like a specific talk it is still not too late to contact me and I will do my best to arrange it. Next year we will be reducing the number of meetings to five instead of seven and will be changing the evening and the starting time so please take note of these changes when you see the 2014 diary. I would like to take this opportunity of wishing everyone a very happy Christmas and all good health in the coming year. Kind regards.

Tilly Hale

LIVERNORTH Carol Service 2013

8 DECEMBER 2013 - 2.30PM

As always, the Carol Service will take place in the Freeman Chapel and will be conducted by the Reverend Nigel Goodfellow, Head of Chaplaincy and a Governor of LIVErNORTH.

Last year we had a completely different style of service when three children took part – Matthew and Thomas Jones (sons of Prof David Jones) and Laura Wakeford Hale (Tilly's granddaughter). I am now racking my brains trying to think of something different for this year – at the moment nothing comes to mind – any ideas would be gratefully received.

However, some things stay the same. We will have music and we are very grateful to Dorothy Barker, the Chaplaincy Visitor on Ward 12, who plays the piano to accompany our singing. We also have a soloist (Helen) who is accompanied by her friend (Gillian) and we have various Bible readings and some form of reflection. If you would like to help with any of these please do let me know as it is so much nicer to have volunteers than for me to have to telephone round and ask people if they can help out.

The Carol Service last for about 45 minutes and is followed by mince pies and tea and coffee. This gives everyone time to catch up with friends and have a nice natter in a lovely warm environment. The Service is open to all – LIVErNORTH members, families, friends, anyone in the Freeman who feels like attending, and it really is a case of the more the merrier. We do hope to see you there.

Christmas Cards - an apology

Last year I was talking to Pam Yannez (previously Pam Buckley) and we were discussing the cost of postage for Christmas cards. We had both seen an item about how much it costs to feed homeless people at the various Christmas shelters and we were both horrified at how few cards we could send where the postage would pay for these meals.

I decided there and then that I would have to cut back on the number of cards I post. I usually send out somewhere in the region of 200 cards. Obviously some of these I manage to give out by hand, and some are to my family and friends abroad where it is one of the few contacts we have with each other, but a lot of them are to members of LIVErNORTH and other such organisations.

This year, I will not be posting as many cards – this may mean YOU do not receive a card from me but I will be donating the savings made on postage to one of the homeless charities. Please, if you don't get a card from me, don't think I have forgotten you or that I don't think about you – it is just that I really feel terrible for the amount of money that we all spend on postage in this way. Please feel free to take me off your list too.

So this year, through the newsletter, I would like to wish you all a very happy Christmas and good health in the New Year.

Tilly Hale

Ascites or encephalopathy?

Do you have ascites or encephalopathy? Would you be willing to take part in a research project?

d-LIVER is a project which is taking place across Europe to develop new ways for providing care to patients with advanced liver disease. A system is currently under development which would allow regular monitoring of patients with liver disease through measurements carried out at home. These measurements would include blood tests carried out using a finger prick sample of blood (similar to the sample used by patients with diabetes) as well as measurements of weight, blood pressure, heart rate and temperature. The system would be linked to the hospital by the internet so that the results can be monitored closely by doctors allowing any deterioration to be picked up early and small changes to be made to treatment to prevent further deterioration. The two areas where we think this system is likely to bring the greatest benefit are in patients with ascites (a build up of fluid in the abdomen) or encephalopathy (intermittent confusion due to a build up of toxins). It is envisaged that better care will bring improvements in patients' quality of life and reduce the number of visits and emergency admissions to the hospital.

While the system is in the early stages of development we are carrying out a research project at Newcastle to look at the current impact of advanced liver disease on quality of life. This is being done using questionnaires which ask about how liver disease impacts on day to day life as well as how much contact patients have with medical services. We are asking people to complete these questionnaires 6 times over the course of a year (once every 2 months). The questionnaires take around 30 minutes and are completed at home and posted back.

If you have, or have previously had, ascites and/or encephalopathy and attend the Freeman Hospital we would be keen to hear from you if you would be interested in taking part in this study. For more information please email james.orr@newcastle.ac.uk.

The Gift of Life, by John Holland

There I was, at three laps of a mile, My race nearly run, running out of time, With failing liver; an imbalance of bile, Desperate to be thrown a life-line.

The hourglass sands had nearly run through, But due to an act of supreme nobility, A donor's organ lives on within me, life anew, And I cherish this responsibility.

Birdsong, flowers over the garden gate, A second chance has been given back, Thanking daily my good turn of fate, A baton of hope for my next lap of the track.

John Holland is a liver transplant patient from Carlisle. Thank you John for sending your poem.

Numbers Club £250 winners

Norma Birch of Wideopen, Numbers Club Draw - 11th September 2013 Professor Julia Newton, number 129 was drawn for the £250 prize.

Eileen Hayton of Great Lumley
Numbers Club Draw - 23rd October 2013
Doctor Pete Thelwell, number 52 was drawn for the £250 prize.

Just for laughs: Brenda and Terry are going out for the evening. The last thing they do is put the cat out. The taxi arrives and as the couple walk out of the house, the cat scoots back inside. Terry returns inside to chase the cat out. Brenda sitting in the taxi does not want the driver to know the house will be unoccupied and explains to the drive, "My husband is just going upstairs to say goodbye to my mother". Several minutes later an exhausted Terry arrives and climbs back into the taxi saying, "Sorry I took so long, the stupid idiot was hiding under the bed and I had to poke her out with a coat hanger several times before I could get hold of her and get her out"!

Great North Run

LIVErNORTH Great North Runner Alison Wilkinson writes, 'Please find attached a photo of myself, and another of me and Andrew Chaytnor in our Liver North t-shirts! We enjoyed it very much and can't wait to hopefully run it again next year! I am collecting in my sponsor money and will forward it to you as soon as possible. Thank you for offering me a place to run for you.'



Alison Pitts sent us her photo (right), saying, 'It took me 2 hours and 29 minutes to complete the race which I was really happy with as it was my first GNR.'





Jeremy French sent us a photo of himself and Robin and Rosie Hamar (left).

Chris Tosh, who writes about his Great North Run on the next page, also sent a photo of himself in his LIVErNORTH shirt, and a scene from the run (right).



Chris Tosh's GNR

My decision to embark upon this famous half marathon came as I am sure many have before following a late night conversation with my wife. Mell is currently awaiting a Liver transplant following a genetic condition that has led to cirrhosis of her Liver. In my moment of madness, I blurted out, I am going to run the Great North Run for LiverNorth, now I am hardly Mo Farrah and after she had stopped laughing, agreed that it was certainly a very worthy cause to help especially with the help and support that we had and are receiving from them.

My online application was completed and as part of me still felt daunted at the prospect of 13.1 miles, I was beginning to feel excited at the thought of trying to push myself to something new. I set up an online training plan and was full of the best intentions, especially when it was still over 200 days until the run! However, the time seemed to speed up and very soon, my race number and LiverNorth running top arrived in the post.

My sponsorship was really taking off too, people were more than generous with their support and the good luck messages just added to the anticipation. Before I had arrived in Newcastle the total pledged was already many hundreds of pounds!

September 15th 2013 dawned; I remember the dawn very well because I had lay awake all night unable to sleep with giant butterflies doing a Riverdance in my tummy. I was soon on the Metro making my way to the city centre, all around there were runners dressed in the most unusual costumes and charity t shirts from every good cause imaginable. The atmosphere was very friendly as everybody chattered with their new friends.

I don't think there was a dry eye on the start line of the 46 000 runners when they played 'Abide with Me' over the PA system and asked everybody to remember the varied reasons why we were all there. It certainly made me feel humbled to think that all I had to do was run 13.1 miles when Mell and many others are struggling with their own personal marathons on a daily basis.

The start gun fired at 10:40, but it was well past 11:00 by the time the start line even came into view. The sight and sound of the Red Arrows flying low over the Tyne bridge brought goose bumps!

The actual run itself seems to be a bit of a soggy blur, filled with many chants of Oggy, Oggy Oggy! I do remember the amount of people stood in the pouring rain cheering and willing everybody on, the children wanting to Hi 5 the runners and the amazing experience of it.

My lasting memory will be of Elvis singing at a bus stop after about 11 miles and the amazing view of the Red Arrows display as I jog/crawled along the seafront towards the finish line.

