



# Addenbrooke's Liver Transplant Association

Honorary President - Prof. Sir Roy Calne FRS

Honorary Vice President - Prof. Graeme Alexander

NEWSLETTER – SPRING 2023

## A Plea from the Chairman



In Septemebr 2017, after a 10 month wait, I received my 'Gift of Life'. During my recovery, I thought long and hard as to how I could repay the kindness and support from the clinicians and nursing staff who were with me every step of my transplant journey and recovery.

During my initial assessment, I was visited by Joyce, one of the friendly ALTA Visiting Team, a lady who encouraged me to embrace the journey and look forward to a life of change and enjoyment.

Nearly six years on and I have done just that, embraced every opportunity that life presents to me. During that time I committed to giving something back in appreciation of what I had received. So in 2018 I became a volunteer visitor for ALTA, visiting ward D5 and G5 on a Friday; there are quite a few of you I would have met during that time, before Covid prevented visiting in 2020.

ALTA are now in the situation that the number of Trustees and members of the Visiting Team has greatly reduced, which does not bode well for the future.

I know we have sent out many requests in the past, for people to come forward, who are prepared to give up one or two hours a week as a memembr of the Visiting Team, to support patients and their families who are going through the same journey as all ALTA members.

As a Trustee, we meet four times a year to discuss issues around liver transplant and our work with the research department and the Tranplant Coordinators.

If you feel you can help, please send your details to [info@alta.org.uk](mailto:info@alta.org.uk)

Thank you.



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### British Transplant Games



The registration for Coventry 2023 is now open. With over 25 Sports to compete in, for all ages, there is something for everyone.

As we have mentioned before, you do not have to be an Olympic, World or National champion to compete, just the excitement to join people in celebrating the 'Gift of Life' with like-minded people. There is so much fun to be had being part of the games and also making new friends from across the country.

I hope you will join us at Coventry. For full details and how to register please go to the following link.

<https://www.britishtransplantgames.co.uk/coventry-2023>

ALTA will sponsor members who compete in the Transplant Games to help with the cost of entering.



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## Celebration Day and AGM

As some of you will know, last year was the first time since the Covid Pandemic that we were able to meet in person and through the kindness of John and Gill Kitchener, ALTA held a summer celebration in the gardens of their home.



The feedback from members and guests, who attended, has encouraged ALTA to consider a summer event this year and we are pleased to announce that a Summer Celebration Day will be held on **Saturday 8<sup>th</sup> July 2023 at the**

**Hexagon Room, The Frank Lee Centre, Addenbrooke's Hospital.**

To make full use of the day, ALTA have changed the financial year end to 31<sup>st</sup> March to enable us to incorporate the AGM at the beginning of the proceedings.

We are arranging for guest speakers to give an insight into research, being a Donor Family and a World and British Transplant Games competitor.

As with most events, there is a restriction on the number of people who can be accommodated in the respective venue and also for catering purposes. It will be helpful to the ALTA organisers if you could let us know if you will be attending and the number of people in your party.

Details can be sent via email, [info@alta.org.uk](mailto:info@alta.org.uk) or by post to,

**The Secretary, Homefield, Little Heath, Gamlingay, Sandy, SG19 3LL.**

Attendance will be free, but donations to ALTA can be made via cheque made payable to Addenbrooke's Liver Transplant Association, via our website at [alta.org.uk](http://alta.org.uk) or in collection boxes on the day.



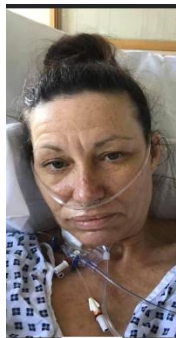
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### **My Liver Cancer/Primary Sclerosing Cholangitis PSC journey – by Caroline White**



*"I always hated my clinic appointments after I'd had my MRI, as it was usually bad news. My PSC was more progressed or the liver was more enlarged. However, on this particular day I wasn't expecting the news I received.*

*As I entered the room with the nurse there were other people there as well as my usual consultant. I automatically assumed they were trainees observing a clinic appointment. How wrong was I! When the words "You've got cancer Caroline" were spoken, my world crashed down around me. A cancer nurse stepped forward with words of comfort, which I didn't really hear as my head was spinning around like a spinning top.*

