

Report on the CLL Support Association Bristol Conference 20 July 2018

"CLL Support Association conferences are very helpful: you go away uplifted."

"I'm inspired to help promote the Association."

"An invaluable event, many thanks."

These comments, received in feedback from our Bristol attendees, capture the impact of the Conference on our members. Satisfaction levels for all aspects measured were very high, ranging from 84% to 98%. (Appendix 2.)

This report is for:

- our guest speakers, Prof. Chris Fegan and Dr Stephen Man
- our member speakers
- all those who attended the Conference
- CLLSA trustees and coordinator
- the Leukaemia Care charity rep. attendee
- anyone who is interested in CLLSA conferences

It is based on all the evidence collected at the Conference. Slides of presentations have been uploaded onto the CLLSA website together with video recordings of the two guest medical and two in-house CLLSA presentations.

The report has the following sections:

- What worked well: bullets and commentary
- What could have been better: bullets and commentary
- Appendix 1: Composition of Attendees
- Appendix 2: Analysis of returned Feedback Forms
- Appendix 3: Discussion Group Feedback– Me, my clinic and CLLSA
- Appendix 4: The Conference Programme

What worked well

- Up-to-date and inspiring presentations from guest and member speakers
- Extra time allocated for questions and answers
- Successful recruitment of CLLSA profile-raising champions
- The fit-for-purpose venue and its helpful staff

What could have been better

- Coordination and facilitation of discussion groups
- The timing of the Conference

Commentary on what worked well

- Up-to-date and inspiring presentations from guest and member speakers

The highlight of the Bristol Conference was Prof. Chris Fegan's presentation: "CLL treatment – who needs treatment and how do we move from where we are to cure?" He gave an up-to-date and wide-ranging account of treatments and their effectiveness. His message had a nice balance of realism and optimism, delivered with a touch of humour.

One member wrote: *"Presentations were excellent. I might not have absorbed all of it, but I'm so pleased it has been recorded, so will go on the CLLSA website."*

Our second specialist speaker, Dr Stephen Man, a researcher, gave a very clear presentation on "CLL and the immune system", illustrated with an excellent choice of graphics and similes to assist the understanding of our lay audience.

The 98% score for presentations, and 40 citations as the aspect of the Conference most liked (Appendix 2), related equally to the un-videoed, double act by Bert and Gail Wiegman on a patient's and partner's individual experience of FCR therapy. Four photographic slides illustrated the ups and downs of diagnosis and treatment, and its impact on everyday life. Practical tips for coping were given. Traditionally CLL patient stories end our conferences, but bringing this item forward to open the Conference at Bristol, emphasized our Association's member-led focus. Thirty-nine percent of Bristol member attendees (Appendix 1) were partners, so it was good to embrace their role too within the CLL community. Three feedback respondents made specific mention that this joint presentation was an aspect they particularly liked. " (Appendix 2).

Readers are referred to the two videoed presentations on our website, covering our Association's plans for recruiting a range of member volunteers and our recent and forthcoming activity on: reversing NHS England's arbitrary ruling on access to Ibrutinib; fundraising; Charitable Incorporated Organization (CIO) status and trustee elections; the #makebloodcancervisible initiative for this September's Blood Cancer Awareness Month. Members were thanked for their crucial part in the success of these activities.

- Extra time allocated for questions and answers

Prof. Fegan kindly agreed, not only to extend the allocated time for public questions and answers by quarter of an hour, but also to be available in the lunch period to answer members' questions one-to-one.

We were able in this way to respond to the multi-level and huge range of concerns our members have, often relating to their own individual case. Many patients regard this access to expert, up-to-date, medical advice a vital part of our conferences.

We reintroduced a section on "burning questions" in our discussion groups, successfully pioneered in conferences in 2017. This is an opportunity to tap into the experience and knowledge of fellow members. Questions, which remained unanswered, have been logged (Appendix 3) and a CLLSA response given in italics.

- Successful recruitment of CLLSA profile raising champions

Our Association has just one part-time paid worker – the CLLSA coordinator. Trustees, advisers and our members make a huge difference to what we can achieve.

We launched a programme to recruit volunteers to specific roles in May at our Birmingham Conference. We were very pleased to recruit 25 champions at the Bristol Conference, who will be raising our Association’s profile at their respective CLL clinics. Roger Huxley is the trustee liaising with these champions.

As part of our marketing strategy, we asked members what they most valued about our Association. Responses are recorded in Appendix 3. We know that saying how you have personally benefitted from CLLSA is a convincing selling point to your consultant, nurse and GP. Many of them have not heard of our Association.

All our members have personal skills and experience from their working lives, be it professional or voluntary. Some of these “transferable skills”, volunteered at Bristol, have the potential to benefit CLLSA. Examples are given in Appendix 3.

