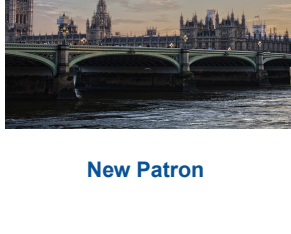


CLLSA NEWSLETTER

A regular newsletter brought to you by the Chronic Lymphocytic Support Association

APRIL/MAY 2019

Our top stories in this newsletter



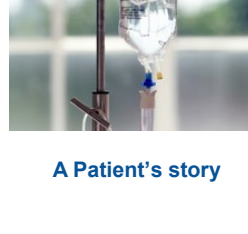
New Patron



New Support Groups



Cambridge Conference



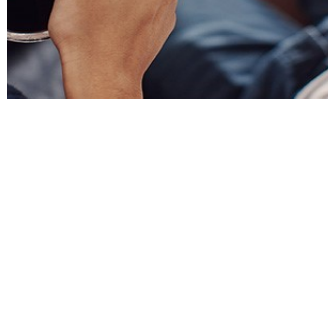
A Patient's story



Our New Patron

We are very pleased to announce that Lord Forsyth has agreed to become our official Patron.

Lord Forsyth has been very active on our behalf by asking questions of the Health Minister in the House of Lords, particularly about the availability of Ibrutinib for CLL patients. Lord Forsyth was able to arrange a meeting with the Minister, Lord O'Shaunessy, who responded positively. This was instrumental in our being able to overturn previous NHS England guidelines which would have limited access to Ibrutinib for patients in remission for more than three years. We are very grateful to Lord Forsyth for his support and look forward to working with him for the benefit of CLL patients in the future.



New Support Groups

Our sister charity, Leukaemia Care have announced new support groups specifically for CLL patients. The first four are in Cambridge, Leicester, Nottingham and Southampton.

If you would like any more information, contact:

emailsupport@leukaemiacare.org.uk

We can also announce our own new support group

Members Sue Cracknell and Elizabeth Pearson have launched a Local Branch on the Isle of Wight. They ran a stand at the Cancer Well Being Fair in January to launch the branch and spoke with cancer patients who attended the event. They are now working with two haematology consultants and the Clinical Nurse Specialist to promote the branch and CLLSA in the chemotherapy treatment waiting room. If you are local and want to join the branch, their email address is:

cllsaow@gmail.com

Cambridge Conference



In this, our second conference of the year, Dr George Fellows gave the keynote talk on 'CLL—where are we now and where are we heading?' This covered in easy to digest sections diagnosis, current treatment and future prospects for treatment. Dr Fellows is a consultant haematologist and clinical lead for Lymphoma and CLL at Cambridge University Hospital NHS Foundation Trust and one of the leading CLL consultants in the country, and we are most grateful for his agreement to speak to us.

The morning session was a team presentation from the Psycho-Oncology Service, Liaison Psychiatry, Addenbrooke's Hospital on 'Approaches to Psychological health in Cancer' This was the first time we have included this topic in our conferences and it was very well received. This section was not videoed, but we will be putting together a collection of tips from the talk for future distribution. The videos of the rest of conference can be found [here](https://www.cllsupport.org.uk/article/cambridge-members-conference-08-mar-2019):

<https://www.cllsupport.org.uk/article/cambridge-members-conference-08-mar-2019>

Our other Conferences this year. Make a note!

Bournemouth 18 May (registration open now)

Newcastle July 19 (registration open now)

Nottingham September 5

London— 21 November

Places go very quickly, so book yours now!

New AbbVie videos about living with CLL

Pharmaceutical company AbbVie have embarked on a programme to increase awareness of the problems facing CLL patients, and we were pleased to be asked to help. In the first two videos David Innes, our Chair, and Nick York, a former CLLSA trustee, give their personal experiences of living with CLL. Many patients will identify with their comments, and AbbVie aim to promote these videos widely on social media to carry the message to a wider audience.

You can watch these interesting short videos here

<https://www.youtube.com/watch?v=3y01pO9cEB4>

https://www.youtube.com/watch?v=6_XmcWfKWh8

New Ten Year NHS Cancer Plan Announced

Trustees attended the launch of the NHS new ten year plan to tackle cancer in the UK. Many of the initiatives and aims outlined in the plan are encouraging, but we feel there is still insufficient emphasis on blood cancers.

We continue to monitor the way in which the resources behind the NHS 10 Year Plan can be harnessed to help those of us with CLL. The main thrust of the plan is focused upon early diagnosis and we are playing a full part in bringing our stories to the table. We are attending a next steps event in May entitled **Developments in Data for Rare and Less Common Cancers** and it will be important, along with the other blood cancer charities, to get our voice heard.

A Patient's Story

My FCR experience by Pauline Stow

Five years after being diagnosed with CLL my lymphocyte count had risen to the extent that I was given the green light for treatment. I was enrolled on the FLAIR trial. With four treatment paths (only three currently open to recruitment) I was hoping to get some ground breaking new drugs.

Instead I was assigned to FRC - the same treatment I'd have without the trial. I was disappointed but this was the treatment that my consultants had consistently held as the gold standard and at least it was a known quantity. The other trial drugs hadn't been around long enough for their long-term side effects to be documented, and, if my remission was short I would be prescribed the new drugs anyway.

My treatment

Once the treatment is decided they don't hang about. Before I knew it I was in Barts in London receiving my first round of Rituximab. I travelled to London for a couple of days every month for six months, docking myself into my ninth floor room (with a bonus view of St Paul's Cathedral). The nursing staff on the ward and my Consultant were brilliant I felt treated as an individual, not the trial guinea pig I was!