*Strangely I was crying but there were no tears, looking back I think my body was in shock trying to process what I'd been told. My consultant was very kind, he slowly talked me through each stage, how the tumour was found, how they looked back at previous MRI's, where 'my little passenger' as I had named it, was starting to grow. Thankfully there had been two years between the MRI's meaning my tumour HCC was slow growing.*

*Over the past month, without my knowledge my hospital NNUH & Addenbrookes had been discussing my case and working on a care plan. Because I already had PSC for the past 20 years I was heading towards a transplant anyway. However, 'my little passenger' had brought it forward, meaning that I was in a good place, not too ill but ill enough to require the transplant.*



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*Fast forward 6 weeks from my consultation, I found myself on a bed at the NNUH having a procedure called TACE (trans arterial chemoembolisation). It was explained to me as magic little balls, which blocked the blood supply to 'my little passenger'. I must admit I did feel unwell for around a week after this procedure, but it worked! I had another MRI some weeks later, which showed no tumour was present. 'My little passenger' had disappeared. Now I could move forward onto the next process, the transplant assessment.*

*Addenbrookes was my home for the next stage. The care plan, 3 days of tests, blood samples & meetings with lots of different departments. One of which was meeting the wonderful team who are ALTA. Talking through their own journeys it reassured me I wasn't alone & others had been through the process with positive outcomes. At the end of my 3 day stay I was told I had made the list! I would, after signing some forms go live & would start the wait for the call.*

*My call came 10 months after I went live on the list. I made a quick recovery after my transplant & was back to playing sports again at a competitive level in 5 1/2 months.*

*Looking back on my cancer/PSC journey I couldn't have been in better hands. Each process was explained to me without too much technical language, I was offered support from the NNUH cancer department, however I didn't take it up as I felt I could cope with the process, as I was well informed from the team of consultants between the two hospitals. I continued to play sports & even completed a 75 mile cycle ride whilst on the list. Keeping fit before my transplant helped me recover afterwards.*



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*My advice to those who are now starting their own personal journeys is have faith in your consultants and Addenbrookes. The process may seem slow between consultations & treatment sometimes but be assured that in the background your care plan is being managed. Ask questions at consultations, keep fit, stay hydrated, stay positive and good luck!"*



### Love Your Liver Road Show

All too often liver disease is only found when it is quite advanced. This means treatment is less likely to work. But the good news is that some cases of liver disease could be prevented.

The British Liver Trust ***Love Your Liver Road***

***Show*** events are for people who want to find out more about their liver health or are worried that they may be at risk of developing liver disease.

At the roadshow you can take the live\_health screener to see if you might be at increased risk of liver disease. You can also have a free, liver scan. This is a quick, simple, and painless test, carried out by one of the Specialist Liver Nurses.

The roadshow is being taken all over the country, visiting locations in England, Northern Ireland, Scotland and Wales.

The aim is to visit as many areas of the country as possible each year.



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Below is a list of where the ***Love your Liver Road Show*** will be visiting.

All events run from 10am - 4pm. Exact dates locations and within a town/city to be announced and can be subject to change, please check here just prior to the event.

### **May:**

Derry/Londonderry: Thursday 11th May - Guildhall Square, Guildhall Street, BT48 7BB

Belfast: Friday 12th and Saturday 13th May - City Hall, BT1 5GS

Bolton: Monday 15th May - Victoria Square, BL1 1RJ

Manchester: Tuesday 16th and Wednesday 17th May - Cathedral Gardens, Corporation Street, M4 3BG

Stockport: Thursday 18th May - St Peter's Square, SK4 1AE

### **June:**

Aberdeen: Sunday 11th June - St Nicholas Street, AB10 1BF

Dundee: Monday 12th June - City Square, DD1 3AJ

Edinburgh: Tuesday 13<sup>th</sup> June – Location TBC

Hounslow: Tuesday 27<sup>th</sup> June – Bell Square, TW3 3HH

Brixton: Wednesday 28th June - Windrush Square, SW2 1JQ

Stratford: Thursday 29th June - Opposite Stratford Library, E15 1EL

### **September:**

Peterborough: Monday 25th and Tuesday 26th September - location TBC

Nottingham: Wednesday 27th and Thursday 28th September - location TBC

Leicester: Friday 29th September - location TBC



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And Finally.....

***Spring is in the Air !***



*Photo by Sue Gray*



*Crochet Daffodils by Gill Kitchener*