- The fit-for-purpose venue and its helpful staff

Our venue for the Conference was the spacious top floor of the museum “We the curious” in Millennium Square, central Bristol. It suited us well, being self-contained, with en-suite catering provision, generous terraces with lovely views, a good AV system and helpful staff. With a 92% satisfaction rating, it was second to the score given to presentations (Appendix 2).

Commentary on what could have been better

- Coordination and facilitation of discussion groups

Feedback from attendees shows that they were, on the whole, happy with the discussion groups. (84% satisfaction, Appendix 2.) Meeting with fellow CLL patients and partners, and exchanging experiences and tips, is a major attraction of our conferences. The small discussion groups provide an opportunity for this.

From an organizing trustee’s perspective, however, the discussion groups did not work so well at Bristol. This was due, in part, to the lack of adequate coordination between the two organizing trustees for recording the discussions. The paperwork needed better streamlining and better clarity on the feedback sought from groups.

Several groups (six out of ten) operated without a briefed facilitator. We had been unsuccessful in recruiting and briefing in advance volunteer facilitators to assist trustees. Few groups had someone both willing to put themselves forward and with a skill for drawing out contributions from fellow members. Feedback received was often incomplete. This is reflected in the analysis of returns (Appendix 3).

- The timing of the Conference

A small minority commented on problems with heavy traffic on a Friday, and at the start of the summer holidays, compounded by the number of events that day in central Bristol and expensive parking, the 10% discount available to our conference attendees notwithstanding.

We received a request for a Saturday conference so that members, who cannot get leave from work during the week, are able to attend.

Composition of Participants at the Bristol Conference 2018

Attendees:

Advance place bookings made:	80
Total in attendance on the day:	74
Cancellations on 18/7/18: 4)	
No show on the day 20/7/18: 5)	9 (11% of 80)
Last minute registrations: 2	
Waiting list, not accommodated: 0	

Cancellation and no show rates varied from 6% to 15% in 2016 and 2017.

The average was 11%. With adequate notice we are able to reallocate relinquished places.

First time member attendees	33 (69%)
Returning member attendees	15 (31%)
(Unknown status members	<u>3</u>)
Total members	51*

**Information from feedback forms. Some members did not complete a feedback form.*

For comparison, first timers were 51% overall in our 5 conferences in 2017.

Trustees: MA; OJ; RH; GW	4
Healthcare Professionals:	
Clinician/Researcher: CF; SM	2
Charity Reps: LeukaemiaCare NY	1
CLLSA coordinator:	1
CLL patients (excluding trustees):	40 (61% of 66)
CLL partners (excluding trustees):	<u>26</u> (39% of 66)
Total:	74

Discussion Group composition:

CLL patients	26 (59%)
(Of whom on medical monitoring/ "watch and wait": 18 (69%))	
Partners	<u>18</u> (41%)
Total	44

NB.

- 1. Data returned was incomplete. There were 54 who stayed for the group discussions.*
- 2. Trustees are included in the 54, and in the above table.*
- 3. For comparison, in 2017 the % ratio of patients to carers was 68:32 and the % ratio of ww patients to other patients was 78:22*

Analysis of returned feedback forms from participants

Satisfaction levels for each of the 5 aspects measured at Bristol, July 2018

	Not so good	Fair	All respondents			Total respnd	%*	% 1 st time attend	% 2 nd plus attend	% 2017 all 5 conferences
			Average	Good	Excellent					
Advert, register	0	5	4	22	19	50	84%	82%	84%	90%
Location, facilities	1	1	1	12	36	51	92%	92%	92%	92%
Event materials	0	0	6	25	20	51	86%	85%	84%	92%
Group discussions	2	2	3	18	22	47	84%	84%	83%	88%
Presentations	0	0	0	6	45	51	98%	98%	99%	93%

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 are rounded to a full % figure.
A score of 80% would indicate overall: “good”.
A score of 100% would indicate all respondents rated it “excellent”.
2. There were 51 completed feedback forms, from a total of 74 attendees, i.e. 70% return. Trustees (4), CLL coordinator (1) and visiting speakers (2) do not complete a feedback questionnaire. Charity reps sometimes do. A return of 51 from the 67 members and one charity rep is 75%. We aim for a minimum return of 60% to be confident of findings.
3. Of the 51 completed feedback forms, 3 did not indicate whether they were first time attendees. (Their returns have been included in the “All respondents column”.) Of the remaining 48 returns, 33 were from first-time conference attendees, i.e. 69%. This compares with Birmingham (May 2018) 48%; Leeds (March 2018) 51%; London (November 2017) 43%; Oxford (September 2017) 69%; Leicester (July 2017) 28%; Liverpool (May 2017) 53%, and Cambridge (March 2017) 60%.

