

Our CLL Support Communication, Support and Advocacy Programme for 2024

In 2024 we will be 20!! Below is a summary of the activities we will be undertaking in the next year, set out under the headings of Communication, Support and Advocacy.

COMMUNICATION

Website improvements and maintenance

The website contains a wealth of information. It will be regularly maintained and updated throughout the year. The website will support our 20th Anniversary celebrations and fundraising campaign.

Newsletters and bulletins

Quarterly newsletters will be emailed to members in Spring, Summer, Autumn and Winter. These will ensure that members are fully informed of the Charity's activities. Special bulletins will also be emailed to members to alert them to topical/pressing issues.

Conferences

Four conferences will be held, one of which will be in a devolved nation. All conferences will be free to attend for our members and each will feature CLL Specialist guest speakers plus patient speakers. The conferences will be live streamed and a professionally edited videos from each will be available on our website. The September conference will also include an opportunity to celebrate our 20th Anniversary.

Webinars

We will continue our programme of webinars. These will be a mix of planned and responsive webinars with CLL Specialists addressing specific topics/issues, and facilitated discussion webinars utilising break out rooms.

Publications and Guides

We will begin work on a third edition of our Patient Guide, to ensure the information contained remains accurate and up to date, and produce other publications where a need has been identified.

SUPPORT

Helpline and Under 60s Group

Our helpline will continue to be available as a first port of call for those with pressing issues or who just need to talk. We will continue to run and manage our very successful Under 60s WhatsApp group which provides a safe space for information and knowledge sharing and mutual support.



Health Unlocked

We will continue with our platform on this site which is actively moderated by appointed administrators and volunteers.

Support ACT sessions

Our programme of Practitioner-led Acceptance and Commitment Therapy sessions to help people manage the worry, anxiety and stress associated with CLL will continue. We will offer group courses (6 drop-in sessions per course) for up to 20 participants per session. We will also offer a limited number of free one-to-one sessions for those who may require individual support.

Support ACT website

The Support ACT section of our website, which provides a suite of emotional wellbeing self-help exercises will be updated and refreshed.

Challenge 20

As part of our 20th Anniversary celebrations we will be encouraging members to participate in a wide range of mental and physical wellbeing activities with a common theme of 20. Certificates will be available to participants. There will also be 20th Anniversary membership and fundraising campaigns.

ADVOCACY

UK CLL Forum

We will continue our close links with the UK CLL Forum, our sister charity for medical and clinical professionals specialising in the treatment of CLL. Our Chair will continue to sit on their Executive Committee and we will continue to work with them to provide relevant guides and booklets for those affected by CLL and SLL. We will also continue to be involved with the associated research oversight group. If requested by the UK CLL Forum, we will support the delivery and recording of a CLL Forum education event for Healthcare Professionals.

Blood Cancer and Other Communities

We will continue our involvement with the Blood Cancer Alliance, with individual blood cancer charities and with Cancer52.

Pharmaceutical Companies

We will meet regularly with Pharmaceutical Companies involved in the treatment of CLL and SLL and will engage with their activities where we can help by bringing the patient perspective, e.g. as patient advocates or by reviewing documents.



Health Technology Assessments

We will seek opportunities to input to this work from a patient perspective, both in England and the devolved nations.

Clinical Trials

We will continue to represent the interests of those with CLL on clinical trials, bringing the patient perspective to their work.

Survey of Members

We will run a further survey of our members, building on the very successful one carried out in 2022.

Blood Cancer Awareness Month

We will again use videos to raise awareness, linking this with World CLL Day and also celebrating our 20th Anniversary. September 2024 will be quite a month for us!

Social Media

We will increase our presence on Social Media, raising awareness and developing fundraising opportunities.

Agreed by the Trustees at our meeting in October 2023