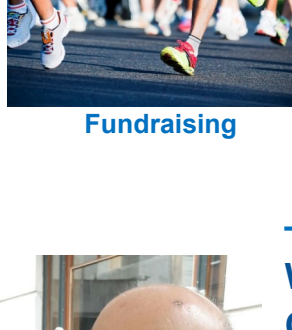
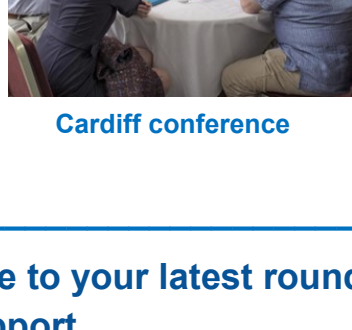




Our top stories in this newsletter



Fundraising



Cardiff conference



A patient's story

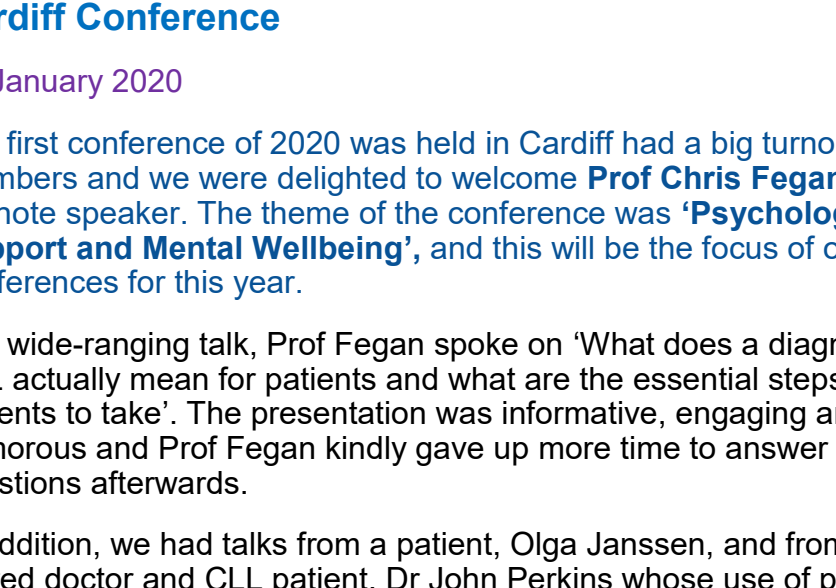


Welcome to our latest roundup of news and events from CLL Support

Difficult to believe it's February already! Our year started with a very successful conference in Cardiff, and I hope the new decade has started well for you too - we look forward to supporting you in 2020. One of our aims in 2020 is to reach even more people affected by CLL and so I want to highlight in these newsletters the work we are doing with other charities and other partners to reach out to patients and carers alike.

Diagnosis of CLL or SLL can be devastating, and our core mission is to support as many of you as possible in any way we can.

I hope you enjoy this newsletter and I look forward to meeting many of you at one of our conferences.
Marc Auckland, CLL Chair



Cardiff Conference

23 January 2020

Our first conference of 2020 was held in Cardiff had a big turnout from members and we were delighted to welcome **Prof Chris Fegan** as our keynote speaker. The theme of the conference was **'Psychological Support and Mental Wellbeing'**, and this will be the focus of our conferences for this year.

In a wide-ranging talk, Prof Fegan spoke on 'What does a diagnosis of CLL actually mean for patients and what are the essential steps for patients to take'. The presentation was informative, engaging and humorous and Prof Fegan kindly gave up more time to answer lots of questions afterwards.

In addition, we had talks from a patient, Olga Janssen, and from a retired doctor and CLL patient, Dr John Perkins whose use of props to illustrate his CLL journey amused everyone.

In a very full programme there were also presentations on emotional wellbeing from Janice Reece, a Macmillan Consultant Clinical Psychologist and the importance of good nutrition by Sarah Draper, a Specialist Oncology dietician.

The 'Under 60's' table has grown and grown and they always add their own brand of welcome enthusiasm.

Our conferences are a major feature of our work and there will be five more conferences this year. The provisional dates are as follows:

- March 25 Leeds
- May 21 Leicester
- July 23 Glasgow
- Sept 26 Oxford
- Nov 19 London

Look out for when bookings are open.

Videos and summaries of all our conferences can be found on our website: cllsupport.org.uk



A Patient's Story

Thoughts on my CLL by 'Newdawn' who is one of our administrators on Health Unlocked

This month will herald the second-year anniversary of my CLL diagnosis.

Over these two years I've had time to reflect on what it means to have CLL and how it's affected me physically and emotionally. I've been reading the experiences of others and the diverse presentation of this cancer never ceases to amaze me. The way we experience it varies so enormously, too, and sometimes it's all too easy to forget the inner pain that it inflicts on our loved ones and carers simply because this is a cancer which has unpredictability, misunderstanding and non-traditional response running through it.

Medics can somehow live with 'chronic' because it doesn't mean 'now' - it means ongoing. My GP told me as much. He must be primed constantly to 'acute', 'immediate', 'life threatening'. Even a response in some doctors that causes minimisation. Oh, it's the 'best cancer to have'...you're more likely to be hit by a bus'...'you'll die with it not because of it'. And for some very lucky people it's true. Then I read individual experiences of fellow CLL'ers with their compromised lives, brutal fatigue, social isolation, inner fears and struggle to maintain a robust quality of life.

