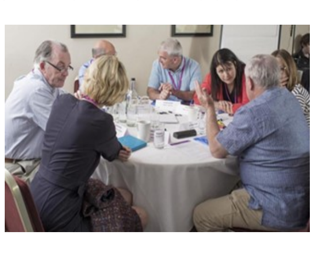
CLL SUPPORT
Helping people affected by CLL and SLL

Newsletter

December 2019 Issue No 6

Our top stories in this newsletter

Our new look



Nottingham conference

A patient's story

Our new look.
Why we decided to make the change.

Marc Auckland, CLL Support Chair wrote to all members in November:

"After much thought, discussion and research, I am delighted to announce that we will be rebranding ourselves as CLL Support with a new, easier to navigate website, new booklet, leaflet and logo. The official name of the charity will remain the Chronic Lymphocytic Support Association, but **CLL Support** is shorter, says exactly what we do and is easier to remember for those people we want to influence. It will be the new 'face' of CLLSA and we hope that everyone will like it and appreciate why we have felt the need to make these changes.
Strengthening our brand is an essential way for us to make an even more significant difference to everyone living with and affected by CLL.

To make sure we are heard by the people and institutions we need to influence, we need to raise our profile. We are, in some ways, in competition for attention with our much larger sister charities with their far greater resources. As the only UK charity dedicated to providing education, support and advocacy on behalf of CLL patients and their families, we need to make sure we are noticed and listened to."

Nottingham Conference

5 September 2019

The patient experience was the focus of the morning at our Nottingham Conference. The afternoon was devoted to a videoed presentation and question and answer session on "CLL in 2019 and beyond" given by Dr Christopher Fox, consultant haematologist and CLL Research Lead at Nottingham University Hospitals.

Three patients, two of them videoed, told their CLL stories. Their powerful testimonies brought alive for the audience the experience of a CLL diagnosis, its treatment and impact on lives.

Our three presenters were an inspiring, often humorous, prelude to Christopher Fox's presentation on the rapid advances now being made in CLL treatment.

The full conference report and videos are on our website www.cllsupport.org.uk

A Patient's Story

My story by Valerie Hatch

In 1994, I was 36, and six months pregnant with my first child. My midwife noticed that my white cell was high at a routine blood test. I was summoned to the antenatal clinic about a week later.

There I met a haematologist who would not tell me the name of my condition but told me the symptoms, which I looked up in the hospital's medical library. I got my diagnosis and the average life span of ten years but determined to get on with living life.

As my white cell counts increased, so did my glands, especially in my neck. Throat infections started to flare up and, by 1998, I started to tire and could not make it up and down the hill twice a day to the nursery

I was given options as, being so young, they had no idea what to do with me. The normal treatment at the time was Chlorambucil. The other options were high dose chemo or a Stem Cell Transplant. It was my decision.

I decided on the STC. My brother was a match and after 4 months of Fludarabine to reduce the CLL burden, I had an SCT in February 1999. This was a success.

I did try going back to work when Luke started nursery but didn't last long so I tried working from home instead. All worked well until the percentage of the graft still working started falling. In August 2003, it had fallen to 25% and I needed a Donor Lymphocyte Infusion to boost it back up.

I was soon not able to walk much because my feet were so sore. Graft versus host disease had set in with a vengeance! This continued for years affecting many areas of my body and causing much disability. The high doses of steroids saved my life but robbed me of strength. I emerged gradually from this, but it wasn't until 2011 that I was able to work again.

My family and friends again rallied around and, when I couldn't, looked after the children and did my housework. I will be eternally grateful to my friends and family for the help they gave.

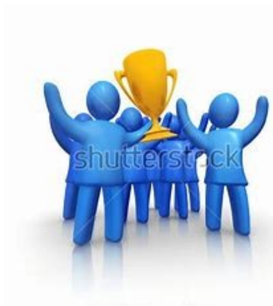
I retired at 60 due to lack of energy and increasing hip pain. Earlier this year, I had a hip replacement, and this threw my body into chaos. My haemoglobin had dropped and my CLL specialist thought it was time for treatment. I am now on a trial taking Zanubrutinib, a second-generation Ibrutinib drug. I started this in July2019 and so far, apart from bruising and a little bleeding and some weight loss, I am tolerating it quite well.

My children are now grown. Gemma is married and working as a doctor and Luke has graduated from university. How grateful my husband and I are that I have lived this long to see them grown and happy! I have loved, and do love, my life despite having to make adjustments for my illnesses. I try to help others because of the blessings I have received.

Under 60s' Club

CLL tends to be an older person's disease, and as a result, younger patients and their partners can feel isolated. We feel this is unfair and decided to try to do something about it, so we launched the Under 60's Club at the Bournemouth conference. Our trustee

The CLL Support Under 60 Club started around a table in May 2019 at the Bournemouth Conference. We formed a WhatsApp group of seven. Then we grew to 14. Now, after the last CLL Support e-newsletter, we are 35! And it still feels like we are sitting around that table in Bournemouth. We share news of doctor's appointments, holidays and travel insurance, family milestones, CLL symptoms and conferences. We don't all chat every day, but we are here for each other and we are here for you if you would like to join us.
Contact norah.grant@cllsupport.org.uk



CLLSA Champions

We now have over a hundred Champions around the country. Champions are members who have volunteered, for example, to put leaflets into clinics whenever they attend for an appointment. This is extremely valuable in increasing our membership and helping more patients. Being a Champion doesn't take much time and can usually be fitted in normal clinic appointments. We are always looking for more Champions. If you would like to help, please contact marc.auckland@cllsupport.org.uk who will be able to give you more information.