I was soon at the finish line with my medal around my neck and a smile on my face the size of Tynemouth.

That one was for you, Mell x

Trans Pennine Trail Cycle Challenge

On the 29th May, 11 *National Grid North West 2* staff took part in a 4 day bike challenge, to raise money for LIVErNORTH. We did this challenge for LIVErNORTH because they supported the father and family of a colleague of ours, Nathan Farrell Jones, and all we heard about were the lovely stories of care and support, up until, and after Nathan's father passed away. It really touched all of us and we felt it was the only charity we wanted to do it for.

The challenge was over 4 days, along the Trans Pennine Trail from Southport to Hornsea, and involved cycling 210 miles, and camping for 3 nights, along the trail. We had a vehicle supporting us along the way. We had tremendous support from Paul Williams, Alan Dumbill and the Delivery Engineers trying to fit this into the plan, so that it caused minimum disruption.

The majority of riders were novices and had bought their bikes in the months leading up to the challenge. We put in some much needed training on various cycling routes in the build up to the main event.

The team consisted of 11 NW2 members, 4 from the Deeside team, 7 from the Capenhurst team and the ages ranged from 21 to 63:

Sean Ward Substation Craftsperson

Steve Richards Field Technician

James Simpson Substation Craftsperson John Pealing Substation Craftsperson

John Hewitt SAP Craftsperson (Support Vehicle)

Stan Edge Retired Substation Engineer
Liam Ward Substation Craftsperson
Luke Dorbin Substation Craftsperson

Tim Hughes Substation Craftsperson (Support Vehicle)

Rebecca Farrell-Jones Team Administrator Nathan Farrell-Jones Substation Engineer

The ride was a challenge, riding through Liverpool and Manchester, through to the delights of the Pennines. Throughout the ride, we were helped massively by John Hewitt and Tim Hughes, who were driving the support vehicle, providing the cyclists with lunch, much needed replenishment and the occasional breakdown cover.

Day 1. We set off from Southport proceeding through Liverpool, covering 50 miles in poor conditions onto Warrington for our first overnight stop. We were joined by recently retired Stan Edge, who was a great addition to our team.

Day 2. We were packed up and ready to go when we had our first major breakdown. Liam Ward's back tyre had blown resulting in him having to cycle 20 miles on the dreaded reserve bike. We knew we had a big task on Day 2 as we were heading towards, then over the Pennines. I think it's fair to say we underestimated them, but we battled our way through energy sapping sand tracks, up and down poor ground on almost vertical hills and over cobbly sheep fields into Yorkshire. A late finish after such a hard day's work was rewarded with a chippy and a few well-deserved beers.

Day 3. We were joined by Nathan and Rebecca on our journey through Penistone and onto Selby, where our 3rd and final night's camping was. The day was a lot easier than day 2, but it had its ups and downs, made harder by slightly sore legs. None the less, we made it safely to our destination, knowing we were 3/4s of the way done, with only 56 miles to do on the final day!

Day 4. The moral in the camp was high and knowing we only had that day to complete, we got underway at a surprisingly fast pace, completing the first 30 miles in great time. With just over 25 miles to go after lunch, we knuckled down and rode on through Hull and onto Hornsea. The last 10 miles were tough on a seemingly never ending straight track to the finish. Finally, we turned the last corner to be greeted by the smiling faces of the support team and Delivery Engineer Raphael Kashiri from Capenhurst.

A great achievement by all involved with fantastic help from our support team without whom we couldn't have done it. After National Grid matching, we managed to raise £5274.00 for LIVErNORTH, which we are delighted about and hope it goes a long way to helping those who are less fortunate than ourselves.

The whole team enjoyed the experience and it is something we won't be forgetting!

Our sincere thanks go to everyone involved in this challenge. The late James Farrell-Jones was obviously a much loved and highly respected gentleman, who sadly succumbed after a brave battle with Alpha 1 Antitrypsin. To date, the group has received a total of £7453.96 in his memory. This legacy of James Farrell-Jones will go towards research and as such will help all those who suffer from liver disease.



The Trans Pennine Trail team from National Grid North West 2 who raised £5274 for LIVERNORTH.

The wedding of Rebecca and Nathan Farrell-Jones, son of the late James Farrell-Jones. The couple decided to give LIVERNORTH key-fobs instead of favours as a way of fund raising for the group. LIVERNORTH is indebted to the whole family for their support and wish Nathan and Rebecca a long, happy and healthy life together.



Transplant Cricket Match

The annual cricket match between the doctors and the patients took place on Tuesday 16th July 2013 at the Blue Flames Sports Ground at Longbenton. With the Transplant Patients winning last year's match, the Doctors needed to win this year to put some kind of pride back into their team.

Every year the two teams play for the Ross Taylor Memorial Shield. The match started at 6.30p.m. on a lovely warm summer evening. The match finished with a final score of 76 to 73 runs in favour of the Transplant Patients. Young Alex Crawley went up to collect the trophy on behalf of the patients' team.

The evening finished with a buffet and a Grand Raffle, which raised a total of £115.00 with the help of Carol and Lesley Huntley, Susan Harty and Marion Lee.

Special thanks go to Dave Lee and Graeme Appleby for getting the two teams together, the staff at the Blue Flames Sports Centre and everyone who helped to make the evening a great success.

John Harty

Marjorie at the Transplant Games

LIVErNORTH star Marjorie Batey took part in the 2013 Transplant Games in Sheffield. Marjorie competed in four events - badminton, ten pin bowling, throwing the cricket ball, and shot put. She came home with five medals - two gold, one silver and two bronze. Marjorie raised a fabulous £700 in sponsorship for LIVErNORTH from local churches, family and friends.

Congratulations to Marjorie - and a big thank you to Marjorie and everyone who sponsored her.



Liver disease: who holds the key?

Who holds the key to unlocking the mysteries of liver disease?

Due to the dedication and painstaking work of researchers, the causes of liver disease will be discovered, resulting in treatments being established and crucially, cures being found. Research is not carried out on a whim; before any work can commence, researchers must demonstrate that their proposed research is valid, ethical and most importantly will not put any participant at risk of harm. There is a huge spectrum of research ranging from the highly technical which might involve new equipment, clinical trials involving new drugs and treatments, monitoring experiences and the completion of questionnaires. No matter how complex or how simple the research question might be, each comes with one aim - finding an answer. The involvement of the public and patients (PPI) is now of great importance when research applications are considered by the various authorities. PPI assists in ensuring that the research question is relevant and that participants are comfortable with whatever is required of them.

Critically, researchers rely on having fully informed volunteers to participate in their research and it is with this in mind that I am hoping to create a register of people who are willing to be approached for this purpose. You do not need to be a liver patient, as researchers often need a cohort of people who will act as 'controls' i.e. people who are not suffering from the disease in question but will undertake the same role in the research as the liver patients in order that comparisons can be made.

If you are interested in being involved in research then please complete the form. By completing the form you will be consenting to your details being held on a password controlled database. Any information you provide will be confidential. LIVErNORTH never shares any details with any other organisation. Researchers based at the University of Newcastle upon Tyne and Newcastle upon Tyne NHS Foundation Trust Hospitals will not have direct access to the register but will be able to request that LIVErNORTH contacts potential participants.

Please consider becoming involved because the answer to who holds the key lies with you.

Joan Bedlington

For further information please contact me: Tel/Fax: 0191 370296, Email: info@ livernorth.org.uk or write to LIVErNORTH, FREEPOST NEA2762, Stanley, County Durham, DH9 0BR.

LIVErNORTH Research Register					
Name:					
Address:					
Telephone:	Mobile:				
email address:					
Do you suffer from liver disease: Yes □ No	□ (please tick boxes to indicate choice)				
Are you interested in helping with research int	o any of the following?:				
Hepatitis A \Box	Hepatitis B				
Hepatitis C	Autoimmune Hepatitis				
Non Alcoholic Fatty Liver Disease $\ \square$	Primary Biliary Sclerosis				
Primary Sclerosing Cholangitis	Alcoholic Liver Disease				
Liver Cancer	Cirrhosis of the Liver				
Any research project:	Other (please specify)				
I am interested in being involved in liver disease research and consent to being contacted by LIVErNORTH if participants are needed for a research project.					
SignedDate					
When completed, Please return to: Joan Bedlington, LIVErNORTH, Freepost NEA 2762, Stanley, County Durham, DH9 0BR (No postage stamp required)					

Christmas Dinner 2013

t's that time of year again! If you would like to attend the Christmas Dinner on Wednesday 11th December at 6.30 for 7pm, please complete the booking form below and return it to me with your payment. Last year as always, several people were disappointed. Numbers are strictly limited and on a first come, first served basis.