The medications

I read up about the drugs (and as a retired director of nursing have some insider knowledge) so I planned how to take them to minimise side effects as much as possible. I took anti-sickness pills two hours before my chemo pills, continuing them throughout the cycle and for a day afterwards.

I took the Cylophosphamide in the morning drinking plenty of fluids to make sure it didn't sit in my bladder overnight causing a urinary infection. Fludarabine was my lunchtime "treat".

Drinking lots of fluids particularly before and during each cycle mitigated many of the toxic effects. I ate little and often.

What to do whilst receiving treatment

Avoid infection.

This meant:

No kisses from friends (or snotty grandchildren) and banishing my husband to the spare room at the first sniffle.

Wearing a thick cotton scarf over my nose and mouth when in crowds.

Frequent hand washing and liberal use of antibacterial gel.

Ask for help. If you are feeling nauseous don't suffer silently or assume it is inevitable, ask your GP or consultant. At one point my anti-sickness pills were changed within two hours.

Indulge yourself. For me cornflakes and ice cold milk hit the spot.

The end result

After the first round of treatment I, unexpectedly, felt incredible. My energy returned and I realised how my illness must have slowly accumulated over the previous five - or more years - to have lead to me a point where I'd forgotten what normal felt like. By round three I was back on the golf course and even took a short holiday abroad.

I only lost a couple of strands of hair from my head - and, bonus, all my armpit hair.

Nine months later I'm really well. I don't dwell on having CLL. Life has returned to normal. I'm still cautious, avoiding infection until my bloods return to normal, but the future looks very promising.

You can find more about the FLAIR trial [here](https://www.justgiving.com/fundraising/d-cawley)

Fundraising

We are enormously grateful to our fundraising members, without whom we would struggle to do much of what we do.

Here are just some of the things our members will be up to:

Dan Cawley will be entering an Iron Man contest to raise funds for CLLSA in recognition of the support his mother, Beth, has received. Dan's Just Giving page is [here](https://www.justgiving.com/fundraising/d-cawley):

<https://www.justgiving.com/fundraising/d-cawley>

We will have a team for the **Virgin 10k run** in London on 21 July 2019. This is a great fun event, with lots of music and a carnival atmosphere. Ideal if you or someone you know is a keen - or not so keen - runner. There are a few places left, so get your running shoes dusted down. For more information email Sarah at:

coordinator@cclsupport.org.uk

Finally, a quite amazing feat. **Faye Thornton** will be running a race every month in support of CLLSA from March to December this year because of her father's struggle with CLL. Fay is a very keen runner and is trying to improve on her personal best each time. We wish her well and will be reporting back on her progress from time to time. Fay's Just Giving page is [here](https://www.justgiving.com/fundraising/faye-thornton4):

<https://www.justgiving.com/fundraising/faye-thornton4>

We thank all our fundraisers for their energy and dedication. The funds you raise help us to help CLL patients throughout the country, and we are extremely grateful.

But.....

If that all seems a bit too strenuous, there are still ways you can help us. If you are an Amazon shopper - and so many of us are - Amazon will donate 0.05% of every purchase value to CLLSA.

All you need to do is log on to AMAZON SMILE instead of the usual Amazon site and select CLLSA as your chosen charity. The Smile site is identical to the normal one, so it's a really painless way of making Amazon pay up and providing CLLSA with funds.

Chris Dwyer

It is with great sadness that we learnt of the passing of Chris Dwyer, known to many of us all as CLLCanada on our HealthUnlocked forum.

His unstinting support for CLL patients is even more remarkable considering his own battles with CLL, Richter's Transformation and other debilitating health issues. He bore all this with an infectious sense of humour and compassion.

Chris was many things, a man of many talents. He was an indefatigable defender of the truth and relentless in his exposure of misinformation. His knowledge of CLL and his ability to impart that knowledge with such generosity and humanity was a true reflection of the man.

For his significant contributions in the field of CLL Chris was recognized as a 2018 CURE Magazine CLL Hero last December in San Diego, as part of the 2018 ASH Conference.

We send our deepest condolences to his family, friends and to everyone affected by this loss.

And Finally

David Innes has stepped down from the Chair of CLLSA after four years during which time the Association has grown in membership and influence enormously. We are tremendously grateful to David for all of the work he has done to help raise the profile of the Association and to put us on a secure financial footing, despite having received treatment for his CLL during the period. David will remain as a trustee and retain some of his responsibilities.

His position as Chair will be taken by Marc Auckland.

Marc was diagnosed with CLL in February 2016 and enrolled on the FLAIR trial in October 2018. Marc writes:

Greetings fellow members. I am pleased to take on the role of Chair following David's four years of leadership. David has left the association in good shape. We have highly sought after conferences, a high quality board of enthusiastic and capable trustees, and a website with quality content. We have seen steady growth of the UK membership which gives us the lobbying power and credibility with NHS and Government policy makers and the trust and respect of CLL medical specialists. I will be setting out my vision for the future of CLLSA in forthcoming newsletters, and I think I can promise some very interesting developments.'

We wish Marc every success in his new role

Until Next Time

Be sure to follow us on **Twitter**, **Facebook**, and **HealthUnlocked** for all the latest information and discussion on CLL. Remember, every post you like, share and retweet helps to raise CLLSA's profile, allowing other people living with CLL to discover us. CLLSA is the only UK charity dedicated to providing education, support, and advocacy to help empower people living with CLL.