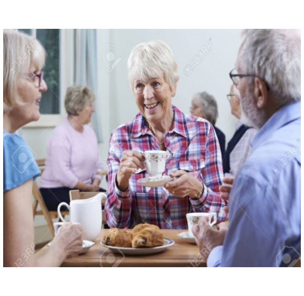
Buddy scheme

Can you help?

Buddy scheme—can you help?

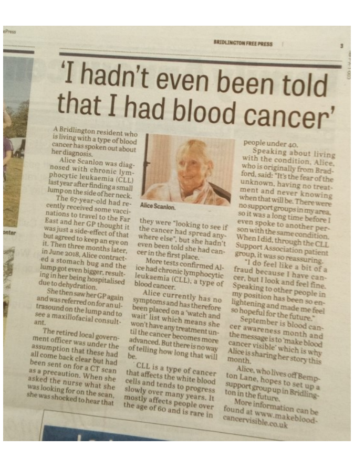
Our joint Buddy Scheme with Leukaemia Care is proving to be very successful, and we are now looking for two new Buddies to help.

Buddies help CLL patients—often newly diagnosed—by speaking to them over the phone and talking through any concerns they may have. Full training and support is provided by Leukaemia Care, and if you feel you would like to help other patients in this way, please contact Kay Drew at: kay.drew@leukaemiacare.org.uk



Local Support Groups

For some time, we have been keen to see how we can help CLL patients on a regional basis. Having CLL can sometimes be isolating, and from the feedback from our conferences, we know that patients value meeting other people living with CLL and their families. So, we are looking to set up local support groups where there is a demand. Our sister charity Leukaemia Care have established Groups in Cambridge, Leicester, Nottingham and Southampton. We have Groups on the Isle of Wight and Guernsey and we would like to get others around the country.



'I hadn't even been told that I had blood cancer'

Alice Scanlon hit the local news with her CLL story, and is keen to start a Support Group in East Yorkshire. If you would like to join please contact: coordinator@cllsupport.org.uk and we will put you in touch.

If you would like to start a group in your area, we can assist you, including a '**how to do' guide to get you started**. Please contact Sarah at: coordinator@cllsupport.org.uk for more information. If you would like to join the Leukaemia Care scheme, contact Kay Drew at kay.drew@leukaemiacare.org.uk

Fundraising

We are enormously grateful to all our fundraisers who give up so much of their time to help us. Without your dedication we would be unable to carry out many of the things we do to support CLL patients and their families. **So, a big 'thankyou' to just some of the people who have raised funds for CLL Support recently:**

Crondall Energy Are our corporate sponsors for this year, and a team ran the Clarendon Marathon raising a magnificent £681.00 for CLL Support. The whole team finished unscathed, apart from a few blisters!

We thank them for all their efforts!

Emma Collins trekked the **Great Wall of China** to raise funds for us in August. She stayed at hostels along the way and it looks like she had a great time as well as helping Cll Support.

Emma is grateful for the help CLL Support has been able to give to her mum.

We are enormously grateful for all our dedicated fundraisers without whose efforts we would not be able to carry out all the work we do.

We know that many more of our members are fundraising for us in all sorts of ways, and if you, or someone you know, is doing a challenge of any kind, do please let us know, and we will publicise it here. If we have left someone out—just let us know and we'll tell all our members.

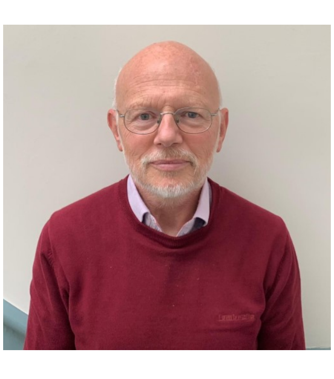
If that doesn't appeal……Don't forget to smile!

A relatively painless way of helping CLLSA if you don't fancy so much strenuous activity, and if you ever use **Amazon,** is to log on to the **Amazon Smile** site instead of the usual one. It's precisely the same, but we will receive a small percentage of whatever you spend. The first time you log on you will be asked to nominate your chosen charity and CLL Support will pop up.

We only receive a small amount (£0.01 per £ spent), but it soon adds up so please do use it!

HealthUnlocked

HealthUnlocked is our international online Forum where you'll find advice and the latest information on CLL and the problems experienced by fellow sufferers. There are almost 13,000 members, and the site is moderated by CLLSA volunteers to ensure the information is up to date and accurate. You don't need to participate unless you want to ask a question, but if you do you will receive a warm welcome from fellow CLL sufferers. Why not have a look at: https://healthunlocked.com/



Trustee News:

We welcome a new trustee this month:

We are pleased to introduce **John Greensmyth**, our latest recruit to CLL Support

Born in Ireland, John moved to Aberdeenshire about 30 years ago and has worked in the Offshore Oil & Gas marine construction industry. He was diagnosed with CLL in 1990 after a blood test in an annual medical and since then he's had most of the available chemo treatments including a Stem Cell Transplant in '97. John has now been on Ibrutinib for the last 5 years. Married with two grown up children his interests include travel, cooking, DIY, rugby and cycling. John hopes to extend the geographic footprint and reach of CLL Support by setting up regional sections in the future.

All our trustees are volunteers and either have CLL themselves or are related to someone with CLL.

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.

Registered Charity: 1178482