

## Report on CLLSA Oxford Conference, 8 Sept. 2017

We would like to thank everyone who contributed to the success of our Oxford Conference. We received many compliments, which made all the hours of preparation worthwhile: *“It was very enjoyable and a great support, thank you”; “very participative; there was a lot of laughter too”*. Another member was so grateful, that he will now be making regular monthly donations to CLLSA: *“CLLSA is worth its weight in gold to me and my wife.”*

This report is for all of you:

- our speakers: consultant Anna Schuh; clinical nurse specialist Julia Ford; trustee Brian Gardom; CLL patients Sue Barclay and Pauline Stow
- our volunteers: group discussion facilitators and setting-up helpers
- everyone who attended: CLLSA members and LeukaemiaCARE reps.
- CLLSA trustees and coordinator
- anyone who is interested in CLLSA conferences

All your feedback on the Conference is welcome. We have included in this report observations made at and after the Conference as well as notes from discussion groups, feedback from our questionnaire and from emails.

The report has the following sections:

- What worked well: bullets and commentary
- What could have been better: bullets and commentary
- Appendix 1: Composition of participants
- Appendix 2: Analysis of returned feedback forms, and donations
- Appendix 3: Answers to unanswered questions
- Appendix 4: Discussion groups' feedback: coping tips; appropriateness of “watch and wait” and “carers”
- Appendix 5: The programme for the day

### What worked well

- Outstanding presentation from Haematology Consultant, Anna Schuh
- Many initiatives for the empowerment of CLL patients
- Well structured and executed programme, with a good ambience
- Featuring collective initiatives for Blood Cancer Awareness Month

### What could have been better

- The quality of audio-visual arrangements
- A lower score for discussion groups, compared with other aspects
- Use of volunteers
- Speed of uploading presentations and videos on the CLLSA website
- Accommodation of people on the waiting list

## Commentary on what worked well

- Presentation from Haematology Consultant, Anna Schuh

Way ahead of all other volunteered “most liked” aspects was the presentation by Anna Schuh, with 15 citations. (Appendix 2). “Presentations” scored 96% satisfaction amongst returning CLLSA conference attendees, and 92% amongst first timers. Members particularly appreciated the accessibility of Anna Schuh’s presentation. One comment – “I understood 90%.” – reflected a common feeling. Members were appreciative of getting an update on treatments and developments from a CLL expert. Anna Schuh’s talk covered: the crucial role of precision diagnostics; the range of treatments and what they specifically target; tips for patients on how to look after themselves. She alerted us to: the FLAIR study, a randomized phase 3 trial comparing ibrutinib and rituximab with FCR as a first treatment for CLL; and the 100,000 Genomes Project using big data sets of consenting patients’ genome data, linked to information on their medical condition and health records, to identify the best of existing treatment and prognostic information.

Anna Schuh’s presentation will be uploaded, both in slide form and in video, on the CLLSA website. It will be essential revisiting for attendees to get the full benefit of the content. Our Oxford Conference audience of 44 members (Appendix 1) constitutes less than 2% of CLLSA membership. It is vital that we make this valuable resource from Oxford available to all.

- Initiatives for the empowerment of CLL patients

Oxford’s policy of “the patient knows best” – respecting the wishes of patients – was a recurring theme of the Conference. It featured both formally and informally. Those brought up in the old school of “the doctor knows best” sometimes need encouragement to trust and voice their own judgement about what is best for them.

Brian Gardom opened his talk, on using Health Unlocked and other recommended Internet resources, with an illustration of how informing yourself can benefit patients. You know what questions to ask clinicians; you manage your condition better; you tend to live longer. The talk was accompanied by an updated CLLSA Information sheet on websites useful for accessing CLL communities and resources for CLL. We will ensure that this gets wider circulation by posting it on our website. A hand-show at the Conference indicated that, possibly, up to 50% are not currently users of Health Unlocked, whilst for others it is a regular port-of-call for getting information on CLL. One enterprising member posted a message on the spot on Health Unlocked, featuring a photo of Anna Schuh in full flow and highlighting the importance she stressed of CLL patients getting an annual flu vaccination.

Our two patient speakers, Sue Barclay and Pauline Stow, both demonstrated the power of being assertive. They had taken the initiative to change their consultants to a CLL specialist, having had a poor initial experience of care in their local clinic.

Earlier, in discussion groups, there were heartening exchanges between members, supporting one another to be a bit less diffident, a bit more demanding. One group discussion facilitator offered to give individual follow-up calls to a two participants to assist them further.

