

## Report on the Liverpool CLLSA Conference, 9 May 2017

This report is based on feedback in discussion with CLLSA trustees and coordinator at and after the Conference, as well as by informal soundings taken from a range of participants at the event itself. These give a qualitative account of the Conference.

Interestingly, CLLSA members' feedback forms give a less critical account than opinions volunteered informally. The feedback forms are valuable for giving a quantitative account of members' experience. They indicate where the weight of opinion lies.

End-of-conference questionnaire returns and written responses to questions asked in the conference discussion groups have been analysed here to give tabular evidence.

The report aims to strike a balance between qualitative and quantitative findings.

### What worked well

- Nicely balanced and informative presentations
- Very strong Liverpool haematology team
- Good use of trustee and coordinator skills
- Beneficial grouping of members by postal code
- Professional use of filming consent forms
- Good location and catering
- Well staffed and stocked information stands of three sister charities

### What could have been better

- The sequence of the programme content
- Conduct of the discussion groups
- Checking of the sound system
- The information supplied on the programme
- Opportunities for meeting and greeting participants

### What worked well: commentary

Presentations were very highly rated by members, (see tables 3 and 4, page 4.) They started with a very informative and lucid presentation by Professor Andy Pettitt of Liverpool University: "Why bother doing fancy tests in patients with CLL?" It was well pitched to be accessible for a lay audience without dumbing down. An announcement by the Chair, Liverpool-based trustee Frank Mercer, to leave questions to the end of the talk and limit participants to a maximum of two questions each, made for an uninterrupted flow and an equitable allocation of questions from the audience. Moreover, it ensured that timing at the Conference was well handled.

Supporting presentations were made by two members of Andy Pettitt's team. Research nurse Jane Tinsley gave a well-delivered presentation on looking after yourself and managing the side effects of CLL. Linda Boyne, Haematology Nurse Counsellor, gave a well-illustrated talk on managing the emotional impact on CLL patients, their families and friends. A fourth member of the Liverpool haematology team, Clinical Nurse Specialist, Darren Keats, joined Jane and Linda to facilitate a discussion group each.

Local patients were justifiably full of praise for the service they receive from the Liverpool team, who are a model of good practice. One of these, Moira Griffiths Parr, gave a polished presentation on her CLL treatment. She was followed by trustee and Watch and Wait patient, John Moore, who spoke movingly of the personal impact of a CLL diagnosis.

Trustees and Coordinator are a well-practiced team in organizing CLLSA conferences. The Liverpool Conference benefitted from the expertise of old hands, but also the fresh ideas of more recently recruited trustees. As Chair for the event, Frank Mercer had a calm and relaxed presence. His introductory comments on the finances of CLLSA benefitted from his professional background as a chartered accountant and set the scene for later small group discussions on how members might assist with fundraising.

New trustee, Olga Janssen, had organized discussion groups by postal code, to facilitate local networking between patients and carers. This was appreciated by members. Feedback from these discussion groups, as well as from those at the earlier Cambridge Conference, is enabling us to build up a good picture of potential support for CLLSA at local level and options for fuller engagement by members. By gathering in members' unanswered questions from discussion groups and sending out a written response from trustees to all attendees after the Conference, CLLSA is providing a valuable supportive service. See pages 5-7 of this report.

A marketing innovation was the use of branded CLL T-shirts for the CLLSA team and branded cloth bags, with a CLL pen, to hold conference materials, for all participants.

Sarah Tobin, CLLSA coordinator, had done a professional job of drafting a filming consent form, to give us the authority to video presentations for posting on the CLLSA website. With a little persuasion in two cases, all six presenters signed their consent.

The tried and tested conference location at LACE, overlooking Sefton Park, provided good facilities, including on-site parking, and an excellent lunch and refreshments.

All five of the charity representatives, who staffed stands from Bloodwise, Leukaemia Care and the Lymphoma Association, felt their attendance at the Conference had been worth the long journey to Liverpool. They gave an important message of our co-operation as charities to support blood cancer patients and their carers.

## What could have been better: commentary

In order to accommodate one of our speakers, who had to leave early, the programme sequence was altered, with discussion groups moved to the end of the day, rather than following lunch, as intended. Although priority should always be given to our speakers' availability, this had three negative impacts. Firstly, one third of participants did not stay for the discussion groups, so we did not have the benefit of their contribution, nor did they submit a completed conference feedback form. Secondly, we missed the advantage of a break from listening to presentations. And finally, the Conference failed to end on a high, as it had done at Cambridge, where we finished with uplifting presentations by three patients and carers.