The meal includes non-alcoholic punch on arrival, fruit juice throughout the meal, a cheese board selection, coffee and mince pies to finish off the meal, all for £11.50 per person (50p cheaper than last year). As those of you who have been before know, the Freeman Catering Department put on an excellent meal at a very reasonable cost and we have a great evening. John Bedlington provides us with a quiz and we also have a tombola to make it a really enjoyable night.

Julie Pyburn 8 Bridlington Avenue Low Fell Gateshead NE9 6XJ

TV Watch

The Freeman Hospital and the James Cook both featured in a recent BBC programme 'Old Before My Time' presented by Cherry Healy, in an episode exploring alcoholic liver disease among young people. Look out for the Freeman's Steve Masson.

You can find the programme online at

www.bbc.co.uk/iplayer/episode/b03fgz0h/Cherry_Healey_Old_Before_My_Time_Alcohol/

Christmas Dinner Booking Form

WED. 11th DECEMBER 2012 - 6.30 FOR 7.00 PM

I would like to I enclose my c	reserve plane heque/postal order fo	aces at a cost of £11.5 or £	0 each.
I/we require	vegetarian ma	ain course(s).	
Starter: choose			number
	ble Broth with Port & Ginger		
Desert: choose			
	ristmas Pudding & B	Brandy Sauce	
	lixed Berry Pavlova confirmed)		
	te your choices clear	ly)	
We cannot gua people with wh	arantee seating arran nom you would like to	gements, but if you wis share a table we will o	sh to indicate do our best!
I would like to	be seated near		
Name			
Address			
		Tel:	
Please return with cheque or postal order made payable to LIVErNORTH to: Julie Pyburn, 8 Bridlington Avenue, Low Fell, Gateshead, NE9 6XJ			
Fill in & detach the section below if you want YOUR OWN REMINDER			
	places at	for 7.00 p.m. Wed 11th £11.50 each and have	
Vegeta	าง. ble Broth	Melon with Po	ort
Christn	nas Pudding	Mixed Berry F	
Vegeta	rian main course(s)	·	





Another fantastic Autumn Fair! Thanks as always to Denise Robertson, LIVErNORTH's patron, who once again opened the Fair and gave a lovely welcoming speech. Denise also drew the winning numbers for the prize raffle. She was presented with a token of our appreciation by Lucy and Laura, pictured above left. As patron to many charities, Denise asked us some time ago not to give her presents, flowers and the like - so instead we give her a small gift voucher, which we know she then passes on to one of her other charities.

LIVERNORTH AUTUMN FAIR 2013

INCOME				EXPE	NDITURE
KNITTED ITEMS	£	56.00	CHARITY DRAW TICKE	тs£	188.40
TOMBOLA	£	212.60	BANQUET ROLL	£	15.95
TOILETRIES	£	133.01	PRIZES	£	500.00
PRIZE DRAW	£	217.00			
JEWELLERY	£	65.15			
GAMES	£	48.75			
Toys	£	47.48			
CRAFTS	£	62.00			
Household	£	64.80			
CAKES	£	96.89			
REFRESHMENTS	£	135.60			
BRIC-A-BRAC	£	92.05			
TOTAL STALL:	s £	1231.33	TOTAL EXPENDITURE	£	704.35
	_			_	
CHARITY DRAW	£	3095.00			
CHARITY DRAW DONATIONS	£	811.58			
1 ST PRIZE DONATED	£	500.00			
DONATIONS	£	1544.60			
GROSS INCOM	E <u>£</u>	7182.51	NET PROFIT	£	6478.16
BALANCE	£	7182.51		£	7182.51

The annual Fair took place on 28 September and was opened by our Patron, Miss Denise Robertson, MBE. Last year I completely forgot to remind Denise and only realised late the evening before the Fair. This year I had notes in my diary from July, saying "remind Denise" and she very kindly confirmed that she had received the reminders and would be coming. She turned up on time and as always was such a lovely supporter of LIVERNORTH and the Fair. She toured all the stalls, spending money at each of them, and after drawing the winners in the Grand Draw she and her husband departed, laden with their various purchases and their winnings from the Tombola. At the start she was presented with tokens – originally we gave her flowers but were told to save our money so we decided to give her tokens which she can use for herself or pass on to one of her many other charities (Denise is patron of over 30 charities and works very hard for them).

We had the usual stalls, including Bric a brac, Toiletries, Tombola, Games, Crafts, Cakes, Knitwear, Plants and Household and Jewellery. Apart from the Grand Draw we also had various small raffles which were very well supported. And as always, we had refreshments with some marvellous cakes and pies to have with our teas and coffees.

We are fortunate in that the majority of the items sold are donated and we are very grateful to everyone who helps us in this way. The Tombola Stall has over 200 prizes and almost all of them are given to me and the same is true for the Toiletries and the Jewellery.

The Fair, including the Grand Draw, raised almost £6,000 on the day, with more money coming in later.

Our thanks to all the people who donate, who come along and spend their money, who run or help on the stalls, and who bake cakes and provide refreshments.

Next year the Fair will be on Saturday 20 September and Denise Robertson has very kindly agreed to open it once again.

Tilly Hale

LIVERNORTH AUTUMN FAIR 2013

PRIZES

(28TH SEPT 2013)

Game	Solutio n	Prize	Won by
Toothpaste Journey	36	Heroes Donated by the Diamond Family	Laura Wakeford Hale

PRIZE DRAW

	Prize	Winning Number	Won by
1	Decorated Cake Donated by Val Donkin	00112	K A Thompson
2	Handmade Quilt Donated by Donor Families	00190	D Inch
3	Wine Donated by M Oliver	00082	D Taylor
4	Toiletries Donated by J Pyburn	00142	J Humphrey
5	Chocolates Donated by K Wright	00027	A Bray

LIVERNORTH 2013 GRAND CHARITY DRAW PRIZES

(DRAWN ON 28TH SEPT 2013)

	PRIZE	WINNING NUMBER	WON BY (SOLD BY)
1	£500 CASH FIRST PRIZE M HALE	01309	N KARA (SELF)
2	BARBOUR QUILTED JACKET THE BARBOUR TRUST	03137	SAMM MURRAY (S BURGON)
3	£25 GIFT VOUCHER M&S NEWCASTLE UPON TYNE	00424	J CLARKE (SELF)
4	2 PREMIER ENCLOSURE TICKETS 2013 NEWCASTLE RACECOURSE	02994	JIM (E RAINFORD)
5	CAR VALET BENFIELD MOTOR GROUP	00323	W BAILEY (KEN BROWN)
6	AFTERNOON TEA FOR TWO MARRIOTT NEWCASTLE GOSFORTH PARK	03333	A THOMPSON (CHARITY BOOTH)
7	2 BOTTLES OF WINE MORRISON'S BYKER	02415	M WILLIAMSON (SELF)
8	£10 GIFT CARD TESCO NORTH SHIELDS	00942	S GRESHAM (SELF)
9	£12 ASDA GIFT CARD MARJORIE BATEY	00574	B DALTON (SELF)
10	2 COURSE LUNCH FOR 4 AT THE LINDEN TREE PUB MACDONALD LINDEN HALL	01689	E NORMAN (SELF)

Using MRI in liver disease

On October 23, 2013, LIVErNORTH had a talk by Dr Pete Thelwall, Reader in Magnetic Resonance Physics at Newcastle University. Dr Thelwall has kindly provided a summary of his talk for LIVErNEWS.

MRI scanners are widely used in diagnostic imaging: they provide an excellent tool to look inside the body, but are non-invasive and safe. Unlike x-ray-based medical imaging methods (eg. CT scans), they don't use ionising radiation and so don't have the small but present risks associated with x-rays. This makes MRI scans well suited to research studies, where scientists use measurements from MRI scans to understand disease processes and to monitor the effects of treatment regimes. MRI is a very flexible technique, allowing us to make many different types of measurement of the body's structure, function, and biochemistry.