Most “watch and wait” patients do not have access to a clinical nurse specialist. CNS Julia Ford’s presentation on her role at Oxford was a revelation for them of how a CNS is key to helping patients understand their condition and navigate the system. More than that, she

demonstrated the value of having a friendly, reassuring face, or voice on the phone, to turn to for advice. Julia was able to stay for the discussion group of Oxford residents and contribute valuably to that group's discussion.

- A well structured and executed programme, with a good ambience

We received many compliments on the programme's informative and varied content and the friendly, supportive ambience. Scores for all five aspects measured were above 80%, or "good", and in most instances above 90%, edging towards an unattainable 100%, i.e. unanimously considered "excellent". We have listed some of the nine volunteered comments for what was "most liked" about the programme, its organization and ambience beneath the table of scores given in Appendix 2. The splendid lunch and cakes were clearly a welcome bonus, "most liked". Our two most experienced trustees both commented on the benefits of a smaller conference, which they felt made for an informal and inclusive ambience.

Participation by members was encouraged. CNS Julia Ford opened her talk on "Support in the clinic and beyond" by asking the audience what they knew about the CNS role. A straw poll was used by Brian Gardom to establish levels of previous knowledge about Health Unlocked. Compere, Olga Janssen, invited participant responses in her opening and closing comments. Where members' questions were not answered on the day, they have been responded to subsequently. (Appendix 3)

- Initiatives for Blood Cancer Awareness Month

The Oxford Conference on 8 September coincided with the start of Blood Cancer Awareness Month (BCAM). This gave us an opportunity to showcase the many initiatives to raise GP and public awareness about blood cancer, and more specifically Leukaemia and CLL.

Members were invited to take and wear the "spot leukaemia" ribbon provided by our sister charity Leukaemia CARE, and to use the CLLSA emblazoned cloth bag, when out and about, to trigger conversations and raise awareness. Posters on the wall listed six symptoms to look out for: Can you #SpotLeukaemia? Members helped themselves to a copy of the executive summary of Leukaemia CARE's survey of over 2,000 leukaemia patients (including 1,000 CLL patients) and its 10 recommendations for service improvement. Many were surprised by Olga Janssen's public announcement that neither her GP nor her consultant haematologist had been aware of CLLSA; they took batches of CLLSA flyers to deliver at their next GP and clinic appointments.

CLLSA has engaged a Public Relations consultant to help the campaign to raise awareness. A number of articles have appeared in the local press as a consequence. Two short, informative videos on CLL, both shown at the Conference, have been posted on social media.

Fourteen CLL patients, recruited by CLLSA, feature in Janssen Oncology's installation "MakeBloodCancerVisible" in Paternoster Square, by St Paul's in London. It has 104 plinths of patients' first names with descriptive plaques to represent the 104 people diagnosed with a blood cancer daily in the UK. A 3-minute video of CLLSA members involved in the installation was shown at the end of the Conference to underline the message: "We are all in this together."

## Commentary on what could have been better

- The quality of audio-visual arrangements

Inadequate sound systems have been a recurring criticism of our conferences. Dissatisfaction at Oxford was marked. (Appendix 2 “least liked”; 9 comments) There was a disturbing crackle from the mic. worn by Anna Schuh, only rectified by resorting to the hand-held mic. in the question and answer session following. One hearing impaired member found the earlier distortion painful through his hearing aids and had to be persuaded to stay.

The close proximity of tables made it a strain to hear in the discussion groups, especially for the hard-of-hearing. Group situations are particularly difficult for hearing-aid wearers, due to the magnification of background noise.

Three people observed that it was difficult to see the bottom of the screen from the back of the room.

Two observed that the air conditioning was too cold in the morning.

CLLSA needs to ensure that future conferences are better served. We should:

- consider engaging the services of a sound specialist
- look into the benefits of using a hearing loop
- have less proximity between discussion group tables: break-out rooms?
- check projection is well positioned before the conference
- check air conditioning is set at a comfortable temperature

- A lower score for discussion groups, compared with other aspects

Discussion groups scored 85% satisfaction, the only aspect to score less than 90% (Appendix 2). This is not unusual. There are many variables for discussion groups, not all of which are within our control. Some groups gel better than others. Expectations and needs differ, with some in the group having attended many CLLSA conferences before and others, often the ones who benefit the most, attending for the first time. Facilitators need to be flexible to meet the needs of the people in their group. Difficulty hearing was undoubtedly a contributing factor to some dissatisfaction at Oxford.

Feedback from Oxford indicates that some found there was insufficient structure to discussion: *“group discussion could have been more focused”*.