We were short of group discussion facilitators for what was a complex and time-constrained exercise in member consultation. One briefed facilitator failed to show. A substitute was found, but, along with other healthcare professionals who helped out as facilitators, was outside her comfort zone, when it came to discussion of how to support CLLSA.

A few felt that the resultant frequent public interjections on the next stage of the consultation exercise, from Olga Janssen, coordinator of the discussion groups, impeded the flow of conversation in discussion groups. Some of the questions posed on finances were too vague for members. They would have welcomed more specific proposals on which to give an opinion. ( See page 8: Contributing to funds and fundraising) The CLLSA Membership Committee are agreed that discussion groups will need a review for the next CLLSA conference in July.

Traditionally, CLLSA conferences have alerted members to the opportunity to give financial support via an envelope with a Gift Aid Declaration, included in their information packs. Good publicity was given to this opportunity at Cambridge, where the income generated was £780 + Gift Aid. At Liverpool, where less publicity was given, the income was £185 + Gift Aid.

The sound system depended on presenters positioning themselves close to the mike throughout. It was unfortunate that the detail of Andy Pettitt’s talk could not be heard by members at the back of the hall towards the end of his presentation. This could have been readily corrected by one of the CLLSA team alerting Andy to the problem, as soon as it arose. Observations on difficulty in hearing have been made before at CLLSA conferences in 2016. Trustees need to take preemptive steps to avoid this in future.

The CLLSA Coordinator sends out the programme as a reminder to all registered a week in advance. This has the advantage of reducing the incidence of non-attendance. However, due to late submissions on speakers and the title and content of presentations, the programme was short on detail. It did not do full justice to the professional standing of the presenters and whet the appetite for the high-quality presentations they gave.

Two experienced trustees felt that we should recruit local volunteers, coming to the conference, to assist with setting up. This would liberate trustees to attend to the important job of meeting and greeting participants on arrival, a welcoming touch much liked by participants. Trustees are skilled at this informal, personal interaction with members, which helps CLLSA keep its ear to the ground. Furthermore, it is valuable for establishing the friendly and approachable face of CLLSA.

**Table 1. Composition of attendees**

<b>Liverpool</b> (May 2017)			<b>Cambridge</b> (March 2017)	
Attendees	72		82	
<u>Cancelled/no show</u>	6	8%	5	6%
First timers	17	53%	33	60%
Returners	15	47%	22	40%
Trustees (FM, JM, CT, AC, OJ)	5		5	(DI, CT, RB, AC, OJ)
Coordinator	1		1	
Clinicians/HCPs	4		2	
<u>Charities</u>	5		1	
CLL patients	31	66%	43	69%
Carers	13	27%	17	27%
Others	3	6%	2	3%

Notes

1. Incidence of cancellations/no show was 11% over all 4 conferences in 2016.
2. Data on first timers and returners is taken from the yellow feedback forms.
3. Data on CLL patients, carers and others is from the composition of those who stayed for the discussion groups. Twenty five attendees left early before the discussion groups.
4. Of the 31 CLL patients, who stayed for the discussion groups, 15 (48%) were on watch and wait. This compares with 60% watch and wait of the CLL patients at Cambridge.

## Table 2. Rate of conference feedback returns

72 attendees 35 49%\*

57 attendees 35 61% discounting trustees, coordinator, charity reps, Liverpool haematology team

\*49% compares with 44% from the 4 conferences in 2016, and 72% at the Cambridge conference, March 2017

## Table 3. Satisfaction levels for each of the 5 aspects measured

	All respondents					%*	%1st time	% return	% 2016 confnrces
	Fair	Avrge	Good	Excelnt	Total				
Location, Facilities	0	0	9	27	36	95	96	95	91
Presentations	0	0	3	33	36	98	99	97	89
Event materials	1	0	13	22	36	91	96	89	88
Advert/registration	0	1	15	20	36	91	92	91	87
Group discussions	1	3	10	18	33	86	92	87	83

\* % calculated by multiplying 'fair' by 4, 'average' by 6, 'good' by 8, 'excellent' by 10 and dividing the total by the number of respondents for that aspect, to give an average, which was multiplied by 10. % awarded also shown for first time attenders and for returners, and for all four 2016 conferences. One 'not so good', for group discussions.

## Table 4. Most liked – observations volunteered by attendees

Presentations and information given <i>Excellent info and speakers; accurate information; all the presentations; info on latest treatment/drugs; range of speakers</i>	15
Meeting others with CLL <i>Exchanging views, experience, stories</i>	13
Good organization and ambience <i>Friendly and helpful staff; very warm welcome at registration; everything well organized</i>	5
Excellent refreshments and venue	3

31 respondents, of the 36 returns, answered this question. Some gave more than one thing “most liked”.