At the Newcastle Magnetic Resonance Centre, based at Newcastle University, we develop new ways of using MRI scanners and apply these methods to clinical research. Our centre houses researchers with a mix of backgrounds, such as physicists, clinicians, engineers and biochemists, and our multidisciplinary team is central to our ability to apply novel MRI advances to important questions of human health.

A significant portion of our research relates to liver disease, and we work with local, national and international clinicians and research groups as part of our studies. In the presentation made to the Liver North meeting, I described two recent liver research projects. The first involved the development of a new method to diagnose and monitor a genetic disease called Cholesterol Ester Storage Disease (CESD), which causes progressive liver damage due to the body's inability to break down a type of fat called cholesterol ester. The disease causes fat accumulation in the liver that disrupts liver function, and until recently the only treatment was liver transplant. A new drug treatment has been developed, and we worked with the drug company to find a way of measuring liver cholesterol ester content using MRI so that repeated biopsy measurements could be avoided when monitoring the effects of the drug.

The second project presented focused on developing new a MRI technique for clinical research studies into liver disease. We were interested in monitoring oxidative stress in the liver, which is a process where reactive chemicals can be formed inside cells, with the potential to damage cellular components such as DNA, enzymes and membranes. The liver usually defends itself against oxidative stress, for example by making antioxidants that neutralise the damage-causing reactive chemicals. We created a method of measuring the concentration of these antioxidants, and also measured the rate that they are made by the liver. Our studies show that the concentration and synthesis decrease in liver disease, which we think under some circumstances may facilitate the progression of liver disease. We plan future studies to investigate this further.

These two projects are examples of the type of work we do at the Newcastle Magnetic Resonance Centre: we develop novel MRI methods that allow us to answer important questions of human health.

Many thanks to Dr Pete Thelwall for a really interesting presentation. If you'd like to know more, a selection of slides from the talk are available at www.livernorth.org.uk

Autonomic dysfunction

On 11 September 2013, Prof Julia Newston gave a very interesting talk on autonomic function and the cardiovascular system in cholestatic liver disease. My partner, Tom, can't usually get to LIVErNORTH talks – if he's not travelling for work, he has to stay at home with our daughter to let me be at the meetings. But recently I have been in such a bad state that he decided he needed to come – he is a scientist by training, and my explanations of why I am the way I am can't quite match up to Julia Newton's! I'll try to summarise her talk here for those of you who couldn't make it. (Thanks to Julia for checking my write-up for any glaring errors).

The autonomic nervous system is what regulates blood pressure and keeps the heart beating, and the bladder and gut working – all functions that carry on without us being conscious of them. The main component is the cardiovascular system involving the heart, lungs and brain. There is no research on the role of the liver in autonomic function.

The Orthostatic Grading System (OGS) measures how people feel when they stand up, including blacking out and feeling dizzy. When the OGS is used with people with Chronic Fatigue Syndrome (CFS), 89% of them have orthostatic intolerance – as do 56% of people with NAFLD and 69% of people with PBC. It has been found that people with fatigue have higher OGS scores and more orthostatic intolerance. There is no association between high OGS scores and severity of liver disease.

In PBC, autonomic symptoms associate with fatigue and cognitive symptoms. Orthostatic intolerance worsens over time in PBC, and it can be assessed using 'objective' measures such as monitoring blood pressure over 24 hours. In PBC patients, the 'head of steam' is lower than in matched controls – and those results are similar to those of CFS and NAFLD patients. We can also measure heart rate variability, and fatigued people have significant abnormalities compared to non-fatigued people.

Looking at cardiac functioning, researchers have used tilt table testing, where the table is tilted to 70 degrees which is the angle needed to get blood pooling in the legs. In the tests, blood pressure and heart beat are measured to see how the heart is functioning. This is done over a forty minute period standing at 70 degrees on the tilt table. The heart rate should increase on standing up, but any increase is significantly less in PBC patients, showing that the sympathetic nervous system is not activating efficiently. In PBC patients, the blood is pumped from the heart less effectively. Highly fatigued PBC patients have significant differences to controls in how the heart twists during a heartbeat.

The clinical consequences of autonomic and cardiovascular dysfunctions include acid accumulation in peripheral muscles and longer recovery times between bouts of exercise because of abnormalities in the mitochondrial function – lots of acid is created, and the body can't get rid of it. This associates with how bad the autonomic dysfunction is.

Turning to cognitive function (memory), neuropsychometric tests confirm there are

abnormalities. PBC patients score lower than controls in IQ tests, and lower blood pressure means worse memory. Decline in cognitive function is linked to structural brain lesions and poor autonomic function. Where there are more lesions, there is worse autonomic function. This also has respiratory consequences. People with PBC have a different level of thorassic fluid content compared to NAFLD and PSC. The older literature on PBC talks a lot about breathlessness.

In summary, people with PBC with problems of day-to-day functioning according to the PROMIS HAQ scale (Health Assessment Questionnaire - Patient-Reported Outcomes Measurement Information) which asks about problems reaching for tins, cooking, getting up from a chair, etc, also have autonomic dysfunction. One line of thought is that targeting autonomic dysfunction might be more important than targeting fatigue itself. Julia and David Jones have published an article on this subject:

Newton, J. and Jones, D.E. (2012) Managing systemic symptoms in chronic liver disease, J Hepatol. 2012;56 Suppl 1:S46-55. doi: 10.1016/S0168-8278(12)60006-3.

Julia talked about management of autonomic dysfunction, including developing coping strategies such as pacing and lifestyle changes, as well as taking people off medications that make autonomic symptoms worse, 24 hour blood pressure monitoring, increasing fluid intake to 2.5 litres a day, increasing salt intake if blood pressure is low, and referring people to a specialist if they have a history of falls and syncope.

Finally, Julia told us a bit more about her new role at the Fatigue Clinic at the Campus for Ageing and Vitality, along with a multidisciplinary team including Health Psychologist Vincent Deary and Occupational Therapist Kate Hackett.

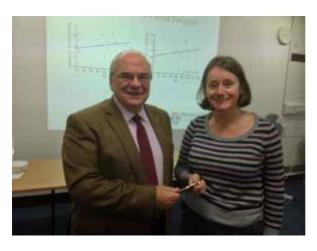


Photo shows Prof Julia Newton receiving her LIVErNORTH pen from Chair John Bedlington.

Living with Sjogren's

This article was written by Victoria Watson of Elementary V Watson Proofreading and Copywriting Services (http://elementaryvwatson.com). Victoria is a North East writer and editor who was recently diagnosed with primary Sjogren's. Originally published on her blog, we reproduce it here with Victoria's permission, for the interest of the many liver patients who also have Sjogren's.

What if I told you that Venus Williams, Olympic medal winner and former world number 1, had a debilitating auto-immune disease? She may have won seven grand slams but Venus has experienced times in her life when she couldn't lift a tennis racquet up. What is this devastating



illness? It's called Sjogren's Syndrome (pronounced "show-grins").

I, too, have recently been diagnosed as suffering from Sjogren's but, up until December 2012, I had never heard of it. You probably haven't either.

Sjogren's is not as rare as you might expect, approximately 3-4% of adults in the UK have it but it is one of the most under diagnosed conditions despite being the second most common. The reason for this is Sjogren's symptoms are so similar to many of the other, more well-known, auto-immune diseases like Rheumatoid Arthritis and Lupus. Like with other auto-immune conditions, Sjogren's patients' immune systems react abnormally, attacking healthy tissue and cells instead of viruses and bacteria that enter the body.

Symptoms can range from joint pain to dry eyes. Possibly the worst symptom, though, is the extreme fatigue. This fatigue is not something that can be cured with a long lie-in or a few naps; it is the kind of exhaustion that made me want to cry every time I woke up, no matter how long I had been asleep for. Like many other conditions, there are few outward signs and therefore people presume you're healthy.

You could go for years, decades even, without a "flare" where the disease rears its head and makes you feel like you're dying. I went ten years

between flares but, as I have gotten older, the time between the flares has reduced and the time it takes to recover has increased. Sjogren's can appear to go into remission but, unfortunately, it will always be lurking in the background. The problem with that is, sufferers can get into a vicious circle of worrying about the illness reappearing but stress increases the likelihood of a flare. When you're living through a flare, it's easy to become depressed and feel like it will never end.