The highest score for discussion groups, in the four conferences to date in 2017, was 91% at Leicester. It may be advisable to adopt the Leicester approach:

- an up-front announcement on: the process and  
essential contextual information
- two topics: one for sharing experiences and coping strategies  
one for debate on a current issue for CLLSA,  
on which we wish to consult our members

We are in the process of building up a team of briefed volunteer discussion group facilitators. All of us are learning and, we hope, improving by doing. Some are able to draw on considerable group management and reporting skills from their professional backgrounds. Others are comparative novices, but are able to contribute usefully due to their knowledge

and experience of CLL and/or their skills of empathy. It will always be the case that facilitators have their own individual style. This makes for variety, which we welcome.

- Use of volunteers

We were grateful to the four local residents who responded to our request to help us set up. However, we failed to give them clear guidance on their role. Our coordinator was fully occupied setting up the computer with materials for projection of presentations. Two trustees filled in, doing the admin at the registration desk, which would have been better done by our volunteers, leaving the trustees free for the important task of meeting and greeting members as they arrived. It must have been frustrating for our volunteers not knowing exactly what was expected of them. We will rectify this at our next conference.

- Speed of uploading presentations and videos on the CLLSA website

CLLSA has a poor track record of getting conference presentations up fast on its website. Attendees want to revisit these whilst the conference is still fresh in their minds. Presenters, especially clinicians, want to be able to direct their patients to their presentations. Members at large want speedy access too.

- Accommodation of people on the waiting list

We now have data on cancellation rates for the past eight conferences. This enables us to overbook by 6% with confidence. (Appendix 1) Had we done so at Oxford we would have been able to accommodate the seven people on our waiting list. There was adequate seating for them.

Report compiled by OJ, 26 September 2017.

## Composition of Participants at Oxford

Attendees	52
Cancellations/ no show	8 (15%)
Waiting list, not accommodated	7
First time member attendees	22 (69%)
Returning member attendees	10 (21%)
(Unknown members	12)
Total members in attendance	44

*For comparison, this year first timers were: Cambridge 60%; Liverpool 53%; Leicester 28%*

Trustees: CT; AC; BG; OJ	4
Healthcare Professionals: AS; JF	2
Charity Reps: LeukaemiaCARE: NY; HB	2

Discussion Group composition:	
CLL patients	31 (65%)
(Of whom on active observation/ watch and wait: 14 (45%)	
Supporters/ carers	17 (35%)
Total	48

NB. Facilitators are included in these figures

*For comparison, this year CLL patients were: Leicester 61% (of whom ww. 40%); Liverpool 66% (of whom ww. 48%); Cambridge 69% (of whom ww. 60%)*

### Note on Cancellation rate

The eight (15%) cancellations at Oxford arrived too late for us to reallocate the places. Apart from two for reason unknown, the reasons given were:  
unwell (2);  
funeral of close relative (2);  
domestic flood (2)

Cancellation rates in 2017 so far have been:

Cambridge	6%
Liverpool	8%
Leicester	15%
Oxford	15%

Cancellation rates in 2016 averaged: 11%

Glasgow	7%
Southampton	9%
Nottingham	11%
London	14%

**This suggests that we can confidently overbook by 6% in future.**

## Analysis of returned feedback forms from participants

### Satisfaction levels for each of the 5 aspects measured at Oxford, Sept. 2017

	Not so good	Fair	All respondents			Total respnd	%*	% 1 <sup>st</sup> time attend	% 2 <sup>nd</sup> plus attend	% 2016 confer-ences
			Aver- age	Good	Excell- ent					
Advert, register	0	0	0	13	21	34	92	93	92	87
Location, facilities	0	0	2	10	22	34	92	92	94	91
Event materials	0	0	1	13	20	34	91	91	92	88
Group discussions	0	1	4	12	14	31	85	88	82	83
Presentations	0	1	0	10	22	33	92	92	96	89

#### Notes

1. %\* Percentages are calculated by multiplying “not so good” by 2, “fair” by 4, “average” by 6, “good” by 8 and “excellent” by 10. The sum is divided by the number of respondents, to give an average out of a maximum possible score of 10. This figure is multiplied by 10 to give a percentage score. Figures rounded to full % point.

A score of 80% would indicate overall: “good”.

A score of 100% would indicate all respondents rated it “excellent”.