## Table 5. Least liked – observations volunteered by attendees

Facilitated group discussions <i>Not enough time for discussions (3); did not like being interrupted by announcements (4)</i>	7
Nothing	6
Sound system, inadequate amplification	3
Individual comments, logged on database <i>e.g. Getting up at 4.30a.m. to leave at 5,30a.m. But it was worth it!</i>	6

21 respondents of the 36 returns answered this question. One gave two answers.

## Trustees' response to members' unanswered questions

We asked discussion groups to log members' questions that the group could not answer. These were collected and trustees, who include a haematologist as well as CLL patients and carers at various stages of treatment, gave their answers after the conference. We hope the information below answers their concerns. It has been sent out to all participants.

1. What level of fatigue can be expected during "Watch and Wait"? I am at Stage A. I suffer from chronic fatigue, usually requiring 2-3 hours deep sleep every afternoon. The rheumatologist has told me this relates to my CLL. The haematologist says it does not as my fatigue is "too extreme".

*This is a difficult one, as the experience among "W and W" patients varies enormously. Fatigue is a well-chronicled condition in CLL. We would recommend asking more questions of the haematologist and GP to get to the bottom of this.*

2. To what extent can pain, apparently experienced "within the bone", particularly in the knee and shin, relate to CLL? Could the pain be related to the CLL effect on bone marrow? NB this question was submitted by the person who also submitted question 1.

*Medical comment: such bone pain is not associated with CLL. It can be seen in other, aggressive acute leukaemias or with certain medications used to stimulate bone marrow function (ie, G-CSF).*

3. If you can halve/decrease chemo because of side effects, why can't you start with a half dose and build up?

*Medical comment: the drugs dose, route of administration (eg, oral, intravenous) and scheduling (daily, weekly etc) are to a (large) degree determined by clinical studies in patients, as well as a lot of pre-clinical work in the laboratory and animals.*

*So, we can only select what we believe to be the best regimen using the data available and changing this when clinically indicated.*

4. Is it possible to lobby insurance companies, as the cost of travel insurance is too high?

*A tough call as insurance companies have their own agendas to follow, namely how to reduce the risk they face with policy holders. The best thing we can do is to continue to keep a watchful eye on those companies that appear to offer the best deals for CLL patients. As always though we should urge "caveat emptor" as it is only when a claim is made that you really find how good that deal was!*

5. How do you disseminate information to those without access to the Internet?

*Another difficult one! CLLSA distributes leaflets to 222 CLL clinics nationwide. We have 163 UK postal members. This is 9% of our membership. The Office of National Statistics says 10.2% had never used the internet in 2016. This compares with 11.4% in 2015. So things are improving, and CLLSA is doing a reasonable job of reaching those who do not use the Internet.*

6. How can we raise awareness of CLL? There are no visible signs, so it is hard for others to grasp.

*Please refer to our piece in the Spring 2017 newsletter on the recently launched All Party Parliamentary Group (APPG) for Blood Cancer, to which CLLSA contributes. The APPG recognizes the problem and is working on raising awareness.*

*CLLSA shall shortly be starting a project with a PR agency to help us raise awareness of CLL and CLLSA.*

*Fundraising efforts by our members also help to raise awareness. Thank you!*

*If you know of any celebrity who has CLL, or is a relative or friend of a CLL patient, and who might be willing to become a patron of CLLSA, please tell us.*

7. Can we have more counsellors and complementary therapists?

*Some GP surgeries as well as CLL clinics have access to counselling services. Ask yours. Often cancer information centres offer these services as well as complementary therapies. Ask your CLL clinic or any Cancer Nurse Specialist at your hospital for advice. Some adult and community education centres run group therapy in complementary medicines. Ask around in your locality.*

8. How does one cope with an under/over attentive partner without hurting their feelings or your relationship?

*We can only offer general advice here. A counsellor will help in individual cases.*

*There is a peer to peer project in the pipeline, sponsored by Abbvie, planned for later this year as a pilot in the Leicester/ Nottingham area, to provide training for carers. We look forward to rolling out the results of the project in 2018.*

*For the over-attentive partner, we suggest that you should be willing to accept some "reasonable" element of sympathy, whilst perhaps making it clear that you have come to terms with your situation and that you are comfortable with the way you are dealing with it.*

*For the under-attentive partner, we suggest you tell them what support you would like. They may be looking for a lead from you on how to best help you.*

