



Hello and welcome to CLLSA's November 2018 e-bulletin, bringing you the latest news and developments on CLLSA's policy, support and educational activities directly to your inbox!

Make Blood Cancer Visible Campaign Highlights



We were delighted to be able to take part in this year's **Make Blood Cancer Visible** campaign in September. The campaign took the form of an impactful travelling display across the country which had life-sized statues representing each of the blood cancer patient charities involved in the Blood Cancer Alliance. Chair of CLLSA, David Innes, captured his feelings on his diagnosis of CLL in a motion-activated, life-sized transparent figure incorporating his voice which went on tour across the UK during Blood Cancer Awareness Month. The campaign figures creatively represented the 'unseen' or invisible nature of blood cancer to help inform, educate and increase awareness of blood cancer. The campaign was very well covered by the media.



CLLSA member John very kindly supported the campaign by sharing the story of his CLL diagnosis in a powerful video. Originally diagnosed with Non-Hodgkin Lymphoma, John explains how his life changed following diagnosis; leaving his career as a professional diver; the impact on his family; and how his son initiated a campaign at university to donate blood and encourage others to join the bone marrow register. If you haven't already seen it, you can view John's video and other campaign videos [here](#).

The Big Picture



CLLSA is part of the **Blood Cancer Alliance**. Our objective for the next 12 months is to persuade policymakers that blood cancer deserves to be treated with the same level of priority as the so-called 'big 4' solid tumour cancers - breast, bowel, prostate and lung. Blood cancer is after all the third biggest cancer killer in the UK - a sobering but important statistic.

Fundraising Fun



As we have said many times we do need your help to keep the charity flourishing. We have plans to explore opportunities with charitable trusts and with companies and these could prove very worthwhile. If you have any experience in dealing with trusts and companies in getting donations then please get in touch with our Chair on david.innes@cllsupport.org.uk. Your help would be enormously appreciated!

There are of course all sorts of other ways to raise money and many of you have helped us over recent months including Gina Shepperd and the team at Silverback Films who helped to raise over £250 through a cake sale and raffle. We were delighted to hear that CLLSA had been chosen to benefit from their fundraising efforts after the father of one of their members of staff was extremely grateful to CLLSA when he was diagnosed with CLL.

Could you or your company help us to raise more funds? If you need any help with preparations for a sponsored run, a cake stall, a coffee morning or any other activity to raise funds for us then please get in touch with Sarah on membership@cllsupport.org.uk. Sarah has all the material that you will need to give a CLLSA feel to your activity.

If endurance events (sporting or baking!) sound too exhausting, did you know that you can raise money for CLLSA while shopping online? Amazon has recently introduced a new system which allows you to nominate your favourite charity to receive 0.5% of the purchase price of anything you have bought. No, there isn't any catch, and we have now registered CLLSA as a nominated charity on the scheme. So all you have to do when you next buy something from Amazon is to go to www.smile.amazon.co.uk, state that you want to support CLLSA and the donation will wing its way to us. Seems simple enough and with the festive season coming up a very nice way to top up our resources thanks to Amazon. Happy shopping!



New Guidelines

The British Society of Haematology (BSH) updated their guidelines for the treatment of CLL earlier this year. Key recommendations are highlighted within the guidelines and can be read in full [here](#).

Member Meetings



We're planning six conferences in 2019. As always these meetings will be free to attend for CLLSA members and provide a valuable opportunity to meet others living with CLL to share experiences and hear presentations from leading CLL experts on the latest developments in CLL treatments.

We'll be circulating exact meeting dates and venue details over the coming months but expect to be in the following localities:

- Liverpool - January
- Cambridge - March
- Bournemouth - May

Newcastle - July
Nottingham - September
London - November

Spread The Word On CLLSA

There are 30,000 UK patients who have CLL. We have 2,500 members in our Association. We are sure more people could benefit from the services we offer. Will you help us spread the word?