Some sufferers will be "lucky" enough to only have dry eyes and/or a dry mouth to contend with but even these symptoms make everyday life difficult. It may mean that you encounter tooth decay because you are not creating enough saliva. You may also find you can't wear contact lenses because there is simply not enough moisture in your eyes to rehydrate the lenses when you blink.

However, some other patients can see major organ involvement. Because Sjogren's attacks the soft tissue in the body, your brain, kidneys and lungs can all be at risk. There is no cure for Sjogren's but it can be managed with topical treatments, anti-malarial drugs and, in severe cases, immunosuppressants. There are also other services available to help you come to terms with the diagnosis and possible implications. For example, you may be sent to a Health Psychologist to discuss your feelings about the diagnosis. Perhaps you'll see a Physiotherapist to help with mobility issues.

Venus confessed in an interview that she had been to see doctors several years before she was diagnosed and was told that they were baffled as to what could be causing her joint pain and fatigue. I was told for twenty years – since the age of nine – that I had either Chronic Fatigue or ME. I was turned away by GPs and other specialists, and some even suggested I was a hypochondriac. I was officially diagnosed in May, 2013. Since diagnosis, I have researched the condition and I am now able to connect the dots and identify that all of the previously unexplained health-related "episodes" can be attributed to Sjogren's.

The thing with Sjogren's is it's so under-recognised that you have to be lucky enough to deal with someone who recognises the signs. The blood tests run by GPs won't show anything up as the tests GPs run are very general. If you get as far as a Rheumatologist or Immunologist, you may still get turned away. You must stand your ground. My specialist

told me that the only definite way to be diagnosed is to have a lip biopsy – which has to be ordered by a doctor. Having said that, I've spoken to lots of people who have been diagnosed without having to have the invasive surgery.

Sjogren's common symptoms:

Dryness of eyes, mouth, etc.

Tooth decay.

Dry cough.

Difficulty, swallowing, chewing, etc.

Hoarse voice.

Difficulty speaking.

Sensitivity to light.

Itchy / burning / stinging eyes.

Mucus in eyes.

Dry skin.

Exhaustion / fatigue.

Joint / muscle pain.

Vasculitis.

Brain fog.

Depression.

IBS.

Sounds fun, no? But, don't worry, I will be writing more articles on my blog on this topic, and suggesting other blogs and books that may be helpful. If anyone would like more information, please email me at victoria.watson@elementaryvwatson.com

Victoria x

http://elementaryvwatson. wordpress.com/2013/09/08/livingwith-sjogrens-syndrome/

Sjogren's poem

I think I've tried everything Reading and gymming,

Meditating, swimming.

Pep talks and dressing-downs,

Smiles despite deep-down frowns.

Chocolate then diet,

Don't want to die yet.

Doctors and pills,

Physios with pins.

Positive mental attitude.

For what I have, gratitude.

Lying in bed,

Shopping 'til I'm in the red.

Nothing's worked yet,

But my job's under threat.

What can I do?

It's making me blue.

Fingertips and toes,

Nothing that shows.

Look 'normal' on the outside,

From people I've shied.

I'm scared of their germs,

Their "When will you learn?"s.

Eyes flicking,

Tongues clicking.

Not even thirty,

No longer flirty.

Fat, limpy,

Pathetic, wimpy.

They don't know how it feels,

The shit life deals.

The never knowing,

When pain will come flowing.

"It's just dry eyes",

Said one.

Tell my lungs and kidneys that,

You Pratt.

But I won't give up,

I'll pee in those cups.

I'll give pints of blood,

Let them hear my heart thud.

Sjogren's.

No grins,

I'll do anything.

Victoria Watson

Helen's Howlers

As LIVERNEWS readers will know, this column goes by the name of Helen's Howlers, Helen Milburn being the original jokes editor. They are now edited by LIVERNORTH Governor, Margaret Bickle (helenshowlers@gmail.com). Enjoy!

If you would like to contribute jokes for Helen's Howers, email Margaret Bickle on helenshowlers@gmail.com

Thanks to David Hastings!

The Talking Clock

Proudly showing off his newly-leased downtown Pretoria apartment to a couple of friends late one night after a rugby game, drunk Dave led the way to his bedroom where there was a big brass gong hanging on the wall.

'What's that big brass gong for?' one of the friends asked.

'Issss nod a gong. Issss a talking Australian clock' Dave drunkenly replied.

'A talking Australian clock - seriously?'
'Yup.' 'Hmmm (hic).'

'How's it work?' the second friend asked, squinting at it.

'Just watch' he said.

He picked up a hammer, gave the gong an 'earshattering bash' and stepped back.

His three mates stood looking at one another for a moment in astounded silence.

Suddenly, an Australian voice from the other side of the wall screamed,

'For god's sake, you stupid idiot. It's ten past three in the morning!!!'

Medical Advice

A man with a long history of migraine headaches goes to the doctor. When the doctor does his history and physical, he discovers that his poor patient has had practically every therapy known to man for his migraines and STILL no improvement.

"Listen," says the Doc, "I have migraines too, and the advice I'm going to give you isn't really

anything I learned in medical school, but it's advice that I've learned from my own experience. When I have a migraine, I go home, get in a nice hot bathtub, and soak for a while. Then I have my wife sponge me off with the hottest water I can stand, especially around the forehead. This helps a little. Then I get out of the tub, take her into the bedroom, and even if my head is killing me, I force myself to make love with her. Almost always, the headache is immediately gone. Now, give it a try, and come back and see me in six weeks."

Six weeks later, the patient returns with a big

"Doc! I took your advice and it works! It REALLY WORKS!

I've had migraines for 17 years and this is the FIRST time anyone has ever helped me!"
"Well," says the physician, "I'm glad I could help."
"By the way, Doc," the patient adds, "you have a REALLY nice house."

Did you Know

In the 16th and 17th centuries, before the invention of commercial fertiliser, everything had to be transported by ship. Therefore, large shipments of manure were common. It was shipped dry, because in dry form it weighed a lot less than when wet, but once water (at sea) hit it, it not only became heavier, but the process of fermentation began again, of which a by-product is methane gas. As the stuff was stored below decks in bundles you can see what could (and did) happen. Methane began to build up below decks and the first time someone came below at night with a lantern. BOOOOM! Several ships were destroyed in this manner before it was determined just what was happening. After that, the bundles of manure were always stamped with the term "Ship High In Transit" on them, which meant for the sailors to stow it high enough off the lower decks so that any water that came into the hold would not touch this volatile cargo and start the production of methane. Thus evolved the term "S.H.I.T", surviving centuries and is in use to this very day.

Beans

Once upon a time there lived a woman who had a maddening passion for baked beans. She loved them but unfortunately they had always had a very embarrassing and somewhat lively reaction to her.

Then one day she met a guy and fell in love. When it became apparent that they would marry she thought to herself, "He is such a sweet and gentle man, but he would never go for this carrying on." So she made the supreme sacrifice and gave up beans.

Some months later her car broke down on the way home from work. Since she lived in the country she called her husband and told him that she would be late because she had to walk home. On her way she passed a small diner and the odor of the baked beans was more than she could stand. Since she still had miles to walk, she figured that she would walk off any ill effects by the time she reached home.

So, she stopped at the diner and before she knew it, she had consumed three large orders of baked beans. She putt-putted all the way home, and upon arriving home she felt reasonably sure she could control any lingering effects. Her husband seemed excited to see her and exclaimed delightedly, "Darling, I have a surprise for dinner tonight." He then blindfolded her and led her to her chair at the table. She seated herself and just as he was about to remove the blindfold from his wife, the telephone rang. He made her promise not to touch the blindfold until he returned. He then went to answer the phone. The baked beans she had consumed were still affecting her and the pressure was becoming almost unbearable, so while her husband was out of the room she seized the opportunity, shifted her weight to one leg and let it go. It was not only loud, but it smelled like a rotten egg

When her husband returned, he instructed her to remove her blindfold.

And when she did, 50 people around her said "Surprise!"

Medical Confessions

gone worse.

The observations below are supposedly true reports by doctors. Hmmm..