So, it got me thinking and considering why CLL should feel so different. Am I being ungrateful and why don't I just forget about it and get on with embracing each day with enthusiasm and optimism? The fact that I've woken today with a really bad sore throat and aching joints signals part of the answer. Ok those symptoms might have happened despite CLL, but the reality is a sore throat is more dangerous to me these days. My inner 'defender' the immune system is wonky and unpredictable and how can I be totally sure the aching joints are not the result of enlarged nodes pressing somewhere?

So that's why I feel CLL is different. It's unpredictable. It changes, it evolves, the genetic profile alters and sometimes the treatment leaves us with even greater battles to fight. How many other cancers result in a 'go away and wait for it to get really bad' and 'sorry, in the meantime there simply isn't much you can do and even less we can give you'. I've tried but not been able to embrace the 'live life madly now, do the bucket list, spend the savings and be outrageous' (well ok maybe the last one occasionally). 😊 Quite apart from the fact that travel insurance companies now view me as a risk to their coffers, I've lost a sense of carefreeness. It's a condition I call ZESTLESSNESS. Not miserable, not a quivering mess but something, somehow has changed. And I know others have documented this feeling so many times.

My old life script has been written over and bits have been scribbled out. Trouble is I don't know what yet. And that's the difference to me because planning, expectation and certainty is well....uncertain! Of course life offers no-one any certainties but I think if we are honest, we could be happily deluded pre-cancer dx that we'd nicely progress to the twilight years and diminishing vigour would be a totally natural journey not one we start to detour along decades earlier.

Can I just add a last reassuring comment that this isn't a plea for reassurance. I'd hate anyone to think it's been written through a veil of tears or hopelessness. Anything but.... It's simply my perception of how this rotten old CLL feels in reality. Warmest regards to all.



Our work with Janssen

Janssen are one of several pharmaceutical companies who donate funds to help us run our free conferences and to develop our literature, which is also available free of charge. This is part of their Corporate Social responsibility programme which they operate with many charities. Janssen have recently embarked on a policy of becoming more patient needs driven and they are trialling a Patient Advisory Committee. This has representatives from several charities representing the needs of the patients who use the treatments they have developed and supplied. The aim is to help Janssen provide the kind of patient-centred products and resources that we, the patients, need.

Two of our trustees, Marc Auckland and Steffi Sutters, are part of the committee. Marc has a dual role as an advisor on the committee, representing the patient, commenting on plans, projects and policy before the committee. He also mentors two board directors helping provide a patient insight into their teams' work and strategy.

Two workstreams he is looking at are developing a measure to evaluate how patient centric Janssens are against criteria developed with input from their patients. This will be used to drive work and measure performance throughout the year. A short survey will be sent to charities members to complete and used to form the objectives.

A second work stream is to explore the possibility of Janssens helping to ensure that all the Clinics and surgeries around the UK have our leaflets and information. CLL support is the first charity to pilot the scheme.

Steffi also works with the haematology team to foster better understanding of the needs of those with blood cancer.



Under 60s' Club (Photo is part of the group at Cardiff)

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 Norah Grant writes:

The CLL Support Under 60 Club started in May of 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 50! 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 confidences. 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 michael.oneill@cllsupport.org.uk who will be able to give you more information.

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

Survey

CLL/SLL Patient Survey. Can you help, please?

We often partner with several CLL organisations around the world in our endeavor to make sure the patient voice is heard.

In our work to improve treatment for CLL and SLL, the kind of information provided by the following survey is vital when we are fighting to gain approval for new treatments. We hope you will take a few moments to complete the survey if it applies to you.
Although this is a Canadian survey, the information provided can be used by CLL Support to gain UK approvals

if you have CLL or SLL and have been treated with the following therapies, you can help by completing our survey:

- [Venetoclax \(Venclexta\) + obinutuzumab \(Gazyva\) for first-line treatment of CLL/SLL](#)
- [Acalabrutinib \(Calquence\) with or without obinutuzumab \(Gazyva\) for first-line treatment of CLL/SLL](#)
- [Acalabrutinib \(Calquence\) monotherapy for treatment of relapsed/refractory CLL/SLL](#)

You do not need to live in Canada to complete this survey.

BY COMPLETING THIS SURVEY, YOU ARE PART OF THE PROCESS THAT MAY HELP PATIENTS GAIN ACCESS TO THESE NEW TREATMENTS IN CANADA AND ELSEWHERE.

You may access the survey by clicking the link below. Thank you for your time.

[Survey for CLL/SLL Patients: Experience with New Therapies](#)



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 a big of the things we do to support CLL patients and their families. So, a big 'thankyou' to all of the people who have raised funds for CLL Support

Our next big fundraiser is the London Virgin 10k run on 5th July

This is our major fundraiser of the year and it is very important for us to get a good team together. We have been allocated a limited number of places and we need to fill them all. This is a fun event and the course passes many of the London landmarks including Westminster, and Trafalgar Square.

You may have a family member or friend who could run on our behalf. Maybe you could get your own team together!

Enter now by contacting: coordinator@cllsupport.org.uk



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

A relatively painless way of helping us 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, and doesn't cost you any more, but CLL Support 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

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 CLL Support 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 Needed!

We are looking for a new trustee. If you think you would like to help us in our work to support patients, let us know.

All our trustees are volunteers and either have CLL themselves or are related to someone with CLL. Trustees attend regular Board Meetings, usually every two months, and responsibilities can vary from helping with conferences to helping with fundraising and IT support. New trustees are given guidance and help from one of the lead trustees until they are comfortable.

If you would like to learn more about this rewarding and interesting work and you feel you have something to offer, please contact: marc.auckland@cllsupport.org.uk

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 our profile, allowing other people living with CLL to discover us. CLL Support is the only UK charity dedicated to providing education, support, and advocacy to help empower people living with CLL.