289 members responded to our survey, to say how they had heard of CLLSA. Here's what they told us:

Source of information about CLLSA

65% Internet search (186)
11% CLLSA leaflet (31)
10% HealthUnlocked (29)
8% CLL clinic (23)
8% CLL consultant (22)
4% A nurse (12)
3% A CLL patient (9)
3% Facebook (8)
1% Twitter (2)
1% My GP (2)
6% Other (17)

Very few members had heard about us from a healthcare professional. We want that to change. Consultants, nurses and GPs are fully occupied taking care of our medical needs. CLLSA can relieve their workload by helping with patient support and information, but we can only do that if they tell their CLL patients about us. Please do talk to your healthcare team about how helpful CLLSA has been to you and pass them a CLLSA leaflet. Ask Sarah Tobin, our coordinator, to send you a few leaflets by emailing her on coordinator@cclsupport.org.uk. We'd love to raise the number of people who hear about us through their CLL clinic to 50%. We'll be taking regular snap-shots from our new membership, who are now being asked to say how they heard about us when they register.

Trustees are giving priority to improving the CLLSA website so that navigation is more user friendly. There is lots of excellent information there, but it needs to be more accessible. The site is a prime resource for those affected by CLL.

Knowing Me, Knowing You

You may remember that CLLSA is a patient-led charity, but do you know the people involved? This month we want to introduce you to six of our Trustees and their motivations for spearheading CLLSA's work:



David Innes joined CLLSA as a trustee in January 2015 and was appointed Chair in May 2015. David primarily looks after CLLSA's links with key stakeholders and plays a pivotal role in advocacy and policy activities including working with pharmaceutical companies, other blood cancer charities, members of Parliament and the House of Lords, and trying to keep the CLLSA ship afloat! David was diagnosed with CLL in May 2011, received BR treatment in 2017 and is now in remission. David's background is sales, marketing and general management.



John Moore has been a Trustee since October 2015. John was diagnosed in 2014 and is currently receiving treatment on the FLAIR clinical trial; ibrutinib plus venetoclax. John's early career was in teaching followed by personnel management roles in the NHS and local government, and then many years as a management consultant working with both public and private sector organisations. As a Trustee, John contributes in many ways, but particularly in support of CLLSA's planning and governance work. John enjoys gardening and walking, and doing lots of other activities, mostly fairly badly.



Rupert Beazley became a CLLSA Trustee October 2015. Rupert was diagnosed with CLL and Nephrotic Syndrome in 2009 (at the age of 49). Rupert was treated with FCR in 2010 and is now eight and a half years in remission. Rupert supports the Board and Charity in the areas of IT, strategy and general business. Rupert runs his own consultancy business helping business owners to extricate themselves from the day to day side of the business giving them options for their future. Rupert also loves gardening and walking with his flat-coat retriever - Summer.



Olga Janssen became a CLLSA trustee in November 2016. She leads the membership committee, which covers information and support for members including conferences, CLLSA's helpline, the news bulletin, as well as working with volunteers and developing member surveys. Olga was diagnosed with CLL in 2006 and continues to be on "watch and wait". Now retired, Olga's professional background is in adult and community education.



Frank Mercer was appointed to the Board of Trustees in the early part of 2016. Frank was first diagnosed with CLL in February 2015 and began a period of "watch and wait" whilst the option of entering into the Flair trial remained under consideration. Frank completed FCR treatment March 2016 with near-complete remission. Frank's background as a chartered accountant led, with some inevitability, to his appointment as CLLSA Treasurer in October 2017.



Marc Auckland became a Trustee of CLLSA in January 2018. Marc has recently started treatment after four years "watch and wait". Marc supports the membership committee with conferences, CLLSA literature, CLL Champions, and supports the strategy and governance team. Marc is retired after years in the telecoms, rail infrastructure, NHS Trust and Post Office. Marc loves gardening and is often found in his allotment, at the theatre and having fun!

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.

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