A man comes into the ER and yells, "My wife's going to have her baby in the cab!" I grabbed my stuff, rushed out to the cab, lifted the lady's dress, and began to take off her underwear. Suddenly I noticed that there were several cabs, and I was in the wrong one. (Dr. Mark MacDonald, San Antonio, TX)

At the beginning of my shift I placed a stethoscope on an elderly and slightly deaf female patient's anterior chest wall. "Big breaths," I instructed. "Yes, they used to be," replied the patient. (Dr. Richard Byrnes, Seattle)

One day I had to be the bearer of bad news when I told a wife that her husband had died of a massive myocardial infarct. Not more than five minutes later, I heard her reporting to the rest of the family that he had died of a "massive internal fart." (Dr. Susan Steinberg, Manitoba, Canada)

I was performing a complete physical, including the visual acuity test. I placed the patient twenty feet from the chart and began, "Cover your right eye with your hand." He read the 20/20 line perfectly. "Left." Again, a flawless read. "Now both," I requested. There was silence. He couldn't even read the large letter on the top line. I turned and discovered that he had done exactly what I had asked: he was standing there with both his eyes covered. I was laughing too hard to finish the exam. (Dr. Matthew Theodropolous, Worcester, MA)

While acquainting myself with a new elderly patient, I asked, "How long have you been bedridden?" After a look of complete confusion she answered "Why, not for about twenty years -- when my husband was alive." (Dr. Steven Swanson, Corvallis, OR)

During a patient's two week follow-up appointment with his cardiologist, he informed me, his general practitioner, that he was having trouble with one of his medications. "Which one?" I asked. "The patch. The nurse told me to put on a new one every six hours and now I'm running out of places to put it!" I had him quickly undress and discovered what I hoped I wouldn't see. Yes, the man had over fifty patches on his body! Now, the instructions include removal of the old patch before applying a new one. (Dr. Rebecca St. Clair, Norfolk, VA)

Brain Teasers

The man who invented it doesn't want it. The man who bought it doesn't need it. The man who needs it doesn't know it. What is it?

I'm light as a feather, yet the strongest man can't hold me for much more than a minute. What am I?

Pronounced as one letter, And written with three, Two letters there are, And two only in me. I'm double, I'm single, I'm black, blue, and gray, I'm read from both ends, And the same either way. What am I?

Isaac and Albert were excitedly describing the result of the Third Annual International Science Fair Extravaganza in Sweden. There were three contestants, Louis, Rene, and Johannes. Isaac reported that Louis won the fair, while Rene came in second. Albert, on the other hand, reported that Johannes won the fair, while Louis came in second.

In fact, neither Isaac nor Albert had given a correct report of the results of the science fair. Each of them had given one correct statement and one false statement. What was the actual placing of the three contestants?

You want to send a valuable object to a friend securely. You have a box which can be fitted with multiple locks, and you have several locks and their corresponding keys. However, your friend does not have any keys to your locks, and if you send a key in an unlocked box, the key could be copied en route. How can you and your friend send the object securely?

Answers

- A coffin
- 2. Breath
- 3. An Eye
- 4. Johannes won; Rene came in second; Louis came in third.
- 5. Put the valuable object into the box, secure it with one of your locks, and send the box to your friend. Your friend should then attach one of his own locks and return it. When you receive it again, remove your lock and send it back. Now your friend can unlock his own lock and retrieve the object.

I never wanted to believe that my Dad was stealing from his job as a road worker. But when I got home, all the signs were there.

A man says to his neighbour, "I just bought a new hearing aid. It cost me £4,000, but it's state of the art. It's perfect." "Really?" answers the neighbour. "What kind is it?" "12:30."

I bet the butcher £50 that he couldn't reach the meat off the top shelf. He said, "No, the steaks are too high."

As I was walking down the street, I noted a man with a large pole in his hand and stopped to ask, "Are you a pole-vaulter?" His response was, "No, I'm German, but how did you know my name was Walter?"

A neutron walks into a bar and says, "I'd like a beer. How much will that be?" The bartender responds, "For you? No charge!"

A string walks into a bar and orders a drink. The bartender turns to him and says, "Sorry, sir, we don't serve strings here." The next day, clinging to a thread, the string returns to that same bar and orders a drink again. The bartender, resolute, again turns and says, "I'm sorry, sir, but like I said, we don't serve strings here. I'm going to have to ask you not to return." Dejected, the string returns home. All night he tosses and turns, wriggles and writhes, and awakes the next morning not at all resembling himself. Catching a glimpse of himself in the mirror, he brightens and jets out his door to that bar. Swaggering in, he orders a drink one more time. The bartender stares at him, squinty eyed, and asks, "I'm sorry, are you a string? You look very familiar." The string locks eyes with the bartender, and states, "No, sir. I'm a frayed knot."

Gripe Sheets

After every flight, QANTAS pilots fill out a form, known as a 'gripe sheet' to tell mechanics about problems with the aircraft. The mechanics fix the problem, and then document their repairs on the form.

Here are some actual maintenance problems submitted by the pilots (marked with a 'P') and the solutions recorded (marked by an 'S') by maintenance engineers:

- P: Left inside main tyre almost needs replacement.
- S: Left inside main tyre almost replaced.
- P: Test flight OK, auto-land very rough.
- S: Auto-land not installed on this aircraft.
- P: Something loose in cockpit.
- S: Something tightened in cockpit.

- P: Dead bugs on windshield.
- S: Live bugs on back order.
- P: Auto pilot in altitude-hold mode produces a 200 feet per minute descent.
- S: Can't reproduce problem on the ground.
- P: Evidence of leak on right main landing gear.
- S: Evidence removed.
- P: DME volume unbelievably loud.
- S: DME volume set to more believable level.
- P: Friction locks cause throttle levers to stick.
- S: That's what friction locks are for.
- P: IFF inoperative in OFF mode.
- S: IFF always inoperative in OFF mode.
- P: Suspect crack in windshield.
- S: Suspect you're right.
- P: Number 3 engine missing.
- S: Engine found on right wing after brief search.
- P: Aircraft handles funny.
- S: Aircraft warned to straighten up, fly right and be serious.
- P: Target radar hums.
- S: Reprogrammed target radar with lyrics.
- P: Mouse in cockpit.
- S: Cat installed in cockpit.
- P: Noise coming from under instrument panel. Sounds like a midget pounding on something with a hammer.
- S: Took hammer away from midget.

Jokes

- 1. How do you know a clock is hungry? It goes back four seconds....
- A doctor made it his regular habit to stop off at a bar for a hazelnut daiquiri on his way home. The barman knew of his habit, and would always have the drink waiting at precisely 5.03 pm.

One afternoon, as the end of the work day approached, the barman was dismayed to find that he was out of hazelnut extract. Thinking quickly, he threw together a daiquiri made with hickory nuts and set it on the bar.

The doctor came in at his regular time, took one sip of the drink and exclaimed, "This isn't a

hazelnut daiquiri."

- "No, I'm sorry," replied the barman, "it's a hickory daiguiri doc."
- "Why the long pause?" asks the bartender. "I don't know," says the bear. "I've always had them "
- 4. Life's been a struggle for my family recently. The other day, my wife opened the front door and a steak and kidney pie hit her in the face. Then my daughter opened a cupboard and was struck by a plate of fish and chips. I was lying in bed this morning and a bowl of spaghetti landed on my head. Honestly, we don't know where the next meal is coming from.
- 5. Finding a woman sobbing that she had locked her keys in her car, a man assures her that he can help. She looks on amazed as he removes his trousers, rolls them into a tight ball and rubs them against the car door. Magically it opens. "That's so clever," the woman gasps. "How did you do it?"
- "Easy," replies the man. "These are my khakis."

Senior Driver

My neighbour was working in his yard when he was startled by a late model car that came crashing through his hedge and ended up in his front lawn.

He rushed to help an elderly lady driver out of the car and sat her down on a lawn chair. He said with excitement, "you appear quite elderly to be driving".

"Well, yes, I am," she replied proudly. "I'll be 97 next month, and I am now old enough that I don't even need a driver's licence anymore.

"The last time I went to my doctor, he examined me and asked if I had a driver's licence. I told him yes and handed it to him. He took scissors out of the drawer, cut the licence into pieces, and threw them in the waste basket, saying,

'You won't need this anymore,' so I thanked him and left!"

Fishina

A fisherman from the city was out fishing on a lake in a small boat. He noticed another man in a small boat open his tackle box and take out a mirror. Being curious the man rowed over and asked, "What is the mirror for?"

"That's my secret way to catch fish," said the other man. "Shine the mirror on the top of the water. The fish notice the spot of sun on the

water above and they swim to the surface. Then I just reach down and net them and pull them into the boat."