9. Is there any evidence that Omega 3 food will bring a platelet count down?

*A quick look at the web shows quite a number of studies looking at omega "3" and fish oils in terms of platelets. There is evidence to suggest impaired platelet function with a bleeding tendency as a result (not severe) – but not a reduced number of platelets.*

10. How long should I take immunoglobulin? And is it beneficial after chemotherapy?

*Medical comment – firstly, be sure you have a good indication to be on immunoglobulin (Ig) replacement in the first place. This may partly determine the duration of treatment. If, like most CLL patient taking Ig, it is to replace low blood IgG levels and associated recurrent troublesome infection or severe infection requiring hospital admission, the first step before Ig should be long-term prophylactic antibiotics. If this does not work, then Ig replacement is used. In general, low IgG levels will not correct with treatment for the CLL itself, so Ig may become life-long. Sometimes, a 'holiday' over the summer months is done as there are less viral problems then. Regular monitoring of the blood IgG level during Ig*

*therapy can show if it is possible to increase intervals between infusions. At some point in time, if you have been infection free for along time, a trial without Ig can be discussed with your haematologist.*

*Finally, Ig can be self-administered subcutaneously at home and I routinely refer patients on long-term Ig and/or with immunodeficiency and CLL to see an immunologist to oversee this and review the patient's immune status.*

11. Where can I find a list of CLL specialist consultants?

*A list was provided some years ago, but it was controversial. We shall discuss it again with the clinical community.*

*In the meantime, do ask at your CLL clinic. It should always be possible to get a second opinion on a condition. Cancer services in England are organized in networks with a specialist one for haematology acting as hub and referrals made from satellite hospitals. Consultants confer with each other all the time and will not be offended if you ask for a second opinion from someone who has a particular interest in and experience of CLL.*

*Medical comment: I'm happy to see you! My name is Samir Agrawal and I'm based at Barts hospital in Central London.*

12. When would any other drug be administered after one treatment of chemotherapy?

*Medical comment: I do not understand the question, sorry!*

## Liverpool Conference tips for coping with CLL

1. Find a support group through a clinical nurse specialist (CNS), Macmillan, Leukaemia CARE, CLLSA etc
2. Go to online CLL forum and CLLSA website and other trusted websites.
3. Keep busy! Live as normally as possible. But listen to your body and rest if needed.
4. Mindfulness and meditation can help.
5. Ensure that you are being treated by a CLL specialist.
6. Ask about counselling support and complementary therapies.
7. Find out as much as you can.
8. Attend CLLSA conferences.
9. Remember that life happens between the treatments.
10. Walk, exercise, relax.
11. Try not to worry too much about it.
12. Keep calm and carry on.

## How Liverpool members might support CLLSA

Table 1. Figures

	not likely	not sure	maybe	quite possibly	probably	sample
Tell your CLL story	4	3	10	6	6	29
Become ambassador	5	4	10	5	6	30
Discussion gp. facilitator	10	8	8	3	2	31
Help run regional group	6	4	12	3	3	28

Table 2. Percentages

	not likely	not sure	maybe	quite possibly	probably	sample
Tell your CLL story	14%	10%	34%	21%	21%	100%
Become ambassador	17%	13%	33%	17%	20%	100%
Discussion gp. facilitator	32%	26%	26%	10%	6%	100%
Help run regional group	21%	14%	43%	11%	11%	100%

Note.: Liverpool already runs a regional support group

## Contributing to CLLSA Funds and Fundraising

### A membership fee?

For: 13; 36% Against: 14; 39% Not sure: 9; 25%

Note

1. Many members found the question too vague. They would have liked a specific proposal.
2. Members discussed this in small groups. There was a tendency to vote alike either for, or against, or noncommittal, within each group.
3. One group suggested £10-£12 annual fee.
4. One group suggested free membership with an invitation to donate.
5. One group recommended charging for conferences but not membership.

### A conference fee?

For: 21; 72% Against: 7; 24% Not sure: 3; 25%

Note

1. Many members found the question too vague. They would have liked a specific proposal.
2. A £10 fee was suggested by one group.
3. One group asked: How would CLLSA identify people who cannot afford to pay?
4. Those against preferred a voluntary contribution to a fee.
5. A more modest lunch was proposed if a fee is to be charged!

## Fundraising

This was not a very productive discussion, judging from feedback forms, which were not always legible: -

- Mandy Wilkinson donates a painting to charity each year. (Arthur Grayley's gp)
- Bag pack Tesco, Asda etc
- Encourage sponsorship through membership and families
- The A... ? Mike Peters a CLL patient "Love Strength Hope" (Arthur Grayley's gp)
- Fundraising at local clubs
- Charity dog walks
- Legacy
- Monthly direct debits