2. There were 34 completed feedback forms, from a total of 46 attendees (4 trustees, the CLL coordinator and keynote speaker excluded), i.e. 74% return. We aim for a minimum return of 60% to be confident of findings.
3. Of the 34 completed feedback forms, 2 did not indicate whether they were first time attendees. Of the remaining 32 returns, 22 were from first-time conference attendees, i.e. 69%. This compares with Leicester (July 2017) 28% Liverpool (May 2017) 53%, and Cambridge (March 2017) 60%.

### Most liked – observations volunteered by attendees

- Anna Schuh’s presentation well pitched for us to understand; update from specialist 15
- The presentations/ speakers 2
- Good to hear from a CNS 3\*
- Patient presentations 1
- Meeting others/ CLLers; sharing with others 10
- Group discussions excellent faciitator 3\*
- Programme, organization and ambience of the Conference v well organized; v. helpful; the informality; very participative; a lot of laughter; friendly environment; whole event excellent; may I say it was very enjoyable and a great support, thank you; informative and friendly; the variety 9
- The catering great food; the cakes; lunch 4\*
- Website information 2
- Jargon buster very valuable 1
- Location 1

\* These three were all from 1st time attendees. These aspects apart, there was no difference between the two groups.

33 of the 34 respondents completed this question. Some gave more than one aspect “most liked”.

## Least liked - observations volunteered by attendees

- Question not answered 12
- Nothing! 2
- Acoustics 9  
Audio poor with crackling mic. in the morning; difficult for hearing impaired, would like to have hearing loop installed; it was like a parrot house for the group discussions; have break-out rooms
- Unable to see bottom of screen from back 3
- Room: cold 1, theatre style preferred 1 2
- No parking/disabled parking 2
- Health unlocked/ internet resources 2  
already use these
- Patient session, patient stories 2  
But many complimented speakers personally on their stories afterwards
- Have topic for group discussions to give focus and structure 2
- Keynote speeches 1
- Weather 1

22 of the 34 respondents completed this question. Some gave more than one aspect "least liked".

Note: There was no significant variation between first-timers and returners for "least liked".

## Suggestions volunteered by participants

- Add a suggestion box to the form  
*Trustees' response: We had this in 2016 for all 4 conferences and received 91 suggestions. There were no common themes emerging. Moreover, it was very time consuming to analyse. We found that the "most liked" and "least liked" responses gave us a good picture of what was working and where we could improve. There was therefore a Board decision to discontinue the suggestion box on the feedback form.*
- Some gentle physical exercise to break the thing down  
*Please feel free to use the one-hour lunch break and the afternoon 15-minute tea break to take a little walk.*
- Have a session on alternative therapies/ supplements: studies and efficacy.  
*We will look into the options for a talk by a dietician at one of our future conferences. In the meantime please see our answers to questions 1 & 2 in Appendix 3 of this report.*
- The jargon buster was very valuable. Please include haemolitic anaemia or haemolysis on the list.  
*We will look into this.*
- Two suggestions for improving the acoustics: Hearing loop and break-out rooms  
*Please refer to the text of this report in the " Commentary on what could have been better".*

## Donations received at the Conference

£240, plus gift aid to be claimed. Cheque also due in the post

## Answers to Unanswered Questions at Oxford

We invited discussion groups to hand in to us any questions, which the group could not answer. Your CLLSA trustees, including a consultant haematologist, give their answers.

### 1. Is turmeric helpful for CLL?

*There is no clear data on this matter in clinical practice. On the other hand, laboratory data indicates turmeric has activity in "cancer". There is little or no harm to be done by taking turmeric in the diet or as a supplement.*

### 2. How does vitamin D help people with cancer?

*Like turmeric, it also remains controversial to what degree vitamin D is useful in cancer. A lack of vitamin D can have a variety of negative effects, including on the immune system. The value of supplemental vitamin D in the absence of any deficiency is not clearly established, although there has been a paper on CLL patients suggesting benefit. Those keen to know the science of this could look at: 1. "Plasma 25 – hydroxyvitamin D concentration and lymphoma risk: results of the European Prospective Investigation into Cancer and Nutrition."*

*American Journal of Clinical Nutrition ([ajcn.nutrition.org](http://ajcn.nutrition.org))*

*2. "Vitamin D insufficiency and prognosis in CLL (2010)" [www.bloodjournal.org](http://www.bloodjournal.org)*

### 3. Why is CLL classed as a disability in the workplace, but you are not entitled to free prescriptions whilst on watch and wait?