"Wow! Does that really work?"

"You bet it does."

"Would you be interested in selling that mirror? I'll give you \$30 for it."

"Well, okay."

After the money was transferred, the city fisherman asked, "By the way, how many fish have you caught this week?"

"You're the sixth," he said.

A rather elderly gentleman (mid-eighties) walks into an upscale cocktail lounge. He is very well-dressed, smelling slightly of an expensive after-shave, hair well-groomed, great-looking suit, flower in his lapel. He presents a suave, well-looked-after image. Seated at the bar is an elderly fine-looking lady (mid-seventies). The gentleman walks over, sits alongside of her, orders a drink, takes a sip, turns to her and says, "So tell me, good looking, do I come here often?"

A rich woman calls her butler to the bedroom. "Jenkins," she says in a low voice. "Take off my dress".

Jenkins takes off her dress.

"And my stockings".

Jenkins takes them off too.

"And my underwear".

Jenkins removes her underwear.

"Now Jenkins," says the woman "If I catch you wearing my clothes again, you're fired".

It was 3am in the morning when a man was woken up by a knock at the door.

"I'm sorry to bother you, but could you give me a push?" said a stranger.

"No way at this time," the man snarled, shutting the door and returning to bed.

"How rude of you," his wife admonished him. "Don't you remember the night our car broke down in pouring rain and a stranger helped push us? What if he had told us to go away!"

Shamed, the man went outside and called, "Hey, do you still want a push?"

From the darkness, a voice responded, "Yes, please."

"Where are you?" yelled the man.

"Over here, on the swing," came the reply.

A man walks into the street and hails a taxi that is just passing by. "Perfect timing," he tells the driver. "You're just like Frank."

"Who?" asks the cabbie.

"Frank Fielding. He's a man who did everything right, all the time. He could have won the Grand Slam at tennis. He could have played golf with the pros. He sang like an opera tenor and you should have seen him dance."

"Sounds like quite a guy," says the driver.
"That's not the half of it. He had a memory like
a computer. He could remember everyone's
birthday. He knew all about wine, which dishes to
order and which fork to eat them with. He could
fix anything, not like me, I change a fuse and the
whole street blacks out."

"Wow, what a man."

"He knew how to treat a woman. His clothing was always immaculate, his shoes polished. He was the perfect man. No one could ever measure up to Frank."

"Amazing. How did you meet him?"

"Oh, I never met Frank."

"So how do you know so much about him?" "I married his lousy widow."

Did you hear about three Hollywood superstars making a film on the great Western composers? There was considerable debate on which star gets which role.

Eventually, there was some consensus and Stallone said, "I will be Beethoven." Tom Cruise said, "I will be Mozart." At which point, Schwarzenegger spoke up – "I will be Bach."

This paper bag is in terrible, unexplained pain, so he goes to see his GP.

The doctor looks into his medical history and runs some tests. "Your condition is incurable, I'm afraid," he tells him.

"My God, how did I catch it?" says the bag. "It's genetic. Sadly, your grandfather was a carrier."

Quotes to Think About

As I hurtled through space, one thought kept crossing my mind - every part of this rocket was supplied by the lowest bidder.- John Glenn

When the white missionaries came to Africa they had the Bible and we had the land. They said 'Let us pray. 'We closed our eyes. When we opened them we had the Bible and they had the land - Desmond Tutu

America is the only country where a significant proportion of the population believes that professional wrestling is real but the moon landing was faked- David Letterman

I'm not a paranoid, deranged millionaire. I'm a billionaire.- Howard Hughes

After the game, the King and the Pawn go into the same box.- Italian proverb

Men are like linoleum floors. Lay 'em right and you can walk all over them for thirty years.-Betsy Salkind

The only reason they say 'Women and children first' is to test the strength of the lifeboats.- Jean Kerr

I've been married to a communist and a fascist, and neither would take out the garbage.- Zsa Zsa Gabor

When a man opens a car door for his wife, it's either a new car or a new wife.- Prince Philip

A computer once beat me at chess, but it was no match for me at kickboxing.- Emo Philips

Wood burns faster when you have to cut and chop it yourself.- Harrison Ford

The best cure for sea sickness, is to sit under a tree.- Spike Milligan

Lawyers believe a man is innocent until proven broke.- Robin Hal

Kill one man and you're a murderer, kill a million and you're a conqueror.- Jean Rostand

Having more money doesn't make you happier. I have 50 million dollars but I'm just as happy as when I had 48 million.- Arnold Schwarzenegger

We are here on earth to do good unto others. What the others are here for, I have no idea.-WH Auden

In hotel rooms I worry. I can't be the only guy who sits on the furniture naked.- Jonathan Katz

If life were fair Elvis would still be alive today and all the impersonators would be dead.- Johnny Carson

I don't believe in astrology. I am a Sagittarius and we're very skeptical.- Arthur C Clarke

Hollywood must be the only place on earth where you can be fired by a man wearing a Hawaiian shirt and a baseball cap.- Steve Martin

The first piece of luggage on the carousel never belongs to anyone.- George Roberts

If God had intended us to fly he would have made it easier to get to the airport- Jonathan Winters

How to Achieve True Inner Peace

I'm passing this on because it worked for me today.

A doctor on TV said, to have inner peace, we should always finish things we start & we will all have more calm in our lives.

I looked around my house to find things I'd started & hadn't finished, so I finished off a bottle of Merlot, a bottle of Chardonnay, a bodle of Jin, a butle of wum, tha mainder of Valiuminun scriptins, an a boks a chocletz.

Yu haf no idr how fablus I feel rite now. Sned this to all who need inner piss. An telum u

15 Tips to improve your writing

Avoid alliteration. Always.

Never use a long word when a diminutive one will do.

Comparisons are as bad as cliches.

Be more or less specific.

One-word sentences? Eliminate.

Go around the barn at high noon to avoid colloquialisms.

Who needs rhetorical questions?

Exaggeration is a billion times worse than understatement.

capitalize every sentence and remember always end it with full stop

Proofread carefully to see if you words out. If you reread your work, you can find on rereading a great deal of repetition can be avoided by rereading and editing.

Place pronouns as close as possible, especially in long sentences, as of 10 or more words, to their antecedents.

Take the bull by the hand and avoid mixing metaphors.

One should never generalise.

Last but not least, avoid cliches like the plague; They're old hat; seek viable alternatives.

Two Priests on Vacation

Two Priests decided to go to Hawaii on vacation. They were determined to make this

a real vacation by not wearing anything that would identify them as clergy. As soon as the plane landed, they headed for a store and bought some outrageous shorts, shirts, sandals, sunglasses, etc.

The next morning they went to the beach dressed in their "tourist"

garb. They were sitting on beach chairs, enjoying a drink, the sunshine and the scenery when a "drop dead gorgeous"

topless blonde in a thong bikini came walking straight towards them. They could not help but stare.

As the blonde passed them she smiled and said "Good Morning, Father. Good Morning, Father," nodding and addressing each of them individually, then she passed on by.

They were both stunned. How in the world did she know they were priests?

So the next day, they went back to the store and bought even more outrageous outfits. These were so loud you could hear them before you even saw them! Once again, in their new attire, settled on the beach in their chairs to enjoy the sunshine, the same gorgeous topless blonde, wearing a very revealing string bottom, took her sweet time walking toward them. And again, they couldn't help but stare.

Again she nodded at each of them, saying "Good morning, Father. Good morning, Father," as she passed by. One of the priests couldn't stand it any longer and called after her.

"Just a minute young lady!"

"Yes, Father?" she said as she stopped and turned back.

"We are priests and are proud of it, but I have to know."

how in the world did you know we are priests, dressed as we are?"

The woman smiled, bent over a bit, and pulled off her sunglasses. "Father," she said in a purr, "don't you recognize me? It's me -- Sister Katherine!"

A Parable of PR

Moses and his flock arrive at the sea, with the Egyptians in hot pursuit.

Moses calls a staff meeting.

Moses: Well, how are we going to get across the sea? We need a fast solution. The Egyptians are close behind us.

The General of the Armies: Normally, I'd recommend that we build a pontoon bridge to carry us across. But there's not enough time - the Egyptians are too close.

The Admiral of the Navy: Normally, I'd recommend that we build barges to carry us across. But time is too short.