Most liked

All 51 respondents commented, sometimes giving more than one aspect as most liked. There was no noticeable difference between first timer attendees’ and returners’ comments. Percentage figures for satisfaction barely vary between the two groups. As at other CLLSA conferences, medical presentations and meeting other CLLers and sharing experiences were the aspects most liked.

Presentations

40 of the 51 respondents singled out the presentations as most liked. Prof Chris Fegan in particular was widely praised.

“Prof. Fegan’s presentation was brilliant.”

“The presentations of the very latest thinking and research by inspired specialists.”

“Presentations absolutely excellent, high level but right speed and humour made all accessible.”

“The two doctors’ lectures were well presented, clear and easy to understand.”

“Very positive message re future treatments.”

“Presentations were excellent. I may not have absorbed all of it, but I’m so pleased it has been recorded so will go on the CLLSA website.”

Most liked cont'd

Meeting other CLLers

21 respondents highlighted this aspect of the Conference.

"Mutual support"; "Great networking"; "Meeting people with similar problems".

"Meeting others with CLL, so that you feel not alone."

"I did not think I would like meeting with other CLL patients, but I did."

Good member story

3 respondents made specific mention of this.

"The patient's story included the patient's partner, more insight and particular advice."

Table allocations by where people live

2 people commented on this.

"Good idea to put people from same area together."

The fun element and humour

3 people mentioned this.

"It was all interesting, informative and amusing." "Informative and in some cases fun."

Good Questions and Answers

We received 2 observations.

"The information provided 1:1 post presentations" (referring to the chance to speak individually to Chris Fegan after his presentation.)

"Q&A session high standard and well managed."

Some pleasing individual comments

"An invaluable event, many thanks. Loved the personal tips and group activity.

Met some interesting people."

"Inspired to help promote the Association."

Least liked

29 of the 53 respondents left this question blank or simply wrote "nothing" or "N.A".

CLLSA Champions

We received 4 comments.

"Input on CLLSA volunteers too much waffle"; "Volunteer input not brilliant, sorry";

"Too much time explaining what is going to happen...e.g how to fill in Champion's form. Just let us get on with the stuff."

Group discussions

4 comments.

"Not enough time for group discussions"; "Group discussions due to no facilitator"; "Sadly group discussion left a little high and dry".

Timing, traffic and location

4 comments.

"Timing not great with school holiday traffic." Getting there through traffic."

"Cost of parking. City Centre location." "Long way to travel."

Other Comments

"Too short. When might the next one be?"

"No alternative treatments mentioned."

"Would have liked more about how to avoid infection."

"Absence of online participation."

"First lecture too complicated...level of clinical details it was assumed delegates understood."

"Would have liked break for a walk about."

"Sound system not perfect (not possible to hear everything)" Only one comment on this.

Feedback Received from Group Discussions

We had two aims for the small group discussions:

- To give attendees an opportunity to learn from each other's experience
- To recruit volunteers to be Champions for the CLL Support Association

Composition of groups

Due to early departures, the 70 attendees allocated to tables were reduced to 54 for the small group discussions. The ten groups were accordingly reconfigured to make eight groups. Information returned on the composition of these groups was incomplete, with data received on just 44 members, as follows:

26 of the 44 were patients: 59%

18 of the 26 patients were on "watch and wait": 69%

18 of the 44 were partners of patients: 41%

(Note: from registration data:

26 (39%) of 66 conference attendees were partners, trustees not included. Appendix 1.)

Access to a Clinical Nurse Specialist

23 patients responded: 18 do have access (78%); 5 do not (22%).

A thumb-nail portrait of CLL clinics

We wanted to get a picture of the range of CLL clinics to assist us in the promotion of the CLL Support Association in clinics. We asked for information on: size, facilities, staffing and services. An example was given by Olga: *"My CLL clinic is West Middlesex, a general district hospital. When asked, a consultant haematologist there estimated they have 100 CLL patients, of whom some 12 are receiving treatment."* Attendees' feedback did not expand on their CLL clinics, other than tell us the name of the clinic. However, this information is useful to help us locate where we have the potential of a local CLL Support Association Champion.

What information patient attendees got on CLLSA from their clinics

This question too was designed to assist the promotion of the CLL Support Association in clinics. We received 26 responses:

7 (27%) had received information on the CLLSA from their clinic.

19 (73%) had not received any information on CLLSA from their clinic.

Information received included, in one instance, getting a CLLSA leaflet; two were told of CLLSA by a consultant and one by a CNS.