*You need to have a valid medical exemption certificate for free prescriptions. Patients can apply for this and get free prescriptions if they have cancer and are undergoing treatment:*

- for cancer
- for the effects of cancer
- for the effects of cancer treatment

### 4. When will non-live vaccine be available?

*We assume you are referring to vaccination for shingles. There are currently trials for such a vaccine, the results of which so far prove encouraging for the 50 + age group. The trial on patients aged 70 and older is incomplete. It's not possible to predict the outcome at this stage.*

### 5. When is the best time to start finding out about trials?

*When treatment needs to be considered, the option of a clinical trial should always be looked at, as well as standard treatment.*

### 6. Why aren't all the clinical trials open in all the hospitals?

*It is not possible to open all trials in every centre treating patients with CLL. The logistical resources required for running trials is considerable and it is not financially viable, as well as there being a need for sufficient expertise in terms of trial staff and medical staff.*

### 7. Why aren't there any CLL conferences in the West of England (Devon)?

*We try to make sure there is a good geographical spread to our conferences, and offer them in towns, which act as a hub for a region. London apart, the locations change each year. In 2018, CLLSA conferences are planned for Bristol, Birmingham, Leeds and London. We offer bursaries to those who find the travel expenses prohibitive. Please contact Sarah Tobin, our coordinator, for advice on bursaries. [coordinator@cllsupport.org.uk](mailto:coordinator@cllsupport.org.uk).*

## Oxford Discussion Groups' Feedback

### Members' tips for coping with CLL

#### Whilst on watch and wait

Have a rest when needed  
Live for the day  
Live healthily  
Try to be positive  
Read Health Unlocked  
Join a support group  
Imagine worse scenarios, then look forward

#### During treatment

Take your anti sickness pills well in advance  
Side effects should be controlled, as FCR is not easy  
Keep a positive attitude. Listen to your Clinical Nurse Specialist (CNS)  
Try to make food flavoursome  
Keep doing what you would normally do  
Use a spreadsheet/ drug chart for pills

#### After treatment

Enjoy life

### “Watch and Wait” and “Carers”: are these terms appropriate?

This question was raised by CLLSA members at our recent Leicester conference.

#### Watch and Wait?

In four of the six groups, the consensus was that this is an inappropriate term. One of the groups was comfortable with the term “watch and wait”. The sixth group did not indicate its preference. A show of hands at the end of the Conference indicated that there was a ratio of 3:1 in favour of “active observation” over “watch and wait.”

#### Carers?

Three groups disliked the term “carers”. They preferred the term “supporters”. A fourth group was happy with the term “carer”. Two groups did not report on their preferences. We conclude that there is a ratio of 3:1 in favour of “supporters”.

The Conference will recommend to the CLLSA Board that the terms “active observation” and “supporters” replace the terms “watch and wait” and “carers” in CLLSA literature.

CLL SUPPORT ASSOCIATION  
**Oxford Conference 8 September 2017**

Jarvis Doctorow Hall at St Edmund Hall, Queen's Lane, Oxford. OX1 4AR

## Programme

- 10.00     **Arrival.** Refreshments
- 10.30     **Welcome** and introduction. Olga Janssen, Trustee
- 10.45     **What's new in CLL?** Dr Anna Schuh  
 An introduction to CLL and a review of modern management.
- Professor Anna Schuh is Director of Molecular Diagnostics at the University of Oxford and an Honorary Consultant Haematologist. She has participated as a principal or chief investigator in over 30 early or late phase clinical trials in chronic lymphocytic leukaemia. A number of these led to subsequent NICE approvals and have changed clinical practice in the UK and worldwide. Her primary research interest is with the development, evaluation and implementation of new technologies for precision diagnostics with a particular focus on genomics (the study of genomes, the complete set of genetic material within an organism.)  
 Dr Schuh is Chair of the UK CLL Forum.
- 12.10     **Health Unlocked - Using Internet resources.** Brian Gardom, Trustee  
 Please bring a battery-operated laptop if you would like to explore the Health Unlocked site live after this talk, in an informal workshop during the lunch break.
- 12.40     **Lunch**
- 1.40     **Advice from a CLL clinical nurse specialist.** Julia Ford, CNS
- 2.10     **Group Discussions**  
 An opportunity to share, with others who live near you, your experience and tips for coping with CLL, and to discuss associated issues from a patient and carer perspective.
- 3.10     **Tea**
- 3.25     **Patient/Carer CLL stories**  
 Sue Barclay; Pauline Stow; Stuart Chambers, cancelled
- 3.55     **Closing comments and next steps.** Olga Janssen, Trustee
- 4.00     **Departure**

CLL Support Association  
 Registered Charity No. 1113588  
[www.cllsupport.org.uk](http://www.cllsupport.org.uk)