Moses: Does anyone have a solution? Just then, his Public Relations man raises his hand.

Moses: You! You have a solution?

The PR Man: No, but I can promise you this: If you can find a way out of this one, I can get you two or three pages in the Old Testament!

Puny Words

Parasites: What you see from the top of the Eiffel

Tower

Pharmacist: A helper on the farm. Polarize: What penguins see with.

Primate: Removing your spouse from in front of the TV

Relief: What trees do in the spring.

Rubberneck: What you do to relax your wife. Seamstress: Describes 250 pounds in a size 6. Selfish: What the owner of a seafood store does.

I Love You, Sweetheart

A group of women were at a seminar on how to live in a loving relationship with your husband. The women were asked, "How many of you love your husband?"

All the women raised their hands.

Then they were asked, "When was the last time you told your husband you loved him?"

Some women answered today, some yesterday, some couldn't remember.

The women were then told to take out their cell phones and text their husband: "I love you, sweetheart."

The women were then told to exchange phones and to read aloud the text message responses. Here are some of the replies:

1. Who is this?

- 2. Eh, mother of my children, are you sick?
- 3. I love you too.
- 4. What now? Did you crash the car again?
- 5. I don't understand what you mean?
- 6. What did you do now?
- 7. ?!?
- 8. Don't beat about the bush, just tell me how much you need?
- 9. Am I dreaming?
- 10. If you don't tell me who this message is actually for, someone will die.
- 11. I thought we agreed we would not drink during the day.
- 12. Your mother is coming to stay, isn't she??

Travel Insurance

Travelling in the European Economic Area (EEA) and Switzerland

The European Economic Area (EEA) is a free trade zone between countries of the European Union (EU), Iceland, Norway and Liechtenstein. The regulations on access to healthcare in the EEA also apply in Switzerland. Your European Health Insurance Card (EHIC) lets you get state healthcare at a reduced cost or sometimes free. It will cover you for treatment that is needed to allow you to continue your stay until your planned return. It also covers you for treatment of pre-existing medical conditions and for routine maternity care, as long as you're not going abroad to give birth.

The rules are different if you intend to move abroad or are going abroad specifically to have treatment. Each EEA country listed below has specific guidance on how to access healthcare or claim refunds.

If you find yourself in an emergency during your visit in Europe dial 112. The European emergency number is valid all in all EU/ EEA member states and is free of charge. You can use it to reach emergency services such as ambulance or police from any telephone or mobile phone free of charge.

Countries covered: Austria Belgium Bulgaria Croatia Cyprus Czech Republic Denmark Estonia Finland France Germany Greece Hungary Iceland Ireland Italy Latvia Liechtenstein Lithuania Luxembourg Malta Netherlands Norway Poland Portugal Romania Slovakia Slovenia Spain Sweden Switzerland

For more information, check out www.nhs.uk/NHSEngland/Healthcareabroad/EHIC



AMBULANCE, FIRE or POLICE

999 or 112

EITHER NUMBER WILL CONNECT YOU TO THE EMERGENCY OPERATOR

FOR MEDICAL ADVICE RING NHS DIRECT:

08 45 46 47

ZERO EIGHT, FORTY FIVE, FORTY SIX, FORTY SEVEN Round-the-clock clinical information, confidential advice and reassurance. Healthcare professionals, including nurses, trained health advisors and dental advisors deal with a wide range of health queries.

FOR CRIME NON EMERGENCY RING:

101

EXAMPLES: if your car has been stolen, if your property has been damaged, if you suspect drug use or dealing in your local area, to report a minor traffic accident, to give the police information about crime in your area or to speak to the police about a general enquiry. If you call 101 and it IS an emergency, they will direct you to the 999 operator.

Important! Parking Permits

We have the kind permission of the head of operations at the Freeman Hospital to print our own parking permits for LIVErNORTH activities in the LIVErNEWS. This means that parking whilst attending our meetings is free but there are some conditions and the use of the system is to be closely monitored. We must use the multi storey car park at the rear of the hospital, and we must display a permit for the appropriate day in the windscreen. Failure to do so could mean a fine.

Here are your parking permits for the next few meetings - cut out the ones you want and ensure they are on show when you park. For lunchtime PBC meetings, please let Tilly have your car registration number two weeks before the meeting, which she has to pass on to Security. Then you can park in the multi-storey as for the evening meetings. If you do not pass on your car registration you are likely to be fined. If you park in the main car park, you will have to pay the parking charge.



FREEMAN HOSPITAL MSCP

LIVErNOR¹ VOLUNTEE PARKING PERMIT

Valid only on 8 December 2013 from 13.00 to 17.30 Meeting in Freeman Chapel

FREEMAN HOSPITAL MSCP

LIVErNOR¹ VOLUNTE PARKING PERMIT

Valid only on 11 December 2013 from 18.00 to 22.00 Meeting in Freeman Canteen

Insurance

We are still looking for some expert help to put together a leaflet on travel insurance for LIVErNORTH members. If you know someone who could help, please let us know!

In the meantime, we have had recent reports from members of being able to get reasonably priced holiday cover from the following companies:

www.miaonline.co.uk	01268 782745
Post Office	0800 1699999
JLT	0845 6886005

In the past we have also had reports of success from the following companies. But beware! We've had a lot of people mentioning that some of these numbers no longer work, or that they were refused cover (or offered it at vast cost). Please, if you have any feedback about insurance companies, whether good or bad, let us know. We'll share the news in this column.

Able2travel Age Concern	0870 7506711 0845 6012234
Bib Insurance Brokers	01325 353888
www.bibinsurance.co.uk	
FirstAssist Insurance	0800 1694078
City Bond	0117 9246877
Churchills*	0800 200388
CNA	01452 623623
Direct Travel*	08000 681603
Freedom	01223 454290
Intune (Croydon)	0800 0223192
Jardine/Lloyd Thompson	0121 2246934

Leisure Care Insurance	01793 514199	
Marcus Hearn	0207 7393444	
Norwich Union Direct*	0800 121007	
RIAS*	0800 552100	
SAGA	0800 0964556	
Sainsbury's	0845 3161453	
Sladdin & Co Ltd.	0800 7313989	
Tesco Insurance	0845 3008800	
www.the-life-insurance.co.uk		

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

Next LIVErNEWS

If you have ideas, jokes or articles, please send them in! Margaret Bickle is the Howlers editor. Any other items can be sent to me or John. All contributions welcome!

Any items for Issue 47 (Spring 2014) should be sent to me by 24 January 2014).

Thanks! Fiona x

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Gift of Life - Derby Liver Support Group (for transplants and liver disease) Contact: Sister Gerri Casey 0133 234 0131 bleep 1926

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Haemochromatosis West Midlands Support Group Kieran Lynch, Coordinator Telephone; 0121 457 8986 info@HaemochromatosisWM.org.uk www.HaemochromatosisWM.org.uk

Helping Hands Support Group (BATH) Helpline 01225 834966 helpinghandsblt@yahoo.com Mersey Liver Support Group Tel 0151 2207066/ 2289866 or 01772 496987 leeandalan@aol.com

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info@britishlivertrust.org.uk
www.britishlivertrust.org.uk

To receive a regular FREE copy of the newsletter please contact LIVErNORTH (details above)

LIVERNORTH

Liver Patient Support

If you are worried about liver disease or would like to know how to look after your liver, please telephone one of our helpline numbers:

SYLVIA	01661 881020
SUSAN	01207 271707
ANN	0191 4131827
ALAN	0191 4821802
JOAN	0191 3702961
TILLY	01670 714901
JULIE	0191 4873665

for alcoholism ring:

MICHAEL 01228 810598

Information available online: www.livernorth.org.uk

LIVErNORTH is a Registered Charity (No 1087226)

LIVErNORTH meeting dates

Meetings are open to all liver patients and those who support them.

8 Dec 2.30 LIVErNORTH Carol Service Freeman Chapel

11 Dec 6.30 LIVErNORTH Christmas Dinner Freeman Dining Room

2014 meeting dates will be announced in the next issue of LIVErNEWS

Free parking tokens for LIVErNORTH meetings at the Freeman are on p. 42

PBC meeting dates 2014

29 April 12.00 – 2.00 Freeman Hospital 11 November 12.00 – 2.00 Freeman Hospital

More details about meetings inside on pages 6 and 7