One member, a trustee, reported that her consultant had never heard of the CLL Support Association. Most present found out about the Association by googling.

What CLLSA services conference attendees value and why

This was another question to help us in the marketing of the CLL Support Association.

Responses were:

- networking at conferences
- opportunity to talk to others with CLL on same table at conferences
- presentations by clinicians and others at conferences
- opportunity to speak directly with conference keynote speaker to get medical advice
- conferences are very helpful: you go away uplifted
- information
- the website
- the Health Unlocked Forum on the website

One group facilitator, a trustee, asked about the CLLSA Helpline. No one in this group of seven members had heard of the Helpline, but thought it was a good idea.

Volunteering to be a CLLSA Champion

We recruited 25 volunteers to promote the CLL Support Association at their CLL clinic. Two of these were couples, so we have volunteers in 23 clinics.

Members' transferrable skills

Trustees are aware that members bring a wide range of expertise and experience, not only from their working lives, but also from hobbies and voluntary work they do. This is a valuable resource to the Association for tapping into advice and possible assistance.

Attendees included:

- a member with a strong information technology background
- a medical director of a pharmaceutical company
- a phlebotomist
- a State Registered Nurse
- people skilled in digital technologies
- members of local patient participation groups (in GP practices)

Burning Questions

Attendees were asked to log on the feedback forms any remaining burning questions which they had been unable to answer within their groups. These were their requests:

- how to prevent infection
- advice on healthy lifestyle
- advice on antibiotics – continued infections
- advice on health and diet: does this make a difference?
- what are the magical trigger points to initiate treatment?
- life insurance stipulates it does not cover CLL Stage A. Should you tell the insurance company? If not, who should it be discussed with?

CLLSA response to all the above:

We have a working party reviewing information for members and aim to cover the above points. In the meantime please seek the advice of your CLL clinic where possible. Your holistic needs are one of the areas that Clinical Specialist Nurses may be able to cover.

- Patient on FLAIR trial, not under a CLL specialist. Should this patient be reviewed by a CLL specialist?

CLLSA response: we recommend you ask the advice of the treating consultant about arrangements for review by a CLL specialist. Consultants regularly confer on cases and should not be offended by your question.

Postscript

Some groups volunteered observations and suggestions:

- The Association needs a patron who is a CLL patient and a celebrity.
CLLSA response: alas, we have tried, but to date we have been unsuccessful.
- A more dynamic approach to fundraising
CLLSA response: We hope the summary provided at the Conference post the discussion groups in the "Update on CLLSA developments" encouraged members about our fundraising activity.
- Can the CLLSA put any information on hospital websites? Also PALS?
CLLSA response: Our priority is to ensure the CLLSA website is optimal – we are working on this. Secondly, we see CLL clinics in hospitals as a good place to raise awareness of CLLSA and what it can do for patients and their partners - hence the Champions initiative.
- Support for the Health and Wellbeing Conference (sic)
CLLSA response: members are advised to google for more information on this.

CLL Support Association Conference – Bristol

Friday 20th July 2018

We the curious, One Millennium Square, Anchor Road, Harbourside, Bristol BS1 5DB

Programme

- | | | |
|------------|---|--------------------------|
| 10.00 a.m. | Arrivals, refreshments, meet table companions | |
| 10.30 a.m. | Welcome and introduction to the day
by a CLLSA trustee | Olga Janssen |
| 10.40 a.m. | Members' CLL stories
A patient's and partner's experience of FCR treatment | Bert and Gail
Wiegman |
| 10.55 a.m. | CLL treatment – who needs treatment and how do we move from where we are to cure?

Prof. Chris Fegan is a consultant haematologist and Director of the School of Medicine at Cardiff University. He is Research and Development Director of the Cardiff and Vale University Health Board; at their recent conference he said: " <i>Innovation is a key driver as it creates new drugs, medicines and treatment for patient care...</i> " | Prof. Chris Fegan |
| 12.40 p.m. | Lunch | |
| 1.40 p.m. | CLL and the immune system

Dr Man is a Reader in the Division of Cancer and Genetics at Cardiff University. His research focuses on the role of the immune system in cancer. An expert on human T cells, for the past five years has been studying their role in leukaemia, with the aim of transferring findings for patient benefit. | Dr Stephen Man |
| 2.20 p.m. | CLL Support Association champions
Trustees' plan for recruiting member volunteers | Roger Huxley |
| 2.40 p.m. | Me, my clinic and the CLL Support Association
Facilitated small discussion groups for sharing knowledge, experience and tips amongst members and beyond. Afternoon tea will be available. | Olga Janssen |
| 3.40 p.m. | Update on CLL Support Association developments | Olga Janssen |
| 4.00 p.m. | Conferences closes | |